

Accessing Medicaid's Child Mental Health Services: The Experience of Parents in Two States

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

In 2002 the Bazelon Center for Mental Health Law sought to gain a better understanding of the experiences of families receiving Medicaid whose children had a diagnosis of serious emotional disturbance. Focus groups were conducted in New York and Oregon to investigate whether children were receiving the expanded range of child mental health services described in the Medicaid state plans (4,5). These states were selected because of the comprehensiveness of their Medicaid child services plans. Sixty-eight parents of 86 youths discussed their experiences.

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In this column we describe four experiences that were common to the parents who participated in the focus groups: crisis-oriented systems in which identification and treatment of disorders were delayed, the scarcity of child psychiatrists, limited access to intensive services, and a "cookie-cutter" approach to services.

Crisis-oriented systems

Many parents reported that it was extremely difficult to find mental health care providers and public systems that would recognize the severity of their child's disorder. Gaps ranging from six to 15 years were reported from the time that parents thought that their child had a mental disorder until the disorder was accurately diagnosed. 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." Many parents saw their children deteriorate before they received an accurate diagnosis.

Parents also reported that providers assumed that they had poor parenting skills. Providers made this assumption even about parents who had adopted children with special needs who would be expected to have behavioral and cognitive problems because of premature 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 al-

cohol syndrome diagnosis] came just this year at 15."

Even when a child received an accurate diagnosis, the services provided were usually minimal and inadequate given the severity of the child's disorder. Most parents reported that their child's therapy sessions were scheduled 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

Parents reported limited access to all types of mental health providers, especially child psychiatrists. Among the few child psychiatrists in the two states, many did not accept Medicaid 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, another three months—and then in the meantime she was off the deep end and out of her mind."

Lack of access to intensive services

Parents reported that treatment plans emphasized medications and psychotherapy, but many families felt that their child also needed more intensive services, such as in-home services, day treatment, and other supports. Home-based services have a strong record of effectiveness and can help families handle difficult moments with their child (1,6). One par-

ent said, “[It would have helped] if I had gotten some kind of home-based services with 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. But if I had somebody come into my home and teach me . . . certain things that I should know about my child, it would have helped.”

Children with extremely serious disorders for whom providers and treatment teams had recommended residential care were expected to be handled at home by their families. However, the families were provided with no supports, and the children received few 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 that 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 (7). However, families felt that mental health care providers did not individualize the types or package 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 different.’” 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 statement of the President’s Commission on Mental Health (3): “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.” The focus group participants in New York and Oregon reported that serious disorders were not accurately diagnosed until years after parents suspected that their child had a disorder and that too few services—and the wrong kinds of services—were provided.

States can improve their child mental health systems by shifting from a crisis-oriented approach that serves few children to a broader approach that emphasizes early identification and community-based treatment. What this will take is cross-agency collaboration, redirection of resources and greater parent involvement. States should fund a significant expansion of evidence-based community rehabilitation services such as day treatment, in-home service providers, and other approaches known to prevent children from deteriorating to the point where they need expensive 24-hour care. State agencies should also work to improve the ability of staff in mental health, child welfare, education and juvenile justice to recognize serious mental disorders and to give greater consideration to parental concerns and environmental factors. Other steps to take include the development of an effective behavioral health screening tool that can be used in pediatricians’ offices to both improve early identification and

meet Medicaid’s screening mandate. Additional recommendations can be found in the complete focus group reports (4,5). ♦

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Submissions for Datapoints Invited

Submissions to the journal’s Datapoints column are invited. Areas of interest include diagnosis and practice patterns, treatment modalities, treatment sites, patient characteristics, and payment sources. National data are preferred. The text ranges from 350 to 500 words, depending on the size and number of figures used. The text should include a short description of the research question, the database and methods, and any limitations of the study.

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