

Obtaining Child Mental Health Services Through Medicaid: The Experience of Parents in Two States

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With the significant advances in mental health services for children over the past decade, an array of effective, evidence-based interventions can now be provided to children in the community, which means that many children now have the opportunity to remain with their families and peers (1). During the same period, states across the nation have adjusted their Medicaid programs to include these effective services (2). Nevertheless, many children do not receive such services. The President's Commission on Mental Health found that the "mental health maze is more complex and more inadequate for children" than for adults and that families cannot get an "accurate diagnosis for years" (3).

In 2002 the Bazelon Center for Mental Health Law conducted a series of focus groups with parents of children who had a diagnosis of a serious emotional disturbance and who were receiving Medicaid in order to gain a deeper understanding of their experiences. The focus groups investigated whether the expansion in the range of children's mental health services described in the Medicaid state plans has resulted in receipt of these services by children in two states. New York and Oregon were selected because of

the comprehensiveness of their Medicaid child services plans. Sixty-eight parents discussed their experiences with 86 children and adolescents. (Visit www.bazelon.org for more detailed information on the study.)

In this column we discuss four common experiences of parents seeking treatment for their children and adolescents: crisis-oriented systems that delayed identification and treatment, scarcity of child psychiatrists, limited access to intensive services, and the existence of a "cookie cutter" approach to services.

Crisis-oriented systems

Parents reported extreme difficulty in finding mental health providers and public systems that would recognize the severity of their child's disorder. Some parents reported gaps ranging from six to 15 years between the time they believed their child had a mental disorder and the time the system provided a diagnosis of the disorder. A parent of a four-year-old said, "I'm trying to tell them now that children don't normally bite themselves and pull their own hair out. My daughter's doing this and no one will listen." During the period before an accurate diagnosis, many parents saw their children deteriorate.

Many parents reported that providers assumed that they had poor parenting skills. This happened even in the case of families that had adopted children with special needs who would be expected to have behavioral and cognitive problems due to pre-

mature birth or maternal substance abuse. One adoptive parent said, "I knew at three weeks when I received her, because she was born addicted to drugs. She was diagnosed with ADHD [attention-deficit hyperactivity disorder] at four, when they were going to kick her out of preschool. And then the FAS [fetal alcohol syndrome] diagnosis came just this year at 15."

Even when a child did receive a diagnosis, the services provided were usually minimal and inadequate in light of the severity of the child's disorder. Most parents reported that their child's therapy sessions were spread far apart—one to two months between sessions—and that case managers were inexperienced and poorly trained. As a result, children frequently had crises that parents believed were preventable.

Scarcity of child psychiatrists

Although parents reported limited access to all types of mental health providers, finding a child psychiatrist was reported to be the most difficult. Of the small number of child psychiatrists in the states, many did not accept Medicaid at all or were not accepting new Medicaid patients. As a result, many children—both new and established patients—experienced months-long waits for appointments. One parent said, "You get in and there's a three-month wait for an [initial] appointment. To get her meds reevaluated it's another three months, and then, in the meantime, she was off the deep end and out of her mind."

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Lack of access to intensive services

Parents reported that treatment plans emphasized medications and psychotherapy, but many families felt that their children also needed more intensive services, such as in-home services, day treatment, or other supports. Home-based services have a strong record of effectiveness and can help families handle difficult moments with their child (1,4). One parent said, "I feel that if I had gotten some kind of home-based services when he had his greatest need at age 5—because I just was not able to handle what was happening at the time, he was just so overwhelming—if I had somebody come into my home and teach me certain things that I should know about my child, it would have helped."

In some cases, families were expected to handle, at home, children who had extremely serious disorders that providers and treatment teams had recommended for residential care. Yet they had no supports, and their child had little or no services. One parent recalled her experience, "He came home on a stipulation that he was going into residential placement. So he came home to us for a six-month period knowing that he had to go into residential placement, but there wasn't any wraparound service . . . [counseling] was all we were offered."

A "cookie cutter" approach

Most families who received services felt that they had to accept existing services and were given little choice in terms of types of services and providers. The principles of care supported by the federal Center for Mental Health Services emphasize that services must be designed to meet each child's individual needs (5). However, families felt that mental health care providers did not individualize the package or types of services. One parent said, "Sometimes when they tell you this is all they have to offer, this is the best they can do, I've gotten to the point where I tell them, 'I want more than this, I want you to offer something different. . . . No, it's not going to 'have to work'; you're going to do something differ-

ent.'" Even when parents pointed out that what was provided was not helping their child, changes were rarely made.

Conclusions

The findings of these focus groups support the following statement of the President's New Freedom Commission: "Many more individuals could recover from even the most serious illnesses, if they had access to treatment tailored to their needs, to support and services in each of their communities. State-of-the-art treatments, based on decades of research, are not being transferred from research to community settings (3)." Focus group participants in these two states reported that their difficulties began immediately with delays in diagnoses as providers overlooked risk factors. Parents felt that their children with serious disorders did not receive an accurate diagnosis until years after the parents suspected a disorder and then received too few services and the wrong kinds of services to benefit them. ♦

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