

The Arc of Illinois

March 25, 2010

Leaders in The Arc:

It was an interesting day in the Capitol yesterday. I continue to hear that legislators are going to finish their work May 7th, a good three weeks before the official session end of May 31st! The problem here is that tomorrow legislators leave Springpatch for a two week Spring Break! When they return, they will only have 18 days in the legislative session to pass a state budget that is \$13 billion in the red!

If that is going to be the case, passage of another "lump sum" budget is a very real possibility again this year leaving it to the Governor to decide what gets funded and what gets cut!

Well, you have another opportunity to make your voices heard. When the boys and girls of the State Legislature take their Spring Break, you need to corral them!

Your message:

1. We need new revenue. We cannot cut our way out of a \$13 billion deficit.
2. Revenue needs to be targeted for human services.
3. The 2.5% cuts to community services must be restored.
4. All non-Medicaid grants which were eliminated must be restored.
5. The waiting list of over 19,000 children and adults needs to be eliminated.

Set up your appointments with your House and Senate members in their local office today!

Here is a story that I worked on with Sarah, the reporter from Medill News. Featured in the story are Director Romano, Charlotte Cronin, Gaye Preston and Kristin MacRAE

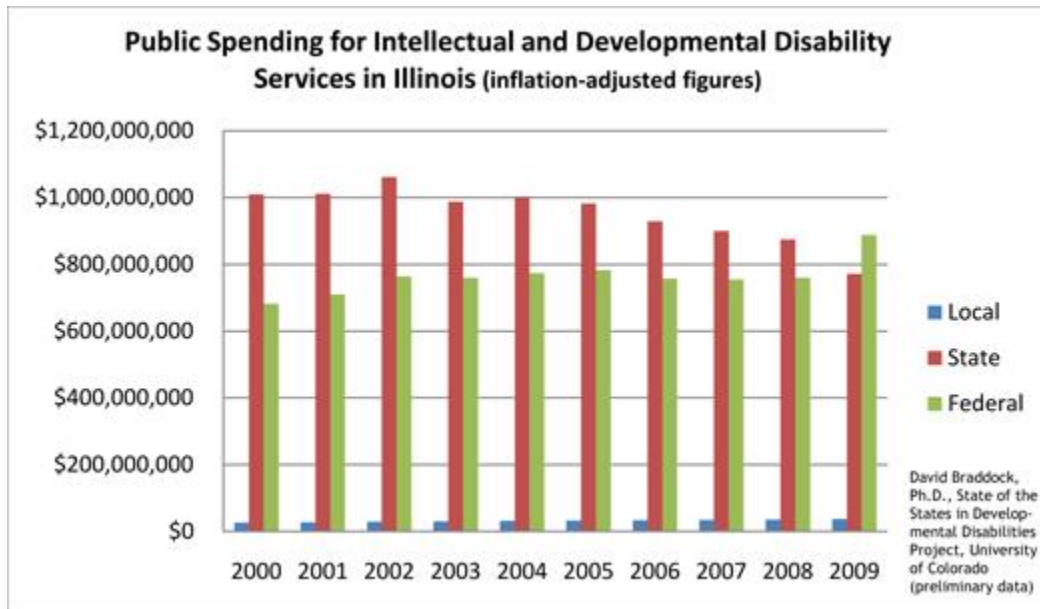
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Sarah Marchmont/MEDILL

In recent years funding for intellectual and developmental disability services in Illinois has shifted dramatically. State funding has decreased by \$200 million dollars in less than a decade, but federal funding is increasing. Illinois is pushing agencies to convert to a funding system that is federally matched so the state funding will decrease even more.

Underfunded disability service providers fear more cuts this year

by [Sarah Marchmont](#)
March 17, 2010

Alex Cruz is 19. He loves music and movies. He's a sociable guy who likes to dance and his mom says he's always performing — he has no problem taking a microphone and getting people to join in the fun.

Alex also has autism.

His mother, Matilda Cruz, is a widow who lost her job in July. The same month, the state stopped funding Community Support Services Inc., which provided services she depended on for help with Alex.

Alex participates in several programs provided by Community Support Services Inc. “They really do help Alex in a lot of things,” said Cruz, a Berwyn resident. “We depend on this program.”

The Cruz family is not alone.

Throughout the state, funding for these programs is tenuous — 12 percent grant funding cuts, funding approved only a few months at a time — and advocates worry the situation will worsen this year.

The more than \$11 billion state budget deficit compounds the problem. “The state has very few options in terms of what services it cuts so disability and human services are sort of hanging out there,” as something that can be cut, said Tony Paulauski, executive director of The Arc of Illinois, a member of a national advocacy group for people with intellectual and developmental disabilities.

The fact that it is an election year adds another layer of complications to the situation. “Now we’re looking at major public policy issues that can devastate the human service safety network,” Paulauski said.

Though Gov. Pat Quinn released a preliminary budget within the last few weeks, there are no details as to what specifically will be trimmed, and Paulauski is worried.

“The governor has said that there’s going to be cuts,” he said. “But there’s no detail there so we don’t know what he has targeted.”

Right now the annual budget for services for people with intellectual and developmental disabilities stands around \$1.4 billion, according to Paulauski. Cost of living increases have rarely been added to the budget in the last several years and, looking at inflation-adjusted dollars, the overall budget is decreasing.

Paulauski and other advocates recommend increasing the income tax and expanding the sales tax as ways to increase revenue. Anyone who says you can cut your way out of this isn’t living in the real world, he said.

“We’re in a doomsday scenario, this is real serious stuff,” Paulauski said.

The waiting list

The developmental disability division of the Illinois Department of Human Services has a system for tracking services individuals are requesting from the state. It’s called the PUNS list— Prioritization of Urgency of Need for Services.

About 19,000 people are on that list, said Charlotte Cronin, executive director of the Family Support Network of Illinois, a statewide advocacy group for people with developmental disabilities.

In some cases the people are receiving some services, but need more, and in other cases, they aren't receiving any aid at all.

"This is a system in complete crisis," she said. "Not only do we have all these people not receiving services, but the services they are receiving are critically underfunded."

One of the goals of the PUNS list is to help with budget planning because the state is more aware of the needs, said Sheila Romano, executive director of the Illinois Council on Developmental Disabilities, a federally funded state agency.

Some people fall into the emergency category, meaning their needs are critical. But Romano said the system has shortfalls — not even all the emergency needs are being funded.

Funding issues with back payments from the state

Besides not having enough money to begin with, the state isn't timely in paying the service provider agencies what it owes.

For Community Support Services Inc., the organization the Cruz family depends on, 70 percent of their budget comes from the state, said Gaye Preston, chief executive officer and president.

When the state doesn't pay the agency, the agency goes to the bank for a line of credit. The banks want other collateral because they know the state hasn't been reliable for payment.

Community Support Services Inc. had to pledge its headquarters to the bank; other organizations are running out of things to pledge.

Last month, the state owed the organization \$750,000, Preston said. "We've maxed out our line of credit."

CSS isn't alone. "Many agencies are on the brink of closing simply because they've used up all their lines of credit," Cronin said.

Hopes for this year's funding

Compared to other states, Illinois' budget for services for people with developmental disabilities has been underfunded for years, Romano said. There are also concerns with the way the money is spent.

Advocates for people with disabilities say too much money is being spent in institutional settings instead of community-based services.

"The money we do spend, we don't spend as wisely as we should," Romano said. "We spend [the money] inefficiently. We spend a large portion on people living in institutional settings and that's a much higher cost."

The CARC supports 1,500 adults with developmental disabilities every month and operates several neighborhood group homes. They can't fill vacancies in a house unless they get a referral from the state.

Some agencies are closing their community homes because the state isn't authorizing funding, said Kristin MacRae, president and chief executive officer of the association.

"It's taken us a long time to get referrals from the state because, I think, that's how they're controlling money and the funds is [that] they're just not referring people to service," MacRae said.

Funding has been decreasing over the years. Occasionally there's an increase in terms of base funding, but it's not keeping pace with costs, Preston said. "Organizations have had to continue to do more with less."

"Agencies are losing their ability to provide anything that even resembles quality services," Cronin said.

In the past, agencies such as CARC were funded by grants from the state. The association's budget this year is around \$22 million, but they're anticipating losing several million soon.

"What we're hearing is that as of July 1 they're going to discontinue all the grant funding, which, for our agency, is over \$4 million," MacRae said.

As it cuts funding, the state is forcing agencies to convert to a fee-for-service system and to participate in a federally matched waiver program, instead of relying on state grants.

With the waiver program, the state is reimbursed about 50 percent by the federal government, MacRae said, but some people who currently receive funds will be ineligible under the new system, and the fee-for-service system will cause the providers to lose money. (See related sidebar)

While the funding that trickles down to the individual family may not always be much, it's capable of a huge impact.

Alex Cruz receives four hours of respite care a week. Sixteen hours a month. And then he participates in a few other programs provided by Community Support Services Inc. as well.

The respite care, where a Community Support Services Inc. employee named Pat works with Alex, is a time when Alex would learn how to take public transportation to increase his mobility. Sometimes the two would go out just for fun to a museum.

When the program was cut last summer, Alex missed Pat keenly, asking if he could call him on the phone.

Pat, an elderly man, is also a father figure to Alex after his own father passed away several years ago.

For Alex's mother, Matilda, it's a much needed break, and for Alex it's a time to be with a friend and have some fun while learning life skills.

After the cut, the respite programs were reinstated after a few months, but it was just one more setback in the history of underfunding and funding cuts for disability services in Illinois, with no good news in sight, advocates say.

"There are so many things they can cut," Cruz said. "I can't believe they want to cut these programs."

Sarah Marchmont/MEDILL

Kristin MacRae, CEO and president of CARC, a service provider for people with developmental disabilities, speaks about her hopes for the outcome of the state's budget this year. As much as agencies like hers need more money, all she's asking for this year is to be paid on time and to not receive any more cuts.

Disability service providers forced to convert funding systems

Agencies that provide services to the disabled are converting to a fee-based system that will be funded in part by the federal government.

With a fee-for-service system, an agency bills the state for services it provides to clients. However, once the conversion is complete, it's expected that the agency can only bill the states for clients who are part of the Medicaid Waiver Program.

The federal government matches the program, so the government will reimburse the state about 50 cents for every dollar they spend on disability services.

With this program, which is already instituted on a smaller scale, the state of Illinois can decrease its costs for disability services.

"So you can see for them the incentive to get more people in the waiver [program] when they get half their money back," said Kristin MacRae, chief executive officer and president of CARC.

Right now, most service provider agencies depend on a combination of grant funding and fee-for-service funding.

Service providers are expecting, according to MacRae, that all grant funding from the state will be cut come July 1, which is forcing them to convert completely to a fee-for-service system.

The Illinois Department of Human Services did not return calls for comment.

When service providers are funded by grants, the money comes through the general revenue funds and is given to the agencies ahead of time. In a fee-for-service system, agencies get paid after the service is performed. And in Illinois' case, the payments are way overdue.

Another problem with fee-for-service, from the provider perspective, is that the agency only gets paid when people attend a program. The agency's staff and overhead costs don't change whether or not clients attend, but they won't get paid unless a client shows, MacRae said. She is anticipating that CARC will lose \$2 million.

Converting systems is also going to hurt the clients, MacRae said, because some people will no longer be eligible for services.

Eligibility is based on multiple factors, such as income levels and severity of the disability. Furthermore, individuals have to be eligible for Medicaid to be eligible for the waiver program.

If families don't participate in Medicaid, they'll be ineligible for government-funded services, MacRae said. "We're going to become totally Medicaid."