October 2017

New Horizons

Housing That Supports Independence

Disability Advocates Arrested Protesting Medicaid Cuts

Over 100 disability rights advocates were arrested while protesting Medicaid changes in a proposal to overhaul the nation's health care system. Hours later, the GOP plan appeared doomed.

U.S. Capitol Police forcibly removed 15 activists — many in wheelchairs — from a Senate Finance Committee hearing on Capitol Hill Monday afternoon after their roaring chants of "no cuts to Medicaid, save our liberty" delayed senators from proceeding. The protesters were dragged from the hearing room as lawmakers looked on. Another 166 demonstrators were arrested in the adjacent hallway.

Some were charged with disruption of Congress, while others were cited for crowding, obstructing or incommoding and a portion of the demonstrators also faced charges of resisting arrest, according to Capitol Police.

The majority of those detained were members of the disability rights group ADAPT who came from across the country to oppose the Graham-Cassidy bill, which would repeal the Affordable Care Act and fundamentally alter Medicaid.

By Monday evening, the Republican proposal appeared to be nearing collapse as Sen. Susan Collins, R-Maine, joined Sens. John McCain, R-Ariz., and Rand Paul, R-Ky., in announcing that she would oppose the measure. With Democrats and independents against the plan, Republicans could not afford to lose more than two votes from their own party.

Collins' announcement followed the release of a preliminary analysis of the Graham-Cassidy bill from the nonpartisan Congressional Budget Office indicating that the plan would leave "millions" without health insurance.

The GOP proposal would grant states significantly more discretion over health care and impose first-ever caps on Medicaid. Under the plan, federal spending on Medicaid would be reduced by about $1 trillion between now and 2026, according to the CBO analysis.

That would leave states to chip in more of their own funds or cut costs by reducing payments to providers, restricting eligibility, slashing optional services or enhancing program efficiency. States would likely resort to a mix of those approaches, the budget office said.

Disability advocacy groups have united against the proposal, arguing that cuts to Medicaid would lead states to curtail home and community-based services, which are considered optional.

"Forcing disabled people and seniors into institutions just to pay for tax cuts, which is what this bill does, is not equality. It's not liberty," said Dawn Russell, an ADAPT organizer from Denver. "Graham-Cassidy is a policy for a much crueler and meaner country than this one, and the people who support it should be ashamed of themselves."

The renewed push to repeal the Affordable Care Act comes as the clock is ticking for Republicans. Thanks to a procedural maneuver, a health care bill could pass with only a simple majority by Sept. 30. Beyond then, however, 60 votes would be needed.

Even with momentum for the Republican plan waning, disability advocates are continuing to push their members to call senators since there hasn't yet been a vote.

"The danger right now is if Senate offices think that folks aren't as outraged about this bill as the last, so every individual voice adds to the overwhelming wall of pressure we're fighting to maintain," said Julia Bascom, executive director of the Autistic Self Advocacy Network.

Reprinted from Disability Scoop **by Michelle Diament** | September 26, 2017

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“My Two Cents”

By *Tim Doherty, Executive Director*

So, one of the hot topics today in our country, is the use of “Free Speech” which is guaranteed by our Constitution and First Amendment. Usually this revolves around some kind of protest or some action that certain groups are usually against. Recently we have seen this in protests involving racial equality and the mistreatment of minorities by law enforcement officials. Today, it is often said that we are a divided nation, yet when disaster struck in the form of hurricane Irma in Texas, Jose in Florida, and Maria in Puerto Rico, American’s came together to help one another. So, this begs the question, on what level are we divided and again, on what level are we united?

Let’s also keep in mind that our nation was founded upon a rebellion from a foreign nation that wanted to control the destiny of our citizens. So, controversy is a part of our national make up. For sure, even our founding fathers, were not always united in the cause to break from Great Britain. There continued to be disagreements during the revolution, with some remaining loyal to the Crown. In the end, we did come together as a people and formed a unity of states--a United States.

Today, the most recent controversy, comes from the NFL, with players and coaches “ taking a knee” during the singing of our national anthem. This lack of respect for our flag is to show that not all of us agree with what is happening in our nation today. Certainly, our country is still struggling with racial equality and treatment of minorities—Our history here has not been good. But I honestly don’t know from these protests, exactly what they are pointing to and how we are to address these issues.

But our flag and the national anthem represent many different aspects of America, so much more, most of which are good. We are the land of opportunity, which is why so many immigrants want to come to our country. Our freedom’s have provided the wealth, which most of these NFL player protesters enjoy today—each and every one who “took a knee” are millionaires. And let’s not forget all the men and women, minorities included who have given the ultimate sacrifice for this country. Disrespecting the Flag and our anthem, disrespects those folks as well.

Finally, isn’t there some other way to raise a voice in protest rather than to disrespect our flag? Maybe the NFL could sponsor a dialogue prior to the games, which would offer speakers the opportunity to make their case, and call attention to injustice. Or donate funds to inner city schools, or revitalize poor neighborhoods, or sponsor police education programs. I just think that much more constructive action could be taken that would help to heal and mend these wounds, than by protesting the singing of our national anthem, or our flag, symbols that represent us all.

From Norman's Desk

New Jersey will be holding its Seventh Annual Disability Pride Parade and Celebration in Trenton this month. The event is organized by the Alliance Center for Independent Living based in Edison, and I'm proud to have been a part of the parade since the beginning.

I have told this story many times, and the underlying philosophy remains important to emphasize each year. I have recruited people with disabilities to march in past parades. One year my neighbor sarcastically asked me: "Are you proud of that stutter of yours?" Since I'm always reminding him that he cannot see too well and that he is dangerous in a power-chair, his well-aimed barb is routine banter between people comfortable with their disabilities. His comment, however, started me thinking about the incongruity of pride and disability.

It is incongruous to take pride in not being able to do something. There must have been some onlookers at the parade in the past asking: What are these "broken-down people" with crutches and in wheelchairs doing marching around proclaiming their pride? How can they be proud when they can't do anything for themselves?

Well, that is the point. Society's view of people with disabilities can be so negative, so weakening, so smothering of spirit that overcoming that negativity can be empowering and something to be proud about.

As people with disabilities, we put up with so much crap imposed upon us by society, the government, the system, and the people in our lives that it is a wonder that any of us have the energy and initiative to be independent, productive, or active.

But we are independent, productive, active, and we need to own it and show our pride in what we do!

This applies to every person with a disability no matter what their situation. Our lives are a precarious "high-wire acts" of low income with under-funded supports that keep us more dependent than independent. One false step drops us into the abyss of institutional living to be trapped and robbed of personal initiative, independence, and dignity.

Yet every day we get up to perform on the "high wire" defying negative attitudes, preconceptions, prejudices, and fears. Some do it with drudgery. Some do it with gusto. Most people with disabilities live our lives somewhere in between. We do it every single day.

This is why we should have pride. This is why we need to display our pride publicly and loudly. This is why we celebrate our pride in ourselves and our community.

Norman A. Smith, Associate Executive Director - ProjectFreedom1@aol.com
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Target Unveils Clothing For Kids With Special Needs

by Shaun Heasley | August 17, 2017 DisabilityScoop

Target is rolling out a collection of sensory-friendly apparel for children and says adaptive clothing for those with disabilities is on the way too.

The new offerings are part of the retailer's house brand Cat & Jack and are available exclusively on the store's website.

Beginning this week, Target is marketing a selection of t-shirts and leggings with flat seams that are free from bothersome tags and embellishments in order to "minimize discomfort when in contact with the skin," the company said. In addition, the retailer's sensory-friendly leggings include extra room in the hips and a higher rise to accommodate older kids who wear diapers.

The items are modeled after existing Cat & Jack styles and range in price from $4.50 to $7 each.

"We heard from our guests — and members of our own team — that there's a need for sensory-friendly clothing for kids that is both fashionable and affordable," Meghan Roman, a spokeswoman for Target told Disability Scoop. "With this insight, we set out to introduce a limited selection of sensory-friendly kids' clothing within Cat & Jack that's affordable and offers kids stylish options to feel comfortable and confident to take on their day."

Adaptive styles will be added this fall, Roman said. Those offerings will likely include items with zip-off sleeves, side openings to make dressing easier or openings in the back for those who are sitting or lying down.

Both sensory-friendly and adaptive styles will become a regular part of Target's clothing options for children.

When asked about adult sizes, Roman indicated that the company will "evaluate how we move forward based on guest feedback and the performance of (the Cat & Jack) pieces."

Hamilton Happenings

DATE	DAY	PROGRAM (in Community Room)	TIME
3-Oct	Tue	Hamilton Games	Prog. Time 5:00—7:00 PM
5-Oct	Thu	Hamilton/Lawrence Shopping 	Bus Leaves PFR 9:30 AM
15-Oct	Thu	Hamilton Games	Prog. Time 5:00—7:00 PM
20-Oct	Fri	Hamilton Games	Prog. Time 5:00—7:00 PM
24-Oct	Tue	Hamilton Games	Prog. Time 5:00—7:00 PM

Lawrence Goings On

DATE	DAY	PROGRAM (in Community Room)	TIME
5-Oct	Thu	Hamilton/Lawrence Shopping 	Bus Leaves PFR 9:30 AM
18-Oct	Wed	Lawrence Games	Prog. Time 3:00 - 5:00 PM
25-Oct	Wed	Lawrence Games	Prog. Time 3:00 - 5:00 PM

Robbinsville Events

DATE	DAY	PROGRAM (in Community Room)	TIME
4-Oct	Wed	Robbinsville Games	Prog. Time 6:30—8:30 PM
18-Oct	Wed	Robbinsville Movies	Prog. Time 6:30—8:30 PM
25-Oct	Wed	Robbinsville Games	Prog. Time 6:30—8:30 PM
30-Oct	Mon	Robbinsville Games	Prog. Time 6:30—8:30 PM

Hopewell Events

10/3/17	Tue	Heart to Hearts Chair Massage	1:15 PM to 3:15 PM
10/5/17	Thu	Hopewell Twp Influenza Immunizations	4:00 PM to 5:00 PM
10/13/17	Tue	Mercer Home Health Hosting Pokeno	3:00 Pm to 4:00 PM
10/25/17	Wed	Heart to Hearts Chair Massage	9:30 AM to 11:30 AM

Group Home Evicts Man With Special Needs For Using Medical Marijuana

by Eric Russell, Reprinted from the Portland Press Herald/TNS | September 26, 2017

SKOWHEGAN, Maine — For two months, Mark Madore has called the emergency department at Redington-Fairview General Hospital home.

There are two twin mattresses on the floor in a small room where he spends most of his time — asleep and awake. Two more mattresses are attached to the wall with athletic tape to protect him when the seizures come. A small whiteboard hangs on the wall that lists basic information, including the hospital staff member assigned to him any given day. Under the “notes” section are three words that have been there since he arrived: “Waiting for placement.”

Madore, who is diagnosed with neuromuscular disease and seizure disorder and has intellectual disabilities, is among hundreds of adults with disabilities who receive residential services under a MaineCare program known as Section 21.

Until recently, the 34-year-old had lived in a group home in Embden for about a decade. He was abruptly evicted in July after he started using medical marijuana to treat his seizures, which was not authorized by the home that provided his care.

His mother, Cathy Madore, said she takes responsibility for the medical marijuana, but disagrees with the outcome. She just wanted to help her son. Instead she left him homeless. “Even a stray dog gets to go to a shelter,” Cathy said. “He’s a person.”

Maine’s system for providing services to adults with developmental disabilities has been fracturing for years, mostly because of insufficient funding and poor oversight. A recent federal audit revealed that the state failed to investigate a majority of critical incident reports for adults in residential facilities, including 133 deaths over a 30-month period from January 2013 through June 2015.

Officials with the Department of Health and Human Services have both downplayed the report’s findings and insisted the system has improved, but providers, families and advocates don’t believe that’s true.

Madore’s ordeal is a good example of how broken the system has become. Although his diagnoses entitle him to services, there has been a constant shortage of funding, which has led to a shrinking number of group homes, leading in turn to longer wait time for people trying to get in. As of Aug. 31, there were 1,631 adults with developmental disabilities on a waiting list for residential services. Some will wait years.

And if Madore’s family wants him to continue using medical marijuana — as his doctor has recommended — that could complicate things further. The program that provides his services is federally funded, but in the eyes of the federal government, marijuana is illegal. That conflict has not been tested in court.

Cathy Madore has visited her son almost every afternoon at the hospital. It’s more than a half-hour drive each way, and she has had to cut back her hours at work — she’s an education technician for a local school — but she does it.

The staff at the hospital is great, she said, but she’s noticed changes in Mark. He doesn’t sleep or eat well. He is more subdued, largely because of medication he was given to limit his aggressiveness. Hospital staffers aren’t trained to manage his behavior, Comis explained.

Multiple times, he has bumped his head, sometimes hard enough to draw blood.

Cathy, whose voice is constantly weary, said she and her husband, Norm, cared for Mark in their home in Belgrade when he was younger. He attended public schools and received special education services that included one-on-one care. He was safe. But eventually he aged out of the services inherent in a school setting. Cathy and Norm both worked, and Mark couldn’t stay home alone. So they applied for residential services through MaineCare for adults with development disabilities.

The state manages two programs that provide the bulk of care for this population. Section 21 places adults in residential settings — often small group homes — with integrated care depending on their needs. Section 29 is for families who receive services in their own home. For years, the state has struggled to manage resources for this population. Both programs are costly — an average of $100,000 annually for Section 21 and $22,000 for Section 29 — and even though federal law mandates that services be provided, wait lists have been common, particularly for Section 21.

Three years ago, the state settled a lawsuit filed on behalf of dozens of clients to clear the wait list for the highest-priority clients, but that didn’t fix the larger problem. When Cathy Madore first applied for residential care for Mark, around 2004, the process was easy. There was no wait list that she remembered.

It took a couple of placements before Mark found the right fit. He was kicked out of one home because of violent behavior, but the Madores were able to find another option. He settled in at a group home in Embden, shared by three other adults. It was staffed 24 hours a day.

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The direct care workers at Mark's group home treated him like family. Cathy said some of them even visited him in the hospital. But his seizures were still problematic. Cathy feared that every major episode meant further loss of cognitive functions. She met with her son's primary care doctor this spring and he suggested a new medication: marijuana. Patients with epilepsy have been using medical marijuana to treat seizures, and recent studies have suggested it's effective. It was worth a shot, Cathy figured. But how could she try it without jeopardizing Mark's care at the group home?

She pulled aside one of his workers, someone she knew would be discreet, and they agreed to administer the marijuana — authorized by Mark's own doctor — on a trial basis in late May and early June. The owners of the group home, MAC Residential Services, found out and evicted Mark. Steve Austin, the chief operating officer for MAC Residential, explained that the violation put staff and other patients at risk and also threatened federal funding. The worker who administered his medical marijuana was fired as well.

Mark was served with an eviction notice July 1 and had until the end of the month to leave. He didn't make it to the end of the month at the group home. On July 25, he met with his neurologist, who decided to keep him at the hospital in Skowhegan. By the time he was cleared to leave, though, he couldn't return to the home.

The only other option was to return to his parents' home in Belgrade, but Cathy and Norm both worked and he needed more acute care. They tried to get the group home owners to reconsider their decision and even reached out to Disability Rights Maine, the group established to advocate for individuals like Madore, but were told nothing could be done. Cathy was told they couldn't help because of a conflict of interest. So Mark stayed in the emergency department.

Comis, the medical director for Redington-Fairview's ER, was careful not to discuss the specifics of Mark's care but said he's sympathetic to the family's concerns. He also said Mark is not the only adult with developmental disabilities who has ended up unexpectedly in his emergency room. "If people are ending up here, that certainly seems like the byproduct of a broken system," Comis said. adults are on a waiting list but their current living situation — often their parents' home — becomes unsafe, they can end up at a hospital or sometimes a psychiatric institution like Spring Harbor in Westbrook or Dorothea Dix in Bangor. If they are abruptly evicted, like Mark, the same thing can happen.

Funding remains the biggest barrier. Providers — the small agencies that manage group homes and provide direct care services — are receiving less in MaineCare reimbursement than they did a decade ago. Lawmakers did discuss a bill last session that would have increased funding significantly for the Section 21 program. By increasing reimbursement rates, providers say they could afford to pay workers who staff the group homes a higher wage, which would in turn make it easier to find and hire qualified candidates. Higher rates also would make existing group homes more financially stable and able to expand, thus reducing the waiting list. The original amount requested in the bill was $65 million in the first year and more in subsequent years, indexed to inflation. DHHS's recommendation was $26 million, which would bring reimbursements rates back to 2007 levels, plus a 10 percent increase. Neither passed and the bill was carried over.

Lawmakers did include an extra $11.25 million in the current budget to be split between Section 21 and Section 29 services, but the state has yet to finalize the new rules for either, so that money is dormant. Emily Spencer, a spokeswoman for DHHS, said in an email that the new funding hasn't been released because the state needs to finalize the rulemaking process. She didn't say how long that would take, although DHHS officials have told providers they are working hard to expedite the process. But they also seem to acknowledge that the additional resources aren't enough.

Emily Kalafarski, acting associate director of DHHS's Office of Aging and Disability Services, said at an Aug. 14 meeting with the Maine Coalition for Housing and Quality Services that "for things to change significantly it would depend on the Legislature and the governor to appropriate more funding." In the meantime, many group homes have closed within the last year. Those that haven't still struggle to find well-qualified staff because they can't pay much and can't offer adequate training.

For the Madore family, it's back to square one Stuck in the middle are the vulnerable Mainers like the Madores.

A little more than a week ago, Cathy got what seemed like good news: There was a crisis bed for Mark. It was in Bangor, but he could go immediately and stay until a permanent house could be found. Cathy and Norm moved him in on Friday, Sept. 8, and stayed the night in Bangor so they could check on him the next morning. "I'm not sure he knows what to think at this point," Cathy said that Friday. "I guess we'll just have to wait and see." By Saturday he was already gone. Staff had to admit him to the emergency room again. He was hurting himself, and they couldn't restrain him, Cathy said. He stayed in Bangor for a few days before returning to the emergency department at Redington-Fairview in Skowhegan. Back to square one.

Cathy said she doesn't know if she's more angry or sad.
"We're powerless in all this," she said.

October 6
Mirtha Hernandez

October 7
Peter Swierk

October 8
Vinnie Chiavoni

October 12
Carol McKelvey

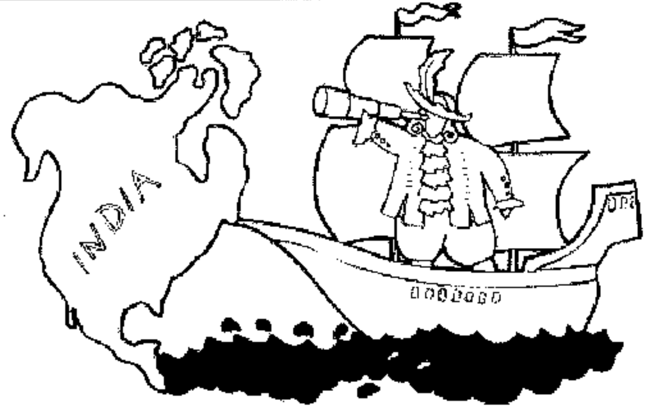
October 17
Jacqueline Smith

October 27
Gary Barris

October 28
Rosemary Ciampa

October 2
Frank & Becky Summers

October 21
Frank & Danielle Vitella



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COLUMBUS DAY WORD SEARCH

America
Atlantic Ocean
Columbus
Discover
King Ferdinand
Queen Isabella
New World
India

October General Recreation

Club Freedom Events Highlighted

2-Oct	Mon	Day Program	Prog. Time 10 AM-3 PM
4-Oct	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
7-Oct	**Sat**	**Disability Pride Celebration**	**Bus Leaves PFR 9:00 AM**
9-Oct	**Mon**	**Columbus Holiday - PF Offices CLOSED**	
10-Oct	Tue	Grocery Shopping - Shop Rite	Bus Leaves PFR 9:30 AM
11-Oct	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
12-Oct	**Thu**	**Columbus Farmers & Flea Market**	**Bus Leaves PFR 9:30 AM**
14-Oct	**Sat**	**Englishtown Flea Market - 5 Must Go**	**Bus Leaves PFI 9:30 AM**
16-Oct	Mon	Day Program	Prog. Time 10 AM-3 PM
18-Oct	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
20-Oct	**Fri**	**Amish Market/Walmart Bristol - 5 Needed**	**Bus Leaves PFR 9:30 AM**
23-Oct	Mon	Day Program	Prog. Time 10 AM-3 PM
24-Oct	Tue	Grocery Shopping - Shop Rite	Bus Leaves PFR 9:30 AM
25-Oct	Wed	Equestrian Riding at Hopewell	Prog. Time Varies
26-Oct	**Thu**	**Dine Out - Dinner - Cracker Barrel**	**Bus Leaves PFR 4:30 PM**
30-Oct	Mon	Day Program	Prog. Time 10 AM-3 PM

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