

The least among us

Alaska's developmental disabilities providers look for allies in the state government

By *Brendan Joel Kelley*

THIS COMING SATURDAY, on his Fox News program *Geraldo at Large*, Geraldo Rivera is devoting the show to the long waiting lists where people with developmental disabilities languish while waiting to receive services.

"The waiting list is, in essence, the new institution," Rivera told a Pennsylvania blogger associated with The Arc, a national network of service providers for the developmentally disabled. "It's imprisoning in some ways, handicapping the families of the developmentally disabled, really handcuffing them in ways that put tremendous stress and strain on their lives."

Though it's doubtful that Alaska will be mentioned on the show, our state also maintains a list of developmentally disabled people who are eligible for services but aren't receiving them due to inadequate funding. Each year the Department of Health and Social Services prepares a report on this list, and the report for 2008 is due any day now. When the last annual report was released last December, there were 943 individuals on the waiting list. They've been waiting for services an average of 3.7 years.

At the beginning of December, a couple of weeks before Republican Governor Sarah Palin released her budget, state Senator Johnny Ellis (D-Anchorage) wrote Palin a letter asking her to address the waiting list, known officially as the Developmental Disabilities Registry.

"During your time on the campaign trail with Senator John McCain as the Vice Presidential nominee, I was very pleased to hear you speak on multiple occasions about the problems faced by special needs children in our country," Ellis wrote. He then pointed out that as of October 1, the registry contained 993 individuals, mostly between the ages of 4 and 17. "I respectfully request that you do your very best to provide the funding necessary to fully eliminate the Waitlist," Ellis continued, before asking Palin to include funding recommended by the governor's Ad

Hoc Committee on the DD Registry in her budget.

But that money wasn't included in the budget that Palin released on December 15. And for service providers in the developmental disabilities community, the waiting list is far from the only problem. Organizations like The Arc of Anchorage, Hope Community Resources, and many other home and community-based service providers are barely afloat financially, because the rates at which they're reimbursed aren't commensurate with the actual costs.

Ellis is hoping to change that with a bill he'll introduce in the next legislative session. The bill would evaluate reimbursement rates for home and community-based service providers annually.

"THE NUMBER ONE THING we want [the legislature] to do is establish a regular rate review process for how they pay us," says Gwendolyn Lee, executive director of The Arc of Anchorage. "The current system is not equitable."

Even if the waiting list were eradicated by sufficient funding from the state, Lee says, it would bring those people to a service provider system "that's weakened in its ability to deliver high quality services, and can't find the workers to meet the needs of the existing people."

At The Arc, which offers a large variety of services to those with developmental disabilities, under-funding has resulted in high turnover despite cost-cutting measures. "We have deferred maintenance; we have cut health insurance; we do not give raises; we ask people to do more," Lee says. "We are stretched; the rubber band is truly stretched."

Simply put, The Arc can only afford to hire workers at the lowest possible wages, making for high turnover and training costs. This means that the person with a disability has a constant revolving door of people coming and going from their life, each one having to learn the individual's critical issues, health issues, and personality nuances. "It's really depressing for the staff who are trying to deliver quality if they're constantly hiring and retraining people to do the very basics," Lee says.

There's a real danger to not addressing the financial concerns of home and community-based service providers, says Ellis. "If these community services no longer provide these services because they can't afford to, based on the poor reimbursement from the state and/or the feds under Medicaid, then there will be people without services in the community who will have to be institutionalized at greater public expense and more human tragedy."

"It all comes down to how we think about our fellow human beings," Lee says. "Do we have an attitude that the least of these is the most important, and everyone is entitled to fair access to basic community life?"

SIX YEARS AGO, THE STATE realized that the system for reimbursing service providers was flawed and froze the reimbursement rates while studying the issue. Last year, for the first time, the legislature granted an increase in rates, which varied according to the type of services provided. But there is still no mechanism in place for rates to keep up with inflation and cost of living increases.

To study the problem, the state hired an auditing firm, Myers and Stauffer, which attempted to analyze the service providers' costs versus reimbursements. The technique that the firm used, however, was unwieldy for many of the smaller sized organizations that provide services for the developmentally disabled.

"I don't think they got great participation," Ellis says. Indeed, some of the provider response

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rates were as low as 9 percent, while only a couple categories gathered responses from over 50 percent of the providers, due to the complexity of the audits.

Meanwhile, hospitals and nursing homes are reimbursed for their costs based on an annual rate review, which is what the home and community-based developmental disabilities providers are asking for. The difference between the two groups, Ellis says, is that "frankly, hospitals and nursing homes have powerful lobbyists in Juneau. These community-based services have never been joined together in a really organized group and have never really had effective lobbyists to get what they need."

"I'm going to put this bill in to the legislature, but it's a really difficult bill to get through, to do what the service providers want—regular rate review and adjustment. I've said to them that they need to create a coalition of people all over the state, clients and service providers and workers to say, 'we need the same thing that the hospitals and nursing homes have.' I think maybe the time has come."

IT'S NOT JUST GERALDO RIVERA that's put the spotlight

on the issues the developmental disabilities community faces. Governor Palin did so herself when campaigning to be vice president, telling families with special needs children that they would find an ally in her, while she held her baby boy Trig, who has Down syndrome.

"I understand that statement," Lee says. "As a parent of a new child with disabilities, it's easy to say 'I feel your pain, I understand your situation, I'll work to improve it.' It's easier said than done to really be an advocate. She is in a very different position than a lot of our families that may not have the circle of support that she has. I think that every family that heard that statement is watching now. We are now anxious to work with her to make that her legacy. It's an incredible opportunity for her, but she has to be willing to do it."

"This morning I heard Governor Palin say that we need to tighten our belts," says Ann WingQuest, The Arc of Anchorage's director of public affairs. "We're beyond tightened anymore. It frightens me when I hear her say that, because we have been so weakened and so stretched. She did say that we're not supposed to look to the government to make us healthy; the problem with our population is that their health care needs are not something that they elected. It wasn't like they were smoking and drinking and becoming obese. These are genetic or birth defects or whatever, and they need help."

Ellis is also looking to the governor to stand by what she campaigned on. "[Palin] got a lot of acclaim on the campaign trail as an advocate for kids with disabilities, not just kids with Down syndrome, but kids with disabilities. Now it's time to live up to that, and I'm hoping and inviting the governor to work with me to pare down the waiting list for DD services, to consider the bill on rate adjustment for DD providers and other community-based service providers. So this would be a real opportunity for Sarah Palin and myself and other legislators from both sides of the aisle to work together and put our money and our commitment where our mouths are. And I expect that she will, I just hope that we do enough to help those people that need the help the most."

There's still a chance that agencies such as The Arc and their advocates in the legislature might get their wishes. Governor Palin's communications director Bill McAllister says, "all of this is pending. The Department of Law is evaluating the rate re-basing issue. And the wait list is under review in the [Department of Health and Social Services] commissioner's office." ♦

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