

# DISABILITY RIGHTS IN ACTION

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

## ADAPTers Fight for Disability Integration Act and Against Electric Shock Torture

ADAPT went to D.C. this May to fight for the Disability Integration Act (DIA)! DIA is a bill that would give people with disabilities a choice to live in the community by requiring insurance companies to cover home and community based services whenever they would cover a person to live in a nursing home. The DIA has been held up in the U.S. Senate by the Health, Education, Labor, and Pensions (HELP) Committee, so ADAPT paid a visit to two important Committee members. ADAPT visited the offices of Senators Patty Murray (D-WA) and Lamar Alexander (R-TN) to ask them to cosponsor the bill. In the end, Alexander chose to have ADAPT members arrested - while Murray cosponsored the bill!

Activists also visited well-known political organizations which had not yet supported the DIA. ADAPTers occupied the lobbies of the Center for American Progress and the Heritage Foundation. After the protest, both organizations released statements in support of the DIA. Later, ADAPT visited AARP. ADAPT blocked AARP's parking garages and its entrances, and shut down elevators. ADAPTers were rewarded for fighting through extreme heat and discomfort with an agreement by AARP leadership to meet and discuss their support of DIA. Activists followed up on the protests with Hill visits to numerous Representatives and Senators. As a result of these efforts, four Senators and

six Representatives have cosponsored the DIA since the action.

In addition to supporting the DIA, ADAPT also continued a year and a half long fight against torture at the Judge Rotenberg Center (JRC). The JRC is the only place in the United States where electric shocks are used as aversive therapy on residents, including children with disabilities. The Department



*Sophie and Jonathan pay a visit to the residence of Alex Azar, Secretary of Health and Human Services.*

**Debbie Bonomo**  
*Board Chair*

**Bruce E. Darling**  
*President/CEO*

**Visit us on the web:**  
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**(585) 546-7510**

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*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,

The Disability Community continues its fight to incorporate disability rights into civil rights! We have persisted in securing additional support for the Disability Integration Act, and we will not rest until this legislation becomes law. Many individuals still do not grasp the fundamental rights of life and liberty for disabled Americans. In fact, incarcerated citizens are legally protected from the electric shock torture that continues to be conducted at the Judge Rotenberg Center upon our people.

Many other things have been going on here at CDR. I invite you to check out our upcoming events on page 3, and to catch up on some of our programs and services on pages 4-6.

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

*Bruce E. Darling*

## Staff Highlight: The Busy Bea Award

Every year, CDR awards the “Busy Bea” award in honor of the effort of Beatrice (Bea) Hapeman. It is in the spirit of the professional and personal commitments Bea demonstrated to CDR’s mission of Integration, Independence, and Civil Rights, that CDR proudly honors a new “Busy Bea” Award recipient each year. For the last three years, the award has gone to three CDR employees. While we are fortunate to have many dedicated, driven, and diligent staff members, these recipients have taken their roles to extraordinary levels. They exemplify the quotation “leadership is action, not position.” Their contributions range from the national (service and support of disability rights advocacy), to the organizational (always available to help peers in other departments), and virtually everything that falls in between. Each and every day they illustrate how their roles are more than just a job. They are truly committed individuals.

*Photo on left, Susan Stahl (2016) is one of our Transition Specialists, and a veteran employee.*

*Staci Kominiarek (2017) is the Director of Program Development & Quality Improvement, although her work ethic goes beyond her title.*

*Photo on right, Ericka Jones (2018) is a Systems Advocate, and earned the award after only three years at CDR.*



## Accessible Trick-or-Treat

**OCT 25** 5PM–8PM  
Thursday

**Fun, safe, & fully-accessible Halloween!**

**Center for Disability Rights**  
**497 State Street, Rochester, NY**

**Free for children up to 10 years old!**  
**Adult supervision is required.**

Please contact us if you have a child older than 10 years of age with a disability that you feel is appropriate to attend this event.

**[events@cdrnys.org](mailto:events@cdrnys.org) / 585.546.7510**

We are a scent-free and non-smoking environment.

Candies • Costumes • Snacks • Games • Prizes



MARK YOUR  
CALENDAR!

**October 25, 2018**

**Halloween Accessible Trick-or-Treat, 5:00pm—8:00pm**  
497 State Street, Rochester, NY

**November, 2018**

**Thanksgiving Lunch**  
*To Be Determined Soon!*

**December 13, 2018**

**End of Year Party, 5:00pm—9:00pm**  
The Strathallan, 550 East Avenue, Rochester, NY



## Updates From Advocacy Team

It has certainly been a busy few months for the Advocacy Team!

The last few months were a whirlwind for the Advocacy Team! It almost seemed like there was so much legislation to fight for and so little time! The team did find a win, however, with the Language Equality & Acquisition for Deaf Kids (LEAD-K) bill passed by the Senate! This is an encouraging result that we can hold on to as we work to reintroduce this bill next session!

In the mix, we also visited Albany twice for legislative days where we talked to legislators about important subjects such as Complex Rehab Technology (specific equipment on wheelchairs such as tilt functions or specialized cushions to prevent pressure sores), opposition to Assisted Suicide bills, and supporting the Visitability bill so disabled people have more access to homes in the community!



If all that were not enough, we also saw the addition of four cosponsors in the Senate and six cosponsors in the House for the Disability Integration Act (DIA)! The Disability Integration Act would give people with disabilities the fundamental right to live in the community rather than being forced into nursing facilities and institutions.

Want to join us on our Advocacy Trips? Call us at 585.546.7510 or email us at [advocacy@cdrnys.org](mailto:advocacy@cdrnys.org) to join our Advocacy Group!

## ADAPTers Fight *Continued From Page 1*

of Health and Human Services (HHS) can stop this torture, so ADAPT handed out flyers outside HHS headquarters and spoke to its employees.

ADAPT continued the “Stop the Shock” campaign at a smaller action a month later in Indianapolis, Indiana, where HHS Secretary Alex Azar lives. Activists snuck onto Azar’s front lawn in the early morning, knocked on his door and played recordings of the actual torture at JRC. ADAPTers chanted for hours through pouring rain, and stood their ground despite threats from police. The police refused to provide communication services to Deaf ADAPTers and threatened to have powerchair users transferred to manual chairs and to keep all arrestees in custody for three days. Eventually, the police arranged for paratransit to transport the 26 arrestees to jail. The action was widely covered by local media, so Azar’s neighbors are aware of how he has failed the disability community.

Due to the ADAPTers who contributed to these actions in person or from home, the DIA is now closer to passage and the Stop the Shock fight continues. Thank you to everyone who is supporting these efforts!

### What’s New In Albany

The Advocacy Team would like to share several policy victories from this year’s legislative session:

- LEAD-K (A10710/S5992) was introduced in the Assembly and passed in the Senate.
- Legislation legalizing physician-assisted suicide (A2383/S3151) did not make it out of committee.
- Legislation establishing the Office of the Advocate for People With Disabilities (A10706) passed the Assembly.
- An improved version of legislation preventing housing discrimination based on legal source of income (A10610) made it out of Committee.

### Contact Advocacy



**(585) 546-7510**  
Ask for Advocacy!



**[advocacy@cdrnys.org](mailto:advocacy@cdrnys.org)**  
Email Our Team!

**Get Involved  
With Us Today!**

## CDR Collaborates with RHA on Opportunity

This summer, CDR and the Rochester Housing Authority (RHA) submitted a Request for Proposal (RFP) to the United States Department of Housing and Urban Development for the Mainstream Voucher Program. This would allow CDR to direct consumers to these vouchers, in order to depart or avoid living in an institutional setting. However, we are also pleased to strengthen our relationship with RHA, and look forward to the possibilities that lay ahead for addressing our consumers' housing needs.

One of the most significant barriers we face in transitioning and diverting consumers from living in institutional settings is the lack of affordable, accessible, and integrated housing. We cannot directly provide housing, but we collaborate with landlords and property managers on behalf of consumers. In fact, CDR has managed nursing home transition services years before we had funding to provide this service.

The parallel missions of both agencies, combined with CDR's experience serving the disability community, made for a self-evident partnership. If the funding opportunity is awarded, we will publish an update in the next edition of the newsletter. CDR is prepared to hit the ground running to implement this program, and we will utilize our new collaborative relationship with RHA, regardless of the outcome.

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## Nursing Home Transition Program Brings Forth a New Employee

My name is Julie Sidebotham; I am an above the knee amputee, and I am in a wheelchair. I was living in Monroe Community Hospital (MCH), and I did not know who I could turn to for help with moving back to the community. I then learned about the Center for Disability Rights and the Open Doors Transition Center. Ann Kaplow, a Transition Specialist at CDR, met with me at MCH and provided me with the necessary resources so that I could live independently.

I was later contacted by CDR for an open position as a Peer Mentor. When I found out that I could give back to CDR by becoming a Peer Mentor, I jumped at the chance. While working as a Peer Mentor, I would go to nursing facilities and talk with individuals who were getting ready to discharge back home; I told them my story and provided positive encouragement. I personally understand that when you are faced with a sudden disability, it changes your life forever. You do not think you will ever be back to your old self or "normal" again. However, I could show others that being disabled does not mean one needs to stay in an institution for the remainder of your life.



Soon after serving as a Peer Mentor, I was hired as a Transition Specialist at CDR. I now am on the front lines toward working with nursing home residents who wish to be discharged, just like I was. I am very happy to have this job, to give back to CDR, and to help others in my community. I love my work and having earned an opportunity to work more closely with others who are facing what I went through. Finally, I would like to thank CDR for giving me the opportunity to return home, and to live and work in the community with a disability.

*Our new Transition Specialist, Julie.*

*Editor's Note: as told by Julie Sidebotham.*

## New Roles at Day Services

This past spring, two of our administrators for the Social Adult Day Services programs were promoted. Kelly Peeso is the new Manager, and Curt Sanger is now serving as the Assistant Manager. Kelly is continuing as the lead person for the Rochester recreation center, and Curt has taken on the day-to-day work at our recreation center in Canandaigua. We would like to extend our congratulations to Kelly and Curt, and invite you to check out what the facilities and programs have to offer!

*There's plenty going on at our recreation center in Rochester! To join our Day Programs: (585) 546-7510/kpeesoo@cdrnys.org*



## Christopher Harper's Story: Part 6 — "The Foreigner"



*Christopher Harper playing the piano.  
Photo Credit: Rachel Polter*

There are times when living life with a TBI goes without saying. I have an "unwelcome" guest within my brain structure. For me, adjusting to a way of life doesn't always make sense. The fear(s) of loneliness is "unsettling" for me and possibly for others with a TBI.

I went from working in a professional healthcare position to how my life is now. Over the years since I started my recovery process in 2010, I had to learn how to manage my far distant brain to a destination of "unknown." There have been many complex challenges to a new revival. I had to include decision making and the impact of the processing it takes to attempt to understand others within their society. Like a "foreigner" in a place unfamiliar to me. This mindset illuminates another world. For me, it is like "Waking up Dead". How I perceive others is like a fracture in a new society, a dimension, or an inner being of a lost world. I was hit hard by a TBI. It was the "Breaking Point" in the collectively "moving forward".

The keynote to this subject of the "Foreigner" is a practical lesson of not only me but in theory for others in the similar situation. The process at connecting with others, enhancing personal/professional relationships by becoming better at having conversations with others through resilience and restoration for positive outcome isn't always easy. It is difficult for me to want to live this "symbolic death." These articles highlight the hard core truth of the perplexities of the present day. It creates a buildup of anxiety and hopeless feelings, and struggling to take the "high road", and creating a special bond with those who can and will emotionally support someone like me and others with a TBI.

*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

October 18, 2018  
11:00am-1:00pm  
497 State Street  
Rochester, NY 14608

For dates of upcoming board meetings, please contact Linda Taylor: [Ltaylor@cdrnys.org](mailto:Ltaylor@cdrnys.org)

## Issues With Newsletter?

Have you changed your address?

Are you receiving too many copies?

Would you like your newsletter via email?

For information, contact Linda Taylor: [Ltaylor@cdrnys.org](mailto:Ltaylor@cdrnys.org)



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497 State Street  
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(585) 546-7510

# WAYS TO SUPPORT & JOIN US

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## 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](mailto: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](mailto: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](http://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!**



**Center for Disability Rights, Inc.**  
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Rochester, New York 14608

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## ***PROTECT YOUR FREEDOM!***

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

### **Become a Member of CDR today!**

**Membership year 9/1 - 8/31. Minimum contribution \$5 per year.**

NAME

ADDRESS

CITY

STATE

ZIP

PHONE NUMBER

EMAIL ADDRESS

Enclosed is my contribution of \$\_\_\_\_\_.

Make your check payable to Center for Disability Rights, Inc.  
Mail check, along with this completed membership form, to:

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497 State Street  
Rochester, New York 14608



***\*All Donations are tax deductible.***

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