



## A Newsletter Advocating and Promoting Independent Living for Persons with Disabilities

### HR 620 guts ADA Funding

By Lisa Hayes

How long would you wait to obtain your civil right to access? How long is long enough? On July 26, 1990 I sat with my then 1 year old child watching the news, with tears of joy as President George HW Bush signed into law The Americans with Disabilities Act. Being born with my disability, I've experienced a lifetime of challenges when it comes to access. In my naivety, I thought that finally I would be accepted, valued and recognized, not pitied, marginalized or felt sorry for, for who I am as a PERSON, so I hoped. You supporters of HR 620 let me ask you: have you ever been unable to access a store because you couldn't get in the door? Have to travel 15 miles to find a nail or hair salon because the 10 stores near you are inaccessible? Maybe you got in the door but can't get through the aisle? Have you ever had to wait for a sales clerk to clear the only accessible dressing room because it was used as a storage area? Have you ever been unable to use a restroom because you couldn't get into the stall? Or unable to go to the hottest night club because there was no working elevator? Have you ever had to access a side or rear entrance then seated by the kitchen in that trending restaurant? Have you ever been misdiagnosed because your doctor couldn't get you on the exam table, or given the wrong dosage of medication because you couldn't get weighed? These are just a few scenarios that we, people with disabilities, continue to deal with. *(Continued on page 7)*

### Stop the Shock NOW!

By Shaylin Sluzalis & German Parodi

Restraints, Aversives, Shock treatment--aren't these prohibited barbaric treatment methods of the past? No, they are not, especially at The Judge Rotenberg Center (JRC) in Canton Massachusetts, an institution that tortures people with autism, who are sent (often against their will) from states around the country in attempts to "modify" their behavior through aversion shock "treatment." Recently, ADAPT members from across the country, including Cassie James- Holdsworth, Karen Burrison , Spitfire (Philly ADAPT), and Shaylin Sluzalis, (Williamsport ADAPT) braved winter weather for twelve days in front of Doctor Scott Gottlieb, Food and Drug Administration Commissioner's (FDA) home in DC to demand he sign the regulations that would ban aversion shock treatment. *(Continued on page 7)*



Visit ADAPT's website: [www.adapt.org](http://www.adapt.org), & follow on social media: @NationalADAPT

# The Disability Integration Act By The Numbers

*The Disability Integration Act (DIA) is a proposed federal law that would protect the rights of disabled people by strengthening the community integration mandate in the Americans with Disability Act (ADA). The DIA was introduced by US Senator Chuck Schumer (D-NY) in December of 2015, and US Representative Chris Gibson (R-NY) in July of 2016, and is proudly co-sponsored by our Senator Bob Casey (D-PA). Let's take a look at some of the numbers behind the DIA:*

**1,351,616:** US Residents living in nursing homes (2015)

**\$100,000:** Proposed fine for a first violation of the DIA

**78,735:** Pennsylvania residents living in nursing homes (2015)

**1999:** Year of the *Olmstead* decision, where the Supreme Court found that unjustified segregation of persons with disabilities in institutions constitutes discrimination under the Americans with Disabilities Act (ADA)

**1990:** Year the Americans with Disabilities Act (ADA) was signed into law

**437:** The number of National and local organizations signed on as supporters of the DIA

**More than 80%:** Americans who support legislation like the DIA that would require giving people home and community-based supports and services instead of forcing older and disabled Americans into nursing facilities and other institutions, according to a 2016 AARP Survey

**11:** Different ways that states currently limit access to home and community based services that would be banned under the DIA

**12:** Cosponsors of the House version of the bill: Christopher P. Gibson (R-NY), Louise McIntosh Slaughter (D-NY), Jose E. Serrano, (D-NY), Beto O'Rourke (D-TX), Tammy Duckworth (D-IL), F. James Sensenbrenner, Jr. (R-WI), Paul Tonko (D-NY), John Conyers, Jr. (D-MI), Grace Meng (D-NY), Peter J. Visclosky (D-IN), Dwight Evans (D-PA), and Bob Brady (D-PA)

**9:** Cosponsors of the Senate version of the bill: Charles E. Schumer (D-NY), Kirsten E. Gillibrand (D-NY), Michael F. Bennet (D-CO), Patrick J. Leahy (D-VT), Robert P. Casey, Jr. (D-PA), Bernie Sanders (I-VT), Elizabeth Warren (D-MA), Edward J. Markey (D-MA), and Richard Blumenthal (D-CT)

**3:** Pennsylvania Congresspersons supporting the DIA: Senator Robert P. Casey, Jr. (D-PA), Rep. Bob Brady (D-PA), and Rep. Dwight Evans (D-PA)

*Contact Senator Pat Toomey and your PA Congressional Representatives and ask them to support the DIA! (You can look up your Representative by zip code at [www.house.gov/representatives/find/](http://www.house.gov/representatives/find/))* ★🇺🇸



# Managed Care Updates: Now to be Rolled out in Philadelphia Starting January 2019

By Dan Hart, COO

If you currently use Home and Community Based Services (HCBS) under one of the Medicaid Waivers (Aging Waiver, Attendant Care Waiver, Independence Waiver, OBRA Waiver and COMMCARE Waiver) or an individual who is dually eligible for Medicare and Medicaid, it is important for you to know that important changes are coming. The Pennsylvania Department of Human Services will be replacing these existing waivers with one program called Community HealthChoices (CHC).

CHC is Pennsylvania's new mandatory managed care program for dually eligible individuals and individuals with physical disabilities. This new program will be managed by three for-profit Managed Care Organizations and will be rolled-out in 3 regions over the next three years beginning in January 2018. For our region this changeover will happen on January 1st 2019.

Before it is rolled out in our region, you will get a choice form in your mail to choose one of the three companies, Keystone First Community HealthChoices; Centene Pa Health & Wellness; and UPMC. If you don't choose a company your region, you will be automatically enrolled if you are age 21 or older and:

- Get both Medicare and Medicaid, OR
- Get LTSS in the Attendant Care, Independence, COMMCARE, or Aging waivers, OR
- Get LTSS in the OBRA waiver and qualify clinically for a nursing facility, OR
- Get care in a nursing home paid for by Medicaid

You do not qualify for CHC if you:

- Get LTSS in the OBRA waiver and do not qualify clinically for a nursing facility level of care; OR
- Have an intellectual or developmental disability and get services through the Department of

Human Services Office of Developmental Programs OR

-Live in a state-operated nursing facility, including the state veterans' homes


If you are in a Living Independence for the Elderly (LIFE) program, you can stay in LIFE and you will not be placed in the CHC program unless you ask to change.

## Community HealthChoices Updates

On November 7th the Departments of Human Services and Aging announced that the implementation of Community HealthChoices would be delayed for 2 of the 3 Phases. Phase 2 in the Southeast will now begin on Jan. 1, 2019 and phase 3 in the Northwest, Northeast and Lehigh/Capital regions will begin on Jan. 1, 2020. Phase 1 in the Southwest will still be implemented on Jan. 1, 2018 as planned.

According to an email from Secretary Miller and Osborne, the delay will provide the flexibility of learning from the southwest rollout and allow for proper time to make any needed improvements.

Also, at the December MLTSS Subcommittee of the Medical Assistance Advisory Committee Jennifer Burnett announced her termination from OLTL. Kevin Hancock will take over as the Deputy Secretary of OLTL.

*For up to date information on community health choices please visit the CHC site at: <http://www.healthchoices.pa.gov/info/about/community/index.htm>. *

# Taste of Independence 2017

By Mary Jo Rohrer

The 7th Annual Taste of Independence Fundraiser was held on October 19 at the Sheraton Society Hill. This year's honorees were Senator Bob Casey, Cassie James Holdsworth, and the Sullivan Company. We raised over \$60,000 for the Transition to Freedom Fund, which assists people who are in nursing homes to transition back into the community.

Senator Casey was honored for his work with the ADA and support of the disability community, especially given the current political climate when Medicaid has been threatened left and right. He has fought tirelessly for the rights of people with disabilities and received the Public Official Award. Although he could not attend the event since he was in DC voting on legislation that would have cut Medicaid once again, his assistant Michael Gamel-McCormick was able to accept the award on his behalf.

Cassie James Holdsworth has been fighting for disability rights since 1976, as one of the first members of Disabled in Action (DIA). Cassie helped form Resources for Living Independently in 1980, which today operates as Liberty Resources. Then, in 1987, Cassie started the Philadelphia Chapter of ADAPT, which is one of the most diverse and active chapters of ADAPT, a national grass-roots activist group that has long fought to end the institutional bias in long-term care. For her commitment to freeing our people from unnecessary institutionalization, Liberty Resources honored Cassie with its 2017 Independence Award.

The Sullivan Company and Karen Sullivan, CEO, received the Community Partner award for their quality construction management that helped us build our new beautiful Center's headquarters in a timely manner. Please stop by and see their handywork if you haven't already!

Many thanks to our sponsors and donors for their contributions and support of this year's Taste of Independence, especially our Title Sponsor, PA Health & Wellness. Special thanks to our Board of Trustees: Thomas Earle, Ken Ewell, Sarita Kimble, Deirdre MacDermott, Mary Jo Rohrer, and George Vlastaris. Last but not least, we couldn't have done it without our volunteers. They were committed to assisting with set-up and clean-up, and helped to keep the event run as smoothly as possible. 🇺🇸

*Left to right: Michael Gamel-McCormick accepts Senator Casey's award, Cassie James Holdsworth speaks, and the Sullivan Company accepts its award. Photos by Jana Williams Photography.*



# News & Upcoming Events

## New Website!

We are proud to announce that Liberty Resources has a brand spanning new website! Mary Jo Rohrer and Liam Dougherty worked tirelessly for about a year to make sure it was fully accessible and attractive for all audiences. It has the same URL: [www.libertyresources.org](http://www.libertyresources.org), but a totally different look! Talk about a makeover! We hope you enjoy the new layout, and feel free to contact us if you have any questions or concerns:

Mary Jo: [maryjorohrer@libertyresources.org](mailto:maryjorohrer@libertyresources.org)

Liam: [liamdougherty@libertyresources.org](mailto:liamdougherty@libertyresources.org)



## ADAPT Fun Run 2018

ADAPT heads to Washington, D.C. annually for the Fun Run. It is a chance to raise money for ADAPT and come together in unity. Liberty Resources will be hosting a local Fun Run again this year on May 11th at their headquarters at 112 N. 8th St., Suite 600, Philadelphia, PA 19107. It will be followed by a potluck lunch on the second floor until 1pm. If you'd like participate in the run, or sponsor a runner, visit the official ADAPT website and choose Liberty Resources as your local fun run: <http://www.adaptfunrun.net/>



## Disability Pride 2018

Join us as we celebrate our differences during Disability Pride Week, beginning on Monday, June 11th with a flag raising at City Hall! There will be various events throughout the week, such as a flag decorating day in preparation for the grand finale: The Disability Pride Parade, which is on Saturday, June 16th at 10am. It will begin at the National Constitution Center, followed by a march to City Hall.

Contact Vicki Landers for more information: [disabilitypridephiladelphia@gmail.com](mailto:disabilitypridephiladelphia@gmail.com)

## Save the Date for the 8th Annual Taste of Independence

We will be hosting the 8th Annual Taste of Independence Fundraiser at the Sheraton Society Hill once again this year! Join us for a night of cocktails, delicious hors d'oeuvres, a silent auction, and awards ceremony. Honorary guests will be announced soon, and tickets will be available for purchase on our brand-new website in the coming months. If you are interested in sponsoring the event, contact Mary Jo Rohrer at 215-63634-2000 ext. 322 or [maryjorohrer@libertyresources.org](mailto:maryjorohrer@libertyresources.org).

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## HR 620 guts ADA Funding

**(continued)** I am an unapologetic, proud woman with a disability. I have worked since I was 16 years old, I pay taxes, have a mortgage, yet I still face discrimination and lack access to what able-bodied people can access. So, I ask you again, how long is long enough for me to reap the promise of the ADA? You tell me this will protect the small business owner from scrupulous attorneys who sue for ADA violations; who is protecting *my* civil right? In truth, the ADA violation is real with all of these lawsuits! The crime is that business owners are allowed to pay a fine instead of fixing the problem, even though the ADA already includes support for business owners to seek assistance to fix these problems. So, no I have little sympathy for these businesses. I am angry, that 28 years after the passing of the ADA, instead of a stronger enforcement, we are passing legislation to weaken compliance. So, one last time, how long is long enough to reap the promise of equal access? HR620 is wrong - and while some of you may still not get it; know this: We are fighting this not just for our community; but for you as well. Because whether you realize it or not, you are only temporarily able-bodied. You will age into disability. You will one day experience what we do daily. I implore you, stand by us now; oppose any legislation that weakens our civil right to access; call your senators; support businesses by helping them become more accessible; support legislation that enforces access; because 28 years is long enough! ★

## Stop the Shock NOW (continued)

For two years ADAPT has been protesting to stop shock aversions, which is only practiced at JRC in the United States, and the FDA, being the regulator of the institution has allowed this inhumane "practice" to continue. The shocks administered to these children and adults are 3x stronger than a stun gun, and are being administered on patients several times a day. During the protest camp out, ADAPT educated

Gottlieb's neighbors and the community about the FDA's refusal to stop the shock at the Judge Rotenberg Center. We started each day chanting at 7am when the noise ordinance would end and we would do different theater throughout the day. We would close each night out chanting again before the noise ordinance would begin at 10pm. We also got support from Representative Chris Smith from New Jersey to work on a bill that would ban shock aversions in the U.S. entirely.

On Tuesday, March 20th, 2018, while half of the group was at the Capitol working on behalf of legislation to end the electric shock at JRC, the U.S. Park Police visited protesters who remained in the icy sleet to watch over our camp and threatened us with arrest if we did not leave. Mobilizing to FDA's Headquarters, ADAPT called 10 accessible cabs and traveled over the D.C. line and into Maryland to visit Gottlieb at the FDA. We marched up to the building and entered through an open set of doors at about 8:30 pm, to be stopped by security who at first said they had never heard of Gottlieb and could not contact him, and then barricaded the area. Gottlieb never responded. "Why won't he do his job and protect our people?" asked Cassie Holdsworth, an ADAPT organizer from Philly ADAPT. "The UN says it's torture, and the FDA itself says aversive shock is an unacceptable risk."

At midnight, we decided to leave the FDA and went to the intersection at New Hampshire Ave. and Schindler Dr. outside the FDA where we blocked traffic for 3 hours in a nor'easter before police arrested 11 members. ADAPT will never go quietly and, while they have closed camp for this battle, the war on shock therapy is not finished. "We won't stop the fight to end shock aversion until this inhuman practice is abolished," said German Parodi, from Philly ADAPT. "As long as they torture our people, they will have to deal with ADAPT." ★

# Liberty Works

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Deborah Russell, Chair of the Board • Thomas Earle, CEO

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## ***WHAT'S INSIDE...***

Page 1: HR 620

Page 1: Shock Therapy

Page 2: Disability Integration Act  
by the Numbers

Page 3: Managed Care Updates

Page 4: Taste of Independence 2017

Page 5: News & Upcoming Events

Page 6: Home Choices & Furnishing a Future

Page 7: HR 620 continued

Page 7: Shock Therapy continued