

Chicago Tribune

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BREAKING NEWS AT CHICAGOTRIBUNE.COM

Early Edition

Many towns borrowing big — and taxpayers could end up stuck with bill

TRIBUNE WATCHDOG DEBT SPIRAL

With few legal restrictions or spending limits, some officials continue to fund risky ventures

By Joe Mahr and Joseph Ryan | Tribune reporters

Glenwood Mayor Kerry Durkin knows the dangers of gambling with taxpayer money: A reminder looms just across a bank of trees from Village Hall. Taxpayers in the south suburb have long had to subsidize a golf course that officials bought more than a decade ago. And to try to lessen the losses, the town recently doubled down, borrowing

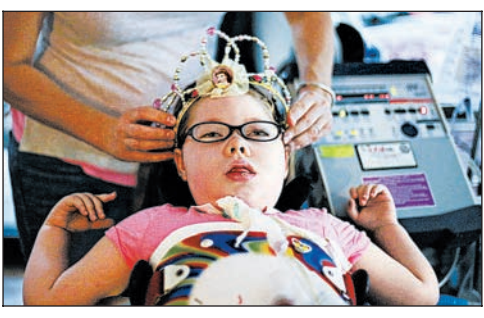
big again to build a new clubhouse. That borrowing — coupled with plummeting property values — pushed Glenwood into a growing list of Chicago-area cities and villages with debt levels once barred by state laws meant to safeguard taxpayers. Though much public attention has focused on soaring state and

national debt, the increase in local IOUs has sparked worries that the next generation in some communities will face crushing tax hikes. “It will drive the cost of living up and drive the cost of business up,” said Grayslake Mayor Rhett Taylor, whose north suburb is debt free. “If we start having businesses pull out and move to Wisconsin and other states, simply because costs are too high, that will have a ripple effect.” As some officials suggest tightening the rules on town borrowing, a Tribune analysis found that by the end of last year, at least 52 towns in the Chicago area ex-

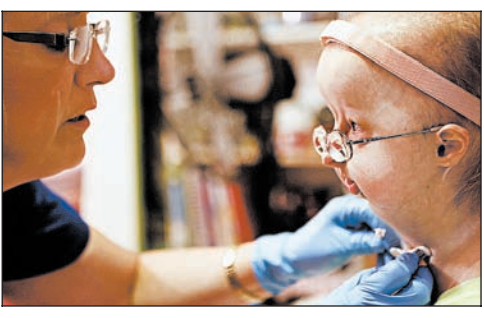
Please turn to **Page 20**



Mayumi Goldberg plays with her son, Quincy, who was born premature with chronic lung disease and uses a ventilator.



Myra Young puts a princess crown on daughter Letty, who has a muscle disorder.



Nurse Tamara Mauradian checks on 15-year-old Michelle Kish's tracheotomy tube.



Octavia Byars holds son T.J. while he takes a break during physical therapy.

Our most fragile

Parents fear cutoff of children's home nursing services

TRIBUNE PHOTOS BY HEATHER CHARLES

Hundreds of Illinois parents whose medically fragile and technology-dependent children receive skilled nursing services at home through a state-run program are anxiously waiting to find out if their sons and daughters will continue to qualify. The parents say proposed changes to the program would make their children ineligible, forcing the youngsters out of their homes and into hospitals or other facilities. Some of them have vowed to fight and filed a lawsuit in July. The changes have been pushed back twice, putting the families in an agonizing limbo. “I can’t put into words how stressed and worried we are,” one mother said. “Anyone who has children and loves them can understand the heartbreak of this.”

— By Deborah L. Shelton, Tribune reporter

Meet the caregivers: Tribune photographer Heather Charles spent several months with four Chicago-area families, documenting their daily lives and challenges as they lived under a cloud of uncertainty.

Please turn to **Page 24**

Road to the ‘fiscal cliff’

How did we get here? It took years of political maneuvering, partisan bickering, delay and obfuscation by both parties, presidents and Congress before the perfect financial storm of the so-called fiscal cliff was created. Full-page graphic, **Nation & World, Page 34**

No shortage of lobbyists: Given the massive stakes, it’s no wonder there are plenty of groups trying to influence the fiscal cliff debate inside the Beltway. **Page 35**

Taxi firms honked off over Uber app

Melissa Harris, Business

A guide to Lower Wacker’s reopening

Chicagoland, Page 6

Heat is on Lovie down the stretch

David Haugh, Chicago Sports



TRIBUNE SPECIAL REPORT



Michelle Kish on her first day attending South Elgin High School. In the large photo, she is with her sister, Sarah, from left, her mom, Mary, and nurse Jane Swanson. In the smaller photos, from top, she is in her chorus class next to Jewel Benzing; giving her dad, Brad, a kiss; and lying on her mom's lap and receiving medical care from nurse Tamara Mauradian.



T.J. Byars works on his physical therapy with his mom, Octavia. She also helps him pick activities for the day from a folder with pictures. Octavia Byars is a single mom and has a part-time job outside the home. T.J. requires care 24 hours a day, so she is worried she would have to place him in a hospital if he lost his waiver for home nursing services.

Our most fragile

Continued from Page 1

PHOTOS BY HEATHER CHARLES
STORIES BY DEBORAH L. SHELTON
dshelton@tribune.com
Twitter @deborahlskelton

chicagotribune.com/fragilekids

Hear from parents of medically fragile children, and see more of Heather Charles' photos of the kids.

‘This isn’t a luxury’

MICHELLE KISH, 15, BARTLETT

Michelle Kish has much to look forward to: school. Christmas. Her sweet 16 birthday party in March. Even so, despite her mother's efforts to shield her daughter from worries, Michelle sometimes asks if she will have to move into a hospital. "I tell her we are going to pray about it and work it out as a family," Mary Kish said. Michelle was born with a rare genetic disorder, Hallermann-Streif syndrome, a cranio-facial condition that also can cause heart, stomach and lung problems. She is legally blind. She is tube-fed, and she needs a ventilator to breathe up to 12 hours a day — 24 hours if her health takes a bad turn. She has a form of dwarfism and uses a walking cane. In every other way, she's a typical teenager. She's chatty, develops crushes, and likes to socialize and decorate her room. The Bartlett family's income normally would be too high to qualify for Medicaid services, but a waiver issued under the state's program for medically fragile children allows Michelle to receive in-home nursing care. If Illinois changes the program's income requirements enough to disqualify them, the Kishes would not be able to afford those services, Mary Kish said. In-home nursing care costs about \$200,000 a year, she estimated. "Michelle requires 24/7 (care)," she said. "There's a reason why she's had nursing care since she was born. This isn't a luxury." Her husband, Brad, a biomedical engineer, has to travel about 70 percent of the time but dives right in to help when he comes home. If a nurse isn't available, the couple take turns staying up all night. If they lose coverage, the Kishes say they have three options: try to take care of Michelle on their own, which Mary said probably would last about a week; permanently hospitalize her; or get divorced so they can qualify for services through Medicaid. "It'll kill me," said Mary Kish. "But I'm a brave person, and I'll somehow get through it. ... I would never, ever, ever abandon my children, either one of them."

Heavy load for single mom

T.J. BYARS, 7, LANSING

T.J. Byars, 7, requires round-the-clock care. He is developmentally delayed and lives with multiple medical problems, including epilepsy, cerebral palsy and juvenile arthritis. After having aspiration pneumonia last year, he got a tracheotomy that keeps his airway open. But with help, he has been able to live at home in south suburban Lansing — exactly where his mother, Octavia, wants him to be. A typical day in the Byars' home starts with 5 a.m. breathing treatments for T.J. that last about 45 minutes. He gets a bath and an hour of television, and on some days his mother takes him out for a walk in his wheelchair. He receives speech and other therapy and home-schooling. At night, he'll play with his sister Dametria Gist, 17, who helps with his care. "I'm constantly moving, the suctioning and all those things," Byars said. "I never would have thought I'd be able to handle something like this. I couldn't even have imagined doing this, (but) for your child, you build strength." After T.J. received the tracheotomy, he qualified as "medically fragile" under the state's waiver program. He is eligible for 77 paid hours of nursing care a week, Byars said. Byars' fear is that her son will lose those services if the state changes the way it determines medical necessity and level of care. She said she might be forced to place T.J. in a hospital to be sure of his safety. Days are long and hard for Byars, a single mother, but the state's program allows her time to sleep and work part time as a dispatcher for a transportation company. During days or nights when she doesn't have a nurse, she handles T.J.'s care on her own. "I don't know what I would do if the waiver was taken away because I don't know how I would be able to stay awake 24/7 to take care of him," she said. "There's just no way that can possibly be done."



Celestia “Letty” Young in her home, clockwise from top photo, with her father, James, and receiving a kiss from her mother, Myra, at The Moody Church in Chicago as nurse Lisa Barnes prays in the background.



Quincy Goldberg needed a ventilator after being born prematurely at 24 weeks with chronic lung disease, but he is slowly being weaned from it and by the end of November was breathing on his own for nine hours a day. His parents, Michael and Mayumi, don't think their son would have gotten this far if he hadn't been able to live at home.

When insurance falls short

CELESTIA “LETTY” YOUNG, 4, CHICAGO

Shortly after Myra Young gave birth to her first child, William, she bundled him up and took him to work with her. She planned to do the same when her daughter was born.

But Celestia “Letty” Young was born with a rare muscle disorder called congenital fiber type disproportion, which requires intensive medical care. Now 4, she is ventilator-dependent, tube-fed and unable to walk.

Young said Blue Cross-Blue Shield of Illinois covers most of Letty’s care but not private-duty nursing at home, which she said costs about \$200,000 a year. That’s where the state’s waiver program comes in.

“People might think we are lazy, irresponsible people who are trying to feed off the state,” Young said. “That’s not true; I have primary insurance. All we are asking for is for what my insurance doesn’t cover.”

The Youngs would still qualify for services under the program’s new income standards, but they say they can’t afford the co-pays being proposed on top of other medical costs. They also are concerned about a state proposal to replace nurses with health care workers with less training, who they believe would provide lower quality care.

They estimate they already spend more than \$10,000 annually in co-pays, deductibles and other out-of-pocket costs. Young also had to cut back her hours as a horse trainer and riding instructor to tend to her daughter.

“I love my children more than anything,” she said. “I will do whatever I can do for them.”

Young has been active in trying to prevent the changes from taking effect. She took Letty to a public hearing so the head of the Illinois Department of Healthcare and Family Services could see a child up close who could be affected. At one point, she burst into tears as she spoke to state officials.

“I can’t put into words how stressed and worried we are,” she said. “Anyone who has children and loves them can understand the heartbreak of this.”

A temporary safety net

QUINCY GOLDBERG, 18 MONTHS, CHICAGO

Unlike some families whose children live with lifelong chronic medical problems and rely on the waiver program for years, Michael Goldberg’s 18-month-old son, Quincy, needs only temporary help.

Quincy needed a ventilator after being born prematurely at 24 weeks with chronic lung disease, but he is being slowly weaned off and by the end of November was breathing on his own for nine hours a day.

His parents, Michael and Mayumi, don’t think their son would have gotten this far if he hadn’t been able to live at home, where he gets his nursing care through the state program. He is slightly delayed developmentally but is rapidly catching up.

“The biggest thing is, he’s starting to vocalize,” Michael Goldberg said. “He can’t speak because of the trach, but we can hear him whispering things like mama and dada. He mimics us in both English and Japanese.”

Mayumi gave up her job as a nail technician to help take care of Quincy. Michael is an investment analyst whose income would make the family ineligible for in-home services under the new rules.

If the changes take effect before Quincy is well enough to live without the services, the couple is considering a divorce. Michael would move out of the home so Quincy could qualify for Medicaid on his mother’s income.

“We can’t care for Quincy safely without help,” Michael Goldberg said.

Even after Quincy is fully recovered, the Goldbergs said they won’t forget about the families who need long-term services, and they are actively advocating for the waiver program to continue unchanged.

“The state has the ability to improve the quality of life of these families,” Michael Goldberg said.

Caring for medically fragile children

More than 1,000 medically fragile, technology-dependent children in Illinois currently receive in-home skilled nursing services paid for by Medicaid. About half are in a waiver program for families whose income exceeds Medicaid’s usual eligibility requirements or who do not qualify for other reasons.

What’s changing? State officials have proposed changing the program’s income requirements and definition of “guaranteed care,” as well as imposing co-pays.

Why? The changes were part of legislation aimed at closing the state’s budget holes.

Who’s affected? Most of the children need ventilators, feeding tubes or other medical interventions to survive. Parents say they cannot afford the cost of in-home nursing care, which averages \$11,000 to \$16,000 a month.

When will it happen? The Illinois Department of Healthcare and Family Services has sent the proposed changes to the federal Centers for Medicare & Medicaid Services for approval. The state had planned to implement the changes Sept. 1 but sought two extensions from Medicaid officials. Illinois recently asked for an April 30 deadline.

State officials say: “We are aware of the families’ concerns, but due to the fact we have pending litigation, we cannot comment in detail. The department has indicated that we are willing to work with the Legislature and federal authorities in order to implement a modified program that meets the needs of both the families and the state.”