



“What I can tell you is that the intention of this change is not to save money,” Bailey says. “Any quote-unquote ‘savings’ are invested in children’s services to increase the capacity and access to other necessary services for these kids.”

But advocates say they’ve yet to see funding increases in other programs commensurate with the loss in personal care hours.

“The state is saying it’s going to make funding available through a different mechanism, but that mechanism hasn’t been fully explained to families or even defined at this point,” says Quinn, who works with the families of children with disabilities.

Quinn says as many as 170 families in Rutland County alone will see their hours reduced or eliminated.

“And those families will have significant needs as a result,” Quinn says. “And it’s a big question mark as to how those needs are going to be met.”

Bailey emphasizes that no one has lost funding yet, thanks to the transitional funding that in some cases has gone on for more than a year. But she says she doesn’t know when the plug will be pulled on that funding, or how much notice families will get.

“We’re working with provider networks to reach out to families who have received (reduced hours) to have those families come into the network, so that we can more clearly identify their child’s needs and provide services that match those needs,” Bailey says.

Advocates like Schwartz, however, worry that families are headed not into a land of new opportunities, but a bureaucratic dead end.

“At the same time this is ending, nothing is being put in its place to help the families,” Schwartz says. “That’s the main concern here, that it’s just changing the service and cutting people off.”

The Children’s Personal Care Services program offers Medicaid-funded home care to children with “significant disabilities or health conditions,” and recipients’ diagnoses include autism, cerebral palsy and Down syndrome.

Bailey says the new evaluation method derives from concerns about whether the program was being used for its statutory purpose — to help Medicaid-eligible children with conditions that “substantially” impact their caregiving needs.

The program is not meant to supplant age-appropriate child care, but to provide supplemental assistance to parents whose children need help with such basic things as eating, bathing, grooming or going to the bathroom.

Bailey says a review of the program a few years ago found that more than a quarter of the children receiving benefits had a lone diagnosis of attention-deficit hyperactivity disorder. She says the discovery prompted policymakers to ask whether that was the kind of condition for which the program was intended.

She says scrutiny of the program was part of a broader re-examination of human services generally, to counteract institutional inertia and think anew about who’s getting what services and why.

“Part of that effort ... was to better align things, to integrate things where it made more sense, and to really have a more holistic approach,” Bailey says. “We’re really trying to get to the place where families have more direct access to services that will best benefit them and their children.

Bailey says it doesn’t necessarily make sense to invest hundreds of personal care hours into helping a child accomplish certain basic activities if, with exposure to another program, the child could quickly attain those skills for him or herself.

According to advocates, however, the new evaluation tool has had the effect of reducing considerably the eligibility hours of children who suffer from a range of debilitating conditions. Of particular concern is the reduction of hours for children who need “cueing and supervision,” as opposed to “hand-on-hand” assistance.

“A child may be physically able to bathe himself, but needs somebody standing there saying, ‘you need to turn on the water, you need to pick up the soap, you need to put soap on the washcloth,’” says Nancy Breiden, staff attorney at Vermont Legal Aid’s Disability Law Project.

Breiden is representing 16 affected families in their appeal of the reduced hours.

“And that cueing and supervision is something that in our view, under federal Medicaid regulations ... is covered under the definition of personal care services,” Breiden says.

Schwartz says the difference between “cueing and supervision” and hand-on-hand assistance can be a meaningless one, practically.

“The point is that somebody has to be there,” Schwartz says.

Schwartz and other advocates say that without home care hours, many parents will be forced to leave their jobs, something that could have severe consequences for families who in many instances are already financially vulnerable.

In Wisconsin, after the evaluation tool was introduced there, a coalition of disability groups conducted a survey of the families who’d seen their personal care hours reduced as a result.

The Internet survey wasn’t scientific, but the results, based on responses by 53 families and published in December of 2011, were noteworthy: 58 percent said they had “experienced greater stress on a daily basis,” and 32 percent said their family’s ability to work had been affected.

“The idea of transitioning families to other services is fine conceptually, if there are other services to transition people to,” says William Ashe, executive director of Upper Valley Services.

Ashe’s organization, which serves Orange County, is one of the 16 “designated agencies” that will be asked to supplement services for families affected by the personal care program changes.

“But I think what a lot of families are confronting is that they have been pretty successful with the personal care program, but that there aren’t a lot of alternatives available for them to just be moved over to,” Ashe says.

Bailey says the state will allocate an additional \$1.2 million to the designated agencies for “family managed respite” services, money intended to go to the same population that has been affected by the reduction in personal care hours. But advocates say that given the resource-intensive nature of the program — the Children’s Personal Care Services program cost more than \$23 million in fiscal year 2012 — the new appropriation is just a “drop in the bucket.”

Following the outcry from families, advocates and providers, the Agency of Human Services has initiated a rule-making process designed to evaluate changes to the program. Bailey says she has total confidence in the integrity of the new evaluation tool, but the state is willing to hear advocates out on their concerns, and that it might be open to changes.

The state will hold two public hearings on the new rules this week, one at 9:30 a.m. Monday, the other at 6 p.m. Tuesday. Both will be broadcast at Vermont Interactive Television sites across the state.

Breiden and other advocates say they’ve appreciated the state’s receptiveness to their concerns. But they say that if the future doesn’t include a reinstatement of personal care hours, or a dollar-for-dollar offset to compensate for their loss, then Vermont will have dealt a serious blow to

families that can ill afford it.

“This is a very big thing for these families, and we’re pleased right now with the way the state has responded to our concerns,” Breiden says. “But the proof is going to be in the pudding.”

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Glad to see this important story being covered, but the author needs to incorporate person first language. Instead of: "how they determine whether disabled children in Vermont" it should read "how they determine whether children with disabilities in Vermont".

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