

Developmental Disabilities: A Tale of Two Funding Streams

The history of Medicaid funding and services for the developmentally disabled differs significantly from that for the mentally ill and others in North Carolina. It includes two Medicaid funding streams: Intermediate Care Facilities/Mental Retardation (ICF/MR) and Home-Community Based (HCB) Services, the North Carolina version of which is called the Community Alternatives Program for Persons with Mental Retardation/Developmental Disabilities (CAP-MR/DD). Essentially, ICF/MR funds residential services, while CAP-MR/DD was intended to help people living at home and supports community-based services. It does not provide room and board funds. For each dollar of funding in these streams, 32 cents comes from the state.¹ The difference between the treatment options supported by the two funding streams — and the costs of those options — is marked.

A study published in 1997 and updated in June 1998, "Where Does North Carolina Stand?" notes that in 1997, North Carolina had more people in mental retardation institutions per capita than the national average, at 28.8 persons per 100,000 residents compared to 20.0 persons per 100,000 residents nationwide. It stated that in 1997, 2,141 individuals with developmental disabilities were served in large (16 beds or more), "state-operated" facilities.² Holly Riddle, executive director of the North Carolina Council on Developmental Disabilities,³ a state-established council that advocates for people with developmental disabilities, says that while the number of persons per capita served in these facilities has been going down both at the state and national level during the past decade, the percentage reduction in population in North Carolina's Mental Retardation Centers has been significantly below the U.S. average.

While agreeing with Riddle that the trend to move developmentally disabled people from institutions to communities must continue to move forward, Patricia Porter, chief of the Developmentally Disabled Section of the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, disagrees with

some of the 1997 study's assertions. The state operates five regional retardation centers, and the study's inclusion of facilities with more than 16 beds includes many that are privately run. The private facilities are largely funded, however, through the ICF/MR stream.

Porter says that 2,200 (5 percent) of the state's 41,000 people with developmental disabilities receiving services through the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services were served in the state's five retardation centers in 1996-97.⁴ That group included only 24 people under the age of 18. The average cost per bed per day in these centers was \$255.

In 1997, according to "Where Does North Carolina Stand?", it cost on average \$31,558 to support an individual for a year in the community under the Community Alternatives Program (CAP).⁵ It cost \$88,695 to keep a person in an intermediate care facility under ICF/MR.⁶ This includes room and board and comprehensive 24-hour care and services, while the Community Alternatives Program costs do not include these services. Despite these costs, and the state's long history of advocacy for serving people with developmental disabilities in communities, North Carolina treated only 52.3 developmentally disabled people out of 100,000 in the general population through the community-based funding stream (CAP MR/DD) compared to the national rate of 88.5 per 100,000.⁷ In addition, North Carolina is providing home and community-based waiver services to 39.6 percent fewer people per 100,000 residents (50.6) than is the case nationally (83.8), and its percentage of Medicaid dollars spent on Intermediate Care Facilities (77.4 percent) is disproportionate to the percentage of Medicaid recipients housed in these facilities (56.2 percent).⁸

Riddle says eligibility for the two programs is the same. A key difference in how the funding streams work, she says, is that the Intermediate Care Facilities program attaches funds to facilities, while the Community Alternatives

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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

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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.