

DISABILITY RIGHTS IN ACTION

A Newsletter of the Center for Disability Rights, Inc. / Spring 2018

Why Disability Groups Oppose Assisted Suicide Laws



Diane Coleman receives the 2016 Adele Carlson Advocacy Award.

People are often surprised to learn that all of the major national disability rights groups that have taken a position on assisted suicide bills oppose them. Why would groups like ADAPT and the National Council on Independent Living oppose a "right" to doctor prescribed suicide for people with "terminal" conditions?

First, assisted suicide sets up a double standard, with suicide prevention provided for some, but suicide assistance given to others, depending on their health or disability. If this were based on race, sexual orientation or other diverse groups, we'd call it bigotry.

Those of us with disabilities have good reasons to be skeptical about the so-called "choice" of assisted suicide in our cost cutting health care system. Under these laws, anyone could ask for assisted suicide, but only doctors may decide who gets lethal drugs.

Doctors used to exercise near-total control over the lives of people with disabilities, discouraging parents from raising us at home, sentencing us to institutions, and imposing their own ideas about what medical procedures would improve our lives.

Disability groups started paying attention to the problem of doctors making life and death determinations in the 1980s, in court cases involving the right to refuse treatment. These cases involved men on ventilators stuck in nursing facilities, who wanted the right to live in apartments or real homes, or else "pull the plug." They did not get the right to live in real homes instead of facilities, but courts granted them a "right to die."

Then the 1990s brought Dr. Jack Kevorkian, who conducted assisted suicides using lethal drugs, with two-thirds of his body count being people who were not terminally ill. The difference between being disabled and dying was not recognized, and as disabled people know, terminal predictions are

Continued on Page 4

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WHAT'S INSIDE

**INTEGRATION
INDEPENDENCE
CIVIL RIGHTS**

2

Meet Our Staff
CDR Highlights

3

Upcoming Events!
Mark your Calendar

4

Catch Up on Advocacy
Local & State Impact

5

Learn About Our Programs
At all four CDR Locations

6

Features
Updates of Interest

7

Ways to Support & Join Us
Stay Involved



Center for Disability Rights works to ensure the full integration, independence and civil rights of people with disabilities and seniors in the community.

Dear Friends,

Many New Yorkers believe that they have to choose between getting healthcare and having sufficient funds necessary to live in the community. We have offered a Pooled Trust for years, in which consumers can receive Medicaid while depositing excess income in the trust to pay their bills. Last December, Governor Cuomo signed legislation that will require the state government to notify disabled residents of this option. This information will positively impact many disabled individuals, as well as save the state tax dollars.

Many other things have also been going on here at CDR. I invite you to catch up on many of our programs and services on pages 4-6, and to check out our featured staff member in the article below.

Please contact us to learn more about CDR and how you can get more involved with us. Stay tuned for more fun events and exciting news for next year!

Bruce E. Darling

CDR's Staff Highlight: Linda Taylor

During the past year, CDR and the disability community have needed to stretch their resources to not only fight for positive change, but to defend the ADA and Medicaid funding. Stormy seas need a steady hand, and our Executive Administrative Assistant is the perfect example of this phrase. We would like to take this opportunity to thank Linda for her dedication, perseverance, and kindness in making CDR a successful organization.

Linda's duties go far beyond working for CDR President Bruce Darling and our Board of Directors. She is an invaluable asset to every member of our staff, whether for a director or a clerk, and has been particularly resourceful for our new employees. When our disability advocates are traveling across the country, she keeps everything running in place. For every event that we put together, she is always counted on to ensure our plans become a reality.

Linda has worked at CDR since 2006, and was employed at RCIL for six years prior to the opening of our current facility shared between both organizations. In addition to her many years of service to the disability community, she has served our country in the United States Coast Guard Auxiliary for seventeen years. You also may not know that for the warmer half of each year, she resides on a trawler! Hopefully the weather will be favorable once you're reading this newsletter.



Linda Taylor at our ADA Gala.

Join Us for ADAPT Fun*Run on April 29, 2018!



Grab your wheels, your skates, your dog, or your family and come to our Rochester Fun*Run for Disability Rights 2018! Join us on April 29th at 1—3pm at Genesee Valley Park's Roundhouse Shelter to support Disability Rights while you run, roll, or walk!

It gets even better! Everyone who comes will receive a raffle ticket for a variety of prizes. If you bring a friend who is new to Center for Disability Rights, Regional Center for Independent Living, All About You Home Care, or ADAPT, you will receive an additional raffle ticket! You can also buy additional raffle tickets for \$1! All proceeds goes to disability rights' efforts.

Interested? Contact Stephanie Woodward at swoodward@cdrnys.org or (585) 546-7510!

MARK YOUR CALENDAR!

April 29, 2018

Rochester Fun*Run, Roundhouse Shelter, Genesee Valley Park
1:00pm—3:00pm

May 5, 2018

Clean Sweep: Join CDR's Volunteering Team & attend a free Red Wings game!
Contact Ericka Jones at 585.546.7510 or ejones@cdrnys.org

May 13, 2018

ADAPT trip kicks off by the 13th annual FUN*RUN
Washington D.C. / May 13—May 17

June 24, 2018

ADA Picnic, Dogwood Shelter, Genesee Valley Park
1:00pm—3:00pm

July 19, 2018

ADA Gala at the Riverside Convention Center
6:00pm—10:00pm

Updates From Advocacy Team

One of the many advocacy initiatives conducted by the Center for Disability Rights in 2017 was working to pass the Pooled Trust Notification Law. This legislation received bipartisan support throughout the entire process and was passed by the New York State Legislature, with also receiving Governor Andrew Cuomo's approval on December 18, 2017.

This bill amends the New York State Social Service law thereby requiring the New York State Department of Health to inform eligible consumers of the Pooled Trust option in the Medicaid Notices of Decision. For individuals in need of Medicaid in New York State, who have excess income and have a disability, there are three methods available to them with the Pooled Trust option being the most beneficial one for the consumer. Through the use of a Pooled Trust, these consumers are not forced to have to choose between receiving necessary medical support services like attendant services, medical supplies to paying for food, rent, or other related living utilities.

This law officially goes into effect on June 16, 2018 and the Center for Disability Rights remains hopeful with the Pooled Trust Notification Law more members of the Disability community will be able to remain in the community!

Want to join us on our Advocacy Trips? Call us at (585) 546-7510 or email us at advocacy@cdrnys.org to join our Advocacy Group!

Assisted Suicide Laws *Continued From Page 1*

often wrong. The difficulties disabled individuals faced in getting help to live were not considered, or worse, they were seen as good reasons for suicide.

In Oregon, where assisted suicide is legal, the top five reasons doctors give for their patients' suicides are not about pain, but psychological issues related to needing help from others. People feel a "loss of autonomy" (91%) or that they are a "burden" on others (42%). Consumer-controlled attendant services could address these concerns. But the Oregon law doesn't require doctors to tell patients about or provide them.

Disability advocacy groups also worry about the increasing prevalence of abuse of disabled elders, with federal authorities estimating that one in ten elders is abused, mainly by family and caregivers. An heir or abusive caregiver can suggest assisted suicide and sign as a witness to the request, "certifying" no coercion. No independent witness is required when the deadly drugs are taken, so who would know if it was voluntary?

Disability rights advocates have become a leading voice in the debate over assisted suicide. Lawmakers should recognize the dangers to many elders, ill, and disabled people who are not safe from mistakes, coercion, and abuse.

Editor's Note: Diane Coleman is the President/CEO of Not Dead Yet, and a member of the CDR/RCIL Board of Directors.

What's New In Albany

CDR welcomed our new Policy Analyst, Katy Carroll, in January. Katy is a licensed attorney in the state of New York. She serves on the New York State Independent Living Council and the National Federation of the Blind of New York.

On February 12, we traveled to the capitol for the annual NYAIL lobby day. We met with state legislators and discussed disability issues important to our community.

Local & National Updates

Our second annual *Free Our People Film Contest* is underway! We are seeking stories that demonstrate institutional bias, whether through a narrative film or a documentary. Learn more at <http://cdrnys.org/free-our-people-film-contest/>

March 1 was the National Day of Mourning. A memorial was held in Rochester to honor the lives of disabled people who were murdered by family members, aides, or other people who were supposed to be helping the disabled person.

Contact Advocacy



(585) 546-7510
Ask for Advocacy!



advocacy@cdrnys.org
Email Our Team!

Get Involved With Us Today!



Social Adult Day Services

Although we may not yet be rid of snow, spring brings forth many exciting holidays and reasons to celebrate! Save the dates for Easter, Cinco De Mayo, Mother's Day, Memorial Day, and Father's Day- each Friday before the holiday will mark an event. Other plans will commemorate foods- licorice, donuts, ice cream, and wine. Additional pursuits will tie in American history, Ramadan, scrabble, and a spelling bee. Last but not least, do not forget about our annual Spring Planting!

Pam and Pat enjoying lunch at the Memorial Day picnic at the Rec Center!

To join our Day Programs: (585) 546-7510 / nelliott@cdrnys.org

Community Habilitation

CDR provides Community Habilitation (Com Hab) services to adults who receive services through the OPWDD Waiver. Community Habilitation services can be delivered at any non-certified location, including the individual's home. Supports include adaptive skill development, assistance with activities of daily living (hands-on), community inclusion and relationship building, training and support for independence with travel, transportation, adult educational supports, development of social skills, leisure skills, self-advocacy, and informed choice skills; each to help the individual access the community.

As with all direct services under the OPWDD Waiver, consumer choice is the driving force. Individuals identify goals they would like to achieve, and work with their support team to identify the steps they will take (with the support of their individual Com Hab staff) to make their goals a reality. Our Com Hab program provides services and support to 27 women and men in the Rochester area: 14 deaf and 13 hearing waiver participants.

In October of this past year, Stephanie King joined the Community Habilitation team in her new role as the Manager of Community Supports. Stephanie came to Waiver Services from her role as a Transition Coach here at CDR, and she has brought with her sense of humor, excellent organizational skills, attention to detail, and her commitment to the mission and vision of CDR.

All About You Home Care

AAY would like to give a late welcome to Gina Natarelli, our new Director of Nursing. Gina joined the team in late November, and has nursing experience in wound care and home care. She joins AAY nurses, Anne Weiss and Kathy Moore in the vital role of providing AAY Personal Care Assistants (PCAs) with regular oversight, supervision, training, and designing care plans for AAY service recipients that reflect and detail their individual level of care.

AAY nurses are also responsible for conducting the PCA certification classes and all in-services. The most recent group of those who completed the PCA certification class are coming on board to join us in providing service to the women and men in the Rochester area. After successful completion of the PCA certification course, all PCAs go through an extensive background check prior to being hired and beginning work, and then receive individual training from one of the AAY nurses any time they work with a AAY consumer they have not worked with before, and any time an individual's plan of care changes.

Olympic Fever in Canandaigua

The Social Adult Day Program in Canandaigua recently hosted an Olympic competition, in which participants had the opportunity to each win “100 Grand” per contest — whether finishing first, second, or third. Our versions of the Biathlon, Ski Jump, and Speed Skating did not require dealing with snow, ice, or heights. Curling and hockey also took place in the warm confines of our recreation center. We extend our congratulations to all of our participants, and would like to acknowledge some of the winners!



Photos from left to right: Biathlon winners; Norma, John & Brenda; Curling winners: Brenda, Sonja & Donna; Ski jump winners: Vivian, Norma & Nick.

Christopher Harper's Story: Part 4 “The Crossroads To Revival”

An accurate diagnosis of a brain injury goes undetected. “The little known fact” of brain injury is living with encrypted messages with no code breakers. It is like peering through a thin sheet of glass that is wavy and misty. I was engaged to a “hidden” reality and blank slate of crisis. Physicians and health care providers face multiple causes, which overrides effective and efficient medical practices.



Photo Credit: Rachel Polter

Many with brain trauma face new “properties” broad-based in anger, restlessness, mood swings, loss of sleep, decreased appetite, and anxiety. One lives with a backdrop to a variety of services that cannot intellectually be understood. The shaping of events unfolding leaves me in a “prison of darkness.” The four years post-accident produced a less promising future, the loss of seven jobs, utility shut off notices, eating from food pantries, and facing homelessness. I lost my children, who turned their backs on me through lack of understanding of an undiagnosed brain injury. The physicians’ lack of knowledge gives alibis to sound clinical awareness of TBI. They lack an understanding on the manifestation of real outcomes for brain injuries. For me, the outcomes were fear and vulnerability, while not knowing what was happening to me. Alone, I was distraught as the desire to live life dissipated.

I have learned now to never give up with building a “safety net,” a common goal for all of us with a TBI that can only bring success with bridging the gap in a new world. Without a “safety net” of support, the inner community will be the framework to mind, or major impact of wellness and confidence. My brain injury will always be with me; however, keeping a positive mindset is the one asset I can count on, to motivate me to be the best I can for myself and others.

Editor's Note: This brief account introduces us to the TBI community, from an excerpt of a novel being written by Christopher Harper entitled “Abandon Town.”

Upcoming Board Meeting

April 19, 2018
11:00am-1:00pm
497 State Street
Rochester, NY 14608

For dates of upcoming board meetings, please contact Linda Taylor:
Ltaylor@cdrnys.org

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WAYS TO SUPPORT & JOIN US

PAGE
07

DONATE TO CDR: SUPPORT OUR PROGRAMS AND SERVICES

CDR is always in need of donated items from the community to support individuals with disabilities living independently in the community!

Please contact CDR's Development Department, at Ltaylor@cdrnys.org, to donate an item or gift to CDR, or inquire about specific items needed at this time.

All donations are truly appreciated! CDR is a 501(c)(3) organization. All gifts are tax deductible. Thank you for your generosity and support!

LEARN HOW TO GET INVOLVED WITH OUR COMMITTEES!

CDR has a variety of committees that support the organization. We are in need of enthusiastic and knowledgeable community members to join our various committees and support the overall mission of the organization.

Interested? Contact Linda Taylor at Ltaylor@cdrnys.org for more information about all of the different opportunities we have for you!

Get Involved with CDR Today!

START YOUR CAREER WITH CDR TODAY! JOIN OUR TEAM

Interested in starting your career with Center for Disability Rights?

Visit our website at www.cdrnys.org for a complete list of our current job postings! Apply online, or stop into our State Street office or any of our three other office locations and join the CDR family!

All About You Homecare (AAY) is looking for talented individuals to join the AAY team! Contact us to learn more about employment opportunities! Job postings for AAY can be found on CDR's website.

INTERESTED IN VOLUNTEERING WITH CDR? LET US KNOW!

CDR has a variety of events and other volunteer opportunities throughout the year. Whether you are interested in a one time volunteer experience or an ongoing weekly/monthly opportunity; please contact us today and see what we have available!

CDR collaborates with the Regional Center for Independent Living, so there is always a need for volunteers on a variety of projects!



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CDR works for the full integration, independence, and civil rights of people with disabilities.

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