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CATASTROPHIC EXPENSES POOL

Bill Would Provide Insurance Pool For Catastrophic Health Care

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Smiles and chuckles are about the only things that come easily to 2½-year-old Evan Kreighbaum of Stratford, who was born with a floppy body from a muscle condition that makes him so weak that he's needed tubes to help him breathe and eat.

His medical needs are so great — physical therapy twice a week, 16 hours a day of nursing care at home, numerous medicines — that they're costing the family up to \$600 a month now, even though they have insurance. They'll face much heavier expenses once the insurance benefits are exhausted.

Others like Evan — whose coverage falls far short — are a crucial part of the epic debate over comprehensive health care reform at the state Capitol and in Washington, D.C.

Among the many ideas in the patchwork of reforms is a "catastrophic medical expenses pool" advancing through the Connecticut legislature to help some insured families meet their kids' vast health needs.

The pool wouldn't be state-financed but would raise about \$2.5 million a year through a \$1-a-year levy on each state resident who's covered by private health insurance.



"There are pockets of need that are narrow but deep," said Kevin Lembo, state health care advocate whose office would administer the unusual pool.

But \$2.5 million won't go very far, and the legislation isn't a slam dunk in a time when many people are watching every penny and are wary of new programs under state auspices.

Although Deputy Republican House leader Themis Klarides says she'll probably vote in favor the bill, she predicts some colleagues may object to the \$1 levy, which could be viewed as a tax.

"In these economic times, we really have to be concerned about every dollar that goes out, because people are concerned about every dollar," said Klarides, R-Derby.

The proposal would address only a small portion of Connecticut's needs for access to quality care. Yet the pool could serve as a pilot for future reforms and could proceed even if the state's budget crisis limits broader reform this year, proponents say.

"The program will draw to the surface the unmet needs that children and families experience and help us refine our thinking about what a comprehensive and appropriate benefits design looks like," Lembo said.

Scant Opposition

The House might vote on the bill (HB 6152) as soon as Thursday, said its prime sponsor, Rep. Linda Schofield, D-Simsbury — a former executive director of Aetna's Connecticut health plan and a former director of the state's Medicaid program.

No lobbying groups were fighting the bill as of Tuesday. Insurers, who would collect and forward the \$1 levy for the pool, are still reviewing it, said Keith Stover, lobbyist for the Connecticut Association of Health Plans. The Connecticut Business and Industry Association, which represents employers, says it isn't opposing the measure.

That's important because insurers would bill employers \$1 for every employee and family member covered by their health plan, and employers could pay it themselves or pass on the cost to employees. Consumers who have individual policies would be billed directly.

The money could help pay for children's physical therapy, wheelchairs and other medical equipment and supplies, as well as drugs and other items when insurance either won't pay at all or has limits that aren't high enough. The pool could also help reimburse co-pays and deductibles when they add up to unaffordable amounts.

Schofield and Lembo say it's appropriate to create the new state program to direct money for medical costs because the health-care advocate's office can do it most effectively.

Lembo's office, which helps consumers appeal insurance denials, knows how to squeeze as much out of private insurance benefits as possible. The agency would first see whether applicants to the pool have any mileage left on their insurance, said Lembo, who was approved by legislators for another term after Gov. M. Jodi Rell's budget plan tried to eliminate his office.

Three Jobs

It isn't known whether Evan's family would qualify for pool money, which will be based on income, medical expenses, and priorities for distribution that haven't been determined yet. But Evan's mother, 25-year-old Paige Sloman, says "it would take a huge stress off my family."

Evan was born with a condition called hypotonia — low muscle tone — though the cause hasn't been determined. He had a tracheostomy tube inserted so he could breathe, and only recently began to walk. Secretions in his throat often need to be suctioned so they don't block the breathing tube. He is fed through a tube in his belly and has multiple skin problems that require prescription medications.

On Monday, Evan took his first horseback ride at Crystal Wood Stables in Durham as part of a special therapy program — separate from his usual physical therapy. Fussing when first introduced to the horse, Evan was soon smiling as he rode, safely harnessed onto the saddle and being photographed by his beaming mother.

Sloman has fought insurers for at-home nursing care, and her insurance covers only 52 physical therapy visits a year, about half of what she says Evan needs to build muscle tone.

"It's almost like you feel you can't give your child the service because you can't pay it," said Sloman, a fraud specialist at RBS (Royal Bank of Scotland).

It's hard enough for normal families to make ends meet, and having a child with catastrophic needs causes added stress "and you don't have that harmony and happiness," Sloman said. "I feel like I have three full-time jobs: I'm a mom, I work, and I fight insurance companies."

Lembo expects that hundreds of families in similar situations would apply for the pool, though its rules and limited funds could leave many disappointed. The pool could seek grants and federal money in addition to the \$1 per person levy.

It's not for adults, only for children 18 and younger who are privately insured. Eligibility is based on a sliding scale of how much of a family's income is spent on medical care, ranging from 8 percent for lower-income families to 30 percent for the more affluent. Families making more than 25 times the federal poverty level, or currently \$551,250, couldn't qualify.

Even if a family meets income and spending requirements in Connecticut's pool, their child's

medical needs might not be considered high enough priority to get a cut of the limited pool. Under the legislation, a new advisory commission would assist in developing regulations that set the priorities for the state Office of Healthcare Advocate to follow.

The commission that will advise him would include state commissioners of insurance, social services, and public health, the state comptroller, or people they designate. It would also include members of the General Assembly's insurance and real estate committee, the general public, licensed health care providers, and representatives of insurers and employers with self-funded health plans.

•*Courant staff photographer John Woike contributed to this story.*

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