
From Institutions to Communities:

WILL MORE DOLLARS FINALLY FOLLOW SPECIAL NEEDS CHILDREN TO THE LOCAL LEVEL?

by S.D. Williams



Karen Tam

Summary

Children with special needs require a broad range of services — from accommodations to keep them in regular school classrooms to institutionalization to meet psychological, social, or physical health needs. Costs vary greatly for these services, and the case of Dre Smith provides an example of the way expenses can escalate when a child's problems require high-level services in both community and institutional settings. While Dre's name has been changed to protect his identity, his family's challenges are very real.

For those children with difficulties as severe as Dre's, are there savings that can be realized through greater reliance on community-based programs? Is the community equipped to serve a child with needs as great as Dre's? The number of people served by community mental health programs in North Carolina grew thirty-four fold — 3,400 percent — from 8,196 to 277,043 between the years 1960–61 and 1996–97, a period during which the state's population grew by 61 percent. In 1960–61, community-served clients represented 26 percent of all people served by public mental health, developmental disability, or substance abuse services. In 1996–97, they represented 93 percent. Meanwhile, the number of persons receiving institutional care in state-operated facilities actually dropped during the 36-year period, from 23,327 in 1960–61 to 20,979 in 1996–97.

Yet community mental health programs — while serving 93 percent of clients — received only 57 percent of the \$1.4 billion spent for mental health services through the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services in the N.C. Department of Health and Human Services last year. Other imbalances exist, as well. Training schools accounted for 44 percent (\$40.1 million) of the budget of the department's Division of Youth Services, compared to the 43 percent share (\$38.9 million) allocated for community alternative programs. Taking out federal funds, the state actually spent \$39.4 million on the schools, and taking out federal, local, and other funding, the state spent only \$30.2 million on community services for almost 48,000 youth served. But training schools housed only 3.4 percent (1,930) of the 56,344 juvenile offenders served during the course of the year. The state's three schools for the deaf provide another good example. Twenty-two million dollars (78 percent) of the Division of Services for the Deaf and Hard of Hearing's \$28.1 million budget goes to North Carolina's three schools for the deaf, which serve less than one-third of the state's hearing-impaired students. For each deaf K–12 student at these schools, the cost is \$40,472 to \$42,159 annually, depending on which of the schools the student attends. Hearing-impaired students served in their home school districts typically are educated for less than half that amount annually. The 1996–97 state appropriation for the Governor Morehead School for the blind was \$7,764,000. It cost \$21,070 to educate a student there in 1997–98 — exclusive of residential costs. That's less than the per-student cost at the schools for the deaf, but still more expensive than the public schools. No attempt is made here to address the acuteness or severity of problems faced by persons served at the state institution or community level. Rather, the pivotal question is this: How can the state make sure that its funds more often support the needs of people rather than the needs of programs, and are sufficient dollars flowing to the community level where the majority of the clients are served?

Dre Smith (not his real name) has an enormous smile. In the family room of Greenhouse, the Durham group home in which the 12-year-old has been living, he jokes with staff and other residents, happy because he is about to visit his mother. As Dre jokes with staff and fellow residents, the counselor on duty has to remind him several times not to interrupt others and to keep his hands to himself.

The administrative director of the group home and Dre drive across town to a small white-framed house in a modest neighborhood. Dre leads the way inside and calls for his mother. Three of his brothers or half-brothers are in the living room, in which clothes are draped on hangers hooked over curtain rods and door frames so that they will dry in the warmth from the portable heater. The vinyl sofa upholstery is cracked with age and use, but the worn, rented room is clean, and the children are well behaved, at least for this visit. In one corner stand four Easter lilies in large pots wrapped in foil. They came from the funeral service for Dre's stepfather, who died of AIDS a week-and-a-half before.

Gladys (not her real name) walks slowly into the living room ten minutes after Dre and the director's arrival. She is a large woman in her early thirties who is simultaneously cautious and friendly. She is also tired. More than a year before, she had tested positive for human immunodeficiency virus (HIV), the cause of AIDS. Her husband, who had helped get her children off to school in the mornings after she left for her early-shift job in Research Triangle Park, had introduced her to intravenous drug use and the disease. She makes social small talk, then settles back and begins to tell Dre's story as one of the other boys leans against her legs and reads *Sports Illustrated for Kids*.

"I wish that when I asked for help with Dre when he was a lot younger somebody had taken me seriously," Gladys says, adding that she had told a case worker at the Durham County Department of Social Services about Dre's behavioral problems. "He had meningitis as a three-day-old baby, and I've often wondered if that was where his problem started."

Dre sometimes seemed simply out of control as a baby and toddler, different from Gladys' other children, although he could be loving and attentive also, as he is on this day. Occasionally he

interrupts his mother's story to talk about a girl he's met on the school bus.

In 1990, as a rising first grader, Dre was accepted into Fast Track, a study under way at Duke and three other universities funded by the U.S. Department of Education, the National Institute of Mental Health, and the Center for Substance Abuse Prevention. The project attempts to prevent violence, substance abuse, and school failure or dropping out through a variety of in-school and individual services for at-risk children. It continues to provide Dre with a mentor, tutoring, social and emotional skills training, family counseling, and consultations with teachers, among other things. The cost is estimated at \$4,000 per child per year.

Dre's propensity to act impulsively and aggressively, sometimes violently, led to outpatient therapy starting in 1994 at the Durham Child Guidance Clinic, a contract service provided by Duke University to Durham County. Dre is a Medicaid patient, and his family is able to pay little of the \$105 per hour that the clinic charges. He has been given diagnoses of Attention Deficit Disorder and Delayed Expressive and Language Disorder.

Meeting Dre's Special Needs in School

Also during his elementary school years, Dre was labeled Behaviorally-Emotionally Handicapped (BEH). This diagnosis and his language disorder give him access to special education services in the public schools through the federal Individuals with Disabilities Education Act (IDEA). He was one of 159,697 identified children with special needs in North Carolina in the 1997-98 school year, up 5 percent from 152,819 in 1996-97. (Because of statewide special education "head counts" during December and April of each school year, the number of special education students noted in this article are more current than the numbers of children being served by other programs. The latter are compiled after the end of each state fiscal year, which ends June 30). The group of special needs children in North Carolina "includes, without limitation, all children who, because of permanent or temporary mental, physical or emotional disabilities, need special education, are unable to have all their educational needs met in regular class without special education or related services, or are unable to be adequately educated in the public schools."¹ Children may receive special education services if they qualify for one or more of thirteen eligibility categories: autistic, behaviorally-emotionally handicapped, deaf-blind,

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hearing impaired, mentally handicapped, multi-handicapped, orthopedically impaired, other health impaired, pregnant, specific learning disabled, speech-language impaired, traumatic brain injured, and visually impaired.

According to Nancy Spencer, who was the director of special education in the Durham Public Schools until leaving in summer 1998, the Durham system had a special education budget of \$19,587,421 for 1997-98 and 4,253 qualified students on April 1, 1998. The Durham system thus averaged \$4,680 per student for the 1997-98 school year.²

Mardie Meany, section chief for policy monitoring and audit of the Exceptional Children Division of the Department of Public Instruction, says that the number of special education students in North Carolina has been growing at about 4 to 6 percent annually for several years. The rates of population growth for North Carolina's general population and its population of children have ranged between 1 and 2 percent during the 1990s.³

Meany offers several explanations for the disproportionate growth in the number of special needs students, although she is careful to note that these have not been documented through research:

- 1) Educators are doing a better job of identifying students in need of special education;
- 2) The increasing recognition of Attention Deficit Disorder (ADD) and its companion, Attention Deficit Hyperactive Disorder (ADHD), has given a credible psychological label to what were once thought of as simple behavior problems. ADD and ADHD are not categories under the federal IDEA legislation, however. Students with these disorders who receive special education services usually are classified in the "specific learning disability," "behaviorally-emotionally handicapped," or "other health impaired" category.
- 3) North Carolina's ABC accountability program provides an unintended incentive for schools to identify special needs students. Some of these children are exempt from taking state-mandated tests. Because schools receive a yearly report card based on the testing performance of their students, it is to the advantage of administrators and teachers to exempt low-achieving students from the process.
- 4) Finally, because of increased recognition of these special needs, the stigma attached to them has diminished, making more parents and children willing to come forward for help.

In 1997-98, says Meany, the federal government provided North Carolina \$488 per public school student aged 5 to 21 in special education.⁴ The state provided an additional \$2,248.39 for each of these K-12 students. Multiplying by the December 1, 1998, state head count, Meany says these figures come to \$437 million in direct state and federal funds for special education. Local funds and various state, federal, and private foundation or corporate grants can increase this figure significantly in local systems.

Dre was fortunate to attend school in a system that provided him an additional \$1,900 in services for the year. Some school systems (such as Alleghany, Clay, and Madison counties) provide no local funds at all for special education.

Public schools face a dilemma in dealing with special needs children like Dre. While most professionals in the schools have the best interests of special needs children at heart, they are under significant pressure to raise the academic performance of all students. Becoming better "counselors" while they are being told to become better educators will be extremely difficult for teachers. Penalizing schools for low achievement scores that result from educating significant numbers of special needs children only makes the burden greater.

Dre Is Placed in an Institution

Life for Dre started on a downhill slide in winter 1996-97. Gladys informed the children that she had become addicted to narcotics and had contracted HIV. It was a blow to the solar plexus of an already troubled family. "I know that's when Dre really started worrying," Gladys says. She turns to look at Dre, who has been sitting beside her on the sofa, talking softly about the girl he has met on the school bus, not like a disturbed child in another world but like a knuckle-headed boy hoping to get some attention. Now he quiets, and although he still wears a slight smile, he looks off thoughtfully. "Yeah," he says, "I worried."

His behavior went from bad to worse, and when he started middle school in the fall of 1997 at the Durham Arts Magnet, where he and his problems were new to the faculty and staff, things fell apart. His mother entered drug rehabilitation at a state institution in Butner, and Dre started lashing out in school, verbally and physically. He says that one day he finally broke down and told a teacher about his mother's addiction and HIV. The teacher called Dre's social worker. Ultimately, Dre's behavior led to involuntary commit-



N.C. Division of Archives & History

Dorothea Dix Hospital, main entrance, 1938

ment to the Children's Psychiatric Unit at John Umstead Hospital.

The police picked Dre up at the home of relatives, where he had been staying since his mother entered rehab. They brought him to the emergency room at Duke University Medical Center, and he struggled most of the way there and after arrival, so that he was put in a secure room. Given a meal, he threw his tray and food against the wall. His mother was in an institution and would probably die from AIDS, he feared, and his own problems spiraled out of control.

His psychiatric report noted "chronic neglect, chaos, and violence" in Dre's family. He was found to be a danger to himself and/or others, taken to Butner, and admitted to the Children's Psychiatric Unit at John Umstead Hospital.⁵

No one can be institutionalized as a result of a classification under the Individuals with Disabilities Education Act. The IDEA categories are simply the list of conditions that make one eligible for special education services. In some cases, such as for the deaf and the blind, eligibility can open the doors to state-operated residential schools. Dre's IDEA eligibility had nothing to do with his involuntary commitment, although once

hospitalized, he did receive special education services at the Children's Psychiatric Unit's Pine Valley School. Dre remained at the unit from September 12, 1997, until January 30, 1998.

John Umstead Hospital is one of several major state-operated facilities that serve either children exclusively or children and adults. These facilities include:

- four regional psychiatric hospitals (Broughton Hospital in Morganton, Cherry Hospital in Goldsboro, Dorothea Dix Hospital in Raleigh, and John Umstead Hospital in Butner)
- two schools for emotionally disturbed children (Wright School in Durham and Whitaker School in Butner)
- five youth-services training schools (C.A. Dillon School in Butner, Dobbs School in Kinston, Juvenile Evaluation Center in Swannanoa, Samarkand Manor in Eagle Springs, and Stone-wall Jackson School in Concord)
- three schools for hearing impaired children (Eastern North Carolina School for the Deaf in Wilson, Central North Carolina School for the Deaf in Greensboro, and N.C. School for the Deaf in Morganton)
- one school for visually impaired children (the

Governor Morehead School in Raleigh)

- five mental retardation centers (Children and adolescents are rarely served in these centers. They are Black Mountain Center in Black Mountain, Caswell Center in Kinston, Murdoch Center in Butner, O'Berry Center in Goldsboro, and Western Carolina Center in Morganton)

All of these are operated by divisions within the N.C. Department of Health and Human Services (DHHS). The state also operates a Willie M. facility at John Umstead Hospital — the Butner Adolescent Treatment Center and another at the N.C. Special Care Center in Wilson. (The Willie M. program, while structurally within DHHS, has an independent budget and presents a special case. Created as the result of a class action suit filed in 1979, the Willie M. program provides services for children with mental, emotional, or neurological disabilities and accompanying violent or assaultive behavior.) DHHS, rather than the Department of Public Instruction (DPI), runs the educational programs in all of these facilities, although DPI is responsible for overseeing their compliance with state educational requirements. The only funding coming from the Department of Public Instruction to these institutions' educational programs is the \$488 (1997-98) per child of federal money.

Dre's stay at the Children's Psychiatric Unit in late 1997 and early 1998 cost \$336 per day.⁶ Like him, 98 percent of children who are patients at the hospital have a special education as well as a mental health diagnosis.

The Psychiatric Hospital Debate

North Carolina's four state psychiatric hospitals have been the topic of debate for more than a generation, for both financial and clinical reasons. With the advent of psychiatric medication in the 1950s, the movement to treat people with mental illness in local communities grew. Community-based treatment was considered more humane and often more effective than the "warehousing" of patients in institutions. The desire to cut state budgets further fueled the deinstitutionalization trend, and while deinstitutionalization has been the accepted policy and the reality since the early 1980s, issues surrounding it continue to surface. A recent study commissioned by the N.C. General Assembly called for replacing the state's four psychiatric hospitals with smaller, less expensive facilities. The report also suggested that children should not

be treated in the hospitals.⁷ That suggestion prompted protests from numerous professionals.⁸ Nevertheless, the legislature acted on the report by appropriating \$2 million to plan a smaller but modern mental hospital on the Dorothea Dix Hospital campus in Raleigh and appropriating \$750,000 to the State Auditor's Office to study how the four psychiatric hospitals and 40 mental health centers can better work together to provide high quality services.⁹

According to Allan Spader, executive director of the North Carolina Council of Community Programs, North Carolina spent about \$1.4 billion for services through the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS) of the Department of Health and Human Services in 1996-97. Approximately 57 percent of this went to communities, and the remainder paid for state-operated programs. (See Figure 1.)¹⁰

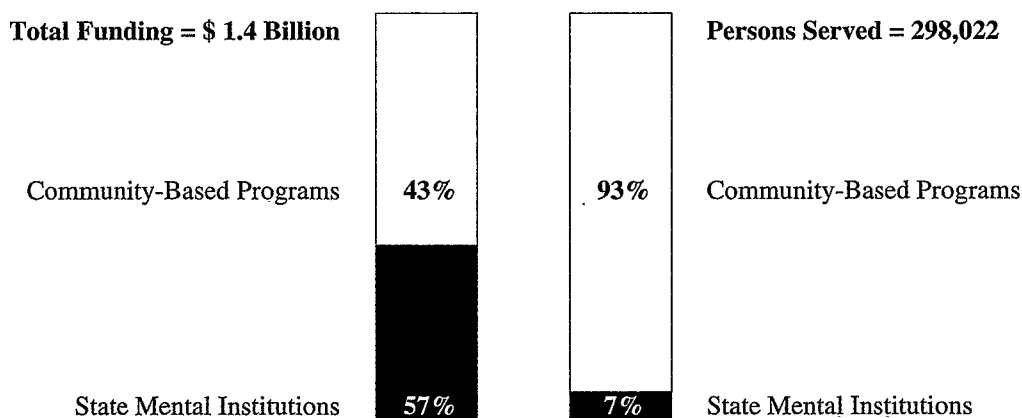
State and federal mental health funds flow through MH/DD/SAS to 40 area mental health, developmental disability, and substance abuse authorities (that administer the funds that cover all 100 counties), and thus to the state's community-based programs. Although local area programs received a larger direct state appropriation (\$296.3 million) in 1996-97 than did the four psychiatric hospitals (\$146.0 million), they served disproportionately more people, a trend evident in most services through MH/DD/SAS. The boards of the area authorities are appointed by county commissioners, and Spader's Council of Community Programs is the professional association of these authorities.

Mike Pedneau, director of Dorothea Dix Hospital in Raleigh, says that discrepancies in cost between institutions like state mental hospitals and community programs are to be expected because patients admitted to hospitals have more serious problems that require more expensive treatment. "Virtually all the adolescent admissions to the state hospitals occur following failure of community

"The real financial and clinical challenge for the state in years to come, lies in the number of people served in the community."

—ALLAN SPADER, EXECUTIVE DIRECTOR
N.C. COUNCIL OF COMMUNITY PROGRAMS

**Figure 1. Proportion of Funding of State Mental Institutions
and Community-Based Programs versus
Number of Persons Served, 1996-97**



Source: N.C. Council of Community Programs for total spending on mental health, N.C. Division of Mental Health, Developmental Disabilities and Substance Abuse Services for clients served in residential and community-based programs.

services to one degree or another," says Pedneau. "Most such failures occur because of the degree of acting out and dangerousness and/or the clinical complexity of the child's emotional disturbance." Pedneau draws the analogy of a patient receiving care at the office of a family practitioner's office versus a hospital. "Clearly, acute psychiatric inpatient care in both state and local public and private hospitals is going to be, and should be, more costly per person served. I dare say you or I would not expect to have a gall bladder removed, acute pneumonia treated, or a heart bypass procedure done in a physician's office."

The real financial and clinical challenge for the state in years to come, says Spader, lies in the numbers of people served in the community. As shown in Table 1, the number of people receiving institutional care at state-operated residential facilities has declined over 36 years: from 23,327 in 1960-61 to 20,979 in 1996-97. While the decline in actual numbers was small, it came at a time when the state's overall population grew by 61 percent. In 1960-61, approximately one-half of 1 percent of the state's population was served in these institutions. If that rate held true, the state facilities would have served 37,100 people in 1996-97 rather than

20,979. The small decline in absolute numbers at the facilities is only the tip of the iceberg in terms of the shift from institutional to community care. The facilities are serving a dramatically decreasing portion of the state's clientele.

The number of people served by area authorities grew thirty-four fold — 3,400 percent — between 1960-61 and 1996-97, from 8,196 to 277,043. In 1960-61, community-served clients represented 26 percent of all people helped by public mental health services in North Carolina; in 1996-97 they represented 93 percent. The number of children served annually by public mental health programs rose from 32,000 in 1992 to 58,000 in 1997, an average of about 5,000 per year. Before 1992, their number rose between 2,000 and 3,000 a year.¹¹

Who pays for community-based services? Funds come from a variety of sources, but the state picked up the largest share, 38.9 percent, in 1996-97. (See Table 2, p. 88.) Medicaid funding was a close second at 33.6 percent. Other federal funds, county appropriations, and miscellaneous other funds made up the remainder for a total of \$762.8 million in 1996-97. Medicaid requires the state to provide a match of approximately 35 percent for

Table 1. Number and Percentage of People Served by Community Mental Health and State Division of Mental Health, Developmental Disabilities, and Substance Abuse Services Institutions in North Carolina, 1960-61 to 1996-97

	People Receiving Institutional Care		People Receiving Community-Based Care		Total Persons Served
	Number	Percent of Total	Number	Percent of Total	
1960-61	23,327	74%	8,196	26%	31,523
1970-71	30,019	32	63,791	68	93,810
1980-81	25,658	13	171,712	87	197,370
1993-94	21,825	9	225,167	91	246,992
1996-97	20,979	7	277,043	93	298,022

Note: The figures for state-operated institutions include psychiatric hospitals, mental retardation centers, alcoholic rehabilitation centers, and other special care institutions.

Sources: Information provided to the author by Mark Botts, Institute of Government, University of North Carolina at Chapel Hill. Original sources: Data for FY 1960-61, 1970-71 and 1980-81 derived from *Strategic Plan 1983-89*, vol. 1, Quality Assurance Section, N.C. Division of Mental Health, Mental Retardation and Substance Abuse Services (Raleigh, N.C.: 1981), 39. FY 1993-94 figures provided by Deborah Merrill, Data Support Branch, N.C. Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, memorandum to M. Botts, December 8, 1994. Data for FY 1996-97 from *North Carolina Area Programs Annual Statistical Report*, Management Support Section, N.C. Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (Raleigh, N.C.: 1997).

its portion.¹² Traditionally, the Medicaid system has allowed North Carolina to count as its match state funds that were already being spent for a variety of reasons and on a variety of clients by the 40 local area programs. With a change in accounting procedures this year, however, the matching funds must be set aside as a direct match, which will result in a shortfall of state funds to non-Medicaid clients. The Council of Community Programs advocated for an additional \$38 million to make up for this shortfall, and the General Assembly adopted legislation to provide the required matching funds.¹³

Schools for Emotionally Disturbed Children

Although he was not referred, Dre might have been a candidate for Wright School, the North Carolina Reeducation Center. Located in

Durham, Wright School is a state-operated program. Officially, Wright School serves all of North Carolina, but because the program's five-day-per-week schedule can pose weekend transportation problems for families, according to Director Deborah Simmers, the students generally come "from Charlotte to close to the coast." Each of the approximately 75 children ages 6 to 13 that attends the school during the year arrives after "communities have exhausted all their resources and are at their wits' end," says Simmers. "We are a diagnostic setting — we're very good at identifying strengths and special needs," she says. "Our real job is to work closely with the home and local school, teaching parents management skills for dealing with these kids."

Most children who come to Wright School already have an IDEA label. All come for medical/psychiatric diagnoses, the most common of which are Attention Deficit Hyperactive Disorder and Bi-

polar (manic depressive) Disorder. The school is not run as a psychiatric unit, however. It focuses on social and educational skills. The goal for the children is not a "cure" but rather increased capacity to have success in their education and in social relationships in the community.

Simmers says her staff, which consists mostly of "teacher-counselors," begins conducting liaison work with each child's local school upon the child's admission. Ideally, each child would visit his or her regular classroom periodically during a Wright School stay. The reality is somewhat different. "The way the schools work is that, after the child has given up his desk, another student is often assigned to that class in our student's place. And often, instead of forging a stronger relationship with us, many schools say, in effect, bring him back when he's ready." She adds that schools are under increasing pressure from many quarters to raise overall performance and that any lack of attention to these children is unintentional.

Wright School's budget for 1997-98 was \$1,517,395. That breaks down to a cost of \$278.53 per day per bed.

Whitaker School, in Butner, offers similar

services for adolescents. It was established in 1979 as part of the *Willie M.* lawsuit settlement. In fact, the child Willie M. himself was treated there, but it has always treated other, non-Willie M. children as well.

"Our group tends to need longer term care than many troubled adolescents do," says Joseph Murphy, the school's executive director. "Children stay at the psychiatric hospitals for weeks, usually because they pose an imminent danger to themselves or others or there is some kind of crisis. Our average stay is eight months."

Whitaker, like Wright School, works to involve a child's community in his or her treatment. Numerous meetings are held with family, community mental health counselors, Willie M. and court counselors if applicable, and others. The program is more expensive than training school. Whitaker's 1996-97 budget was about \$2 million. That year, it treated 51 children, and Murphy placed the per-bed, per-day cost at \$250 to \$260. All of the funds are provided by the state, and in 1998 a proposal to close the school was discussed, then dropped, within the N.C. Department of Health and Human Services. In the 1998-99 state



Jim Bounds, The News & Observer

budget is \$250,000 to design a new, 33-bed Whitaker School.¹⁴

Murphy points to a recent study to emphasize the success achieved by Whitaker's long-term program. In 1997, groups of students who had been out of Whitaker for 6 months, 12 months, 18 months, or 24 months were contacted and interviewed. Averaging across these groups, 80 percent had not been in any new trouble with the law, 79 percent were continuing their education, and 87 percent had not been in any psychiatric or detention facility more restrictive than Whitaker.¹⁵

Youth Services

Dre is not in trouble with the law, but many of his contemporaries are. In 1987, there were 10,587 youths under the age of 16 arrested in the state; in 1996 there were 21,668, a 104 percent rise. (The state counted 15-year-olds in a 15-to-19-year-old grouping for general population purposes in the 1980s, so an accurate figure for the rate of population growth from 1987 to 1996 for children 1 to 15 cannot easily be ascertained, and thus the rate of rise in the general youth population cannot easily be compared to the rising rate of youth arrests. The general youth population certainly did not rise by

104 percent, however. The state's overall population grew by less than 17 percent from 1987 to 1996.)¹⁶ The rate of arrests per 1,000 juveniles has risen steadily for a generation, from a low of 6.48 in 1982 to an all-time high of 10.6 in 1996.¹⁷

The Division of Youth Services in the Department of Health and Human Services served 56,344 children with a budget of \$89.9 million in 1996-97. More than \$40 million (44 percent) of that budget went to the division's five training schools, which served 1,930 children. Twelve percent of the funding went to detention centers, which served 6,495 children. Just under \$40 million (43 percent) of the budget supported 47,919 children in a variety of community-based services, but some of that funding came from nonstate sources. The state's cost for community services was \$30.2 million. (See Table 3, p. 90.)

Only 3.4 percent of the children served by Youth Services spent any time in a training school. Asked why these schools used such a disproportionate amount of the budget, Richard F. Rideout, Youth Services' deputy director, replied, "We serve the overwhelming majority of these children in communities, but there are some whom the courts decide should be in training schools. Building, maintaining, and staffing facilities is simply expen-

Table 2. Mental Health, Developmental Disabilities, and Substance Abuse Services Area Authority Revenues by Source: Amount and as a Percentage of Total Revenues, 1996-97

Revenue Type	Amount (millions)	Percentage of Total
State General Fund	\$296.3	38.9%
Medicaid		
Federal	150.6	
CAP-MR/DD*	106.2	
Medicaid Subtotal	256.8	33.6
Non-Medicaid Federal	85.5	11.2
County	73.3	9.6
Other	50.9	6.7
Total	\$762.8	100.0%

*Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities. Funds in this column include federal, state and local money.

Source: Philip Hoffman, Management Support Section, N.C. Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, memo to the author, August 10, 1998.

sive, whether they're training schools, hospitals, mental retardation centers, or anything else."¹⁸

The juvenile justice system in North Carolina is split between the judicial and executive branches of the government. The Juvenile Services Division of the Administrative Office of the

Courts provides court intake services, probation services and aftercare services. The Division of Youth Services provides community services to youth seen by the courts, operates 8 of the 12 juvenile detention centers in the state (the others being operated by their home counties: Mecklenburg, Forsyth, Guilford, and Durham), and operates North Carolina's five training schools. Its programs broke down as follows for 1996-97:

- Nearly 600 nonresidential programs tailored by localities served 35,041 children at an average per-child cost of \$923 per year.
- Sixty-one Governor's One-On-One Programs in 65 counties matched mentors and adult volunteers to 1,823 youth at an average yearly cost of \$1,690.
- Five Eckerd Therapeutic Camps received 281 new admissions and graduated 240 youth at an average cost of \$27,335 per child.
- Multi-purpose Group Homes, run by nonprofit organizations on contract to the Division of Youth Services, had 238 new admissions and 232 terminations and an average cost per child of \$8,510.
- There was a total of 5,546 admissions to detention services — short-term alternatives to adult jails for children awaiting hearings. The average annual cost of operating a bed in these facilities was \$47,165.
- There was an average daily on-campus population of 836 at the state's training schools, which are designed to bring about behavioral changes in youth who have violated the law, been adjudicated delinquent, and been assigned to these schools. The annual per bed cost was \$48,411, or between \$134 and \$135 per day. (Seventeen percent of the students in these schools receive special education services.)¹⁹

"Building, maintaining, and staffing facilities is simply expensive, whether they're training schools, hospitals, mental retardation centers, or anything else."

—RICHARD F. RIDEOUT, DEPUTY DIRECTOR,
N.C. DIVISION OF YOUTH SERVICES

Referrals from juvenile courts and law enforcement agencies to Youth Service's community-based programs rose 43 percent from 1993-94 to 1996-97, to 12,079. Like Dre, these children pose a challenge to their communities, and their increasing numbers intensify that challenge.

The Governor's Juvenile Crime Initiative has proposed, among other things, adding 208 beds to the training schools. Out of an overall request of \$43.2 million, the proposal earmarks \$11.5 million for construction in 1998-2000 and \$10.4 million for operating the new beds in 2000-01. As this article went to press, the Senate and House had whittled the \$43.2 million down to \$17 million and \$6 million, respectively, and the actual budget contained only \$1 million for planning and design.²⁰

Schools for the Deaf and for the Blind

Unlike the number of children with social, emotional, or mental health problems, or youth in trouble with the law, the number of deaf, hard-of-hearing, blind, and visually impaired children in North Carolina does not rise and fall with any social indicators except for the overall population of the state. There is, for example, about a one-tenth of 1 percent general incidence of blindness in the U.S. population.

The Division of Services for the Deaf and Hard of Hearing operates three residential schools — one each in Morganton, Wilson, and Greensboro. In the 1996-97 school year, they served 736 residential students, of which 277 were preschoolers, 331 were residential students in grades kindergarten through 12, and 128 were kindergarten day students. That same year, 2,299 hearing-impaired children were educated in the public schools.

The Schools for the Deaf operate both as schools that must offer the state's standard course of study and as centers for deaf culture. This dichotomy has been the cause of debate over several years. At a January 13, 1998, meeting with legislators, a group of parents of deaf children stated: "Barriers to an emphasis on education in the Schools for the Deaf appear to be related to the eagerness of the Division of the Deaf and Hard of

Hearing to hire 'politically correct' deaf and hearing teachers, institute ASL [American Sign Language] voice-off strategies, and [to promote] deaf culture."²¹

Deaf culture is, in fact, a formidable force. It is not simply a subculture of the American mainstream but is a culture with its own language — American Sign Language — which is not a visual representation of English. Like any culture, it can seem foreign to those who are not part of it — to people who can hear — yet it provides a richness of experience, folklore, history, etiquette, art, and other factors that can enhance the lives of the deaf and hard of hearing, many of whom feel that they have been treated paternalistically and poorly by the culture of the hearing.

Numerous challenges face those who educate the deaf, and those challenges have not always been met. The 1988 Presidential Commission on Education of the Deaf stated that "the present status of education for persons who are deaf in the United States is unsatisfactory."²² A recent report issued by the Eastern North Carolina School for the Deaf (ENCSD) in Wilson noted that people with hearing impairments on average read at a third-to-fourth grade level and that "on average, ENCSD students are performing below the national average of students who are deaf and hard of hearing."²³

End-of-grade test results from 1994 through 1997 have left both parents and educators at the N.C. Schools for the Deaf dismayed. The reading passing rate rose, but only from 3.9 percent to 5.2 for these schools' students who took the test; math

scores rose from 13.4 percent to 18 percent but then fell to 11.3 percent. Scores dropped yet again in 1997–98, with 4.5 percent of students taking the reading test passing and a passing rate of 6.5 percent for those math students taking the test.

"The numbers have dropped, but a lot of things have changed," says Rachael Ragin, coordinator of early intervention and accountability for the three schools at the division level. In 1995–96, for example, only 56 percent of students who took the test were tested at the appropriate grade level. That number rose to 78 percent in 1996–97 and 100 percent in 1997–98. The percentage of students taking the test also rose, from 42 percent in 1995–96 to 78 percent in 1997–98. "We're testing about twice as many children, and we're testing them on grade level," says Ragin. "To me, those are significant improvements in the program, but I would like to see more children passing. I'd like to see all of the children passing."

An internal division report notes that mainstreamed hearing-impaired students who are not exempted from testing have a passing rate of less than 35 percent.²⁴ The report cautions that differences in these two groups other than academic ability and educational environment may affect the scores, but does not elaborate.

Division leaders are straightforward in saying that "the results are not pretty"²⁵ and say they have taken steps to correct them. The leadership has been changed at each of the schools, but an extensive assessment of student performance started only in 1997 as a basis for strategic planning. Some par-

Table 3. State Funding for Training Schools and Community Services, 1996–97

	State Spending (millions)	% of Total Spent	Children Served	% of Total Served	Unit Cost
Training Schools	\$39.4	57%	836 average daily population — total number served, 1,930	4%	\$48,411 per bed per year
Community Services	\$30.2	43%	47,919	96%	\$631 per child

Note: Community service programs also receive nonstate funds. Total spending from all sources for these services in 1996–97 was \$51.8 million, or \$1,079 per child. The state received \$681,819 in federal funds for training school use in 1996–97. This nonstate figure is not included in the \$39.4 million above.

Source: Richard F. Rideout, *Division of Youth Services Sourcebook: 1997*, Raleigh, N.C., pp. 5, 29, and 34.



Karen Tam

ents have called for the schools to be placed within the Department of Public Instruction, but division leaders believe the problem has to do with longstanding “paternalistic” efforts to maintain rather than educate students, and that these are being addressed. Also, these three schools, like the Governor Morehead School for the Blind, are part of a cradle-to-grave health care and assistance continuum for people with these disabilities and may not mesh with DPI’s mission.

The Schools for the Deaf and the Governor Morehead School have been exempt from the state’s ABCs of Public Education program, under which all of North Carolina’s other public schools operate. The ABCs program charts student and school progress in core subjects in lower grades and progress in content areas in upper grades. Educators are given incentives — financial bonuses — to surpass their school’s mandated progress rate, and students who perform poorly on tests may be held back or required to attend summer sessions. Even within the ABCs, special needs students may be exempted from testing, but that decision must be reached jointly by the members of the student’s Individualized Education Plan committee, which includes parents.

In 1998, the General Assembly passed House Bill 1477,²⁶ sponsored by Rep. Gene Arnold (R-Nash), which will require these and all of North Carolina’s state-operated schools to be a part of the ABC program. It also will provide teachers with higher pay but cut administrators at the Schools for the Deaf by half. In addition, it requires closer supervision of students, a requirement growing out of spring 1998 reports of student-on-student sexual abuse at the Schools for the Deaf.

Twenty-two million dollars (78 percent) of the Division of Services for the Deaf and Hard of Hearing’s \$28.1 million budget goes to the three schools, which serve less than one-third of the state’s hearing-impaired students. A 1993 study recommended that, because of the cost, one or all of the schools be closed, but the report eventually was shelved.²⁷ The total cost per K–12 student ranges from \$40,472 to \$42,159, or approximately \$27,000 exclusive of residential costs. (See Figure 2, p. 92.) The cost for preschoolers ranged from \$10,547 to \$14,348. For both groups, the costs at Central North Carolina School for the Deaf in Greensboro were highest. The Division of Services for the Deaf and Hard of Hearing estimates that the cost of educating a hearing-impaired student for

one year in the public schools ranges from \$16,000 to \$23,000, depending on how much funding the local school system can allocate to this population. The Department of Public Instruction puts the figure far lower.²⁸

The schools also operate a network of early intervention services and preschools within their geographic areas. Most deaf children in North Carolina arrive at school — whatever that school might be — with a language delay of two to four years, a developmental period that is never regained. A later lack of educational achievement results at least partly from this loss.

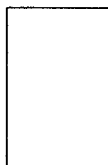
The Governor Morehead School is the center of the state's services for the blind. It is home to only about 100 residential students each year, but it operates preschools around the state that serve 300 visually impaired children, serves as a conduit for continuing education for educators, oversees a master's degree program in blind services, undertakes student assessments in the public schools, and coordinates other services. Over the years, it has educated a number of notable people, including folk singer and guitarist Doc Watson, country singer Ronnie Millsap, and jazz pianist Paul Montgomery.

**Figure 2. Cost of Attending
N.C. Schools for Deaf versus
Public Schools for Hearing-
Impaired Students**

Schools for the Deaf
\$27,000 per year*



N.C. Public Schools
\$16,000–23,000
per year**



* Minus residential costs.

** N.C. Division of Services for the Deaf and Hard of Hearing estimate. The Department of Public Instruction considers this estimate too high. See note 28, end of article, for more.

Source: N.C. Division of Services for the Deaf and Hard of Hearing.

Eighty-four percent of the Governor Morehead School's residential students qualify for free/reduced price lunches, and 60 percent have multiple disabilities. Similar to students at the schools for the deaf, they generally score significantly lower on end-of-grade tests than do their visually impaired mainstreamed peers. In 1996–97, for example, 5.9 percent of Governor Morehead students taking tests passed end-of-grade reading tests in grades three through eight, while statewide 34 percent of visually-impaired students passed. End-of-course scores for high school students were similarly lower at the Governor Morehead School. In 1997–98, the Governor Morehead School came under the state ABCs plan as a pilot project. Test scores increased significantly, with 42.9 percent of students in grades three through eight passing the reading test. High school students showed similar improvements, and one re-mainstreamed Governor Morehead School student made the honor roll at the Wake County Public Schools' Broughton High School.

Governor Morehead students represent a subgroup of visually impaired students with stronger needs than many of their peers. A report by the N.C. Division of Services for the Blind notes that the school "is doing the job it was set up to do . . . meeting the needs of those students with visual impairments *whose needs cannot be adequately met by local school districts*" (emphasis added) but that the Governor Morehead School and the public schools are not adequately preparing visually impaired students for the future.²⁹

Part of the solution has been to make the Governor Morehead School the center of a hub of services rather than an isolated campus. For example, the school is one of 12 sites in a collaborative effort with the Department of Public Instruction to create alternative tests for special needs students, not just those who are visually impaired. It also is actively exploring the opportunities that new technology will open for the visually impaired, having successfully competed for \$373,000 in federal and University of North Carolina-General Administration grants for distance learning technology in 1997–98.

Charles M. Bernardo, hired as the school's new superintendent in June 1997, had been, among other things, superintendent of the Montgomery County, Maryland, school district, one of the nation's largest. He brought a regular education background to the job.

"My background would have led me to believe that the school should be administered through the Department of Public Instruction, but

In time — I don't know how many days or weeks or months it was — my stylus finger grew, my hand grew, my strength grew, and I learned to align the paper on the slate properly and write Braille correctly. I remember that in order to memorize which dots stood for which letters I would think of combinations of dots as telephone numbers, and of the letters formed by the combinations as standing for members of my family. When I punched (or dialled) one, three, six, I got "u," for Umi; when I punched one, two, three, four, I got "p," for Pom; when I punched one, three, four, I got "m," for Mamaji. The Braille letters would race through my fingers into the stylus, along the guide, and down the slate, filling the paper with simple English words, like "cat," "mat," and "sat."

—VED MEHTA FROM "BELLS"

from *Staring Back — The Disability Experience From The Inside Out*

we work very closely with the people there, so where we fall on the administrative chart doesn't really matter," Bernardo says. "There is a structural but no operational divide."

He adds that the school has maintained the support of parents by being part of a cradle-to-grave care program and by assuring them that the school operates like a standard public school but with special services. The school works closely with DPI on teacher licensure, training, and design and delivery of the curriculum.

The 1996-97 state appropriation for the Governor Morehead School was \$7,764,000.³⁰ It cost \$21,070 to educate a student there in 1997-98 — exclusive of residential costs. The school served 1,447 clients directly, although most of these were educators of the blind. Of the children it served directly, 100 were students at the school, 300 were enrolled in satellite pre-school programs, and 30 were part of a new, short-term skills program for visually impaired, public school students in grades K through 8. By contrast, a total of 572 visually impaired students were taught in the state's public schools in 1996-97. The most rapidly growing part of the school's enrollment is its satellite pre-school program, where enrollment is expected to exceed 500 by the year 2000.

The numbers of hearing and visually impaired children are not increasing at the same rate as those of other special needs children, but those numbers rise as the state's population grows, and even inter-

nal reports indicate dismay with the educational progress of deaf and blind children. Rep. Arnold's bill holding these schools accountable under the state ABCs plan will provide at least a basis for comparing educational achievement at these schools with similarly impaired children statewide and with the general population.

Children with Developmental Disabilities

A primary issue for children with developmental disabilities is the backlog of people awaiting services. Currently, 7,178 people are on the waiting list statewide, including 2,138 children. (See "Legal Issues Affecting People with Disabilities," pp. 69-77, for more on this topic.) Also of concern are how services will be delivered and paid for and where people will receive these services. (See "A Tale of Two Funding Streams," pp. 95-97 for more on this topic.) The vast majority of state appropriations in the developmental disabilities area are spent on community-based services. In 1996-97, \$93 million of a \$115 million state appropriation went to community-based programs, and 31,522 people were served in community programs, while 2,200 were served in five state mental retardation centers. Almost all children under age 18 were served in community programs, with only 24 children under age 18 in the state's five retardation centers in 1996-97.

Willie M.

Dre is not a Willie M. child, but if the level of his aggressive behavior had been a little higher, he might have been. The term *Willie M.* comes from a class action suit filed against North Carolina in 1979 on behalf of four named children but for the benefit of a larger group: those with a mental, emotional or neurological handicap and accompanying violent and assaultive behavior who had already received some state-funded treatment and had been recommended for residential treatment or had been adjudicated delinquent and had received subsequent treatment or had been assigned to a psychiatric hospital.³¹

In North Carolina, a citizen does not have a constitutional right to mental health treatment like he or she does to a public education.³² However, under a series of federal and U.S. Supreme Court decisions, if the state intervenes in the life of a family to remove a violent child from the community, it must provide treatment, and if a child is judged delinquent and taken from his or her home, whatever subsequent action is taken by the state must be done in the best interest of the child. Unfortunately, the state had no programs to treat these specific children in the late 1970s, and thus the suit was filed.

The court-appointed review board and the state agreed that Willie M. funds would go directly to the program rather than pass through the Department of Health and Human Services (then the Department of Human Resources). That funding system, coupled with the state government's initiation of a unit-cost reimbursement system for accounting purposes in 1983, allowed the Willie M. Section to monitor its costs and outcomes far better than most programs. The suit was finally resolved in early 1998, and a recent report indicates that, while the program was costly, it has been effective at treating these children, for the most part at the community level:

- The total Willie M. budget for 1996–97 was \$82.3 million, of which 68 percent came from state funds and 32 percent from federal Medicaid funds. (Of the 68 percent, \$50.5 million came from the Department of Health and Human Services and \$5.6 million came from the Department of Public Instruction.)
- \$73.8 million (90 percent) of the Willie M. program's total budget went for treatment and habilitation services, of which 57 percent went to group residential services or secure facilities such as hospitals.

- Eighteen hundred children were served at an average cost of \$40,000 each.
- 42 percent of the children cost less than \$20,000 each to treat, while 10 percent (in secure residential settings) cost more than \$100,000 each.³³

"Yes, it's expensive," says Marci White, former Willie M. section chief, "but these are kids for whom we have a legal responsibility." She cites the following as evidence of the program's success:

- 80 percent of Willie M. children are living in their communities.
- Of the 1,500 children served in 1996–97, fewer than 30 were in training schools.
- 86 percent of Willie M. kids are enrolled in school.
- Most had not been physically violent (59 percent) or in contact with the law (75 percent) within the three months prior to the most recent survey.³⁴

The Willie M. program assesses how many risk and protective "factors" these children have, both when they are admitted to the program and regularly thereafter. The factors are drawn from extensive research into social pathology. Any child with four or five of the risk factors (such as physical or sexual abuse or poverty) is considered "high risk;" Willie M. children generally have 12 or 13. Protective factors (an intact family, for example) are bulwarks against the risks. Willie M. children, who receive extensive social and emotional treatment, add four protective and two risk factors a year on average, according to White. She submits that while no program can guarantee success in life, the Willie M. program has succeeded at its mandate and within its budget.

Dre Returns to the Burgeoning Numbers of Children Being Served in Communities

The explosion in the number of special needs children being served by community-based services will continue. The state's desire for people to be treated in community programs has led to an expansion of local resources. At the same time, the number of people identified as having special needs has increased. The state budget is likely to see greater overall costs as the numbers of people receiving community services grows, although the per-person cost will remain lower for community services than for institutionalization.

But back to Dre. After leaving the Children's Psychiatric Unit at John Umstead Hospital, he was admitted to Greenhouse, the residential youth home in Durham, and attended public schools. He stayed for about three months, was discharged briefly when he became disruptive, and returned to Greenhouse. The per-person, per-day cost of a Greenhouse bed is a little more than \$150.

Let's estimate the costs of public service Dre received in the first half of 1998, rounding some numbers and making reasonable assumptions about attendance at sessions:

- \$2,000 for Fast Track;
- \$18,000 for a 120-day stay at the group home;

- \$2,100 for weekly individual therapy (assuming he attended twenty sessions over the course of six months);
- \$2,340 for special education; and
- \$10,416 for thirty-one days in the Children's Psychiatric Unit at John Umstead Hospital.

These total to \$34,856 worth of publicly funded services provided by public or nonprofit organizations over six months. It's a ballpark figure but a reasonable one based on actual costs-for-services and realistic assumptions. Of course, the past year was a particularly difficult one for Dre. Prior to 1997, he had not required any in-house

A Tale of Two Funding Streams

—continued

Program allows funds to follow people, creating options for people to be supported in their own homes or in very small (1-3 person) settings.

Despite providing waiver services to fewer people than is the case nationwide, Porter says that the CAP/MR-DD funding stream has grown by 650 percent in North Carolina over the past five years. She adds that for 1998-99, the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services will add 1,700 federally allocated CAP/MR-DD "slots" (roughly equivalent to people) to CAP/MR-DD with \$15 million in new federal funding, of which the state's share is \$6 million.

Porter also notes that the CAP/MR-DD funding stream is not the only source for community funding available in North Carolina for serving people with developmental disabilities, as is the case in some other states. North Carolina actually spends the lion's share of its own money on community programs. In 1996-97, out of a total appropriation of \$115 million, the state spent about \$9 million on the five retardation centers and \$93 million on community programs. One report cites North Carolina as one of 15 high-growth states in fiscal effort to fund community services for people with developmental disabilities between 1992 and 1996. Unlike most of the 15 states, North Carolina's funding growth did not come in the face of law-

suits.⁹ In North Carolina's communities, 31,522 people with developmental disabilities were served in 1996-97, compared to the 2,200 in the five retardation centers. Still, 5,830 people were on waiting lists for services that year.

Porter and Riddle agree that there is an extensive waiting list. In fact, 7,178 developmentally disabled people are currently on Area MH/DD/SAS program waiting lists for services in North Carolina. Of those, 2,138 (30 percent) are children. About 2,200 (30 percent) of the people on waiting lists, according to Porter, are not eligible for either Medicaid stream, because they are not sufficiently disabled. These people are dependent primarily on state funds for services.

The 1997 study, "Where Does North Carolina Stand?" concludes by stating: "Considering only Medicaid-reimbursable services, North Carolina's level of fiscal effort is comparable to other states. However, the concentration of above average ICF/MR and below average HCB [home-community based, or the CAP/MR-DD program] waiver utilization means that fewer people are supported per Medicaid dollar expended in North Carolina than in the nation as a whole." Porter says this will change with the addition of the 1,700 new "slots."

In 1996, according to the study, it cost an average of \$57,123 per year to serve a developmentally disabled North Carolinian who is eligible for long-term services. The U.S. average was \$47,711, although Porter cautions that different states use different criteria for determin-

treatment, but there is no guarantee he will not need it again. As he moves into adolescence, any outbursts will be deemed more dangerous by those around him.

Building a Better System

The state faces at least three major challenges in serving children with special needs and their families: (1) the number of children requiring special education and/or other special services is growing; (2) more treatment options are needed to serve them; (3) and finally, it is in the interest of the federal, state, and local governments to provide

ing their costs and that figures may not be comparable.

In its final report of October 1997, the North Carolina Managed Care Customer Leadership Initiative — a diverse group of people with disabilities and their families, funded as a project of the N.C. Council on Developmental Disabilities — has called for the pilot demonstration of a capitated system. In it, people with developmental disabilities and their families would have significant control over the public funds that provide their services and supports. The group recommends the development of an “individual budget.” This budget, translated into a voucher, would allow a person with a developmental disability to purchase in an open market the services and supports called for in a person or family-centered plan.

“Customers” — as the report labels people with disabilities or their families — would be assisted in this process, at their election, by a “support broker” or “community guide,” accountable to the individual or family as opposed to the service provider sector. This approach, the report contends, would allow a customer to tap the informal supports of family and friends, along with generic community and specialized services, to create a package that meets his or her unique needs.

As it is, Developmental Disabilities Council director Riddle says, the ICF-MR system provides each person with a full menu of costly services that, in many cases, sets the boundaries of choice and exceeds the standard of “no more

services as cost effectively as possible. Addressing these three issues is the immediate and long-term challenge facing the state. For the past several years, it has been crafting what it hopes will be a viable solution.

Carolina Alternatives (CA) is a Medicaid pilot program under way since 1992–93 at 10 of the state’s 40 area mental health authorities, covering 32 counties.³⁵ It serves children exclusively and is a mental health program rather than a program serving children with developmental disabilities. At its core is a waiver of traditional Medicaid fee-for-service provisions and guidelines as to what services may be provided for clients and by what

or no less than what is needed.” Even the Community Alternatives Program, Riddle says, has long narrowed customer choice to pre-approved providers. “This often significantly decreases customer access to services and supports essential to achieving life goals and outcomes consistent with increased economic productivity and full citizenship,” Riddle says. “A system such as that outlined by the Customer Leadership Initiative promotes self-determination.” Systems based on principles and practices of self-determination will, Riddle believes, ultimately enhance customer satisfaction. This, she says, will decrease overall costs and promote inclusive schools, workplaces, and communities for those affected by developmental disabilities.

—S.D. Williams

FOOTNOTES

¹ Patricia Porter, section chief of Developmental Disabilities, telephone interview with the author, August 8, 1998.

² Gary Smith, *Where Does North Carolina Stand?* N.C. Managed Care Customer Leadership Initiative, Raleigh, N.C., June 1998, pp. 3–4.

³ Statutory authority for the Council on Developmental Disabilities is found in G.S. 143B-177.

⁴ Patricia Porter, memo to the author, August 10, 1998.

⁵ Smith, p. 11.

⁶ *Ibid.*, p. 4.

⁷ *Ibid.*, p. 6.

⁸ *Ibid.*, p. 11.

⁹ David Braddock et al., *The State of the States in Developmental Disabilities*, fifth edition, American Association on Mental Retardation, Washington, D.C., 1998, p. 50.

providers. A full year of Medicaid funds are given at the beginning of the fiscal year to the 10 local authorities, based on standard projections and history of previous need. These "block grants" become the basis of a public-private system of managed care, overseen by the local authorities. They may use the money as they feel best and are responsible for spending within their limits.

Because it is a newer program and because its children utilize a variety of services in order to achieve myriad outcomes, Carolina Alternatives cannot track success or failure at the client level as easily as the Willie M. system. The financial end of the concept, however, is simple: the area authorities are directly responsible for their Medicaid payments. Under the traditional nonwaiver system, if a county decides to send a child to a state hospital, Medicaid pays the fee directly to the hospital, with no consequences for the area authority's budget. In Carolina Alternatives counties, that money comes directly from the local budget. Thus, community-based treatment and fiscal responsibility are rewarded. According to the N.C. Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, total annual Medicaid expenditures and average Medicaid expenditures decreased substantially in 1996 and 1997, while the same expenditures rose dramatically in non-Carolina Alternatives counties.

But what about quality of treatment? Carolina Alternatives is, after all, managed care and easily prone to the same fiscally motivated restrictions that some complain about in private medical managed care.

So far, Carolina Alternatives is getting good marks from people in the mental health field. "We like working with Willie M. and Carolina Alternatives-county kids, because they have more comprehensive support and treatment services available to implement the new strategies we recommend to support successful community-based care in their communities," says Wright Schools director Deborah Simmers.

"As soon as a client of ours goes to a state institution, we assign a case manager to work with the social worker at the institution and with other community providers," says June Kersey, the Carolina Alternatives coordinator at Orange-Person-Chatham Mental Area Authority. "It makes good sense to do this even in a non-CA county, but we've strengthened our case management because of the increase of our overall responsibility under the waiver."

Under Carolina Alternatives, Kersey says, the

Orange-Person-Chatham Area Authority has the flexibility to contract with a broader range of service providers. Thus, Carolina Alternatives can pay for paraprofessional counselors to conduct regular home visits as well as, for example, private clinical social workers for therapy. "Our provider panel has grown to 90 types of agencies, facilities and individual providers," Kersey says, "so we can more easily treat kids with special diagnostic needs."

Carolina Alternatives also has succeeded in increasing the numbers of people who receive mental health services. The *penetration rate* in Carolina Alternatives counties — that is, the percentage of people served out of all people estimated to be eligible for services — was 5 percent in 1992 and 8.5 percent in 1997. The 1997 rate for non-Carolina Alternatives counties was 6.4 percent.

The N.C. Division of Mental Health, Developmental Disabilities and Substance Abuse Services plans to extend Carolina Alternatives to all 100 counties for mental health services and to include adults as well as children and non-Medicaid patients, says Judy Holland, former head of the division's Carolina Alternatives Branch. But because of the ramifications of the accounting change for the state's match of Medicaid funds, the expansion has been postponed.

Finally, Carolina Alternatives may offer a way to moderate the state's costs for institutionalization. When asked her opinion about studies suggesting that children not be treated in the state's psychiatric hospitals, June Kersey said, "Get real. The hospitals provide an invaluable service and for the most part do an excellent job. What we need are more, not fewer, treatment options for children."

The traditional, nonwaiver Medicaid system, however, financially rewards hospitals for admitting and keeping patients, although the system has become more restrictive over the years. Carolina Alternatives takes the opposite approach. Local communities — not the state or federal governments — are the purchasers of hospital services, and their demand for services could determine the extent and nature of the supply of those services. Because the funding for these hospital services comes out of local budgets, there is an incentive not to overuse those services.

Conclusion

The numbers of children requiring special educational, psychological, and/or other special services is growing at a faster rate than the general population and the youth segment of that popu-

lation. Why? The reasons are numerous and complex. Here are a few: educators are doing a better job of identifying students in need of special education, with attention deficit disorder and its companion, attention deficit disorder hyperactive, fueling growth in at least three categories that entitle children to special education services — specific learning disability, behaviorally emotionally handicapped, and other health impaired. There also is less stigma attached to special needs, making more parents and children willing to come forward for help.

Many more children with special needs are being treated in their communities than in institutions. The number of people served by community mental health programs in North Carolina grew by more than 3,000 percent — from 8,196 to 277,043 between the years 1960–61 and 1996–97, a period during which the state's population grew by 61 percent. Meanwhile, the number of persons receiving institutional care at state-operated facilities actually dropped during the 36-year period, from 23,327 in 1960–61 to 20,979 in 1996–97. Yet community mental health programs — while serving 93 percent of clients — received only 57 percent of the \$1.4 billion spent for services through the Division of Mental Health, Developmental Disabilities, and

Substance Abuse Services in the N.C. Department of Health and Human Services during the 1996–97 fiscal year.

Granted, most of the individuals served in the state's five regional mental retardation centers are much more disabled (and thus more costly to serve) than those persons living in the community. The same may be true of individuals housed in the state's mental hospitals. But this fact does not account for the entire imbalance in state funds going to these institutions in relation to the number of persons they serve.

The N.C. Center for Public Policy Research found similar discrepancies in proportion of total state expenditures compared to number of persons served at other types of state institutions serving children with special needs. Examples include training schools in the Division of Youth Services, and the N.C. schools for the deaf and blind. In the Division of Youth Services, the state spent \$39.4 million on training schools compared to \$30.2 million on community alternative programs. But training schools housed only 3.2 percent (1,930) of the 56,344 juvenile offenders served during the course of the year, while almost 48,000 youth received services through community programs.

The state's three schools for the deaf provide another good example. Twenty-two million dollars (78 percent) of the Division of Services for the Deaf and Hard of Hearing's \$28.1 million budget goes to North Carolina's three schools for the deaf, which serve less than one-third of the state's hearing-impaired students. For each deaf K–12 student, the cost is \$40,472 to \$42,159, depending on which of the schools the student attends. Students served in their home school districts are educated for an estimated \$16,000 to \$23,000 annually.³⁶ Such cost discrepancies might be justified if students at these state schools were receiving stellar services. But consider these facts: on end-of-grade test results, deaf students lag far behind their hearing-impaired peers educated in local school districts; books in the schools' libraries are out of date; and recently reported instances of sexual abuse of students have raised serious questions about the quality of residential care. While it may be that students with the most serious disabilities are the ones enrolled in state institutions, it's equally clear that these students' needs are not being fully met.

As to the imbalance of funding for state institutions versus community-based organizations, clearly it is due in part to the operating costs associated with large, state residential facilities housing clients with the toughest problems. The



challenge to the state, however, is this: How can it make sure that its funds serve the needs of people rather than the needs of programs?

The answer to this question is less than clear. Cutting funds to the state psychiatric hospitals, special schools such as Wright and Whitaker, training schools, and the schools for the deaf and blind could free money for community programs, but simple budget-shifting or cost-cutting presents problems. First, residential facilities do serve a need. Like Dre, some children benefit greatly by receiving services in secure settings. When not only he but his family is in crisis, there really is no place else for him to go. The group home in which Dre lived for much of the first half of 1998 provides supervision, but it is not a secure facility and is not designed to keep children when their behavior becomes dangerous. In the mental health field, many community programs are not able to accommodate children who are violent or suicidal, and children in state facilities often have been in and out of numerous local programs, with limited success. Treatment and education in a secure facility can at times be the best hope for certain children. At mental hospitals, training schools, and state schools for the deaf and blind, a higher level of service or care sometimes is required than is available at the community level.

The second argument against a simple "cost cutting" solution is even more straightforward. If funds to state facilities are cut, there is no guarantee that the money then will flow to communities — in current parlance, there's no guarantee that the money will "follow the children." In the early 1980s, when deinstitutionalization in the mental health field was put into practice in North Carolina, community mental health practitioners essentially were given responsibility for a growing number of discharged mental health patients and other clients but without increased funds or plans to accommodate the increased population. In other words, the funds did not follow people to the local level.

Institutions such as the schools for the deaf and training schools for children in trouble with the law face similar difficult questions. Does the state need three schools for the deaf? A 1993 study by KPMG Peat Marwick for the legislature's Government Performance Audit Committee recommended closing one or all of the schools. Are students who attend these schools receiving an adequate education and the necessary life-skills training to be productive citizens, or can more of these students be served more effectively and at less expense in their local school districts? Can more funds be allocated to

community-based juvenile justice programs versus training schools in the face of the Governor's juvenile justice initiative?

Recommendation

While it is true that some children need the higher levels of service that can be provided at state institutions such as mental hospitals, training schools, and special schools for the deaf and the blind, the imbalance in the amount of money spent at these residential institutions versus the number of persons served should give policymakers pause. Clearly, this is an issue that calls for further study. Thus, the North Carolina Center for Public Policy Research offers the following recommendation:

The North Carolina General Assembly should establish a study commission to examine the imbalance of dollars going to state institutions in relation to the number of persons they serve. The commission should comprise not only legislators but voting representatives from the Department of Health and Human Services' divisions of Mental Health, Developmental Disabilities, and Substance Abuse Services, Youth Services, Services for the Deaf and Hard of Hearing, Services for the Blind, and the Willie M. Services Section.

The study commission should be charged with examining three questions: (1) *First, it should look closely at the question of whether the amount of dollars flowing to state institutions is appropriate relative to the number of children with special needs served there.* Is institutional care too expensive or are costs justified due to the expense of maintaining buildings and administering programs? A corollary question to examine is whether community-based programs receive sufficient funding to meet the needs of their varied and growing clientele. Are costs for room and board reflected in reported community-based program costs? (2) *Second, the commission should examine ways to measure the effectiveness of both residential and community programs with a three-year trial period so that future funds can be directed to the most effective programs, whether residential or community-based.* (3) *Third, the study commission should examine ways to reduce the waiting list further for services for persons with developmental disabilities.* The study commission should report to the 2000 session of the N.C. General Assembly with specific findings and recommendations.

Neither the heroic foot-borne relief efforts, anticipation of the horrors ahead, nor the brilliance of the scenery around me struck home as much as the rhythm of the donkey's forelegs beneath my hips. It was walking, that feeling of groping and climbing and floating on the stilts that I had not felt for fifteen years. It was a feeling no wheelchair could convey. I had long ago grown to love my own wheels and their special physical grace, and so this clumsy leg walk was not something I missed until the sensation came rushing back through my body from the shoulders of a donkey. Mehmet, a local Kurd and the owner of the donkey, walked ahead holding a harness. I had rented the donkey for the day. I insisted that Mehmet give me a receipt. He was glad to oblige, I submitted it in my expense report to National Public Radio. The first steps I had taken since February 28, 1976, cost thirty American dollars.

It was a personal headline lost in the swirl of news and refugees. I had been in such places before. In my wheelchair I have piled onto trucks and jeeps, hauled myself up and down steps and steep hillsides to use good and bad telephones, to observe riots, a volcano, street fighting in Romania, to interview Yasir Arafat, to spend the night in walk-up apartments on every floor from one to five, to wait out curfews with civilian families, to explore New York's subway, to learn about the first temple of the Israelites, to observe the shelling of Kabul, Afghanistan, to witness the dying children of Somalia. For more than a decade I have experienced harrowing moments of physical intensity in pursuit of a deadline, always keeping pace with the rest of the press corps despite being unable to walk. It is the rule of this particular game that it be conducted without a word of acknowledgment on my part. To call attention to the wheelchair now by writing about it violates that rule. My mind and soul fight any effort to comment or complain, even now, years after the events I write about.

This quiet, slow donkey ride was easily the farthest I had gone, out onto a ledge that was never far from my mind during the fifteen years I had used a wheelchair.

—JOHN HOCKENBERRY

"WALKING WITH THE KURDS"

from *Staring Back — The Disability Experience From The Inside Out*

FOOTNOTES

¹ N.C.G.S. 115C-109.

² Nancy Spencer, interview with the author, Durham, N.C., April 1998. The actual average amount per child is slightly less than that stated. Spencer said that some of the budget also went toward a summer program for special ed students but did not provide a figure for this activity. The decrease in the average, she noted, would not be significant, as the summer program is a small part of her budget.

³ Demographic information from North Carolina Office of State Planning website at www.ospl.state.nc.us.

⁴ The federal government also provided \$600 per student in special needs preschool funding.

⁵ N.C.G.S. 122C-262 governs involuntary commitments to mental institutions.

⁶ Office of the Director, John Umstead Hospital, memo to the author, May 1998. A study by an outside consultant in spring 1998 put the cost of serving a child at Umstead at \$442 per day. See MGT of America, *Efficiency Study of the State Psychiatric Hospitals*, Executive Summary, Final Report to N.C. Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, March 2, 1998, p. iii.

⁷ MGT of America, p. vii.

⁸ Every person interviewed for this article with whom the topic was raised, while advocating community-based services in general for children and adolescents with mental illnesses, stated that the psychiatric hospitals provided an essential service for children in need of acute care and that closing children's units would remove a treatment option at a time when increasing the diversity of services is needed. Lenore Behar, chief of child and family services in the state's Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, says child advocates and child welfare professionals from across the state began to oppose the suggestion as soon as the report was released. Lenore Behar, telephone interviews with the author, April 1998.

⁹ Senate Bill 1336 (the 1998-99 state budget bill), Section 29, Section 22.

¹⁰ Allan Spader, telephone interview with the author, April 1998.

¹¹ Lenore Behar, telephone interview with the author, April 1998.

¹² The rate of the state match varies from month to month and state to state, depending on a state's overall economic health, numbers of people served, and other factors. North Carolina's rate has been slightly more than one-third for decades.

¹³ Chapter 166 (HB 900) of the 1998 Session Laws.

¹⁴ Senate Bill 1366 (the 1998-99 state budget bill), Section 29.

¹⁵ Stephen R. Hooper, "The Ecological Outcomes of Adolescents in a Psychoeducational Residential Treatment Facility," draft article, University of North Carolina School of Medicine, Chapel Hill, N.C., 1998, table 4.

¹⁶ N.C. Office of State Planning website at www.ospl.state.nc.us.

¹⁷ Richard Rideout, *Division of Youth Services Sourcebook: 1997*, Raleigh, N.C., pp. 24 and 25.

¹⁸ Richard F. Rideout, telephone interview with the author, April 1998.

¹⁹ *Ibid.*

²⁰ Senate Bill 1336 (the 1998-99 state budget bill), Section 8.1(a)(1).

²¹ Sandy Heffinger, Lorraine Gregory, Patricia Salmon, et al., statement read to legislators and the Commission on the Public Schools, Raleigh, N.C., January 13, 1998.

²² Cited in "The North Carolina Schools for the Deaf: A Presentation to the Legislative Commission on the Public Schools, January 13, 1998" Division of Services for the Deaf and Hard of Hearing, Raleigh, N.C., p. 3.

²³ "ENCSD [Eastern North Carolina School for the Deaf] Strategic Plan Zoned for Learning," Wilson, N.C., July 1997, p. 8.

²⁴ "The North Carolina Schools for the Deaf," note 22 above, p. 10.

²⁵ *Ibid.*, p. 6.

²⁶ Chapter 131 (H.B. 1477) of the 1998 Session Laws.

²⁷ KPMG Peat Marwick, *GPAC Pathways*, prepared for the Government Performance Audit Committee, Raleigh, N.C., 1993.

²⁸ David Mills, section chief for Areas of Exceptionality, Division of Exceptional Children, N.C. Department of Public Instruction, believes the average cost of educating a hearing-impaired student in the public schools would be significantly less than \$16,000 to \$23,000 per year. The total would include a federal allocation of \$488, a state appropriation of \$2,248.39, any local funds allocated for special education, and any additional per pupil expenditures for children receiving a regular public school education. These figures rarely would total \$16,000 to \$23,000 per student.

²⁹ "The Governor Morehead Schools for the Blind: A Presentation to the Legislative Commission on the Public Schools, January 13, 1998," Division of Services for the Blind, Raleigh, N.C., p. 2.

³⁰ Charles M. Bernardo, telephone interview with the author, May 1998.

³¹ Marci White, former chief of the Willie M. Section, Mental Health, Developmental Disabilities, and Substance Abuse Services, telephone interview with the author, May 1998. For more on the genesis and structure of the Willie M. program, see Kendall Guthrie and Bill Finger, "'Willie M.' Treatment for Disturbed Youngsters — Ambitious Community-Based Service System Lurches Forward," *North Carolina Insight*, Vol. 6, Nos. 2-3, October 1983, pp. 56-68. The Willie M. court case was *Willie M. et al. v. James B. Hunt, Jr., et al.*, "Complaint for Declaratory and Injunctive Relief," filed in the U.S. District Court for the Western District of North Carolina, Charlotte Division, October 1979, p. 1, Civil Action No. CC 79-0294.

³² Article I, Section 15 of the North Carolina Constitution states, "The people have a right to the privilege of education, and it is the duty of the State to guard and maintain that right," and N.C.G.S. 115C-107 states that "all children" can learn and that the state has a "duty" to provide children with special needs a "free and appropriate public education."

³³ "Report to the Governor and the General Assembly on the Willie M. Program, 1997-98," (reporting for FY 1996-97), Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, and Department of Public Instruction, Raleigh, N.C., pp. 37-46.

³⁴ *Ibid.*

³⁵ The ten area mental health authorities are Blue Ridge Center, Smoky Mountain Area Program, TREND Area Program, Gaston-Lincoln, Centerpoint, Orange-Person-Chatham, Vance-Granville-Franklin-Warren, Wake, Southeastern, and Foothills Area Program. Judy Holland, head of the Carolina Alternatives Branch, MH/DD/SAS, telephone interview with the author, April 1998.

³⁶ The Division of Exceptional Children in the N.C. Department of Public Instruction says the average cost of educating a hearing-impaired child in the public schools is less than \$16,000 to \$23,000 per student. See note 28 above for more.