

STATE CAPITOL HEARING
Families Speak On Disability Rights

Patchwork Safety Net Has Families Worried About Who Will Care For Loved Ones

By DANIELA ALTMARI
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HARTFORD — Sarah Peters is an intellectually disabled 30-year-old who is a passionate about UConn basketball and loves to ride horses. She lives in Killingworth with her parents, who agonize about what will happen to her when they are no longer alive. "She will need support and supervision her entire life," her mother, Rev. Kathleen Peters, told state legislators

on Friday. "We love our children very much, but we cannot do this alone." Rev. Peters was one of dozens of family members who shared their concerns with lawmakers at an informational hearing at the state Capitol on Friday. One by one, they told their stories and expressed their fears in a room filled with capacity with policymakers, disability rights advocates and fellow family members. The crowd was so large that some people had to watch the proceedings on television screens set up in two overflow

rooms. A woman from New London County spoke of her 21-year-old son with cerebral palsy, who is non-verbal and must wear a diaper. He needs assistance with just about every aspect of daily life and DeMatteo said she doesn't know what will happen when she is gone. Dawn DeMatteo, a single mother from East Haven, is apprehensive about the

future for her 21-year-old son with cerebral palsy, who is non-verbal and must wear a diaper. He needs assistance with just about every aspect of daily life and DeMatteo said she doesn't know what will happen when she is gone.

Summary of Media Coverage

the **ct**mirror
For CT adults with developmental disabilities, housing help unlikely until parents die

By Levin Becker | February 10, 2014

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CT NEWS Junkie
 BECAUSE YOU NEED IT, BAD.
Parents to Lawmakers: Where Will Our Children Live When We Die?

Posted to: Civil Liberties, Equality, Health Care, Housing, Jobs, Labor, Nonprofits



The Arc
 Connecticut



AP Associated Press

Lawmakers focus on developmental disability issues

By The Associated Press
 POSTED: 02/07/14, 9:36 AM EST

HARTFORD >> A group of Connecticut lawmakers is gathering comments from state residents concerned about the long-term care of their adult developmentally disabled children. State Sen. Beth Bye says lawmakers have heard from many who worry what will happen when they are no longer able due to death or disability. She said they've been told their loved ones will stay at home with them until they die, but "we're not going to be

Family Hearing Day
 Connecticut State Capitol
 February 7, 2014

For CT adults with developmental disabilities, housing help unlikely until parents die

By: Arielle Levin Becker | February 10, 2014

Scott Langner was so excited when he learned he could one day move into an apartment with friends that he soon began talking about the invitations he'd use for his housewarming party.

He'd seen his older brother and sister go off to college and then their own apartments, and his parents hoped that Scott, who has developmental disabilities, autism and a seizure disorder, would eventually be able to move into a home with his friends, with supports funded by the state Department of Developmental Services.

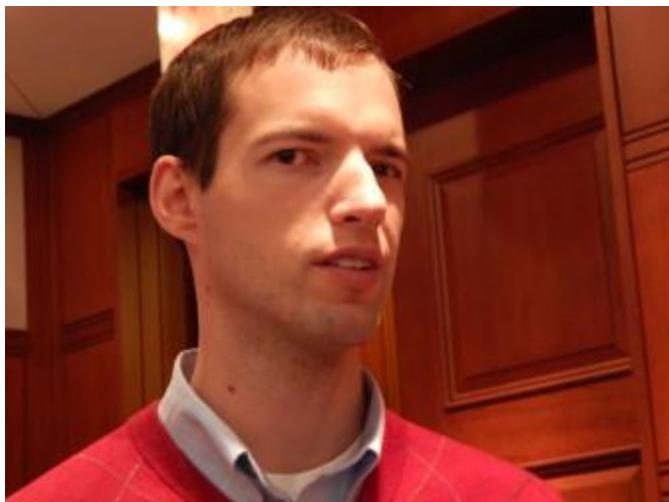
But last year, they learned that was unlikely to happen. His mother, Collette Bement Langner, said they were told that DDS no longer has the money to provide him residential supports, and that Scott would likely live with his parents until they die.

Now Scott, 27, is reluctant to even consider developing skills that would help him live more independently. When his mother suggested learning to cook, he told her, "I don't want to talk about that anymore. That makes me really sad. I don't want you to die."

Payment rates to primary care providers who see Medicaid patients rose dramatically in 2013, and so did the number of providers participating in the program.

"He now feels that in order for him to move into an apartment, it will have to mean that we had died," she said.

Langner worries too: If her son can't get support to live more independently until she and her



husband die, they won't be around to help him make the transition, to help those providing support understand the best way to solve problems that come up or make sure they know how to handle his seizures. And under the department's current policy, he'd have to move into whatever housing were available, even if it's across the state from where he lives, works and helps coach soccer.

"You could lose your parents, your home, your job and your friends all at the same time," she said.

Scott Langner

The erosion of state funding for people with developmental disabilities has left many parents worried about what will happen to their children when they die or become unable to take care of them.

The two-year budget Gov. Dannel P. Malloy and legislators adopted last year left DDS's budget \$36 million below what the department had projected it would need to maintain current services, and advocates and service providers say that followed two decades of chronic underfunding. The department handled the cut by reducing provider rates and individual budgets and cutting staffing, spokeswoman Joan C. Barnish said.

In a letter to clients and their families last April, DDS officials offered those waiting for services little hope and explained that "resources need to be focused on emergency cases."

Priority for funding is given, they wrote, to people in three situations:

- Those with an emergency need for services, such as when a caregiver dies "and there are no other family members who can step in to help";
- Someone at risk of imminent harm, such as from abuse or neglect or an extraordinary health and safety issue;
- People in a Medicaid waiver program whose health and safety needs are not being met.

"The majority of individuals waiting for residential services do not meet the above criteria," Commissioner Terrence W. Macy and Deputy Commissioner Joseph W. Drexler wrote. "Without additional funding to address the waiting list, families who do not meet these criteria will continue to wait for services."

"We die agonizing"

Hundreds of families, many waiting for services, showed up at the state Capitol complex Friday to implore lawmakers to restore funding for developmental services. So many attended that they filled multiple hearing rooms, including the largest one in the building.

One woman told legislators that she wakes up nearly every morning to her 15-year-old son banging on the walls, so loud that neighbors threaten to call police. Her son, who has developmental delays, routinely eats his feces, and his doctor has said he needs constant monitoring. But she said her family is unable to get residential services for him. She said they're among the state's "lost families," stuck between the school system and the developmental services system and unable to get residential services.

Another mother choked up as she told lawmakers about her son, "We will be too old to take care of him, and I'm asking for your help."

Joe Duffy, whose 30-year-old daughter has intellectual disabilities, said the state faces an emergency, particularly in housing, and said DDS is in "fiscal paralysis."

"We are told that our loved ones will stay home until we die. They're welcome to stay home forever. We're not trying to get rid of our beloved children, adult children included," Duffy, 70, said. "But there is that fact of mortality."

Waiting until parents die is troubling for parents -- and worse for their children, he said.

“We die agonizing about where our loved ones will go,” he said. Meanwhile, their sons and daughters will suffer the double trauma of losing their parents and lifetime home at once.

“Anyone who knows anything about people with intellectual disabilities knows that stability and continuity are very important,” Duffy said.

Walter Glomb, whose son Nick has Down syndrome, said groups of parents are working to develop creative housing options, such as having their children live in their own homes or rental homes with support.

But Glomb said that even creative solutions will require some help from the state. “Very, very, very few of us have the personal resources to see that our children are cared for for whatever time they’re going to live beyond [our lives],” he said.

In a statement released after the hearing, Barnish, the DDS spokeswoman, praised the families for their advocacy. The hearing drew many legislators, including some who have formed an Intellectual and Developmental Disability Caucus.

“DDS appreciates the frustration when residential supports are not available for proactive supports allowing people to naturally progress towards more independence while living with their family or moving to their own home in the community,” she said. “DDS will continue to balance the needs of individuals and their families within existing resources.”

“Haves and have nots”



Leslie M. Simoes, executive director of The Arc Connecticut, an advocacy organization, said funding cuts to an already fragile system have created “a time bomb waiting to go off.”

But part of the problem, she said, is not the total amount of funding, but the way DDS’ budget of more than \$1 billion is spent.

“We have a system of haves and have nots,” she said.

Leslie M. Simoes

Simoes and other advocates note that the state spends significant sums of money operating six institutions with relatively few residents. Southbury Training School has about 350 residents, and five regional centers house fewer than 200 people.

The per-person cost for a resident at Southbury Training School was \$330,675 in 2010, and slightly more at the regional centers, according to a report prepared for the legislature's Program Review and Investigations Committee. Group homes cost significantly less, particularly those run by private nonprofit agencies rather than DDS.

None of the state-run institutions accept new clients, and the terms of a 2010 legal settlement requires the state to evaluate all Southbury Training School residents for community placement. Residents and their guardians can decide whether to move or not.

"There's money in the system. It just depends on the political will to make changes to really reallocate what money we have," Simoes said.

But families of Southbury residents have said they're wary of the prospect of their relatives going into the community system, which even service providers consider starved for resources.

Simoes praised the care provided at group homes but said many people with developmental disabilities don't need 24-hour supervision and don't want to live in that type of setting.

Yet even when families are willing to pay housing costs and just need DDS to provide supports, Simoes said, the department has said it can't help because it lacks the resources.

"These families are going to care for their kids until the day they die, which they will do willingly," she said. "But then they know that once they die their child is going to have to withstand the loss of a parent and then have to go into a new home on top of that. That's inhumane."

"He'd have a life"

At one point, the Langners thought they had a solution: Along with the parents of four of Scott's friends, they would build, rent or buy a home. Their five sons could handle their own hygiene and things like cleaning. What they'd need from DDS, Collette Bement Langner said, would be some support, like help with grocery shopping and cooking. She said the department told them that wouldn't be possible because they're not considered an emergency.



"We said, 'OK, if we could just arrange for all 10 parents to all die at the same time, then our five sons could get to live together,'" she said.

Langner wants her son to live with friends, rather than in a group home. Scott has many skills and she thinks he doesn't need many hours of support. He has a job, participates in Special Olympics bowling, track and field and floor hockey, and coaches in the Tolland soccer program he participated in growing up.

:Collette Bement Langner

But he's naïve about the world and easily taken advantage of, his mother said. He's afraid of the stove. And he's prone to seizures, something that always worries his parents.

When he's with his friends, Scott is animated, friendly and outgoing. But at home with his parents, he's more like a sullen teenager, his mother said, favoring one-word answers.

"He's isolated," she said. "If he were able to be in his own apartment, he would have friends he could talk with, interact with, plan things with."

"He'd have a life. And he doesn't have that now."

Hartford Courant

Families Speak Up For Disability Rights At Capitol

A Patchwork Safety Net Has Replaced Institutional Care

By **DANIELA ALTIMARI**, dnaltimari@courant.com

5:51 p.m. EST, February 7, 2014

HARTFORD -- Sarah Peters is an intellectually disabled 30-year-old who is a passionate about UConn basketball and loves to ride horses.

She lives in **Killingworth** with her parents, who agonize about what will happen to her when they are no longer alive. "She will need support and supervision her entire life," her mother, the Rev. Kathleen Peters, told state legislators on Friday. "We love our children very much but we cannot do this alone."

Rev. Peters was one of dozens of family members who shared their concerns with lawmakers at a informational hearing at the state Capitol Friday. One by one, they told their stories and expressed their fears in a room filled to capacity with policy makers, disability rights advocates and fellow family members. The crowd was so large that some people had to watch the proceedings on television screens set up in two overflow rooms.

A woman from **New London County** spoke of her developmentally disabled sister-in-law, who sat in the living room all day and placed M&Ms in a bowl until she began attending a day program for adults with similar disabilities a few years ago. Now middle-aged, she participates in group activities and has many friends, but her caregivers worry about what will happen if funding dries up.

Dawn DeMatteo, a single mother from **East Haven**, is apprehensive about the future for her 21-year-old son with **cerebral palsy**, who is non-verbal and must wear a diaper. He needs assistance with just about every aspect of daily life and DeMatteo said she doesn't know what will happen when he finishes school in June.

"I would just ask each of you to take a few minutes," she said, her voice cracking, "think of one of your children in this situation and how you would feel."

State lawmakers, led by Sen. Beth Bye, recently formed a caucus on intellectual and developmental disabilities. The group, which is believed to be the first such state-level caucus in the nation, provided the forum as a way for families to raise their concerns and express their fears.

"Fifty or 60 years ago, families didn't have a choice about where their loved ones went: they were told by medical professionals, 'if you have a child with a disability, put [him or her] in an institution and forget you ever had them,'" said Leslie Simoes, executive director of The Arc Connecticut, an advocacy group.

But the patchwork safety net that has largely replaced institutional care is not adequately serving all families, Simoes said. The state Department of Developmental Services has an annual budget of about \$1 billion, she said. It costs about \$380,000 per year to provide services to each of the 353 people living at **Southbury** Training School. The cost per year at the state's regional centers is about \$400,000 per person, Simoes said.

"You're talking about a lot of money that gets spent on a very small percentage of the population served," Simoes said.

In contrast, the average per person cost at group homes ranges from \$220,000 to \$120,000 per year, Simoes said.

Meanwhile, countless families are caring for their loved ones on their own. "They don't have any peace of mind right now to know where their loved one will go after their gone," Simoes said. The message, she said, is: "Keep your children at home while you can and then, when you die, we'll take care of them."

Shelagh McClure and Tom Fiorentino's 23-year-old son Daniel has Down syndrome; he lives at home but is fairly independent. "Looking ahead to his future we realized there really was no plan in place and frankly no prospect of funding for any plan...in the...future," McClure said.

Added Fiorentino: "There's no waiting list because there's nothing to wait for. What we're being told is, 'your child will get a placement when the last caregiver dies...you've got an agency with a billion dollar budget that is appropriated in such an odd and inefficient way and you've got hundreds and hundreds of families just waiting."

Simoës said advocates are pressing for major changes. "We're looking for a whole system overhaul that really looks at the resources that are available, and how they're being allocated and what works for families," she said.

Joan C. Barnish, director of communications for the Department of Developmental Services, referred to the hearing as "an extraordinary event" and pledged to "continue to listen."

"DDS applauds their advocacy for themselves, their family members and for all the people who need support," Barnish said in a written statement. "DDS appreciates the frustration when residential supports are not available for proactive supports allowing people to naturally progress towards more independence while living with their family or moving to their own home in the community. DDS will continue to balance the needs of individuals and their families within existing resources."

For the last three years, the department had been actively working to transition "away from costly models to person centered supports," Barnish said, noting that the state has been recognized nationally for its efforts.

"DDS will continue to listen and learn from individuals and families. Our commissioner will continue to work with the governor and the legislature on ways to best use the available resources to serve our citizens with intellectual disability and autism," Barnish added.

Near the end of the hearing, lawmakers heard from Daniel Lenz, a developmentally disabled 33-year-old who lives in an apartment and has a job. He thanked the Department of Developmental Services, as well as the Farmington Valley ARC for providing him with a ride to his job and to the movies, and all the other help he needs to live a rich and full life.

His father, Rick Lenz, said he could not "imagine what Danny's life would be like today if he had come home from school and sat in our living room watching television until he was 33...his life would not be what it is today."

Parents to Lawmakers: Where Will Our Children Live When We Die?

by Christine Stuart | Feb 7, 2014 1:24pm



CHRISTINE STUART PHOTO

Left to right: Reps. Tony Hwang, Tim LeGeyst, Jay Case, Sen. Beth Bye, and Rep. John Hampton.

Joe Duffy is 70. He worries what will happen to his 30-year-old daughter, Kate, who has multiple developmental disabilities, when he dies.

“This is really a public health emergency, especially in the area of housing,” Duffy said.

He said they’ve been told their loved ones will stay at home with them until they die, but “we’re not going to be around forever.”

Leslie Simoes, executive director of The Arc Connecticut, said she knows families who have been on this emergency wait list for housing for eight to nine years. If someone isn’t suited to live in a group home and can remain mostly independent, then there aren’t any services for them provided by the state Department of Development Services.

She said the system is set up in such a way that it doesn’t meet individuals needs because it either offers a group home placement, or nothing. There are many individuals that don’t need that 24-hour custodial level of care.

But the problem is when these individuals, if they're lucky enough to qualify for services through the state, only get "day service" money. There's nothing to meet their residential needs and there are more than 2,000 people at the moment on the waiting list, Simoes said.

"We do not want to be regarded as a bargain-basement approach," Duffy said. "Our people, we feel, are as informed as anyone else who needs a hand up. That's why we're all here today."

Lisa Roland's 19-year-old son has Down Syndrome and she is looking for meaningful employment and housing opportunities for him.

She said she's looking for ways the state Department of Developmental Services can use its more than \$1 billion budget effectively. She said her son is fairly independent and doesn't need a group home or 24-hour care. She said she wants some of the money the state saves when it moves a person out of institutional care at [Southbury Training School](#) to be spent on services for individuals on the housing wait list.

Roland said she will need to start applying for services for her son when he turns 21. Until then he receives care through the educational system.

"We're staring into the abyss," Roland said. "And we're scared."

She said they've already decided to sell their West Hartford home and move closer to the center of town because there's no transportation options where she lives and her son can't drive, but he can use the bus.

Walter Glomb of Rockville said he has a 25-year-old son with Down Syndrome who, like Roland's son, doesn't need the 24-hour care that the legacy system provides in institutions and group homes.

Glomb said he's part of a group of parents who frequently shares creative housing ideas for their loved ones and would be happy to share those thoughts with lawmakers.

"While the gears turn slowly at DDS and the legislature, the clock doesn't stop for us," Glomb said.

The legislature approved a \$30 million reduction in the Department of Developmental Services budget last year and Gov. Dannel P. Malloy did not propose restoring it this year, but parents who attended the public hearing Friday were not fazed.

Simoes said these parents are in this fight for the long haul and the formation of the Intellectual and Developmental Disability Caucus was just the first step in getting policymakers to understand what they need to do in order to make a difference.

"It's really a larger systemic issue than the \$30 million cut," Simoes said. "It's a system that really needs to be overhauled."

She said the governor has the ability to turn the funding system on its head by closing Southbury Training School and placing the 353 people who live there into group homes in the community. But families of those who live at Southbury are against moving their loved ones from a setting they've known for years. There are some who have even argued opening the sprawling campus to new admissions.

It costs the state more than \$380,000 per person. Residential housing the community costs about \$120,000 per person.

But Simoes said this isn't about quick fixes. She said establishing the caucus and educating lawmakers is part of a long-term, five-year strategy.

"This is like trying to turn the Titanic," Simoes said. "You can't do that."

The Department of Developmental Services said Friday that it's working on re-balancing the system with the resources it has.

"For the last three years DDS had been actively engaged in systems change working to move our services away from costly models to person centered supports," Joan Barnish, a spokeswoman for the agency said. "Connecticut DDS is recognized nationally as a leader in developing family and person centered supports."

Sen. Beth Bye, D-West Hartford, who co-chairs the newly formed caucus, said she was impressed with the turnout Friday and believes steps can be taken this year to help families.

She said this governor understands supportive housing better than previous ones and she's confident something can be done to turn the current system around.

"It made me look at the budget a little differently," Bye said.

Lawmakers focus on developmental disability issues



Connecticut legislature in 2013. (AP File Photo/Jessica Hill)

By The Associated Press

POSTED: 02/07/14, 8:36 AM EST |

HARTFORD >> A group of Connecticut lawmakers is gathering comments from state residents concerned about the long-term care of their adult developmentally disabled children.

State Sen. Beth Bye says lawmakers have heard from many residents who worry about what will happen when they are no longer able due to death or age-related problems to care for their children with autism spectrum disorder, Down's syndrome and other disabilities.

Bye, a West Hartford Democrat, says funding may not be an immediate issue. She says the Malloy administration has some money for supportive housing.

She says lawmakers instead want to initially hear from residents and understand the extent of the problem and details.

The Intellectual and Developmental Disability Caucus is set to meet at 11 a.m. Friday in the legislative office building in Hartford.



State Representative John K. Hampton

February 7

It was an outstanding day at the Capitol as the Intellectual and Developmental Disabilities Caucus listened to constituents concerns. Way to step up to the plate Simsbury!



State Representative Jay Case shared a [link](#).

February 7

Know that I am here in Hartford, battling on the front lines for individuals with intellectual and developmental disabilities (I/DD).

The turnout today was phenomenal (we packed two rooms and then some!). I was humbled by the outpouring of support for our I/DD community -- and I'm honored to be an advocate for these Connecticut citizens.



Beth Bye

[19 hours ago](#) via [Hartford Courant](#)

Thanks to the families for sharing their stories yesterday. Legislators are listening.

"Shelagh McClure and Tom Fiorentino's 23-year-old son Daniel has Down syndrome; he lives at home but is fairly independent. "Looking ahead to his future we realized there really was no plan in place and frankly no prospect of funding for any plan...in the...future," McClure said.

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Bob Duff

[February 7](#)

MT @LynnWoodhall: Thank you for your leadership & support of DDS Families at today's hearing @BethBye5 @senatorduff - #OurFamiliesCan'tWait

February 7, 2014

Bye Announces Formation of Legislative Caucus For Intellectual & Developmental Disabilities

State Sen. Beth Bye (D-West Hartford) today announced the formation of a new legislative Intellectual & Developmental Disability Caucus—the first such state-level caucus in the nation—that will fight for the interests of individuals with intellectual and developmental disabilities and their families.

“I’ve been meeting with families in my district on these issues for many months. Their stories and their personal situations are heartbreaking,” Sen. Bye said. “It is my hope that working together, we can improve the lives of them and their loved ones.”

The announcement comes at critical time for Connecticut families who are receiving or waiting for services from the state Department of Developmental Services. Many families have voiced their fears for the future of their children after they are gone, and are now sharing their stories with legislators.

Sen. Bye will co-chair the newly formed, 27-member I/DD Caucus along with state Representatives John Hampton (D-Simsbury) and Jay Case (R-Winsted). The first order of business for the newly formed Caucus was to conduct a two-hour informational hearing with the families of, and advocates for, individuals with intellectual and developmental disabilities.

About 100 families submitted written testimony, including several from West Hartford: parents of two children with Fragile X Syndrome, the father of a four-year old diagnosed as autistic, legally blind and apraxia, and the parents of a 30-year-old who has been waiting for DSS housing for at least 12 years.

“The Arc will continue to work with families, other organizations supporting people with disabilities and the state Department of Developmental Services to reinvent a system of support that serves everyone who needs it,” said Leslie Simoes, Executive Director of The Arc of Connecticut, who organized today’s informational forum.

The Arc of Connecticut advocates for and supports people with intellectual and developmental disabilities (I/DD), including Down syndrome, autism spectrum disorders, Fetal Alcohol Spectrum disorders, cerebral palsy and other diagnoses.

