

Legislation aims to improve access to care for mentally ill children



Ray Connor talks with son Shane, 28, outside his home in Oak Park on Sept. 22, 2015. Shane is a beneficiary of an Individual Care Grant for his severe mental illness. Shane is living independently and holding a full-time job, evidence that treatment can work, his dad said. (Antonio Perez / Chicago Tribune)

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Rep. Sara Feigenholtz: State was 'creating a colony of orphans' before change to grant program

New legislation signed recently by Gov. Bruce Rauner aims to give severely mentally ill children better access to residential treatment and intensive community services.

The measure moves the Individual Care Grant program — the main funding source for families struggling to afford treatment — from the Department of Human Services to the Department of Healthcare and Family Services, which should create more flexibility and efficiency, lawmakers said.

Under Healthcare and Family Services, the state's Medicaid agency, the Individual Care Grant — or ICG — can draw federal Medicaid dollars instead of relying solely on state dollars, potentially increasing the number of troubled youth who can qualify for comprehensive treatment. The \$20 million budget and key personnel will also move to DHFS, officials said.

The measure, which passed both legislative houses unanimously and was signed by Gov. Bruce Rauner earlier this month, will be implemented within the next six months.

"If this works, we will get more federal money for mental health, which is urgently needed," said Rep. David Leitch a Peoria Republican and a co-sponsor in of the bill.

An Individual Care Grant assists parents or guardians in paying for some of the costs of care for children under age 18 with serious, chronic psychiatric conditions at approved residential facilities or community mental health agencies.

But in recent years, the grant has become difficult to obtain, with narrow eligibility criteria designed to rein in costs. The biggest barrier to the program is that it requires a child to have a psychosis — such as hearing voices or hallucinating — and excludes children who exhibit other dangerous behaviors, such as suicide attempts.

Some parents have become so desperate that they have relinquished custody of their child, forcing the state to provide care.

"It was a horrible situation," said Rep. Sara Feigenholtz, D-Chicago, the chief sponsor of the bill. "We closed the spigot and were in the business of creating a colony of orphans. But I am hopeful that we are finally rowing in the same direction to benefit children with mental illness in Illinois."

While the legislation does not increase funding or change the criteria for eligibility, proponents say it represents more than moving dollars from one pocket to another. By shifting to DHFS, an agency that may interpret the eligibility criteria more broadly, access could improve, officials say.

"Its goal is to remove unnecessary layers of bureaucracy, consolidate programs related to children's mental health services, and address the crisis of parents choosing to relinquish custody of their children to the state," said Andrew Flach, spokesman for the Department of Children and Family Services, the agency that takes custody of surrendered children. "Ultimately, because DHFS is the Medicaid state agency, they are in the best position to ensure that children who are appropriate for the ICG program receive necessary services to address their mental health issues."

The ICG, established in 1969, was designed to provide financial assistance for those who had failed at all other interventions. But In Illinois, a fraction of children and teens who apply for this level of care are getting it.

In 2015, for the fiscal year ending July 1, 29 children were approved, bringing the total of active youth in the ICG program to 144. In 2010, 60 applicants were approved; in 2005, 107 were approved, according to Department of Human Services annual reports.

Tuition at residential treatment centers — which includes housing, education, medication management, and intensive therapy and supervision — can run \$10,000 a month. The average grant is between \$70,000 and \$75,000, according to DHS.

Many families would go through an arduous application process — including providing dozens of evaluations from clinicians recommending round-the-clock care — to no avail. Families who were denied grants were left with few options, since health insurance rarely covers residential treatment. Some went into bankruptcy or left Illinois for other states to seek assistance.

Still others took the route of last resort: Surrendering children to the Department of Children and Family Services, turning them into wards of the state who are entitled to residential treatment. The number of youth relinquished for mental health treatment has almost doubled since 2011 — from 44 to 85 children as of July 1, according to the agency.

"It became so difficult that people just stopped applying," said Ray Connor, of Oak Park, who started the ICG Parents Group almost 15 years ago.

Connor knows firsthand the better outcomes that can come from providing comprehensive services at an early age. His son, Shane, was at a residential facility for six months at age 13, followed by intensive community services, until age 21. Now, at age 28, he lives independently and holds a full-time job as a warehouse clerk, and is a contributing member of society, Connor said.

The measure was originally drafted to remove the psychosis requirement, but that change was removed.

"I'm disappointed that there weren't more specifics in the final bill," Connor said. "But I'm hopeful that they will be responsive and engage with knowledgeable people to help HFS in redeveloping and managing this program."

Heather O'Donnell, a vice president at Thresholds, a Chicago-based mental health services agency, worked on this issue with lawmakers for two years. The shift to a health care agency will mean "a more liberal, practical and

appropriate view of the eligibility criteria," she said. "It means more kids who need ICGs will get them."

Still, no one should come away thinking the state's mental health problems have been solved, she said.

"This is a step forward, not a panacea. We still have a long way to go."

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