

# The Independent

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

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## Our Braided Stories

This year VCIL celebrates its 40th anniversary, making it a great time to celebrate leaders — of all kinds — who have helped shape our movement. So many people have been part of bringing both disability rights and the independent living movement to communities in Vermont. We want to start this issue off by lauding all Vermonters who have brought their stories and passion for disability rights, self-determination and equity to their lives, their community experiences and their shared advocacy with others. Every person's voice and life experience has helped create and sustain remarkable organizations, essential legislative and policy change and new opportunities for people with diverse disabilities and their families.

In this issue we share excerpts from VCIL's 40th anniversary gala, a few excerpts from a wonderful conversation with Judy Heumann — a disability rights leader and friend of VCIL — and memories, stories and interviews from and about Vermonters. Thank you to each of you for helping us celebrate and for all you do for disability rights and social justice.

~ Deborah Lisi-Baker, Co-Editor



PHOTO BY STEFANIE MONTE

Barry Bernstein, VCIL's founding executive director, and VCIL Executive Director Sarah Launderville are all smiles on Feb. 14 after the Vermont House adopted a resolution honoring VCIL on its 40th anniversary.

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# Letter to the Editor

## The ADA’s Promise

The nation marked the 29th anniversary of the signing of the Americans with Disabilities Act this summer. President George H.W. Bush signed

the act into law on July 26, 1990, proclaiming; “Let the shameful walls of exclusion finally come tumbling down.”

The ADA means curb cuts and ramped entrances. The ADA means equal rights, job accommodations and large-print meeting agendas. The ADA means bigger bathrooms, more designated parking, assistive listening devices at the movies, and eating out at restaurants with family and friends. The ADA means swimming at the public pool. The ADA means diversity and equality in our communities.

On a more personal note, the ADA means so much more than the ability to access restaurants, public buildings and events. It means that I can now enjoy the freedom to go just about anywhere and not have to struggle with stairs or obstacles. Being able to go to a State Park and find accessible entry to the water and changing rooms! The equality the ADA affords me and my peers is inspiring to continue advocating for equal rights for all.

I encourage everyone to help fulfill the promise of the ADA by pushing for better access in their communities.

Susan Sanderson  
Montpelier

## Tribute to Mark Johnson

### In Remembrance

Lest there ever be a time  
somewhere down the road  
come the morrow,  
our dear neighbor and caring friend,  
taken from us very tragically,  
one early morning,  
be too easily dismissed and forgotten;  
we shall always remember,  
our hearts remain grieving,  
still filled with deep sorrow,  
over the sudden loss  
of the “good soul,” the “gentle giant”  
we all knew and greatly miss,  
who to us was Mark Johnson.

Rest in Peace  
Morgan W. Brown  
Montpelier

*Editor’s Note: See page 10 for information on the Mark Johnson Memorial Fund.*

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# Thanking the Torchbearers

by Deborah Lisi-Baker



It is hard to say goodbye to people you know and love. Earlier this year we lost David Sagi, an early and constant leader in the independent living movement in Vermont. And Susan Hasazi died this year, a dear friend of mine and a passionate leader in calling for inclusive

education and the end of all forms of segregation of people with developmental and intellectual disabilities. Both dedicated their lives to advocacy and were equally committed to their families and communities.

Susan told me — so many years ago — that she decided to work to change laws and service systems after visiting an institution for individuals with intellectual disabilities in (I think) Florida. She was a young woman then and described how going into a huge barracks-like building and seeing people left naked, with nothing to do, no kindness or respect shown to them, being bathed by having hoses turned on them, made her realize that it was not enough to teach inclusive education. We had to change laws and attitudes. And that is why I met her working as a volunteer in the early days of the Vermont Coalition for Disability Rights. She taught and she prepared others to teach inclusively and to dismantle segregated programs, but she never forgot the need to speak truth to lawmakers — challenging old assumptions and inspiring new strategies.

I believe I met David when he was on the founding board of VCIL or shortly after he stepped down. He was one of Vermont's leading advocates for accessible communities, a longtime alderman in Rutland and a dedicated manager of the Rutland Vocational Rehabilitation office, as well as serving as the ADA coordinator for the state of Vermont. He was dedicated to getting things done and he was always there for me when I worked at VCIL. His patience and passion for access inspired others to change their own attitudes and work with him to make Ver-

mont more accessible. Together, he and his wife, Mary Jane, were two of the best storytellers. I still smile at how they were able to make me laugh while describing some of the truly awful things well-intentioned doctors said while David and Mary Jane were adjusting to David's spinal cord injury.

VCIL has introduced me to an amazing network of peers, activists and allies. Some are gone and others are still here: listening, mentoring, marching, inspiring, reminding and learning from and making room for others, working for necessary change.

Sarah Launderville wrote a few days ago, in celebration of Marca Bristo, a longtime national leader in independent and disability rights, "I'll never forget her warm smile, her sharp edge and her incredible heart. Don't mistake me, her kindness is matched equally with the sharp advocate that she was. An advocate that allowed for other advocates to find their way. Her leadership was one of relationships, and of getting things done."

I think Sarah's words are one of the best descriptions of a leader that I have ever read.

Celebrating VCIL's 40th, I saw and remembered people from so many movements that are part of disability rights activism in Vermont: parent advocacy, mental health peer support, Green Mountain Self-Advocates, Deaf advocacy and independent living — each person, each family, a part of a braided strand of stories and lives and shared leadership. So many torchbearers!

I am lucky to have met and worked with so many people who know how to honor others as they helped our movement grow. I celebrate that I keep meeting new peer activists, people who will help us all find our way forward; and I am glad that so many people from so many social justice movements are coming together today, seeking and finding and calling for change. And I am glad — so glad — that I can still feel the deep presence of others who have helped bring us to this place of memory and action.



## Stories and Reflections on IL Advocacy

*Editor's note: The following are excerpts from Judith Heumann's speech at VCIL's 40th anniversary bash on May 24, 2019, in Montpelier. Heumann was the keynote speaker. She is an internationally known speaker for disability rights and independent living services. Her list of accomplishments is long and includes cofounding the first independent living center in Berkeley, Calif. Last year she was featured on Comedy Central's "Drunk History" for her role in the nationwide sit-in of federal buildings in April, 1977, to force the government to enact the first major antidiscrimination law allowing people with disabilities unencumbered access to all government facilities.*

### Early Campaigns in New York City

I had worked with a lot of friends setting up an organization called Disabled in Action, which was cross-disability and disabled controlled, with many women on the board; it was really in some ways a ragtag group of people. We worked on issues that the board wanted to work on. We had probably the first hunger strike that was conducted by a group of people who had muscular dystrophy against the Jerry Lewis telethon. We had work going on against sheltered workshops. We had no money.

As a teacher (I taught for three years), I had to get a master's degree after five years. I applied to Columbia and had been accepted into the school of public health and was preparing to go there in the fall. And then I got a call from this guy Ed Roberts in California, who I'd never heard of. We didn't know anything about what was going on at the CIL in California. There was a lot of activism going on in New York. We were having demonstrations and many things going on ... So he called and he said there were two graduate programs going on in Berkeley at the university. Faculty were willing to bring in some disabled students and he had heard about me from a number of people and would I be interested in going?



PHOTO BY ADDIE McINTIRE  
Judy Heumann, left, and Deborah Lisi-Baker share a moment during Heumann's trip to Vermont in May.

Then he talked to me about the CIL and I thought, well, it was kind of interesting; because while they were doing work that was very similar to what we were doing in Disabled in Action, they had different laws in California ... personal assistance services and other laws. I saw it as a real opportunity. So, I went out to Berkeley.

### Working at the First CIL (Berkeley, Calif.)

It was a very interesting period of time. The CIL at that time was really working with people 14 and older. I had had polio, so my experience as someone growing up with a disability was not completely absent from what was going on at the CIL. Gradually over the next couple of years a number of people started moving from New York to California and that is when the CIL began to become much more cross-disability and also intergenerational.

For me, the other issue was growing up in a large city and going to Berkeley. Berkeley is small. You know, I lived in Brooklyn where there are 4 million people and Berkeley has a couple hundred thousand people. So, there were many things that

we were able to do in Berkeley at that time, similar to Vermont because you're all so much smaller. I kind of define it as like being in a candy store because there were so many things that needed to happen, we kind of couldn't pick a wrong issue. We also began to do more international work because other countries were learning about what we were doing. In some way we were all kind of dreaming of a new vision of what should happen ... People were talking about not only what the problems were but what solutions were.

[T]he fact that the legislation [for a national network of CILs] came about at the federal level was a real opportunity for people to be coming together ... Vermont was part of the original cohort of CIL leaders and so we all just naturally worked together.

### The Power of Stories

Stories are so important...[They are] one of the reasons why the independent living movement really began to emerge...Stories go beyond just talking about our disabilities, [to] what are your experiences in the area of discrimination, what have you done and how can we learn from each other? At the end of the day, stories are what drive us and commit us, regardless of disability. People who experience discrimination, whether it's for gender orientation or religion or race or whatever, stories are what I think motivate us and help with creativity.

We need to continue to invigorate ourselves. Because you know, listening today about how your personal assistance services program [Participant Directed Attendant Care] is really stalled — this really is a major problem. The stories of people who are not getting personal assistance services and [those] who are having to struggle for whatever else — sign language interpreters or [more] hours for people who need supported employment. There's lots of issues still out there and I only know a little bit about them. But, telling your story and benefiting from those stories and creating additional agendas about what has to happen, that's important ... And really holding elective representatives accountable.

### More on the International Movement

I first travelled outside the US in 1972 ... I really learned a lot. I learned what national health insurance was and how most countries around the world have health care that most people in the US have no understanding of ... What was important for me even then at the CIL was really trying to look at what other countries were doing that was different. It wasn't just in health care but in personal assistant services, in technology, how there were technology centers in Sweden that you could go and visit, how the government in the Scandinavian countries, not just in the area of disability but in general, had been supporting international development for a long time. So, there was all this work going on.

What I think we have that most other countries don't is legislation like 504 and ADA and IDEA that have strong provisions around how we are able to file complaints and how we can go to court and we can look to changes that have happened because of the CIL movement and because of ADAPT and the Deaf community and blind community and IDD community ...

I would say our failure to ratify the Convention on the Rights of Persons with Disabilities and what's going on with this administration is really on the international level pretty tragic ... because while we have a lot to learn about what other countries are doing, we have a lot to offer ... We need to be a player — a responsible player — on the international scene and that's really lagging right now.

### And Here in Vermont

We all have to recommit ourselves to recognizing the important work we've done, but to also recognize in a state like Vermont, which is small, that there are still thousands of people who are not getting what they need. So that's our responsibility — to change that.



## VCIL Marks Major Milestone

The Vermont Center for Independent Living celebrated its 40th anniversary in grand style on May 24, 2019, at National Life in Montpelier. A good time was had by all! Matt Saltus, a comedian and former VCIL employee, was a masterful master of ceremonies. Other highlights included remarks by Judith Heumann, Barry Bernstein, Charlie Murphy, Deborah Lisi-Baker, Kemal Onor, Sarah Launderville and Ed Paquin. Heartfelt thanks goes to all of the organizations that made our highly successful event possible:

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As VCIL Development Coordinator Linda Meleady, who led the planning for the anniversary bash, wrote:

*Oh what a night it was  
The 24th of May  
To celebrate our 40 years  
In an amazing way*

*Maple was the theme  
Decorations everywhere  
Trees and leaves and acorns  
And Syrup for all to share*



See more photos from the 40th gala on page 18.





PHOTO BY LINDA MELEADY

*Sarah Launderville, left, presents an Ally of Accessibility Award to Deb Mullen of the Friends of the Tunbridge World's Fair.*

## ADA Celebration Features Award Presentation

On July 19, the Vermont Center for Independent Living celebrated the 29th anniversary of the signing of the Americans with Disabilities Act. VCIL is a statewide nonprofit organization directed and staffed by individuals with disabilities that works to promote the dignity, independence and civil rights of Vermonters with disabilities.

People gathered at VCIL's main in Montpelier and watched "Lives Worth Living." In the documentary film, charismatic leaders of the independent living movement narrate the story of a long, hard but successful drive for civil rights. Their efforts brought together a once fragmented population into a powerful coalition that created some of the most far-reaching civil rights legislation in our nation's history.

A highlight of VCIL's ADA celebration was the presentation of an Ally of Accessibility Award to the Friends of the Tunbridge World's Fair. The nonprofit organization provides free shuttle service from the main parking lot to the fairgrounds for the popular annual event. All of the shuttle drivers are volunteers.

Susan Sanderson of Montpelier, who nominated the Friends of the Tunbridge World's Fair for the

award, applauded them for recognizing the need for people to get out into the community, noting that her own sister would not be able to attend the fair were it not for this service.

Deb Mullen graciously accepted the award on behalf of the Friends of the Tunbridge World's Fair, noting that the organization is working to make the fairground's barns and grounds more accessible.

VCIL Executive Director Sarah Launderville said, "The ADA allows for program access and this is a great example of that. Providing these services makes it so people with disabilities can choose to participate in activities that nondisabled folks take part in regularly. Our society benefits when all are included and we applaud these accommodations!"

## Marca Bristo Mourned

The independent living movement has lost one of its brightest stars. Marca Bristo passed away on Sept. 8 from cancer. Until stepping down just recently, she served as president and CEO of Access Living, the center for independent living she founded in Chicago nearly 40 years ago. She cofounded NCIL in 1982 and served as its second president. Marca was a tireless activist who dedicated her life to fighting for disability rights.

Sarah Launderville, a longtime friend of Bristo, described her as a force and a kindred spirit. "Marca was a trailblazing advocate. She will be deeply missed, and my heart goes out to the IL community as we grieve this incredible loss."

Bristo was a staunch advocate for local, national and international disability rights for over four decades. She served as the first disabled chairperson of the National Council on Disability from 1994-2002 and more recently as the president of the U.S. International Council on Disabilities. Her advocacy led to some of our community's biggest achievements, including helping to author the ADA and participating in negotiations for the United Nations Convention on the Rights of Persons with Disabilities.

Marca was in a league of her own. The independent living movement has lost a passionate and visionary leader. She will be missed dearly.

## Jacqueline Kelley: A Dedicated Advocate

by Deborah Lisi-Baker

Jacqueline Kelley is not one to let the world pass her by. In the year since I met her, she has been to Ireland and returned to college in Rhode Island for the fall semester. Jacquie was last year's VCIL's Youth Leader Award recipient, chosen because of the advocacy and disability awareness work she has done at Providence College, where she has joined several campus groups and launched one of her own.

Jacquie explains, "BELIEVE (Be Educated, Live with Inspiration, and Evaluate Equity) educates my college's community on the challenges that people with disabilities face. It also provides those with disabilities a space to talk about their limitations, struggles and ways they persevere in life. BELIEVE is for everyone as we welcome people with and without disabilities. We encourage people to ask any questions they may have since the club is a safe space and we do not disregard any questions. BELIEVE is a place where people can learn about the disability community while also sharing the knowledge that they have."

She was also hired as the college's student ADA consultant.

When she was 2 Jacquie was diagnosed with a form of muscular dystrophy, spinal muscular atrophy, which increasingly limited her ability to walk. Today her mobility and independence has increased, thanks to technology and a helpful and large companion, a 90-pound golden retriever.

"Six years ago, I began using a scooter full-time and almost two years ago I adopted my assistance dog, Moose. Moose is trained to assist me in standing up out of seated positions. He has allowed me to become independent and has helped me to feel safe while traveling. Thankfully, with these aids, my ability to be independent has enabled me to move away from home to study at Providence College in Rhode Island."



COURTESY PHOTO

On Dec. 21, Jacqueline Kelley, center, received the Deborah Lisi-Baker Youth Leader Award. Presenting the award were Lisi-Baker, left, and Kimberly Colville of the Vermont Center for Independent Living. Also pictured is Moose.

Jacquie is majoring in political science and minoring in music. In addition to coordinating BELIEVE, she is active in several clubs and activities on campus. Advocacy is something she does all the time.

"Whether I am writing legislation for Student Congress or showing my peers that people who use wheelchairs can dance, my goal is to create dialogues as disability issues are rarely discussed. I encounter numerous people every day who know little to nothing about accessibility and assistance dogs. It is not a lack of caring, but a lack of awareness of what it is like to live with a disability."

She said, "My advice for people with disabilities who are trying to figure out where they want to go to college is to make sure the school can accommodate your needs. Make sure you are in contact with someone from Residence Life and the Academic Services Office so you can make proper arrangements."

*Continued on page 18*



# Launderville Selected for Top Slot



PHOTO BY MICHAEL CLEGG

*Sarah Launderville, left, fires up the crowd with her passion, as only she can, at the NCIL rally in Washington, D.C.*

Sarah Launderville was elected president of the National Council on Independent Living recently.

She ran unopposed for the position and was voted in for a two-year term at NCIL's annual meeting on July 24 in Washington, D.C.

Launderville said, "Our work at VCIL over the past 40 years has been to work in the community so people with disabilities can live as they choose. So many systems and policies have a bias toward people with disabilities. We, as people with disabilities, need to help shape these systems at the local, state and national level. Through NCIL we band together as advocates across the nation to work on policy priorities important in dismantling ableism and creating a world that allows for greater independence."

The Williamstown resident has headed up the Vermont Center for Independent Living since 2009.

She said, "I'm honored to serve as NCIL president and look forward to the work ahead."

The theme of this year's annual conference was IGNITE. As NCIL's website explains: "The Independent Living Movement ignites action and empowerment. We are not a sedentary bunch. When there is work to be done, we do it. When bad policy threatens our independence and rights, we react. When we know we have a better way, we take action to influence policy and pass laws. We are organized, we are powerful, and we know what we want. All it takes is a spark!"

Launderville was not the only VCIL employee to make Vermont proud at the NCIL conference this year. Ericka Reil, advocacy organizer, and Kimberly Colville, peer advocate counselor, were copresenters of a workshop that covered the basics of human trafficking, such as what to look for if a person is being trafficked and what some centers for independent living are currently doing to prevent trafficking of people with disabilities.

NCIL is the longest-running national cross-disability, grassroots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of individuals with disabilities and organizations, including centers for independent living, statewide independent living councils and other organizations that advocate for the human and civil rights of people with disabilities throughout the United States.



## Mark Johnson Memorial Fund Established

On Sept. 11, 2019, the Disability Rights Vermont Board of Directors established the Mark Johnson Memorial Fund to assist DRVT's efforts to improve the law enforcement response to incidents involving people with disabilities or individuals who are experiencing a mental health or emotional crisis.

Johnson was shot and killed by Montpelier Police on Aug. 9.

DRVT will use the fund to further systems improvement efforts by working collaboratively with law enforcement and other partners and, when necessary, by investigating reports alleging inappropriate uses-of-force.

Donations may be made to The Mark Johnson Memorial Fund, c/o Disability Rights Vermont, 141 Main St., Suite 7, Montpelier, VT 05602.

## Health Justice Commons Takes On Insurance Practices

Online advocate Health Justice Commons have a new website ([www.healthjusticecommons.org/](http://www.healthjusticecommons.org/)) and a new campaign. The health advocacy group has created a Medical Abuse Hotline in memory of Carrie Ann Lucas, a longtime disability rights activist who lost her life when her insurance company denied the medication that worked for her and approved a less effective alternative one that caused significant side effects.

## Call to Action: Hold a Hearing and Pass the Disability Integration Act

Over 852 disability rights organizations are calling on Congress to pass the Disability Integration Act (DIA), a civil rights, bipartisan and bicameral legislation, introduced by Sens. Charles Schumer, Minority Leader (D-NY) and Cory Gardner (R-CO) in the Senate and Rep. Jim Sensenbrenner (R-WI) in the House, to address the fundamental issue that peo-

ple who need long-term services and supports are forced into institutions and losing their basic civil rights. The legislation (S.117, H.R.555) builds on the 25 years of work that ADAPT and other disability organizations have done to end the institutional bias and provide seniors and people with disabilities home and community-based services as an alternative to institutionalization. Disability advocates are calling for a congressional hearing on the bill, which addresses the continuing segregation of individuals with disabilities in institutional settings.

## 3SquaresVT and 13,000 Vermonters at Risk

The Trump administration proposes ending a long-standing state option that has helped 3 million Americans in need get food by proposing to effectively eliminate a long standing and widely used state option in the SNAP program (called 3SquaresVT here in Vermont) for over 20 years. This option allows Vermont, along with 42 other states, to expand access to 3SquaresVT for vulnerable low-income Vermonters (including working families, children, older adults and people with disabilities). If enacted, this rule could cut over 13,000 Vermonters off from crucial benefits that allow them to have enough food for themselves and their families.

Many people across the country are working to preserve 3SquaresVT and programs like it in other states. Hunger Free Vermont and other groups are asking as many people as possible to submit a public comment opposing this change to 3SquaresVT by Sept. 23. For updates visit their website [www.hungerfreevt.org/protect3squaresvt](http://www.hungerfreevt.org/protect3squaresvt) or reach out to Drake Turner, food security advocacy manager at Hunger Free Vermont, at [dturner@hungerfreevt.org](mailto:dturner@hungerfreevt.org) or (802) 231-0394.

## Comment Period Extended for State Plan on Independent Living

The Vermont Statewide Independent Living Council is responsible for submitting a three-year plan

that describes the priorities for independent living goals and objectives for people with disabilities in Vermont. The federal government has extended the time for preparing these reports. The SILC welcomes comments from members of the public regarding services or programs that might be helpful for people to live independently, in a home and community-based environment, with dignity and self-respect.

Crafting the SPIL is the most important function of the SILC per Federal law (Rehabilitation Act of 1973 as amended). Normally, SPILs are re-written every three years with the option of periodic amendments, if necessary.

Comments are welcome through Oct. 15, 2019. Send your comments to Tom Hamilton, VT SILC Executive Director, c/o L64, 43 State St, Second Floor West, Montpelier, VT 05602.

## Bill Proposes Holiday Celebrating Brandon Training School Closure

Vermont Care Partners, the statewide alliance of developmental and mental health community-based agencies, spoke to Rep. Theresa Wood, suggesting the creation of a holiday to celebrate the development of our community-based system of care and the closure of Brandon Training School. In response Rep. Wood sponsored H.332, an act relating to the establishment of Developmental Disabilities Independence Day. The bill has been directed to the House Human Services Committee where it is hoped it will see action during the upcoming legislative session. The proposed holiday would not involve a shutdown of work sites, but simply a day of appreciation for our current services and the progress we have made to achieve full community.

Vermont Care Partners highlights the importance of this proposal with this statement: "In November of 1993 Brandon Training School was closed ... This event was a milestone in the history of Vermont and speaks to our continuing values and efforts to

promote a Vermont that works for all of us. All Vermonters, including people with disabilities, deserve to live with dignity and respect, and the freedom to make their own life choices. After 25 years Vermont is only one out of 11 states that have closed their institutions in favor of a fully inclusive community-based service system."

## Art Sought for Traveling Exhibit

Inclusive Arts Vermont have put out a call to artists for a 2020 exhibition called ANEW, an exhibition showcasing works by Vermont artists with disabilities to travel statewide through the 2020 calendar year. Applications must be received by Sep. 30. For an application or additional information, visit their website, [www.inclusiveartsvermont.org](http://www.inclusiveartsvermont.org).

## New AT Tryout Center Opens at Castleton

UVM's Center on Disability and Community Inclusion has opened an Assistive Technology (AT) Tryout Center on the Castleton University campus. The project is a partnership between CDCI, the Vermont Assistive Technology Project and Castleton.

AT access specialist Ben Wimett is working at both the Rutland and the new Castleton locations. You can find Ben and a range of AT information and resources at the new center on the first floor of the Stafford Academic Center.





# VCDR Report on 2019 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.*



The following is a summary of selected VCDR legislative priorities for the last session. For

a more detailed summary of legislative action you can find the "End of Session Report" on the VCDR website ([www.vcdr.org](http://www.vcdr.org)) We welcome your suggestions as we prepare for the 2020 session and thank all of you who helped advocate for legislative and funding changes during 2019!

## 2019 Selected Budget Decisions

**Deaf, Hard of Hearing and DeafBlind Director:** VCDR advocated for base funding for a director of services for the Deaf, Hard of Hearing and Deaf-Blind. **Legislative action:** The budget adds \$89,000 (GF and Medicaid match) funding for this position.

**Reach Up Benefits:** VCDR and other groups advocated for increased funding in Reach Up benefits, and to reverse the funding penalty created five years ago which penalized families with an adult receiving an SSI supplemental income benefit. The Reach Up benefit for those families was reduced by \$125 a month. That penalty was reduced to \$115 a few years ago. **Legislative action:** The Legislature increased regular Reach Up benefits for the first time in many years, adding \$2.3 million to the program. This raises the benefit from 2004 levels (covering only 35 percent of standard of need) to 2008 levels, covering 49.6 percent standard of need. As a result, benefits for a family of four will increase by about \$60 a month. The budget also added funds to allow for the elimination of about one third of the Supplemental Security Income (SSI) "countable income" penalty. The penalty was reduced from \$115 to \$77.

**Waiting List for Participant Directed Attendant Care:** The Vermont PDAC program, supported with state general fund dollars, makes it possible

for individuals who are not eligible for Medicaid to have help funding the personal care they need to live and work in the community. Today the program serves only 40 individuals, despite the fact that PDAC makes it possible to build careers and move out of poverty. **Legislative action:** No new funding was approved. VCDR did testify in Senate Health and Welfare on the issue.

**Dental and Denture Coverage:** VCDR and other advocates continue to advocate for improved dental benefits and coverage of dentures. **Legislative action:** Dentures were not addressed, but the Legislature did increase funding for Medicaid dental care coverage for adults that allows for two cleanings a year and a \$1,000 annual cap on dental services. The Legislature also requires the Department of Vermont Health Access to convene a working group of interested stakeholders to look at dental issues including access to care and Medicaid funding.

**Choices for Care:** The budget provides \$2.1 million for a 2 percent increase for home and community service providers in the Choices for Care program.

**Rehabilitation Services for the Blind and Visually Impaired:** VABVI sought \$100,000 to support their services and to expand a successful technology program that helped partially sighted and blind individuals access and use new communication technologies. **Legislative action:** No additional funding was authorized, but testimony was taken in the Senate Health and Welfare Committee and the committee continues to look into the program.

**Request to Increase funding to Children's Integrated Services:** Advocates from VCDR and the Early Childhood Alliance spent most of the legislative session working to oppose a cut to CIS proposed by the administration. Advocates' testimony persuaded key members of the House Human Services and Senate committees that any underutilization was a direct result of underfunding and low

reimbursement rates. **Legislative action:** Full level funding was included in the Legislature's final FY20 budget.

**Mental Health Peer Support:** Sixty thousand dollars was included in the budget for the Copeland Center for peer support services.

**Developmental and Mental Health Services:** The budget provides a \$5.2 million increase across the entire system of mental health and developmental services and \$1.5 million in onetime funds to begin developing an electronic medical records system. The Legislature approved the \$7.6 million in developmental services caseload increases requested by the administration. In mental health, the budget provides \$1.5 million to fund community placements for individuals with complex needs. It also funded 12 new acute care beds at the Brattleboro Retreat.

**Woodside Rehabilitation Center:** VCDR opposed legislative action to change Woodside from a treatment facility to a detention facility. **Legislative action:** Authorizes \$260,000 to the Department for Children & Families, Woodside Rehabilitation Center for costs associated with transitioning from a treatment facility to a detention facility.

**Legal Advocacy and Human Rights:** VCDR supported increased funding to Vermont Legal Aid for more attorneys, including a special education lawyer. **Legislative action:** The budget includes a \$25,000 increase for Legal Aid, which can be matched with federal funds. The budget provides \$85,000 for Human Right Commission outreach positions.

### Health Care and AHS Reform Initiatives in the Budget

**Developmental Disabilities Service Payment Reform:** Requires the Agency of Human Services to report on progress made on developmental disability service delivery and payment reform by Jan. 15, 2020. AHS is required to provide information on decisions made on the proposed model and include information on anticipated costs to providers and the state; proposed plans for a uniform assessment; information on how individualized services and community assessment are addressed; degree of stakeholder engagement and input into the model;

how system and workforce sustainability has been addressed; integration of person-centered planning and service; provisions for maintaining choice of provider, service management and service options; and how providers will be held accountable.

Representatives made it clear that the intent of the Legislature is to ensure that nothing that is proposed by AHS differs from the Developmental Disabilities Act. The representatives want to meet with providers and advocates prior to any meetings they have with DAIL. The Legislative Committee on Rules will be involved in approving any changes to DS payment and delivery.

### Agency of Human Services Strategic Plan

The Agency of Human Services "in order to respond effectively to dynamic and changing societal needs, shall identify emerging trends and develop a strategic plan for addressing the most challenging issues the Agency anticipates Vermont will face within the next five to 10 years." The report must address several specific issues, including changing demographics of the state, emerging or increasing trends likely to affect service needs, anticipated budget needs, the effectiveness of current investments, and proposed changes in the AHS structure or policies. An initial update is due to the Legislature by Nov. 1, 2019 and the strategic plan is due Jan. 15, 2020.

### POLICY BILLS & NEW INITIATIVES

**Act 1 (H.3), education; ethnic and social equity studies standards for public schools:** This act creates the Ethnic and Social Equity Standards Advisory Working Group to review standards for student performance adopted by the State Board of Education and, on or before June 30, 2021, recommend to the State Board additional standards to recognize fully the history, contributions and perspectives of ethnic groups and social groups. The Board of Education is required, on or before June 30, 2022, to consider adding ethnic and social equity studies standards into standards for student performance in prekindergarten through grade 12, taking into consideration the report and recommendations submitted by the Working Group. This act also requires the state board to report, to the extent consistent with state and federal privacy laws and regulations,

*Continued on page 18*

## DISABILITY RIGHTS VERMONT ANNOUNCES FY20 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 15-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, 2019 – Sept. 30, 2020.) **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 the adjoining page. 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](mailto:wenyu@disabilityrightsvt.org) or to DRVT, 141 Main St., Suite 7, Montpelier, VT 05602

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

And please visit our website at [www.disabilityrightsvt.org](http://www.disabilityrightsvt.org) – 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 is within the priorities of the grant;
- (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 (hospitals, any state run facilities, designated agencies, emergency departments, facilities for minors), prisons/jails, and community settings, including peer services and designated agencies.

**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, des-

ignated facilities and hospitals, emergency rooms, prisons/jails, residential and therapeutic care homes. Monitor conditions and educate residents, patients and providers about rights, self-advocacy and DRVT services, with emphasis on the integration mandate of the Americans with Disabilities Act.

**Priority 4:** Advocate for self-determination, access to alternative treatment options and community integration. DRVT will advocate for designated agencies to establish relationships with individuals in inpatient settings during discharge planning in order to support people to seek their full potential in the community.



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 [www.disabilityrightsvt.org/Programs](http://www.disabilityrightsvt.org/Programs) or contact us at 1-800-834-7890 and request a copy.

CURRENT 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 the issue is disability, duration of services, covered services, due process or 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 SS 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)
- People with intellectual and developmental disabilities will learn to identify and report disability based harassment as a form of employment discrimination. (PADD)
- Increase knowledge and awareness of the civil and legal rights of people with disabilities. (PADD/PAIR)



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*ALWAYS SHARE  
YOUR STORY -***THE NEXT PERSON YOU TELL  
MAY BE JUST THE RIGHT PERSON  
TO MAKE A DIFFERENCE.****Mike Gruteke  
Council Vice Chair**

Are you a person with a disability or a family member? Do you want to have a larger influence on big, statewide decisions that impact Vermonters with disabilities? Learn how to craft your story by attending a free storytelling workshop. Vermont Story Lab will teach you how to select details and tell your story so that you inspire action by others.

**Save a Date and attend a workshop near you:**

- October 15, South Burlington
- October 22, Montpelier
- October 29, Brattleboro

All workshop will be from 6:00pm to 8:30pm.

More details to be announced soon on:

<https://ddc.vermont.gov/>



The **VERMONT DEVELOPMENTAL DISABILITIES COUNCIL** is a 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 <https://ddc.vermont.gov/> or contact the Council by phone [\(802\) 828-1310](tel:8028281310) or email [vtddc@vermont.gov](mailto:vtddc@vermont.gov)

# Developing a Road Map to Safe, Healthy Aging

Throughout the year Community of Vermont Elders (COVE) staff travel across the state offering educational programming at a variety of venues. These workshops target specific issues that may concern older Vermonters. The ongoing and expanding commitment from the state and related service providers to Aging in Community is beginning to expose gaps in knowledge or understanding of the support structures that allow for healthy aging within our own communities. This fiscal year, COVE is working on a project that will develop a new, community-based curriculum to educate caregivers, families, service providers and community members on the needs of older Vermonters and how best to access assistance for them. This curriculum will cover a variety of topics vital to safe and healthy aging in Vermont, including physical/mental/financial abuse prevention and who to contact if victimized, financial planning, wills and beneficiaries, connecting with neighbors living in isolation, navigating health care benefits, emergency preparedness, and more.

The curriculum will be developed for presentations to caregivers and family members caring for older Vermonters, older Vermonters themselves, health care and hospital workers, assisted living facility employees, gerontology and social services students and workers, municipal workers, regional partners and interested community members. The goal is to break down our silos to ensure that everyone across all sectors has consistent, high-quality information about aging in Vermont.

There are many stories of older Vermonters and their families who are suddenly faced with demanding financial decisions due to a death in the family and these decisions often lead to more loss of money and family disputes. Often people avoid preparing for these events, whether as a result of stigma and denial or a lack of knowledge and perceived lack of access to supportive services. Then they are blindsided by laws they had no knowledge of or are taken advantage of by scammers or fraudsters. This is one of the many ways this curriculum

can help. By educating the people who surround older Vermonters, from their caregiver to their mail delivery person, we can start to eliminate confusion about what is needed to safely and healthily age within our Vermont communities. We are all aging, so the earlier we integrate this information into the mainstream of working age adults, the better prepared we will all be for the eventuality of age. We view this curriculum as a "Road Map to Aging." This can also help to eliminate the stigma of aging and lessen the number of Older Vermonters living in isolation.

To enhance the effectiveness of the curriculum, a resource guide will be created that contains basic information, resources, and contacts. This resource guide will be updated annually and distributed across the state to ensure the most up-to-date information to those who need it.

This work cannot be done by one organization. To integrate the most comprehensive information we are working with many agencies, departments, businesses, organizations, and other stakeholders. The Vermont Senior Medicare Patrol, the Vermont Department of Financial Regulation, Vermont AARP, the Vermont Attorney General's Office, FAST of Vermont and Vermont Legal Aid are just a few of the agencies invited to collaborate on this project. Representatives from SASH and community members working in the areas of nursing, caregiving, law enforcement, and health care will also be invited to collaborate. And of course input is greatly needed from older Vermonters themselves and the family members who care for them.

For more information on the Community Caregiving Curriculum, please contact Marichel Vaught at [Marichel@vermontelders.org](mailto:Marichel@vermontelders.org).

*The Community of Vermont Elders is a nonprofit organization whose mission is to promote and protect a higher quality of life for older Vermonters, through education and advocacy. For more information on COVE and its programs, visit [www.vermontelders.org](http://www.vermontelders.org).*





**RECONNECTING** — From left are Greg Morgan, Barry Bernstein, Yiota Ahladas, Elizabeth Levy and Paul Levy. Deborah Lisi-Baker is in the front.



**A SPECIAL NIGHT** — From left at VCIL's 40th anniversary gala are Nate Besio, Ericka Reil, Matt Saltus and Marty Roberts.

**Jacqueline Kelley**, continued from page 8

Jacque continued, "I also recommend attending a school that has a high presence of students who are differently-abled. I am the only student at Providence College who uses a wheelchair and has an assistance dog. This has been something that I have struggled with since I was a freshman because it often makes me feel alone ... [T]here is such a small presence of people who are differently-abled on my campus. I think it is important to attend a college or university that has some sort of disability-related club so you can get to know others who either have a disability or are interested in the topic. Finally, I believe it is crucial to attend a school that views disability as a form of diversity. I struggle with this at Providence College ... disability-related topics are almost never brought to the table."

Jacque described the feeling of being invalid, in-valid, the incredible isolation experienced when disability is not acknowledged as an identity. BELIEVE is her creation, a way to establish a needed and safe place for conversation and cultural change regarding disability. Last semester Jacque traveled to Ireland to study and Moose went with her. (Past experiences traveling in Europe with a scooter and an assistance animal have made Jacque an outspoken advocate for researching accessible destinations.) Dublin welcomed Jacque and Moose in ways that many European countries don't. "I ended up attending University College Dublin where I resided on campus, in an accessible apartment near my friends, with access to a kitchen. I had no challenges with bringing my assistance dog into stores, restaurants or other buildings." Except for problems transporting her scooter on the airport bus service, "Dublin was fantastic!"

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**VCDR**, continued from page 13

data on hazing, harassment, or bullying incidents disaggregated by incident type, including disaggregation by ethnic groups, racial groups, religious groups, gender, sexual orientation, gender identity, disability status, and English language learner status. Effective date: March 29, 2019.

H. 348/S.137, an act relating to health insurance coverage for hearing aids: Would require private insurance to provide coverage for hearing aids and services at the same level as Medicaid, providing equal access to health for people with hearing loss. The bill is in the House Committee on Health Care and in Senate Health and Welfare.

H. 312, an act relating to open movie captioning in movie theaters: This legislation would require movie theaters to offer "open captions" (subtitles) for a small number of movies each week. The bill has been assigned to the House Human Services Committee.



## got access?

by Deborah Lisi-Baker

### Building a School for Tomorrow

*"Asi deka mesina akpe o." Literally this means one hand cannot clap. Really it means one person cannot do it. We need to have a unified voice to achieve our aims. ~ Sefakor Komabu-Pomeyie*

Sefakor Komabu-Pomeyie serves on VCIL's board while completing policy studies at UVM. She is using her studies to make life better for children with disabilities in Ghana. Her advocacy for inclusive schools in Ghana comes from her childhood experiences with disability and her personal experiences with the transformative power of learning.

Schools in Ghana are not accessible and children with disabilities are often kept out of school, but Sefakor's mom and extended family were determined. Sefakor vividly recalls "how my Mum used to carry me [to school] and cried on me. It [is] an indelible mark left in my memory ... [After I had polio] she still saw good things in me and sent me to school in order to develop my skills and talents." How did she get through childhood in a country where people with disabilities are so stigmatized? Sefakor credits her mother's determination, her family's Christian life and the strength of Ghanaian culture, which is rooted in the extended family.

She sees discrimination and design barriers in both Ghana and the United States. She told me, "Though we are perceived to be in the developing world, I notice life here in the United States isn't that much better for people with disabilities (PWD) than it is for us in Ghana. PWDs here still struggle with the authorities for the same equal rights as we do. We both have the goal to change the perceptions and attitudes of people towards PWDs."

Important differences do stand out: "[One] difference is that the policies/laws are implemented in the US and people can be held responsible for things at times. (That is, if you know how the law works.) In Ghana there is now a national disability rights law, but there are fewer rules to help enforce the law. "On the flip side," she says, "life here is more challenging (culturally) due to the notion of individualism, which is so strong in the United States." She sees many people having to make it on their own or fail without the networks of support that are so strong in Ghana.

Sefakor's commitment shapes everything she does. She brought people with disabilities together. They created a nonprofit, Enlightening and Empowering People with Disabilities in Africa (EEPD) that promotes disability rights and is building the first accessible and inclusive school in Ghana. A community has given them 10 plots of land for the school and friends here and in Ghana are helping raise funds to pay building costs.

What shapes her leadership? She replies, "suffering, passion and education. These are the pillars. I strongly believe that for someone to be a true leader, and especially the transformational leader, that person needs to experience some suffering which can ignite the passion in playing that leadership role. We say in our Ewe language, 'edula fe nue, wokporna efua le' which means you cannot testify for something which you have not experienced. I have a passion that is always burning in me, ignited by the suffering ... With this foundation, a leader can easily learn or get educated formally and be ready to serve his/her community."

*To donate to EEPD Africa's school in Ghana, visit [www.eepdafrica.org](http://www.eepdafrica.org), or mail a check to EEPD Africa, c/o Sefakor Komabu-Pomeyie, 21 University Lane, Apt.129, Colchester, VT 05466.*

# B u l l e t i n   B o a r d



## SAVE THE DATE!

### Disability Awareness Day

will be March 12, 2020, at the  
State House in Montpelier  
Stay tuned for more details.

### Deborah Lisi-Baker Youth Leader Award

Do you know of a Vermonter 22 or younger  
who is moving forward the promise of the  
independent living movement? Then  
nominate the person for VCIL's  
2019 Youth Leader Award! The  
deadline is Oct. 7.

<https://vcil.wufoo.com/forms/mo766380qwe1wf/>

## Vermont Leadership Series Applicants Sought

Green Mountain Self-Advocates and  
the Vermont Family Network are recruiting  
people for the 2020 Vermont Leadership  
Series. The deadline to apply is Sept. 30.

People with the following qualities are  
being sought:

- Stays positive and is good at resolving conflict.
- Communicates and works well with others.
- Seeks inclusion and equal rights.
- Becomes energized by challenges.

For more information, go to:

<https://ddc.vermont.gov/plan-and-projects/leadership-series>

*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](mailto:smonte@vcil.org)

or call

1-800-639-1522