

# DISABILITY RIGHTS IN ACTION

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

## Connecting the US & Japanese IL Movements



*Sarah and Bruce pause for a moment during their travels throughout Japan.*

As the Vice-President and President of the National Council on Independent Living, Sarah Launderville and I were invited to Japan to meet with the leaders of their Independent Living Movement. Sarah and I visited Japan in order to strengthen the relationship between the US and Japanese IL Movements; gain a better understanding of the global work being done to advance the IL Movement; and assist the Japanese in diversifying their movement to better include, neuroatypical individuals, people with psychiatric disabilities, women and LGBTQ+ individuals.

During our visit we had extensive meetings with the founder of the Japanese IL Movement, who is the Director of a Tokyo CIL. We met with Disabled People's International – Japan. Sarah and I were invited to meet with governmental officials and presented at a seminar in Tokyo, where we shared information on the US IL Movement. A highlight of the trip for me was being able to ride on the accessible Japanese Bullet Train, which travels at speeds up to 180 MPH. During the first weekend, Sarah and I had the opportunity to visit several local temples and shrines in Kyoto. While in Kyoto, we spent the evening at a traditional Japanese Inn, which served us amazing food and showed us incredible hospitality.

Sarah and I were dispatched to different parts of Japan. The Muchu IL Center in Osaka welcomed me with open arms. I spent several days with them learning about their center, and the cultural differences within Japan. I presented at a second seminar in Osaka which compared activism and issues between the US and Japanese IL Movements. Later that evening, the Muchu Center hosted another big party that included seven of the nearest CIL Directors. They literally set up a Summer Street Festival in their office/program space. Another event was organized entirely by the youth as a way to build networking relationships with us.

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**Roberta Wallach**  
*Board Chair*

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

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**(315) 789-1800**

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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,

Earlier this year, the state passed a budget that incentivizes institutionalization through incorporating a “carve out” for nursing home placements. This contradicts New York’s 2013 Olmstead plan, will incur increased governmental costs, and most important, it is an attack upon our civil rights. We disabled constituents were clearly not heard, despite the accomplishments we have made, and most especially our victory in saving Medicaid last year.

Many other things have been going on here at CDR. I invite you to catch up on some 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 involved with us. Stay tuned for more fun events and exciting news for the year!

*Bruce E. Darling*

## CDR’s Staff Highlight: Beth Noworatzky



*Beth Noworatzky smiling.*

The Development team is more than just fundraising; we support each and every employee within CDR, as well as for our sister organizations RCIL and AAY. This department is relatively new within the broader organizational history, and it incorporates many “behind the scenes” functions that are not always evident on a day-to-day basis. Our veteran staff member, Beth Noworatzky, serves as our Visual Design and Social Media Coordinator, and does so much more than what her title implies.

You may know Beth as the source behind all of our graphic design materials and managing our Facebook account. Or have seen her as our resident photographer for our events. She is also our website guru, the expert for our marketing needs and strategies, creates the presentations in our main office lobby, and serves as one of our leaders when it comes to events whether great or small. Beth’s technological knowledge, high standards, and consistent initiative make up an incredibly valuable and appreciated combination.

In addition to all of these duties, Beth is a dedicated advocate for the Deaf community. She has given back to her alma mater, the Rochester Institute of Technology, by hosting a college intern each summer and through serving as an adjunct professor. Finally, she serves on the Communications Committee for the Clarke Schools Alumni Council. In what little spare time she has available, she does freelance design and copywriting work, and also pursues food and travel photography as a hobby.

## ADA Gala

Celebrating the 28<sup>th</sup> anniversary  
of the **Americans with Disabilities Act!**  
Rochester Riverside Convention Center

Proceeds to benefit the Center for Disability Rights

Thursday, July 19, 2018  
6 o'clock until 10 o'clock in the evening

For reservations, please contact Ryan Chalmers  
events@cdrnys.org • 585.546.7510

## MARK YOUR CALENDAR!

### June 24, 2018

**ADA Picnic**, celebrating 28 years of the Americans with Disabilities Act  
Genesee Valley Park: Dogwood Shelter / 1:00pm—3:00pm

### July 5, 2018

**ADA Legislative Breakfast**, 8:00am—10:00am  
497 State Street, Rochester, NY

### July 19, 2018

**ADA Gala** at the Riverside Convention Center, 6:00pm—10:00pm  
123 East Main Street, Rochester, NY

### August 2018

**Free Our People Film Festival**, date and time to be announced soon!  
Rochester, NY

### October 25, 2018

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



## Updates From Advocacy Team

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

After the final budget came out in March, we found that the Governor had ignored all our demands for access; including affordable, accessible and integrated housing, increased funding for independent living centers, and creating a funding system to ensure disabled people with high service needs will not be forced into institutions.

After New York State transitioned its Medicaid program from fee-for-service, to a managed care system with managed long-term care (MLTC), a “carve out” was proposed that would lead to people who were currently being served in the community with higher costs, to be forced into nursing facilities. When nursing facilities or other institutions were incorporated within managed care, people with disabilities would not then be forced into institutions. The budget, however, completely unraveled this by including this “carve-out,” making it easier to force people into institutions.

What is even more frustrating is that the U.S. Supreme Court ruled in favor of the Olmstead decision, which states that services must be provided in the most integrated setting. The most integrated setting for the disability community would be to live in the community, and not nursing facilities or institutions.

The state’s decision to include a “carve out” in the budget not only leads to more costs for the state, but it limits the life and liberty of disabled New Yorkers! It may be too late for the budget, but we will continue to fight to Free Our People!

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!

## Japanese IL Movement *Continued From Page 1*

The last day in Osaka was set aside for me to see their city which happened to fall on Vernal Equinox Day, which is a national holiday. A spurt of warm weather gave us the opportunity to see the unexpected bloom of the cherry blossoms as I walked through the Emperor’s residence.

### Next Steps:

- A delegation from Japan – including the Director of the Muchu Center – will be visiting our Center in July!
- Sarah and I have been invited to participate with an international delegation to visit Africa, to be able to learn first-hand about the efforts to spread Independent Living to developing nations.
- We have been asked to develop a plan to support the expansion of Independent Living throughout South America, much in the same way the Japanese have supported IL throughout Asia.

*Editor’s Note: As told by Bruce Darling, President/CEO of CDR.*

## What's New In Albany

April 16<sup>th</sup>:  
The Advocacy team spoke to the Most Integrated Setting Coordinating Council on issues such as accessible transportation and housing.

April 16-18:  
Advocacy team members, in collaboration with Not Dead Yet, met with legislators; asking that they not support any legislation that would include Assisted Suicide.

## Local & National Updates

March 16<sup>th</sup>:  
Our Systems Advocate spoke at a press conference calling for more funding toward RGRTA for accessible transportation services.

We are happy to announce that Sophie Poost has joined the Advocacy Team as a new Systems Advocate! Sophie will focus primarily on housing and employment.

## Contact Advocacy



(585) 546-7510  
Ask for Advocacy!



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

Get Involved  
With Us Today!

## Fondly Remembered: Joe Santacesaria



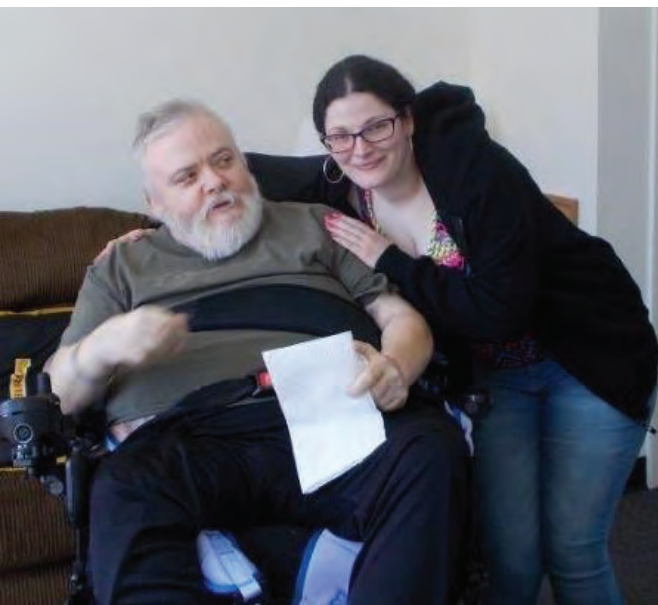
*Joe Santacesaria, founding member of the Center for Disability Rights, smiling in his graduation gown.*

The disability rights community lost a strong advocate with the death of Joe Santacesaria on February 9, 2018. Joe, who had cerebral palsy, was one of the first Rochesterians to graduate from college and live in his own apartment. Joe was the Chair of the Transportation Advocacy Group (TAG), which worked to get lifts on buses in Rochester. Joe was also a founding member and early board member of the Center for Disability Rights. When Rochester got its first buses with lifts, on one bus route only, Joe was determined to ride a bus. He did so even though he had to use Lift Line to get to the bus route, and got stuck in a snow bank downtown. Rest in power, Joe! You are missed.

Joe was called to his Lord on February 9, 2018 while surrounded by his family, at the age of 57. He was predeceased by his parents, Vincent & Gloria Santacesaria; sister-in-law, Nancy L. Santacesaria. Joe is survived by his brothers, Vincent (Susan) Santacesaria & Nicolas Santacesaria; sister, Nancy J. Santacesaria; nieces, Nicole (Serafino) Rosso, Natalie, Nina & MaryHelen Santacesaria; great-niece, Mila Rosso; beloved cousin, Dr. Benedetto Tarantino; several aunts, uncles, cousins & friends.

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## Transition & Diversion Services



*Steven poses with Alyssa Ginevra, Transition Specialist, in his new apartment.*

Steven was in a nursing home for five years. With the help of a CDR Transition Specialist and our Housing Specialist, Steven was able to discharge to his own two bedroom apartment so he has room for his medical supplies and durable medical equipment.

With the Olmstead Housing Subsidy, we were able to subsidize his rent and pay to hold the apartment, while we worked to get him the aide service he needed. We were also able to buy him furniture and home goods with the Olmstead Housing Subsidy.

The Independent Consumer Advocacy Network (ICAN) helped us advocate so that Steven could get 24/7 aide service, after he had not been approved for enough hours for the nursing home to consider it to be a safe discharge plan. Steven said, "I'm happy to be home." About the nursing home, he said, "I felt like I was in prison."

## Christopher Harper's Story: Part 5

### *"Til Death Do Us Part"*



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

There is a wish of the dark entity in brain injured people pertaining to "suicidal idealization." Knowing that not every brain injury is the same, I am theorizing that everyone with a TBI may think of "giving up." Personally, living with a TBI is a daily struggle to remain alive. I am willing to "stick my head out" to emphasize the fears and weaknesses I have had dealing with the "dark entity" of TBI.

The natural course would be to tap into "internal power sources" to stand above this "dark entity." The hope for progress is lost and even the practice for sustainable development is blocked when anyone loses the sense "belonging." I live among people yet am alone with setbacks curbing successful relationships with others. Trying to figure out varying degrees of intellectual difficulties with others is prominent in TBI. It is a platform with limited abilities on the playing field. I spend a lot of brain energy toiling in the fields of being alone.

I want foremost to bridge this gap as I focus again on the "Abandon Town." I only see what is up close, the landscape, and not the horizon. I cannot arrive through the rough "inner terrain," and framework that challenges my soul to gain prosperity versus death. That celestial place of death makes me resign to push forward. And the powerful search for belonging is lived through my literary work. It makes me look into the mirror of who I am, what I can be, as my outline to success.

Without the support of many people, I would not be able to courageously pen these articles. It is the milestone of networking with the possibility of connecting with others with a TBI. So I am happy to share my inner struggles. By days end, for me, it is success that I did not take my life. It is the road separating me from others who cherish life.

The balance to positive outcomes is making health care more effective. Our voices need to ring in the ears of physicians and health care providers to look deep into the brain where the source of the problem (injury) exists. Our advocacy and prompt initiatives are the key to minimizing the road block each of us live and breathe dealing with emotions related to TBI. We must work hard to better understand the difficulties associated with an environment that is confusing, affecting social and interpersonal skills with being able to then communicate with others. The very thing that is most important is a "Safety Plan" that will distract from giving up.

*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

June 21, 2018  
4:00pm-7:00pm  
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?

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



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497 State Street  
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# 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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## ***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.**

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CITY

STATE

ZIP

PHONE NUMBER

EMAIL ADDRESS

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

Make your check payable to Center for Disability Rights, Inc.  
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