

Kansas Health Institute article – January 11, 2010

Waiting lists for state services expected to grow



Photo by [Dave Ranney](#)

Abby Debrabander, center, dances to a Barney exercise video with her sisters, Amanda Jo, 15, and Kelly, 12. Abby is developmentally disabled. Her parents have applied for Medicaid-funded in-home services designed to help them keep Abby in their home. They've been on the program's waiting list for five years.

By [Dave Ranney](#)
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TOPEKA — More than 5,700 Kansans with physical or developmental disabilities are waiting for Medicaid-funded services designed to help keep them out of a nursing home or state hospital.

About 2,000 people on the waiting list are developmentally disabled children or adults who are receiving some government-funded services but are waiting for others for which they are eligible.

But almost 3,800 of the disabled are receiving none of the assistance for which they are eligible and it is not uncommon for a person to wait years before the services become available.

“No one would stand for 4,000 kids on a waiting list to get into kindergarten but somehow a 4,000-plus waiting list for people with disabilities is seen as acceptable,” said Tom Laing, executive director for Interhab, an association representing most of the state's community based programs for people with developmental disabilities. “I see this as a sheer act of discrimination on the state's part.”

But state officials said because the demand for services exceeds what the state is willing to spend most years, waiting lists are inevitable.

“Ideally, we'd like to not have waiting lists, but there are budgetary constraints we have to work with,” said Ray Dalton, deputy secretary for health policy at the Kansas Department of Social and Rehabilitation Services.

Calls to reduce the waiting lists for the disabled typically generate considerable debate each legislative session.

This year that debate is expected to be exceptionally fierce because of the state's budget problems.

According to forecasts, the state will be about \$300 million to \$400 million in the red if it doesn't raise taxes or cut spending for fiscal 2011, which begins July 1. About \$1 billion in state spending has been cut in the past year.

There is no state agency or program that has been left unmarked by the state's fiscal problems and the clamor for more funding is expected to come from all corners.

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More costs in the long run

Advocates for the disabled say it makes no sense to cut spending or underfund the programs that help people live in their homes instead of nursing homes or state hospitals because doing so only ends up costing the state more in the long run.

Most people, given the choice, prefer to live at home and the services that help keep them there are significantly cheaper to the state than supporting someone in a nursing home or state institution.

According to SRS, a typical nursing home stay costs the state about \$3,000 a month versus about \$1,600 a month to provide home care to a physically disabled person.

State officials agree that home and community based services save the state tens of millions of dollars annually.

But home care services, unlike nursing home or state hospital stays, are not considered a Medicaid entitlement.

When a low-income person with a physical or developmental disability ends up in a nursing home or hospital, federal law requires that those costs be covered. It does not require that home care services be covered.

Federal law also mandates special services for school-age children with physical and/or developmental disabilities.

Laing and other advocates argue that it is inhumane and wasteful to spend hundreds of millions of dollars on special education programs and then expect graduates to wait years for services once they finish high school.

“If you’re willing to invest in them while they’re in school, why wouldn’t you invest in their lives after they leave school?” Laing said. “The answer is federal law requires one. It does not require the other.”

‘Waiting lists become acceptable’

Legislators see it differently.

In the current fiscal year, Kansas is expected to spend more than \$304.8 million in combined federal and state Medicaid funds on home and community based services for 7,442 people with developmental disabilities

It is expected to spend \$138.7 million in state and federal funds on in-home services for 7,131 people with physical disabilities.

“When legislators look at that, they see a lot of money and it is a lot of money,” said Ron Pasmore, chief executive at KETCH, a Wichita-based program for people with developmentally disabilities. “Then, they see that that demand for services grows every year — even if they adequately funded the waiting list for one year, there’ll still be demand for more the next year. When that realization kicks in, waiting lists become acceptable. It’s hard for them to get past that, it’s like they’re anesthetized.”

The increase in demand is driven in part by more special education students graduating and needing services while few of those receiving services give them up.

“Essentially, it’s a long-term care system,” Pasmore said. “Early in my career, I worked at Winfield State Hospital. We have people at KETCH now who were babies when I was at Winfield and who will be here for many years to come.”

Winfield State Hospital closed in 1998.

Ending the waiting lists

Two year ago, Reps. Bob Bethell, R-Alden, and Jerry Henry, D-Cummings, introduced a bill designed to eliminate the waiting lists for both the physically and developmentally disabled.

The much-amended legislation — Senate Bill 365 — called for spending an additional \$100 million over four years.

It also called for keeping pace with demand after the initial four years of additional funding and creation of a joint oversight committee on home and community based services.

The bill passed but funding for it was not appropriated.

Henry said he doubts there will be any additional funding set aside this year.

“What’s happened is that legislators who may have been willing to vote for something when the waiting list had 200 or 250 people on it — now, they look at it and see 2,000 or 3,000 or 4,000 people on it and they say, ‘Well, gosh, there’s no way to save it now.’” Henry said. “There isn’t the will to do anything about it.”

Outside the Legislature, Henry is executive director at Achievement Services, an Atchison-based program for people with developmental disabilities.

Leadership

Similar waiting lists exist in other states, so Kansas legislators can’t be singled out for failing to fund home-based services for everyone who qualifies for them.

But Robert Harder, a former SRS secretary and a long-time advocate for the disadvantaged, said the waiting lists persist here because of a lack of leadership.

“The stories of what the people and the families on the waiting lists are going through don’t resonate anymore,” Harder said. “That’s because we’ve got the same people — myself included — making the same points year after year.

“What’s lacking is a spokesman with statewide visibility — either a legislator or someone from the private sector — who will stand up and say ‘Enough. We’re not going to balance the budget on the backs of vulnerable people and kids in school.’”