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A VERMONT CENTER FOR INDEPENDENT LIVING
PUBLICATION FOR
ELDERS AND PEOPLE WITH DISABILITIES

### Lead On!

The voices and images in this issue remind us of a hard reality: The fight for the ADA, self-determination, health care and community services is a fight for our lives. We honor the memory of Justin Dart, who traveled to every state and to Congress to ensure passage of this law, and we tip a hat to his widow, Yoshiko Dart, who is still inspiring us to action.

This issue's contributors remind us that the independent living movement is alive at a Red Sox game, in poetry and kayaking, and in the words and activism of advocates from Japan, Ghana, Vermont and Washington. It is at the heart of the work to end sexual violence and it lives in the work of activists who oppose policies and practices that do not address discrimination, threats to rights and services and the personal and social costs of chronic pain.

Many thanks to our readers and contributors and to all who fight for equity.

As Justin used to say, "Lead on!"

OBAL DARITY

PHOTO BY MICHAEL CLEGG

Yoshiko Dart, center, received a Women's Caucus Award at the 2018 National Council on Independent Living Annual Conference. Congratulating her are Sarah Launderville, right, and Stephanie Woodward. ~ Deborah Lisi-Baker, Co-Editor

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# Letter to the Editor

### The Real Epidemic

I have access to opiates. And I'm curious about what it would be like to get high. The two are connected, aren't they?

Not if you have severe chronic pain, like me.

For people like me, opiates allow us to function. For people like me, they are essential for any quality of life. For people like me, opiates do not give you any kind of a high. They don't eliminate pain completely, either. All they do is dial it down to a slightly more tolerable level. And for people like me, they are a lifeline that is severely threatened right now.

As the hysteria over opioids escalated, I was scared I would be suddenly cut off from my medication. So I decided to go off the morphine. It was completely my idea and my choice, and I did it completely on my own.

I'm in a lot more pain all the time now. My illness (Ehlers Danlos Syndrome) causes my ribs, vertebrae and sacroiliac joint to slip out of place at night. Any and all of my joints can dislocate easily during the day. If you've ever dislocated a joint

yourself, or know someone who has, imagine that pain happening in multiple joints, 24 hours a day, every day, while continuing to do all your regular activities.

The misguided response to the so-called "opioid epidemic" has spawned an epidemic of desperation that is killing people with chronic pain. People on established and effective pain management are suddenly being refused the one thing that allows them to function. Left in agonizing pain with no hope of reprieve, many take desperate measures. For every chronic pain patient that successfully commits suicide, there are likely at least a thousand more considering it—it's a common topic of discussion in chronic pain groups now. That desperation drives some to search for alternatives, and they end up dying from street drugs. All of these deaths were completely preventable.

Chronic pain patients use opiates to be able to engage with the world. They are not the right treatment for everyone, but for many of us, they enable us to live productive lives, to work, to love and to participate. Simply put, they allow us one of the most basic rights of every American guaranteed in our Constitution — to live. We will never stop fighting for that, and we invite you to join us. Our lives depend on it...and yours may too.

Cara Sachs, CPC, ELI-MP

Winooski

Editor's Note: To read the unabridged version of the letter, go to www.vcdr.org.

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### Travelers' Tales

### by Deborah Lisi-Baker



Celebrations of the 28th anniversary of America's major disability rights law happened shortly after Independence Day amid a spring and summer of national and local threats to civil rights. In addition to attacks on the ADA in Washington, racist threats happened closer to

home. First, a local story exposed racism at a camp near where I live, followed by media coverage of racist attacks on a respected Bennington legislator, Rep. Kiah Morris. These stories brought back other memories of black people treated as unwelcome strangers here in Vermont. After speaking at a University of Vermont class, I met one student who said she had never been more terrified than as she traveled down Church Street in Burlington in a wheel-chair — a black woman surrounded by whites looking down at her.

I grew up in small towns in Vermont and New Hampshire. I only knew one Japanese-American family — the father a scientist and a survivor of the Japanese-American internment camps of World War II — and one black family who moved to town later. In high school, two black students joined our bus ride on farm roads as we moved toward town. I remember seeing them seated across the aisle and a few rows in front of me. As a white girl with a visible disability, I knew what it was like to be the stranger; I was keenly aware of how carefully they were looking only forward and not making eye contact with others.

I grew up surrounded by news coverage of the civil rights movement, the war in Vietnam, and the murders of Martin Luther King and Jack and Bobby Kennedy. Images of protest came across the television screen surrounded by commercials for cars, laundry soaps and cigarettes. Without realizing it at first, I began to see how much the disability rights movement owes to the courage of blacks and other

people of color who challenged discrimination in the streets, in courtrooms and in Congress; who took the fight to the streets of Selma and Montgomery and Boston and to the National Mall in Washington, D.C. Without their successful legislative and legal challenges to requirements that they sit at the back of buses and trains, the requirement that they accept segregated schools and movie theaters and the expectation that they should be turned away from hospitals, restrooms and restaurants, people with disabilities would have found it much more difficult to pass disability rights laws — laws which owe so much to earlier civil rights protections black Americans fought for and achieved.

Over the years it has been the stories of so many Americans owning their own race, class, gender and sexuality and speaking up for who they were who helped me realize that my differences, like theirs, are part of our American identity, not apart from it.

Audre Lorde wrote about Vermont in "Every Traveler has one Vermont Poem." She takes us with her down Route 91 during a glorious late summer day. She surrounds us with images of lavender asters, oxeye daisies and intricate shadowed mosses on the bark of trees. And in the last stanza she describes two tanned boys, driving their father's tractor as they harvest a field. Lorde writes:

One boy smiles as we drive past

the other hollers

nigger

into cropped and fragrant air.

Vermont often handles difference as poorly as other places, just as this Vermont poem contains both beauty and ugliness. Only when we own this truth, and refuse to condone racism and other discrimination, can we get past the failures of American and Vermont history. By acting in recognition of our shared democracy we can shape a different roadway, one that belongs to all of us.

### Kindred Spirits: Bonding with Advocates in Japan

by Sarah Launderville

For 15 days in March, I was invited to visit Japan in my role as vice president of the National Council on Independent Living. I traveled with NCIL President Bruce Darling. We were welcomed as we arrived in Tokyo by a group of very vibrant and excited leaders of the independent living movement. My senses were overloaded as I scanned for faces I had met the previous year in Washington, D.C. and I could not stop laughing as I saw my face plastered on headbands worn by my greeters and welcome posters! I had never felt so welcomed anywhere. My mind was filled with curious questions and I could not wait to start my learning.

Our first few days were spent at the Human Care Association with a pioneer in disability rights, their President Shoji Nakanishi.

Mr. Nakanishi had developed the Personal Attendant Services (PAS) program in Japan. It reminded me so much of the Participant Directed Attendant Services Program (PDAC) that VCIL peers helped develop back in the 1980s. In Japan people with different types of disabilities can access the program and for up to 24 hours a day.

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"Independent living will not be losing any momentum if the young people I met have anything to do with it."

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After learning and sharing our systems we met with the Tokyo government. In that meeting I worked to expand the idea with government officials that people who have psychiatric and intellectual disabilities could live in the community. I had learned that many are still stuck in institutions or living with their families. This information was received well, and I will continue to have conversa-



PHOTO BY STEFANIE MONTE
On July 20 at Waterbury Center State Park, VCIL
celebrated the 28th anniversary of the signing of
the Americans with Disabilities Act. VCIL was excited to have some special guests from an independent living center in Japan. The guests were able
to kayak for the very first time. Shigeto Itani is all
smiles as Masae Takahashi paddles.

tions with our new friends in Japan to help influence that change.

That afternoon Bruce and I gave a seminar on the IL movement and the importance of a cross-disability rights movement. After the seminar I learned that a group of psychiatric survivors had traveled three hours to hear the talk and meet me. I had already been overwhelmed by the experiences I was having, but to connect with these women who were working throughout the country to make significant changes in how the system treats individuals with psychiatric disabilities was humbling and uplifting.

That evening we met with young people in the Japan independent living movement and shared ideas and stories. Independent living will not be losing any momentum if the young people I met have anything to do with it. They've been given the benefit of leaders before them to have solid attendant services. They are looking to a future of more accessible spaces and attitudes. They are looking for a future where people are leaving or never being put into institutions, where they are educated and where employment is something much more attainable. They are also looking to challenge the system by using tools like direct action and they were eager to hear our ADAPT stories, where we have come together to push systems and have been arrested fighting for these rights.

The next day, we traveled to Kyoto by bullet train. Our amazing travel guide showed us the sites — beautiful temples and gardens. We talked about culture and access and had a fabulous time. This part of the learning was equally important because it allowed me to appreciate the differences among the similarities in our movements — helpful when trying to work on cross-cultural systematic change.

The following day Bruce and I split up and our adventures continued in different parts of the country; he went to Osaka and I was off to Matsuyama. I was really scared, but my nerves were put to rest when I landed and my life was forever changed. I got off the plane and went in search of my two interpreters and found about 30 advocates welcoming and yelling to me! I heard screams of "I love you, Sarah." This was true independent living love. It's the love you feel the first time you are welcomed and feel part of the movement. The next three days were filled with expressions of that love and with learning. I was welcomed into homes and people shared their life stories with me. They were aweinspiring and full of hope. I in turn had chances to share about my life and together we started planning what we hope will impact and continue to shape the international IL movement.

The people of Matsuyama were so special to me because of their experiences and their desire

to change the world. Not for just a few leaders, but for everyone with disabilities. Their director, Mr. Shigeto Itani, and I felt a connection within the first day and by the end of our visit, between the sobs and pretty epic farewell at the airport, our shared dream of bringing together our centers as sister organizations began to take shape. Instead of "sister centers" I wanted to name it something that had the vibe and heart of what I felt and landed on "Kindred Spirit" organizations.

In July we had the honor of hosting five members of the CIL Hoshizora who came for an exchange of ideas and to enjoy the mountains and scenery here in Vermont. They topped it off with a first-time kayaking trip and a meeting with Lt. Gov. David Zuckerman.

Our centers are forming a relationship that will help build the foundation for future work in independent living. The work will be strengthened because of the broad ideas we are able to help each other implement around accessibility, accountability of systems that are not working, solidarity in disability rights, attendant services, employment and the important issues of how people with disabilities are treated by society.



COURTESY PHOTO Sarah Launderville, left, arrives in Japan amid a group of enthusiastic well-wishers.

### Red Sox Foundation Honors VCIL

by Stefanie Monte



**COURTESY PHOTO** 

Sarah Launderville visits the NESN broadcast booth on July 9. From left are Dennis Eckersley, Launderville, Red Sox Foundation Executive Director Bekah Splaine Salwasser and Dave O'Brien.

What do the Boston Red Sox and the Vermont Center for Independent Living have in common? They both have a lot of fans!

This was abundantly clear over the summer when VCIL won the Red Sox Foundation's \$10,000 first-place IMPACT Award. VCIL received the most online votes of the Vermont nonprofits that were in the running and was honored for its dedication to social justice, diversity and inclusivity.

"I was so touched and grateful when I received the phone call from the Red Sox Foundation official that I literally cried," said VCIL Executive Director Sarah Launderville.

The award was presented during a home game against the Texas Rangers on the evening of July 9. It was a beautiful summer night, with a warm wind and plenty of stars. Launderville attended along

with her 8-year-old son, Evan, VCIL Finance & Operations Officer Michelle Grubb and Development Coordinator Linda Meleady.

When Launderville and Meleady went on the field to accept the huge cardboard check, it was videoed so that everyone could see them on the jumbotron. Grubb said, "It was cute to see Evan take it all in. I can't imagine how it felt for him to see his mom speak to such a large crowd about VCIL, disability rights and access."

She added, "It was amazing to be standing on the red soil right next to home plate and looking out to see the park from the batter's perspective."

The foursome enjoyed premium Green Monster seats, and Sarah visited the NESN broadcast booth, where she was interviewed by Dave O'Brien and rubbed elbows with former Red Sox pitching great Dennis Eckersley. VCIL also received a custom Red Sox jersey, which was imprinted with a "79" as a nod to the year the nonprofit was incorporated almost 40 years ago.

Meleady said, "My first time at Fenway Park was truly spectacular. I had no idea how enormous the stadium is or that they have an organic garden on the rooftop that supplies much of the produce for the team and fan meals. However, this day may have ruined me for future games with all the fabulous treatment we received."

For Grubb, the trip to Fenway was especially meaningful. She said, "My family has been avid Red Sox fans for many generations. I grew up hearing about how my grandfather's favorite summer pastime was sitting his chair listening to Curt Gowdy announce games on the radio."

She added, "I am so grateful for that once-in-a-lifetime experience and for the enormous generosity of the Red Sox Foundation."

And putting an amazing trip to Fenway Park over the top, the Red Sox won the game 5-0!



PHOTO BY MICHAEL CLEGG

Sam Liss, right, accepts the 2018 National Council on Independent Living Annual Conference Region 1 Advocacy Award. Presenting the award were Steven Higgins, center, executive director of Independence Associates, and Hindley Williams, a NCIL youth fellow.

### Amazing Advocates Honored

Sam Liss, right, vice president of VCIL's Board of Directors, was honored at this year's National Council on Independent Living Annual Conference with the Region 1 Advocacy Award. Liss was recognized for his leadership and ongoing dedication to disability rights, especially in the area of work incentives.

Liss is cochair of NCIL's Employment & Social Security Subcommittee and a member of the Vermont Statewide Independent Living Council. He serves on many volunteer boards and advisory committees and embodies the essence of independent living.

Liss said, "I'm pleased to accept the award and even more gratified that a spotlight is being shed upon removing barriers to employment for people with disabilities."

And Sam is not the only amazing advocate who lives in Vermont to be honored this year. Another VCIL board member, Sefakor Komabu Pomeyie, has been selected for the Association of University Centers on Disabilities 2018 International Service Award. This award recognizes outstanding contributions that further programs or policies designed to

create more inclusive communities for people with disabilities and their families throughout the world. Komabu-Pomeyie is a professional teacher and a disability rights activist from Ghana.

### Award Nominations Sought

Know of a business or organization that has worked hard to be accessible? If so, help VCIL recognize them by nominating them for the Ally of Accessibility Award. Fill out this online form:

https://vcil.wufoo.com/forms/2018-ally-of-accessibility-award/

Nominations are also being sought for the Rosemary Miller Dining for All Award. If you know of an accessible restaurant in Vermont that deserves recognition, please fill out our online form: https://vcil.wufoo.com/forms/rosemary-miller-dining-for-all-/

Applications for both nominations will be accepted until Sept. 28, 2018. For more information, email lindam@vcil.org or smonte@vcil.org or call 1-800-639-1522.

### Floating

One loon circles another In the green mirror

their white dazzling With their black

designs over and over

floating together and apart

the mystery of this dance

how they share a lake a marriage without war.

by Phyllis Rachel Larrabee

### CDCI Starts New Five-Year Work Plan

What is the Center on Disability and Community Inclusion (CDCI)?

CDCI helps Vermonters with disabilities and their families live their lives as they choose. CDCI is part of the University of Vermont. There are 67 centers like CDCI in the United States. These centers were created by a law called the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

What is in our new plan? Our work plan is based on three things:

- (a) The needs of people in Vermont and DD Act requirements.
- (b) Expertise of CDCI personnel and affiliates.
- (c) Resources available to do the work, including funding and capacity.

In our work plan, we created five broad goals to match these core functions.

- 1. We teach. We teach in person and online, run educational programs, create innovative courses and give guest lectures. We work to use Universal Design for Learning strategies to promote inclusion, diversity and self-determination.
- 2. We support. We help create a more inclusive community by providing local, regional, national, and international trainings, consultations and other services and supports.
- **3. We study.** We evaluate our projects and conduct research. We do this to improve outcomes and to share what we have learned. We also work with and support researchers in our college, university and external partners.
- **4. We share and connect.** We take the work, findings and stories from our projects, our affiliates and our partners and share them in accessible formats.
- **5. We maintain our center.** We maintain and expand our capacity to fulfill our mission by (a) supporting the people who work at CDCI; (b) strengthening our connections to our university, our Community Advisory Council and other partners; and (c) evaluating our work.

Where can I learn more? You can learn more about our new work plan at our website: https://www.uvm.edu/cdci.

We are also looking for more members for our Community Advisory Council (CAC). Please consider joining! For more information, visit the CAC web page: https://www.uvm.edu/cdci/cac.

You can also follow us on Facebook, Twitter, LinkedIn and YouTube under CDClatUVM or sign up for our newsletter at: https://tinyurl.com/ycc8lo8m.



Every issue is a disability issue, because our community — at 60 million strong — is beautifully diverse.

~ Senator Tammy Duckworth, D-Illinois

### Disability Rights on the Line

Here's three hot ADA issues that disability advocates are speaking up about!

ADA Education and Reform Act of 2017 (H.R. 620): This bill passed in the House. H.R. 620 would amend the ADA to require individuals with disabilities to submit a written notice to the operator or employer of an inaccessible business. The bill requires that the complainant submit written notice that must "specify in detail the circumstances under which an individual was actually denied access to a public accommodation, including the address of property, the specific sections of the Americans with Disabilities Act alleged to have been violated, whether a request for assistance in removing an architectural barrier to access was made, and whether the barrier to access was a permanent or temporary barrier." The amendment would also give the owner or operator 180 days to "remove the barrier or make substantial progress in removing the barrier." Advocates are concerned that the person experiencing discrimination would be forced go through a lengthy reporting and complaint procedure to access rights they are entitled to under the ADA.

The National Council on Independent Living joined with many individuals and organization to protest this bill. NCIL notes, "Businesses have had almost 28 years to remove access barriers and remedy noncompliance with the Americans with Disabilities Act. They should not require a notice and cure period to resolve issues that should have been rectified years ago."

The Disability Integration Act (S. 910 and H.R. 2472): Several health care reform proposals considered by Congress in the last two years threaten funding and policy protections for community-

based disability services. The act would protect individuals with disabilities from proposed cuts to community-based services by requiring that states and other funders of long-term services offer a real choice in how and where individuals receive services; that services be provided in the most integrated setting and give individuals maximum control over their services; require a state plan similar to the transition planning process under the ADA that provides benchmarks and a timeline for complying with the law; ensuring that there is an adequate workforce to support community integration; requiring states to address the need for affordable, accessible, integrated housing that is independent of service delivery; and establishing stronger, targeted enforcement mechanisms so that the law is implemented.

Disability Rights at Risk with Supreme Court Nomination: This month in Washington, D.C., the Senate Judicial Committee is considering President Trump's nominee for the Supreme Court, Brett Kavanaugh. The Bazelon Center has published a report on Kavanaugh's decisions on cases that directly and indirectly affect individuals with disabilities in the areas of health care, self-determination, employment, education, access to justice and voting rights. The report finds that Judge Kavanaugh's decisions continuously ignore the rights, interests and abilities of individuals with disabilities.

In one significant case regarding both self-determination and health care, a lower court found that individuals with intellectual disabilities who may be considered legally incompetent may be able to make choices and should be given the opportunity to state their choice before the district carries out elective surgeries. During the appeal, Judge Kavanaugh ruled against the lower court, stating that individuals with intellectual disabilities do not have to be consulted as they are "by definition" incapable and therefore their choices are not relevant. In her testimony against Kavanaugh's nomination, Liz Weintraub, senior advocacy specialist at the As-

sociation of University Centers on Disabilities, commented on the ruling, "As a woman with an intellectual disability, I know what it is like for other people to try to make decisions about my life, my relationships, and my body. Judge Kavanaugh seems to think people like me don't deserve a say in our own health care, and that to me is dangerous, discriminatory and shows he doesn't really understand the idea of 'nothing about us without us.'"

Katherine Perez, a disabled Latina who also opposes Kavanaugh's nomination, asks us to consider our rights if Kavanaugh is appointed: "A decade from now, when we are litigating disability rights at the highest court will Kavanaugh — and all the other attorneys and judges being groomed for the Supreme Court — understand our experiences?"

Share your thoughts and concerns about national disability rights legislation and the Supreme Court nomination by contacting Vermont's congressional delegation or their staff. Their local contacts are:

### Senator Patrick Leahy

Pollaidh Major

Pollaidh\_Major@leahy.senate.gov

(800) 642-3193

#### Senator Bernie Sanders

Sheila Reed (disability)

Sheila.Reed@sanders.senate.gov

(800) 339-9834

Jessica Early (senior programs)

(802) 862-069

### Congressman Peter Welch

Kevin Veller

Kevin.Veller@mail.house.gov

(888) 605-7270

### Vote for the Future

Your vote is your voice and your voice matters! Nov. 5 is the last day to request absentee ballots and Nov. 6 is Election Day in Vermont. Vermont offers many ways to place your vote. For more information, visit the Vermont Secretary of State's website (https://www.sec.state.vt.us/elections/voters.aspx) or contact your Area Agency on Aging, Disability Rights Vermont, the Vermont Center for Independent Living or Green Mountain Self-Advocates.

### DAIL Seeks New Council Members

The DAIL Advisory Board is seeking new members to advise the state on disability and aging services in Vermont. Individuals can contact DAIL for an application for the board. An application can be found on the DAIL website at www.dail.vermont.gov or by calling the DAIL office at 802-241-2401. After filling out the application it should be sent to the DAIL Commissioner's office, with a resume.

# Share Your Views on Issues Affecting Women in Vermont

The Vermont Commission on Women's Listening Project is soliciting views of Vermont women and men, asking them to weigh in on the most important economic and social issues that affect the lives of women and their families. The goal is to establish a set of policy goals to present to state lawmakers when they return to work in January. Find the survey at women.vermont.gov.

# Worried About Weather Emergencies?

The Green Mountain Emergency Toolkit is available for download from the Center on Disability and Community Inclusion, at www.uvm.edu/cess/cdci/green-mountain-emergency-preparedness-project.

### What Kind of World Do I Want to Age Into?

by Ruby Baker



With parents still in the workforce, and two kids under the age of 5, this question hadn't entered my personal sphere as one of immediate importance. Not until I started working for Community of Vermont Elders (COVE) in April of this year.

While I am acquainted

with nonprofits, my focus had been on food security. The new dimension of age in my work has come with a steep learning curve. From sorting through the alphabet soup to figure out which acronyms belong to which supports, processes and services, to carving out time to attend important events, the last five months have given me a new perspective on life. Not just my life, but Vermont life in general, what it means to be alive in Vermont today.

The above question was posed to me at my interview. And it is the question, the big one, because the answer is different for everyone. The answer lies in how we wish to age. I don't believe that anyone sets out at 20, with stars in their eyes, thinking about their golden years and how they would like to spend them. But age happens. I don't believe many of us set out at 20 with stars in our eyes, thinking about our golden years. Period. But maybe we should.

When I was in my teens, my grandmother lived with us. One summer, for something to do, I asked her to tell me the story behind each piece of jewelry in her padded hinged case. They weren't valuable pieces, per se, but to her there was a story, a person, a bit of her life stored in each one. At 94, that

was a lot of life (and a lot of jewelry). She loved telling these stories. And as the summer wore on, I began to love hearing them. Tales of a daughter of immigrants in NYC during the depression, a Marine in World War II, a mother in the '50s and a world traveler. She passed away the next summer, lying in her own bed with her family by her side. She left me her jewelry box, full to the brim with stories. More importantly, she left me with a deeper understanding of the world and how it was, why it is the way it is, and how people have worked, since the dawn of time, to create the kind of world they want to age into.

So as the executive director of COVE, I now find myself asking "what kind of world do you want to age into?" What are your plans for the future? There is so much that could be done, but what should be done to make Vermont the best place to grow old? We, as a society, must unpack the jewelry box, hear the story, value and respect the person and understand the world through their lens, before we can ever hope to create the best place to grow old. In my role here at COVE, I hope to create a shift in the conversation, such that growing old is something we do with intention, with clear vision and with pride. I am honored to join the driven, dedicated and inspired folks already working to create the best place to grow old. I can't wait to see how the conversation will change as time continues its unbroken journey toward the future.

Building a Safe Harbor for Older Vermonters through Education and Advocacy cove@vermontelders.org 802-229-4731

### VCDR Report on 2018 Legislative Session

The mission of VCDR is to advance the human and civil rights of people with disabilities to ensure full and equal participation in all aspects of community life and the political process.



Negotiations between the administration and the Legislature continued beyond the regular

legislative session, leading to a special session and FY 2019 budget and tax bills that were only agreed upon in the final hours before a possible government shutdown. Throughout this contentious process, the Legislature managed to reverse proposed cuts to disability services and other social programs that were part of the original budget proposed by the administration.

#### FY 2019 BUDGET BILL HIGHLIGHTS

- Reverses administration's proposed cuts to Developmental Services, restores \$4.3 million total (\$2 million general fund).
- Reverses administration's proposed elimination of attendant care services to people with severe disabilities (e.g., quadriplegia, paraplegia, multiple sclerosis).
- Provides a 2 percent (\$1.8 million total) reimbursement increase to community service providers like the visiting nurses that enable elderly or individuals with disabilities to remain in their homes and communities (includes Adult Day, Meals on Wheels, Homemaker, Respite, Companion Services, Choices for Care, Hospice, Personal Care and Enhanced Residential Care).
- Adds \$4.3 million to increase compensation to mental health clinical and direct service staff at designated agencies.
- Funds strategic reform in the adjudication of child welfare cases to better protect children and assist families and increases judicial system resources to respond to the opioid epidemic.
- Reverses proposed cuts to primary care doctors and community health clinics.

- Provides \$200,000 for supportive housing vouchers in mental health.
- Maintains cost sharing assistance for health insurance deductibles and out-of-pocket costs for 6,100 working families.
- Increases child care provider reimbursement for infants and toddlers.
- Provides \$5 million to fund an initiative to address the workforce shortage of mental health and substance use disorder treatment professionals.

#### FY 2019 TAX BILL HIGHLIGHTS

- Collapses top two income tax brackets and lowers all personal income tax rates by 0.2 percent.
- Expands the Vermont earned income tax credit from 32 percent of the federal EITC to 36 percent.
- Exempts taxable Social Security benefits from state income taxes for single filers with less than \$45,000 in adjusted gross income and married filers with less than \$60,000 in adjusted gross income.

#### **POLICY LEGISLATION**

Both a minimum wage increase (S.40) and paid family leave (H.196) bills were passed by the House and Senate but vetoed by the governor.

#### **LEGISLATION PASSED**

Act 173 (H.897) changes the state funding model for special education for all supervisory unions in fiscal year 2021, from a reimbursement model to a census-based model. It also (1) creates an advisory group to assist the State Board of Education in developing its rules to implement changes; (2) requires the Agency of Education to conduct a study of weighting factors used to determine education property tax rates and to consider whether the census grant amount should be increased for supervisory unions that have higher costs; (3) requires the Agency of Education to assist supervisory unions to expand and improve their delivery of services to students who require additional supports; and (4) creates three new positions within the Agency of

Education to support special education services. An advisory group, which includes a VCDR representative, will make recommendations on implementing the new funding system.

The legislation also requires approved independent schools that accept public tuition to enroll students on individualized education programs if placed by the local education agency.

Act 207 (S.280), an act relating to the Advisory Council on Child Poverty and Strengthening Families, establishes the Advisory Council on Child Poverty Strengthening Families for the purpose of examining structural issues in Vermont that lead to families living in poverty and prevent families from moving out of poverty. A VCDR representative was added to this council.

Act 204 (S.261), an act relating to ensuring a coordinated public health approach to addressing child-hood adversity and promoting resilience, aims to better coordinate state services that address child-hood adversity. It establishes a director of trauma prevention and resilience development within the Office of the Secretary of Human Services with responsibility for coordinating government activities that build childhood resiliency and mitigate toxic stress.

Act No. 172 (H.608) creates an Older Vermonters Act working group that will develop recommendations for an Older Vermonters Act that aligns with the federal Older Americans Act, the Vermont State Plan on Aging and the Choices for Care Program. The working group is expected to complete its work and submit its recommendations to the Legislature on or before Dec. 1, 2019.

Act 188 (H.907) adopts provisions relating to rental housing safety, including creating a rental housing advisory board; improving effectiveness of local health officers; enabling rental housing safety inspection reports; creating a database of rental housing units; and creating an accelerated weatherization and housing improvement program.

Act 125 (H.921) creates a nursing home oversight working group to examine the oversight of nursing homes in Vermont, including their financial stability and licensing criteria. The working group must report to the General Assembly by Jan. 15, 2019 with

its findings and any recommendations for legislative action.

Act 200 (S.203) makes numerous changes to the state's mental health laws, including provisions related to mental health parity and plans to increase inpatient capacity. It states legislative intent to increase the number of inpatient psychiatric beds in a manner that will ensure clinical best practice, support the development of UVM Health Network's proposal to expand capacity at the Central Vermont Medical Center campus and replace the temporary secure residential recovery facility with a permanent facility. The act requires the secretary of Human Services to provide regular updates to the Health Reform Oversight Committee pertaining to the status of proposed renovations at the Brattleboro Retreat and the UVM Health Network's proposal.

Act 147 (H.727) creates an exemption to the hearsay rule with respect to statements made by a child 12 years of age or under who is alleged to have been abused or neglected and provides that such a child shall not be required to testify or give evidence at any hearing before the Human Services Board.

Act 153 (H.874) amends the process for providing inmates access to prescription drugs after admission to a correctional facility.

Act 176 (S.166) authorizes state correctional facilities to continue medication-assisted treatment to those inmates who enter a facility while undergoing medication-assisted treatment and for whom the continuation of medication-assisted treatment is deemed medically necessary. It also authorizes state correctional facilities to start medication-assisted treatment with buprenorphine for inmates for whom this treatment is medically necessary and who were not receiving medication-assisted treatment on their entry into a facility.

Act 210 (S.262) contains several changes to health care programs, including Vermont's Medicaid program, the duties of the Department of Vermont Health Access, health care provider taxes, bronzelevel qualified health benefit plans offered through the Vermont Health Benefit Exchange and other programs and entities.

### DISABILITY RIGHTS VERMONT ANNOUNCES FY19 PRIORITIES



Disability Rights Vermont (DRVT) is a private nonprofit agency dedicated to defending and advancing the rights of people with mental health and disability issues. We are empowered and funded by the federal government to investigate abuse, neglect and serious rights violations. Our fifteen-member staff team combined with the seven-member staff of the Disability Law Project of Vermont Legal Aid (DLP) creates the cross-disability legal protection and advocacy system for Vermont. This past year DRVT and the DLP were busy defending the rights of people

with disabilities both through individual case work and systems change.

DRVT is once again looking for comments on our priorities to be approved by our Board for the upcoming fiscal year (Oct. 1, 2018 – Sept. 30, 2019.) We would welcome your thoughts about how our unique system can best serve people with disabilities and mental health issues. DRVT is publishing our current priorities for the Protection & Advocacy for Individuals with Mental Illness (PAIMI) program, for the Protection & Advocacy for Developmental Disabilities (PADD), and the Protection & Advocacy for Individual Rights (PAIR) programs on these pages. These priorities serve to focus the work of the agency and are developed by our Board and our advisory councils, who get input from the community and staff. Your input is appreciated! We strive to do as much as we can with the resources we have ... and we can do that best when folks in the community let us know their greatest advocacy needs!

To help us stay connected to the community we serve, send us your comments at:

wenyu@disabilityrightsvt.org or to DRVT, 141 Main Street, Suite 7, Montpelier, VT 05602

Or by phone: 1-800-834-7890 or, locally, at (802) 229-1355

And please visit our website at <a href="https://www.disabilityrightsvt.org">www.disabilityrightsvt.org</a> – there you will find more particular objectives within the general priorities below.

Case acceptance by Disability Rights Vermont is based on four factors:

(1) the client meets the applicable grant's definition of an individual with a disability;
(2) the case has morit (sufficient evidence to support the claim); and

(3) the case has merit (sufficient evidence to support the claim); and (4) there are sufficient staff resources to take on the case.

### CURRENT PRIORITIES FOR PROTECTION & ADVOCACY FOR INDIVIDUALS WITH A MENTAL ILLNESS

**Priority 1**: Investigate individual cases of abuse, neglect and serious rights violations in inpatient facilities (designated hospitals, any state-run facilities, designated agencies, emergency rooms, facilities for minors), prisons/jails and community settings, including peer services.

**Priority 2**: Reduce the use of seclusion, restraint, coercion and involuntary procedures through systemic efforts. Continue systemic work to create culturally competent, trauma-informed, violence free- and coercion free mental health treatment environments.

**Priority 3**: Reach out to community settings, designated facilities, emergency rooms, prisons/jails, residential and therapeutic care homes. Monitor conditions and educate residents about rights and self-advocacy. Engage in systems work to improve conditions.

**Priority 4**: Advocate for self-determination and access to alternative treatment options and community integration. Use legal advocacy to enforce and expand rights across the state of Vermont.

### PROTECTION & ADVOCACY FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES (PADD) AND PROTECTION & ADVOCACY FOR INDIVIDUAL RIGHTS (PAIR)

(DRVT and DLP work together to serve across ALL disabilities! We list programs separately in some instances because the funding comes from different sources.)

We are currently in the process of drafting our PADD and PAIR priorities and would love to hear from you. We strive to do as much as we can with the resources we have ... and we can do that best when folks in the community let us know their greatest advocacy needs!

For a full listing of our current priorities under each goal please visit <u>www.disabilityrightsvt.org/Programs</u> or contact us at 1-800-834-7890 and request a copy be sent to you.

#### 2018 GOALS & PRIORITIES

- People with disabilities have access to needed health care/long-term care; children with developmental disabilities and/or mental health needs will receive needed services and supports. For example a priority under this goal is to represent individuals with disabilities seeking access to needed health care/long-term care when issue is disability, duration of services, covered services, due process or Early Periodic Screening Diagnostic, and Treatment (EPSDT). Priority given to cases involving children and youth inappropriately placed or held in emergency departments due to lack of mental health services, and services and discharge planning for children and youth transitioning from residential placements (PADD/PAIR).
- Students with disabilities are educated in the most integrated appropriate educational setting, are not harassed, are not unlawfully disciplined and are not unlawfully suspended or expelled from their educational program. Students with disabilities receive an appropriate transition from school to employment and independent living. Resources permitting: Students with disabilities are identified, evaluated and receive a free and appropriate public education and related services. Eliminate use of truancy proceedings for students with disabilities. Federal and Vermont entitlements and procedural protections are preserved (PADD).
- Work toward improved access to appropriate services/supports in the least restrictive and most integrated settings. For example, a priority under this goal is to advocate for people with disabilities in nursing homes, long-term care homes, correctional facilities and other restrictive settings for whom appropriate services/supports may be available in more integrated settings (PADD/PAIR).
- Advocate to improve access to developmental services for children and adults with intellectual and developmental disabilities (PADD).
- Provide advocacy to ensure people with intellectual and developmental disabilities do not have unnecessary or unnecessarily restrictive guardianships (PADD).
- Access to and preservation of SSI benefits for income-eligible children under age 18 or turning 18 whose benefits are terminated on the basis of disability. Maintain maximum Social Security benefits for adults who are disabled and working (PADD/PAIR).
- Provide advocacy to ensure individuals with disabilities will have increased access to businesses open to the public as written in Title III of the ADA (PAIR).
- Provide advocacy for improved access to government services and programs as provided in Title II of the ADA (PADD/PAIR).
- Ensure that adults and children with intellectual and developmental disabilities living independently, in institutions, in juvenile treatment facilities or in parental, family, group or developmental homes, are free from abuse, neglect or rights violations (PADD).
- Increase knowledge and awareness of the civil and legal rights of people with disabilities (PADD/PAIR).



The **VERMONT DEVELOPMENTAL DISABILITIES COUNCIL** is state wide board and a part of a national network that was created by the Developmental Disabilities Assistance and Bill of Rights Act. To have the greatest positive impact state wide, Council members use their lived experiences with disabilities to guide how the Council spends its federal funding. Members and staff work together to spread awareness about critical issues affecting Vermonters with developmental disabilities.

Want to learn more? Visit the website at <a href="http://ddc.vermont.gov/">http://ddc.vermont.gov/</a> or contact the Council by phone (802) 828-1310 or email <a href="http://ddc.vermont.gov/">vtddc@vermont.gov/</a>



### A No Wrong Door System

is a powerful network of aging and disability groups. We work to support people needing long-term care and services.

We focus on providing you with the care and guidance that's right for you.

Let us be part of your team.

Call our Senior HelpLine at 1-800-642-5119



PHOTO BY MICHAEL CLEGG Years after his passing, Justin Dart's wheelchair and hat are still a prominent part of the march during NCIL's Annual Conference.

Editor's Note: Here are excerpts from a speech given by Justin Dart, in South Burlington, on March 23, 1992. Dart was chair of the President's Committee on Employment of People with Disabilities and a passionate and effective organizer for passage of the Americans with Disabilities Act. Justin and Yoshika Dart were early leaders in bringing independent living concepts and advocacy to Japan.

It is estimated that by the year 2001, one out of five Americans will have a disability. That proportion will rise throughout the 21st century. There is a virtual certainty that any family of able-bodied persons will eventually include persons with disabilities who have significant potential to function in society. Disability is not a matter of them and us. It is just us. As people within the normal spectrum of human differences, we who have disabilities have the same unalienable rights and the same unalienable responsibilities as other people.

Empowerment is a word that's been used a lot in American politics. Make no mistake about it. I'm not talking about the same old empty political battles with new labels. I'm talking about fundamental changes in attitudes and systems.

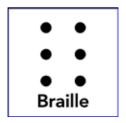
The timid will say we must defend what we already have and I say bull feathers.

We are spending tens of billions of dollars to keep American citizens with disabilities incarcerated in institutions, in rat-infested ghettos and in cells without walls in the streets. Money is not the basic problem. Advocacy, government and business as usual is not the solution. What is required is courageous unified leadership for empowerment.

I have spoken with leaders in other states ... and I will briefly give you my thoughts ... I'll mention five points.

- First, first, last and always, united militant grassroots advocacy is the key to empowerment. Equality has never been voluntarily handed down to a divided, apathetic minority.
- Second, we must reach out to employers, operators of public facilities and government at all levels. We must inform them of their ADA responsibilities including empowerment. We must inform them of their ADA opportunity to have more customers, better employees, more profit and lower taxes.
- Third, all of us must become more effective politicians, individually and as a united movement. We must be aggressive participants in all campaigns and all parties not only as voters but as contributors, leaders and certainly office-holders. Colleagues, the politics of equals is far different from the politics of dependency.
- Fourth, we must become far more effective communicators because no matter how well we enforce civil rights laws, we will not be truly equal until we communicate the message of our equality into the consciousness of the 240-million-plus Americans who will never read ADA or any law but whose thoughts and actions will define our humanity every hour of every day.
- Fifth, America cannot exist as an island of freedom in a world of oppression. We must unite with our oppressed colleagues in every nation to create a worldwide revolution for the establishment of strong civil rights laws and empowerment policy. We have much to communicate, and we have much to learn.

Watch the complete speech at http://credo.library.umass.edu/view/full/mums984-i007.













### got access?

by Kim Brittenham

### Got Support When You're Hurt? Give Support As A Survivor

People with disabilities experience violence more than twice as often. That lived experience as survivors of crime also means we have so much to give the violence-response movement!

Violence can come in many forms — emotional and physical — from partners, care providers, family members and, at times, from strangers. Violence is never the victim's fault. Nobody deserves abuse. People have the right to live their lives without being insulted, controlled, hurt or forced to have sex. People have the right to safe, fair workplaces and to control their own money.

There is help for people being abused or hurt. There is support for people whose painful memories become barriers to happiness and healthy living. People feeling controlled or hurt by their boyfriends, girlfriends or spouses can call a crisis telephone line any time of the day or night: Vermont Domestic Violence Hotline: 800-228-7395, for TTY national line: 1-800-787-3224.

People who have been tricked, pushed or forced into sex can call Vermont's Sexual Violence Hotline: 800-489-7273. Deaf people seeking support can contact Deaf Vermonters Advocacy Services (DVAS) during work hours 8 a.m.-5 p.m: Voice/Videophone: 802-661-4091. People forced to work or have sex for money can get support from the Human Trafficking hotline: 888-373-7888 TTY 711, text 233733.

Crime victims can also receive support and, at times, money to compensate their losses. The Center for Crime Victim Services supports crime victims in Vermont. Its services include Victims Compensation Program, the Sexual Assault Program and the Restitution Unit: 800-750-1213.

VCDR member organizations can help people access any of these services (www.vcdr.org).

Sometimes people feel alone when they have been abused and victimized. People who have experienced crimes and violence can reduce isolation in others by becoming advocates themselves.

DVAS is currently seeking volunteers for data entry and grant research, child care during parenting classes and men who are Deaf to teach sex education. The Vermont Network's 14 local programs and the Pride Center all accept applications for volunteers, staff and board members.

Survivors with disabilities can impact generations to come by helping pass laws to protect victims. Advocacy is needed locally and nationally. Connect with VCDR for opportunities to tell your own story and advocate for the end of violence against people with disabilities.

Follow VCIL's staff serving on the Vermont Human Trafficking Task Force to increase awareness of Vermonters with developmental disabilities being trafficked for cheap labor and sex. VCIL is one of only two CILs nationally on the National Human Trafficking and Disability Working Group.

Thanks to support from Sen. Leahy and others, the Violence Against Women Act continues to exist. It provides the funding for domestic violence programs and shelters across the country and is vital for marginalized victims. People with disabilities, Native Americans, undocumented immigrant and refugee women, women of color, and lesbian, transgender and bisexual women experience more violence than white able-bodied heterosexual people. People living at the margins must stay united in support of VAWA and find ways to collaborate.

Author Kim Brittenham is cochair of the NCIL Violence & Abuse Subcommittee and works to increase leadership of women of color in the violence response movement with the Women of Color Network.

## Bulletin Board

# SAVE THE DATE! VCIL's 40th Anniversary Celebration

will be May 24, 2019, at the Capitol Plaza in Montpelier
Stay tuned for more details.

# Featuring Keynote Speaker Judy Heumann

Heumann is an international spokesperson for disability rights and independent living services. Her list of accomplishments is long and includes cofounding, along with Ed Roberts, the first independent living center in Berkeley, Calif. In the early 1970s, she sued the New York City Board of Education and became the school system's first teacher in a wheelchair. She is currently a senior fellow at the Ford Foundation.

### Reflections on a Movement

Independent living is not doing things by yourself. It is being in control of how things are done.

~ Judy Heumann

The greatest lesson of the civil rights movement is that the moment you let others speak for you, you lose.

~ Ed Roberts



To find out about other disability or senior programs and activities, contact VCIL at 1-800-639-1522 or the Senior Helpline at 1-800-642-5119



For information on the next issue, email smonte@vcil.org or call 1-800-639-1522