Nothing About Us Without Us!

This issue of The Independent celebrates the power of shared advocacy. Recent threats to civil rights and proposed cuts to basic health and community programs have people organizing in every state. In Vermont, organizations like COVE, VCIL, VCDR and Green Mountain ADAPT need your stories and voices to safeguard rights and services for all Vermonters. I know from my own life that it is not always possible to get out to rallies and marches, but each of us has an important story to share. If you are concerned about human rights and social justice, consider becoming part of these organizations and sharing your story and your vision. Now, more than ever, we need to come together to protect basic rights and services. Now, more than ever, we need to be heard.

We hope this issue gives you helpful information and a sense of both the challenges and the opportunities ahead. We are in this together. Reach out to any of the partner organizations whose work is presented in these pages. We know you have an important story to tell and we want your issues and concerns to help shape the legislative and policy agenda of 2018 and beyond.

~ Deborah Lisi-Baker, Co-Editor

Advocates, including a contingent from Vermont, speak up for the Affordable Care Act at a rally in Portland, Maine, on June 28.

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Medicaid Matters

My son Will is 18 and has been on Medicaid for most of his life. He is nonverbal autistic and has epilepsy. He cannot be left alone because of the seizures and without Medicaid helping out we could not pay for personal care attendant services to come into the home so that my husband and I can work full-time. If we did not have Medicaid helping us out we would not be able to have full-time jobs, pay for our home and be able to afford the cost of living needed to live in the state of Vermont.

Two years ago, we went through what no family should ever go through. Will had a grand mal seizure which put him into a coma for two weeks. For the first 24 hours we did not know if he was going to make it through the day. We were told that we would either have to make a choice of letting him pass or take him to Boston. We have secondary private insurance that would not cover it but Medicaid would cover the transport cost. We were also told that our private insurance would hardly touch what his hospital needs were but thankfully he was on Medicaid so we didn’t have to worry; we just could concern ourselves with what was going to happen with our little boy.

After two weeks of being in a coma and one week of being in pediatrics, we were able to bring him home. When we finally received our bill, the cost was $100 for co-pays. My husband and I had been fearful that we were going to lose our home because we would not be able to pay off the medical bills. We had been talking to our parents about possibly moving back in with them and the possibility of what would happen if our home didn’t sell right off. The thought of us becoming homeless scared both of us but we would do whatever it would take to provide the best care for our son.

Will is not seizure free but we have not had a scare like that since. We continue to get round-the-clock supervision for him just in case. We never know if it will happen again, but the thought of worrying if you are going to lose your child and then the thought of becoming homeless because you want to care for your child should not happen to anybody. But if Medicaid is cut it will happen over and over again.

Ericka Reil
Barre
The Social Security Act was established in 1935 and amended 52 years ago to create Medicare and Medicaid. In 2010 the Affordable Care Act made it possible to expand Medicaid and other health insurance options to more Americans. These government programs — and the dignities and freedoms they preserve — are woven tightly into our country’s economic and social systems. Cutting them out can only cause great suffering. And yet they are currently under attack on a variety of fronts. The idea that these programs are un-American baffles me. I can’t help thinking of the words of a woman who spent her adult life raising a family, serving her community and operating a small bookstore in Boise, Idaho. In 1972, as her first Social Security check was about to arrive, Nancy Stringfellow wrote, “Such a lovely brown paper envelope, meaning, indeed, security.” Like most Americans, Stringfellow celebrated the fact that Social Security programs offered the elderly and others a “measure of dignity” when times are hard.

Proposals to cut Medicaid and Affordable Care Act protections have people literally marching into the offices of their senators and representatives telling them that the ACA and Medicaid are life or death issues. How painful, and how peculiar, that we need to call, and write, and march, and even face arrest, to convince some members of Congress not to vote for proposals that will destroy programs that protect the health and well-being of so many people. The most recent proposal to repeal the ACA was just voted down; but significant Medicaid cuts are written into the proposed national budget, still to be debated. These painful realities have people marching in Nancy Stringfellow’s home town of Boise, in our nation’s capital, and in towns and cities throughout our state and the rest of the country.

The senators and representatives whose votes authorized Medicare and Medicaid 52 years ago included two Republican senators from Vermont. Their votes transformed the lives of seniors and children and adults with disabilities in remarkable ways. In 1972, Nancy Stringfellow remembered the hard times before these programs existed. “[i]f you had bad luck or lost your strength you were done for. I was raised in mortal fear of disability or some other natural disaster.” Medicaid funded a social revolution in our country, creating needed health and disability programs. Our country became a better democracy when Congress and state legislatures chose to use federal and state Medicaid dollars to create innovative and cost-effective community services for individuals with disabilities and seniors and health care for millions of Americans.

For a while Medicaid paid for medical care my son and I needed. Later Medicaid funding, and the cancer care it paid for, literally saved my life. It turns out many Americans find out that they or someone they love needs medical care or disability services that only Medicaid covers. Medicaid not only helps individuals and families who need medical care or disability services in the community; it also pays for approximately 64 percent of the people in nursing homes — financial help that is necessary because so many people spend down their life savings in the first few years of care. I am glad that over the years some of my tax dollars have paid for needed services for others. I believe we must and can improve the quality, affordability and effectiveness of health care in this country; but we won’t do it by denying so many Americans basic health and disability services.

A few months ago, I received my own letter notifying me of my retirement benefits and responsibilities. It came in a large white envelope from the Social Security Administration. Printed on the envelope I saw the words, “Securing Today and Tomorrow.” Holding the envelope, I thought of all the people who depend on this promise. On my birthday wish list, I put better health care and disability services for all Americans and a government whose leaders are committed to safeguarding the resources and purpose of the Social Security Act and the ACA, ensuring disability and retirement protections and better health care for all Americans. Responding to these shared human needs is part of the fundamental purpose of a democracy, a social promise we need to renew and extend to all Americans, now and in the future.
Launderville Elected to Prestigious Post

VCIL Executive Director Sarah Launderville did Vermont proud July 26 at the National Council of Independent Living annual meeting. She was elected vice president and will serve a two-year term.

NCIL is the longest-running national cross-disability, grass-roots organization run by and for people with disabilities. Founded in 1982, NCIL represents thousands of organizations and individuals including: individuals with disabilities, 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. NCIL carries out its mission by assisting member CILs and SILCs in building their capacity to promote social change, eliminate disability-based discrimination and create opportunities for people with disabilities to participate in the legislative process to effect change.

Also elected to the NCIL Executive Committee were Bruce Darling, president; Darrel Christenson of Ability360 in Phoenix, Ariz., Treasurer; Dustin Gibson of the Center for Independent Living of South Central Pennsylvania, Diversity Committee chairman; Lou Ann Kibbee of the Southeast Kansas Independent Living Resource Center, secretary; and Sheri Burns of the Silicon Valley Independent Living Center, regional representative committee chairperson. Steve Higgins of East Bridgewater, Mass.-based Independence Associates was elected Region 1 representative and Sam Liss, vice president of VCIL’s Board of Directors, will continue as the Vermont state coordinator for NCIL.

Liss explained, “The state coordinator’s role is to disseminate necessary information among NCIL membership in the state and alert membership for action, if necessary.”

He added, “NCIL is the only national cross-disability organization that is dedicated to promoting independent living for people with disabilities. The ability to live Independently — in a community-based, integrated, setting — in turn, promotes dignity and self-respect and leads to self-sufficiency. Such an outcome is in the best interests of, not only individuals with disabilities, but also society as a whole.”

Launderville said, “I’m thrilled to be serving as vice president of NCIL. There is so much important work to be done and this position allows me to have a front-seat view of all the incredible work in the NCIL community. The vice president chairs the NCIL Legislative & Advocacy Committee, which is made up of 15 committees. This system is a grass-roots way for advocates around the country to work on issues they are passionate about and make real system change at the national level. Over the next few years we have a fight on our hands ensuring that Congress does not roll back our rights under the ADA and to make passage of the Disability Integration Act happen. I’m excited to get to work!”
VCIL Boasts Three New Board Members

VCIL recently welcomed three new members to its board of directors: Zachary Hughes of Montpelier, Sefakor Komabu-Pomeyie of Colchester and John Vincenty of Johnson. They were elected at a meeting on July 12.

Executive Director Sarah Launderville said, “I am excited about what these three individuals are going to contribute to the board and to VCIL. With their diverse backgrounds and experiences, they will be great advocates for the disability rights community. They all bring tremendous passion and enthusiasm to their positions.”

Zack Hughes was born in Texas. For the last 29 years, he has lived in Central Vermont.

He currently works in the field of peer support. He co-supervises two programs at Washington County Mental Health Services, a crisis bed and a peer line, and runs a volunteer-based nonprofit that promotes peer services.

A graduate of Montpelier High School Class of 1998, he went on to complete a general business course and has completed many trainings, both work- and board-related.

He has served on many boards and one governor-appointed committee.

Asked about joining the VCIL board, he replied, “I want to honor my mom’s service here.” Jean Mankowsky-Upham was executive director from 1982-1986. She was a steadfast and visionary advocate for participant-directed attendant care and a passionate and persuasive advocate for full implementation of the Americans with Disabilities Act.

Some disability issues that Hughes is especially passionate about include ADA issues and service animals/emotional support animal issues. He regularly consults on cases.

In his free time, Hughes likes to write, read and travel. He has a regular presence on Facebook.

Sefakor Komabu-Pomeyie is a professional teacher and a disability rights activist from Ghana. She became familiar with VCIL when she served as an intern in 2012. She joined VCIL’s board because she wants to help foster passion for self-empowerment and leadership opportunities for people with disabilities and other disadvantaged communities. She is especially interested in youth-related advocacy initiatives and expanding people’s worldviews. Sefakor contracted polio as a child and her physical disability, combined with her experience working with different groups of people with disabilities across various cultures, has given her a very unique perspective. She is a published author and has received many awards over the course of her academic and professional career. She is a Ford Fellow with other national and International awards, such as the International Alliance for Women Award. Currently, she is living in Colchester, Vt., while pursuing her PhD in the Educational Leadership and Policies Study Department at the University of Vermont. She has a master of arts (Policy Analysis and Advocacy Major) from SIT Graduate Institute in Brattleboro and a bachelor of arts (French and English major) from the University of Cape Coast in Ghana. She also pursued a one-year Certificate Course in Human Rights for People with Disability Organizational Development from Egmont Hojskolen-Denmark. Sefakor is the founder of Enlightening and Empowering People with Disabilities in Africa, a nonprofit organization that seeks to effect positive change for people with disabilities in Africa. She speaks four languages.

John Vincenty is in his mid-40s. He was born with cerebral palsy and throughout his life has had his fair share of ups and downs with people who had minimal understanding of what

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his needs are. Living with cerebral palsy has not been easy for John. He has moved around between several different facilities and homes. He lived in a group home for about 11 years, until January 2017. He has lived with many different people with many different needs. He learned to advocate for himself and was able to get the support he needed to relocate and begin to truly live. John worries that if America stays on its current path, future generations will revert to the old days when times were tougher for people with disabilities. He hopes that by advocating for himself and for others, he can make a difference. He’s glad that he is a position to represent those who can’t speak up for themselves.

In his free time, John enjoys competing in Special Olympics, where he has medaled in skiing. He recently tried kayaking for the first time, thanks to the Northeast Disabled Athletic Association. He got his high school diploma in Carmel, New York, and is currently working on getting into college, where he would like to study human services.

Support Group Meetings for Veterans to Start Up Soon

VCIL and the Vermont Farmer Veteran Coalition are forming some support group meetings for veterans. They will be happening in at least four different areas around the state so individuals do not have to drive as far to attend the meetings: the Northeast Kingdom, southwestern Vermont, Orange County and Lamoille County. The meetings will be starting this fall.

The support group meetings will provide a forum to discuss issues related to farming. They will also be a place to discuss disability issues and anything else on veterans’ minds.

“These support groups will fill a void that very much needs to be filled. I hope veterans will turn out in force for these meetings,” Younkman said.

For more information, contact Tom Younkman at tyounkman@vcil.org or 802-888-2180. The meetings will be held in accessible locations.

VTEDP Ready to Help Vermonters

Do you have trouble using a traditional telephone? Not to worry because VCIL has a program that provides telecommunications equipment to eligible Vermonters who are Deaf, Deaf-Blind, Hard of Hearing or have communication or other disabilities requiring an adaptive telecommunications device to access the publically switched telephone network.

Examples of the equipment that VTEDP pays for include, but are not limited to: CapTel phones, which display the text of the other person on the line for people who have trouble hearing but who can speak for themselves; and voice-activated equipment.

To be eligible, your household income in the preceding tax year must have been at or below 200 percent of the federal poverty line.

For more information about EDP, please email Chanda at mowchanda@vcil.org or call her at 1-800-639-1522.

For information in ASL, call 802-275-0099.

Earl Gerrish of Montpelier, who is Hard of Hearing, received an amplified phone through VCIL’s Equipment Distribution Program. He said the phone has really improved the quality of his life. “A lot of times, I couldn’t hear anything on my old phone,” he said. He encouraged others who have trouble using a traditional phone to apply for the program.
Autumn 2017

VCIL

Bringing Work Incentives to More Vermonters:
One Advocate’s Story

by Deborah Lisi-Baker

Sam Liss, left, and Kelly Buckland, executive director of the National Council on Independent Living, connect at the annual NCIL conference.

VCIL Vice President Sam Liss describes himself as a “native Brooklynite who moved to Vermont by way of Connecticut in 1999 and who loves the Green Mountain State.” A retired pharmacist, Sam now teaches pharmacology and donates a lot of time to the disability rights and independent living movement. When he isn’t working or advocating, he enjoys stamp collecting, music, humor and the company of friends.

Since settling in Bennington, Sam has been active in the work of the Vermont Coalition for Disability Rights, the Statewide Independent Living Council, the State Rehabilitation Advisory Council and VCIL. His advocacy is not limited to work incentives, but over the last several years he has led VCIL’s employment initiatives.

The Ticket to Work and Work Improvement Act of 1999, sponsored by U.S. Sen. James Jeffords of Vermont, makes Medicaid benefits and other work incentives available to Americans who use Social Security disability programs and want to return to work. Though Vermont was one of the early leaders in implementing the law, advocates and state partners continue to find ways to make the benefits available to more individuals. Making needed changes requires gaining the support of legislators and officials in Vermont and federal officials in Washington, activities that take time and a great deal of persistence!

Sam became involved in advocacy for disability rights and work incentives because of his own lived experience with disability. “After being diagnosed with an unusual neuromuscular condition, I realized the importance of advocacy for supports that allow people with disabilities to live and function independently in an integrated community setting. Segregation and isolation is unacceptable to the individual and to society, as is pity and condescension. Many, if not most, people with disabilities desire to and are able to work. I felt, and still feel, that we need to dispense with old notions and allow people with disabilities to fulfill our potential. Society needs to change its view and lawmakers and administrators need to change rules in public assistance programs that discourage and penalize employment.”

Sam’s advocacy, and the work of other concerned individuals, advocacy groups and allies, have paid off. Recently the state requested public comments on three proposed changes to the eligibility and asset policies for the Vermont Medicaid for Working Persons with Disabilities Program (MWPD) that have been approved by the federal government.

One change raises the assets you are allowed to

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have and still be eligible for Medicaid, to $10,000 for individuals and to $15,000 for couples. This is an important victory, allowing individuals and families to return to work and protect savings they may need for disability or family expenses. Other proposed changes allow the state to disregard spousal income while determining eligibility of the MWPD spouse for the program and to disregard “retirement” Social Security after conversion from SSDI. These new rules are expected to be in place by January, 2018.

In July Sam was in Washington, D.C. for the annual meeting of the National Council on Independent Living, where he was voted in as the cochairperson of the Employment/Social Security Subcommittee, and where he and others gave a workshop, “Aging with a Disability: Maintaining Financial Well-being.” He notes, “Of course, while we were gathered at the conference, the overriding issue was health care coverage and how pending legislation would affect people with disabilities. We watched the deliberations in Congress, let our voices be heard and were gratified at the results (at least, for the time being).”

Back in Vermont, Sam continues to work with other advocates and allies in state government to enhance Vermont’s work incentive policies. He knows other changes are needed here and in other states. He highlights the importance of persistence and partnerships, saying, “This last effort lasted several years, but, with the assistance of Chairman Bill Botzow, of the House Commerce and Economic Development Committee, and state administrative staff, the effort has been successful. More people with disabilities will be able to work and work to a greater extent, while retaining necessary health care coverage, including such supports as personal care assistant services. As a result, more people will become self-sufficient.”

To make that happen, Sam and others will continue to look for ways to improve employment and health policy. The stories and concerns of other Vermonters with disabilities are what drive him. He wants to use state and federal policy to create new opportunities and solutions for people with disabilities.

I asked Sam what advice he would like to share with readers of The Independent who may want to be more active in advocacy. His answer? “As a first step, I would suggest contacting an advocacy organization such as VCIL, which devotes much time to issues, such as independent living and employment (an important aspect of IL). With common goals and combined voices and efforts, we can be heard and accomplish rightful objectives. It is important to keep informed, know your subject matter and be willing to collaborate – even compromise at times, if appropriate. We need to have patience and perseverance but, working together in an organized and determined manner, our efforts could very well come to fruition.”

More Tips for Advocates

Don’t give up if you think and feel you are right.

Always have the best interests of all in mind when advocating.

And … think independence, community living and the chance for everyone to strive for a better life.

~ Sam Liss
ADA Public Access Threatened

The ADA Education and Reform Act, a bill which is now being considered by Congress, would gut an important right provided by the Americans with Disabilities Act. The ADA now requires businesses serving the public to remove architectural barriers and other obstacles to access. If H.R. 620 is passed, individuals who are denied access would have to notify the business of the specific barriers and wait for six months to see if the business will make “substantial progress” toward access before taking legal action. Disability and legal rights organizations point out that the ADA has been law for 27 years and a great deal of education and technical assistance has already been made available to help businesses understand and comply with the law. Individuals across the country are notifying their representatives in Congress to share their concerns.

New Savings Program for Vermonters with Disabilities

VermontABLE program is a new savings initiative sponsored by the Vermont Treasurer’s Office that allows eligible individuals with disabilities to save for disability expenses without losing certain public benefits, like Medicaid and Supplemental Security Income. VermontABLE accounts provide individuals with disabilities the opportunity to invest up to $14,000 per year without being removed from public benefit programs.

The ABLE Act of 2014, and related changes in state law, make this program possible in Vermont and across the country. The program began in Vermont in February. By August, 70 individuals were depositing money in their ABLE accounts, with an average account balance of $3,700.

An “eligible individual” is someone who developed their disability before the age of 26. The individual must have been living with their disability for at least one year, or they must expect their disability to last for at least a year. In addition, the individual must be eligible for SSI or Social Security Disability Insurance because of their disability, have a condition that is included on the Social Security Administration’s List of Compassionate Allowances Conditions, or be able to “self-certify” their disability and diagnosis. More information on eligibility, setting up your own account, and on how funds can be used, are provided on the program’s website, https://www.vermontable.com. The enrollment process is explained carefully and happens through a secure web portal.

Recently Gov. Phil Scott said, “We all need to save for future needs, but until now, some disability benefits were structured in a way that actually discouraged people living with disabilities from saving. By giving Vermonters with disabilities and their families new tools to invest, we can provide a framework for more of our neighbors to prepare for the future.”

A range of saving plans are available to eligible Vermonters with user-friendly functionality to allow online electronic funds transfers, easy withdrawals, and a loadable debit card. For more information and for instructions on how to sign up for a VermontABLE account, please visit VermontABLE.com.

Medicaid and Exchange Advisory Board Seeking New Members

Interested in stepping up and explaining why, for example, things like access to assistive technology and other disability and health services are important? Then consider applying to join the Medicaid and Exchange Advisory Board. MEAB was created to advise and inform the Department of Vermont Health Access on policy development and program administration for the state’s Medicaid-funded programs and Vermont Health Connect.

The MEAB is made up of stakeholders who represent a variety of groups, including consumers, businesses and health care providers. These individuals were appointed by the commissioner of the Department of Vermont Health Access and will serve staggered, three-year terms. If you are interested in more information about the MEAB or would like to be considered for a future appointment, please

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contact DVHA Commissioner Cory Gustafson at 802-241-0239 or Molly Waldstein at 802-233-2572.

Health Care Rights and Services in Jeopardy

Republicans and Democrats are working on national legislation to preserve the Affordable Care Act but it may be difficult for members of both parties to come to agreement. What is decided in Washington will have a significant effect on program policies and state budgets. For example, many Republicans in Congress want to convert to Medicaid block grants and waivers that allow the federal government and states to significantly reduce funding for Medicaid, change who is eligible for Medicaid, or cut essential and optional benefits, including disability-related services for children and adults. These are some of the same proposals that brought people out marching for health care this summer. Our congressional delegation, VCIL, VCDR and many other state and national organizations are collecting Medicaid stories, to help save important Medicaid services and the protections established in the Affordable Care Act. Concerned? Sign up for VCDR action alerts (email vcdrvt@gmail.com) and contact our congressional delegation about what is happening in Washington. Our voices matter!

Something to Cheer About: Community Integration

On the positive side, H.R.247, the Disability Integration Act of 2017, has been introduced in Congress and now has 45 sponsors. The bill prohibits states or local governments that provide institutional services for individuals with disabilities who need long-term assistance with daily living activities or health-related tasks, from denying community-based services that would enable such individuals to live in the community and lead an independent life. If passed, states, local governments or insurance providers may not discriminate against such individuals in the provision of community-based services by: (1) imposing prohibited eligibility criteria, cost caps, waiting lists, or payment structures; (2) failing to provide a specific community-based service; or (3) requiring an individual to receive a service in a congregate or disability-specific setting. A detailed text and audio summary of the bill can be found at Congress.gov: https://www.congress.gov/bill/115th-congress/house-bill/2472.

2018 Disability Advocacy Internship in D.C. — Deadline Nov. 6, 2017

Since 2002, the AAPD Summer Internship Program has developed the next generation of leaders with disabilities by connecting disability advocates with internships in government offices and disability programs. AAPD places college students, graduate students, law students and recent graduates with all types of disabilities in summer internships with congressional offices, federal agencies, nonprofits and for-profit organizations in the Washington, D.C. area. Each intern is matched with a mentor who will assist them with their career goals. AAPD provides the interns with a living stipend, transportation to and from Washington, D.C., and fully accessible housing. For more information, or to apply, go to http://www.aapd.com/summer-internship-program/

Looking for Accessible Hotels and Holiday Rentals?

Accomable was founded in 2015 by two friends with spinal muscular atrophy who travelled all over the world. Frustrated by the difficulty of finding accessible places to stay and reliable information, they launched Accomable to make it easier for everyone to travel, regardless of disability. They now have more than 1,100 listings in over 60 countries, all of which have step-free access, high-quality photos and detailed information on a whole range of accessibility adaptations. For more information, visit their website: https://accomable.com/
COVE’s Legislative Update

by David Mickenberg

Choices for Care: CFC is Vermont’s long-term care (LTC) program for low- to moderate-income older persons and adults with disabilities. It provides for both nursing home and home-and community-based care and has been very successful in giving Vermonters a choice as to where to receive services and in saving the state significant dollars.

Prior to July 1, there was some serious question about whether the administration would implement the 2 percent increase for the Choices for Care program. Ultimately the rescissions that occurred came from other pockets and the 2 percent increase was implemented.

Recently state officials issued their CFC savings update to the Legislature in which they found there were no savings generated from CFC. They did say that the money left in the program would be reserved for the 1 percent mandated reserve to be used for unintended pressure in the high and highest needs programs. COVE will have further discussions with the administration about how they calculated “savings.”

Low Income Home Energy Assistance Program: The federal LIHEAP provides assistance paying for home heating for people of all ages, including many older citizens whose household income does not exceed 185 percent of the federal poverty level.

The administration is set to present the status of LIHEAP at the Sept. 14 Joint Fiscal Committee meeting. COVE will continue to advocate for keeping recipients at the same or increased purchasing power as they were in previous years, but much of that is dependent upon the price of fuel and upcoming action on the federal budget for LIHEAP.

Lifeline Act 41: After Act 41 went into effect, the administration was tasked with developing an implementation plan to encourage people to enroll in the Lifeline program, in particular to enroll through other governmental benefits such as SNAP (3SquaresVT) and the Section 8 housing program. The goal for this outreach is to ensure that older Vermonters are receiving all of the benefits to which they are entitled and are able to access them conveniently and consistently. COVE will continue to work with the administration to make sure this implementation is successful.

Family Leave, H.196: COVE supported the coalition working to establish a paid family leave program in Vermont. This important legislation would allow Vermonters to take paid time off from work to care for family members (including grandparents and grandchildren) experiencing an extended illness. H.196 received serious changes during consideration by the House Ways and Means Committee, including reduced payments into the system and reduced benefits for people receiving family leave. It passed the House.

Consumer Protection, S.136: COVE and its partners supported a variety of consumer protection measures designed to protect Vermonters, particularly older Vermonters, who are taken advantage of by unscrupulous businesses. Many of those provisions were included in S.136, the consumer protection bill. This included provisions about debt collection; escrow protections; and other consumer friendly initiatives. During the conference committee process, many of these provisions were stripped out of the bill to give House members more time for consideration next session.

Editor’s Note: For a complete COVE update, and links to additional reports and information, go to www.vermontelders.org or call 802-229-4731.
This is a time of important change and new activities for VCDR and our members. We continue to do our legislative and policy work but we are also reaching out to involve more people in cross-disability advocacy. This update provides a little information on our work during the last legislation but also invites Independent readers to join our work.

Growing Grassroots — A Time for Sharing our Stories

With the help of a grant from the Vermont Developmental Disabilities Council, VCDR is building a grass-roots campaign to involve more Vermonters who experience a physical, sensory, psychiatric, developmental or other disability, and their families, in our work. We are also reaching out for new organizational members and other allies, individuals and organizations who share our commitment to protect rights and services that make self-determination and community participation possible for all Vermonters.

In the next several months VCDR’s website and email alerts will offer new ways to learn about and share disability rights news, involve people across the state in disability advocacy, and share the stories and concerns of Vermonters with disabilities. Individuals, families and allies from all over the state are invited to help shape disability advocacy in Vermont. Disability rights needs all of our voices. Look for our new website and story bank in the year ahead and email or write us if you want to join our advocacy alert network. This is a time when your voice — when all of our voices — are needed and can make a difference.

2017 Legislative Updates

VCDR and the disability community developed our legislative platform, proposed legislation and participated in both budget and policy discussions throughout the legislative session, with success in advancing our disability issues. This is a partial listing of bills and budget issues we worked on. (A more detailed summary of VCDR activities and legislative priorities during the last legislative session is available from VCDR, by emailing us at vcdrvt@gmail.com. It includes links to legislation, summaries of bills and budget and policy reports submitted to the Legislature.)

Mental Health

Bills passed include passage of S.61 (Act 78), which is intended to improve the treatment of individuals with mental health conditions in prisons; H.145 (Act 45), establishing a mental health crisis commission within the office of the Attorney General; and S.133 (Act 82), which requires an examination of Vermont’s mental health care and care coordination. Another bill, S.90, addressing the coordination of Vermont’s response to adverse childhood and family experience has been introduced in the Senate Health and Welfare Committee.

Education

S.130 passed in the Senate. It would address several educational issues. One is of particular concern to VCDR. The bill creates a study committee to look at the eligibility criteria used by independent schools and their responsibilities for providing special education services, and what programmatic and fiscal information on special education that these schools should submit to the State Board or Agency of Education.

Budget Items

H.518, an act relating to making appropriations for the support of government, was vetoed by the governor on June 6, 2017. This bill would have been the fiscal year 2018 budget bill. The governor’s veto was sustained on June 21, and a new budget was passed. The $5 million called for in administrative savings, and the $12.5 million deficit that the ad-
administration had to make up in the August rescissions did not result in any reduction of direct human services.

The Mental Health and Developmental Disability Services budget provides $8.37 million to increase salaries for designated agencies for workers as part of a multiyear stabilization funding plan ($5.9 million for mental health and $2.5 million for DAIL developmental services); it includes investments for crisis services to reduce pressure and cost in the health care system by prioritizing crisis service staff salaries; increasing hours of operation of peer-to-peer “warm” phone line through Pathways for Housing. It also keeps a promise to maintain the FY 2018 rollout of 2 percent increases to designated agencies and other providers that began September 2016.

In other areas of the budget, funding that was restored or added to the final budget bill includes increasing the Reach Up asset limit from $2,000 to $9,000, restored funding for Vermont Legal Aid and the Health Care Advocates office, eliminating a proposed cut to the Cold Weather Exemption program and adding new funding for two new shelters in the Barre/Montpelier area and Rutland, and increases to the Housing and Conservation Board.

Programs that VCDR advocated for but that did not receive new or increased funding in the budget include VCIL’s Home Access Program, the Vermont Association of the Blind and Visually Impaired, Children’s Integrated Services, the Division of Vocational Rehabilitation and the Vermont Traumatic Brain Injury Project.

VCDR will be posting updates on state and national legislation and policy though our Action Alert Network and website. The uncertain budget forecasts from Congress and the president means that no one is certain what federal revenue will be available to help fund services and rights protection in states. VCDR members and allies will stay in touch with state agencies and legislators, to advocate fiscal and policy decisions that will serve all Vermonters, including individuals with disabilities and their families. VCDR will be developing our 2018 legislative and advocacy priorities in November. We hope you will join our Action Alert Network and become part of our advocacy in the year ahead!

DISABILITY AWARENESS DAY 2017
“Break Barriers; Build Bridges”

The annual Disability Awareness Day took place on March 2, 2017 at the Vermont Statehouse in Montpelier. Together with their families and allies, Vermonters with disabilities made Disability Awareness Day a great success once again this year. Over 366 people participated in the day’s activities, including those with disabilities, family members, advocates, members of the administration and many allies. Numerous distinct organizations were represented and people had the opportunity to interact with legislators and take part in legislative proceedings and events arranged at the Statehouse for the day.

The day began with meetings with the governor and representatives from Vermont’s congressional offices, followed by visits with legislators, a press conference, morning and afternoon workshops and testimony in committees. The 2017 graduates of the Vermont Leadership Series celebrated the completion of their leadership studies under the Golden Dome. The finale was an evening social gathering with food, music, keynote speaker Stephanie Woodward and a panel discussion with the Speaker of the House and the Majority leader of the Senate participating.

Disability Awareness Day — like so many of our activities — was supported by a grant from the Vermont Developmental Disabilities Council. Their support, the interest and participation of our legislators, and the hard work of VCDR member organizations, associate members and partners, including the Vermont Statewide Independent Living Council and the Center on Disability & Community Inclusion, made the day a success. Our thanks and appreciation to everyone!

Federal Decisions Shape State Realities

What happens in Washington, D.C., has a powerful impact on rights and services in every state. Proposed federal changes have many people wondering whether important programs, rights, and services will be available in the future. States like Vermont, which have always made good use of federal funds for important disability and long-term care services, will find it hard to preserve these

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DISABILITY RIGHTS VERMONT ANNOUNCES FY18 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 fourteen-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 publishing the priorities to be approved by our Board for the current fiscal year (October 1, 2017 – September 30, 2018.) We would welcome your thoughts about how our unique system can best serve people with disabilities and mental health issues. DRVT is publishing our formal priorities for the Protection & Advocacy for Individuals with Mental Illness (PAIMI) program, a draft for the Protection & Advocacy for Developmental Disabilities (PADD) and the Protection & Advocacy for Individual Rights (PAIR) programs below. 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: jen@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 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.

2018 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 www.disabilityrightsvt.org/Programs 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 wants only the best for people with disabilities and their family members, but we can’t do it without you. The Council encourages you to get out there and...

- **ADVOCATE** by becoming a leader to those in your community and state wide.

- **CHANGE** by educating officials and legislatures about how things affect you.

- **JOIN** the powerful self-advocacy movement and say, “Nothing about us, without us.”

The VERMONT DEVELOPMENTAL DISABILITIES COUNCIL is state-wide board and a part of a national network that was founded by the Developmental Disabilities Assistance and Bill of Rights Act. To have the greatest positive impact statewide, Council members use their real-life experiences 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 [http://ddc.vermont.gov/](http://ddc.vermont.gov/) or contact the Council by phone (802) 828-1310 or email vtddc@vermont.gov
The Independent Autumn 2017

BETH PEARCE Vermont State Treasurer

FOR VERMONTERS WITH DISABILITIES

VermontABLE is a savings program sponsored by the Vermont State Treasurer’s Office. It allows someone with a disability to save and invest without losing certain public benefits, like Medicaid and SSI.

You can open an account with flexible investment options and tax-free earnings. It’s as easy as 1, 2, 3.

1. FIND OUT IF YOU’RE ELIGIBLE by taking a short quiz on the website.
2. CREATE A STABLE ACCOUNT and invest as much as $14,000 a year.
3. SAVE, INVEST, AND SPEND to pay for disability-related expenses.

Account holders can access their funds with own STABLE card.

Contact VermontABLE to learn more by web: www.VermontABLE.com
phone: 1-800-439-1653 or email: team@stableaccount.com

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essential programs while also dealing with severe cuts to other social service and disability programs. The voices and stories of many people with disabilities and their families will be critically important in the continuing national and state debate.

A vote on the federal budget is not expected soon, but a broad range of programs are in jeopardy. Education, health care, mental health and many disability and poverty programs important to Vermonters all face possible federal budget reductions or policy changes. New proposals to cut protections in the Affordable Care Act are being considered again and include significantly reducing Medicaid expansion funds to states. Budget proposals also make Medicaid a block grant program, with much less funding and far fewer eligibility and service protections than those in Medicaid today. For all these reasons, Vermonters need to be sharing their stories about the programs and services that make a real difference.

VCDR wants your story to be heard. For more information, or to join our Action Alert Network, contact us at vcdrvt@gmail.com.

~ Deborah Lisi-Baker

March, and you begin to see
the bare sides of hills surrounded by snow.
The snow is old, crusted;
only one storm in two weeks, and for the rest
this large stillness
broken only by the wind’s occasional calling.
Nothing is still at work. We are trying to cut through
the paperwork and the uneasiness we have
with the numerous tasks and with our itchy unending intent
to change the universe.
I came home to watch March come in
and think of my friend sitting in his wheelchair
unable to get in bed for lack of a spare pair of hands.
The hands he needs are displayed on the glossy pages of magazines,
sporting manicures and a variety of merchandise of all sizes and colors;
they’re the hands of the athlete reaching for the basketball,
and the hands of workers paid 7.50 and benefits for flipping burgers and
stuffing pockets of fries into waxed paper bags;
Any one of these pairs of hands
would be a way to bed
for one friend without attendant care.
I set up my son’s soldiers to march into the magazines
and across the stadiums of my TV into the Medicaid office,
into the legislature, into the Governor’s living room;
to lay down arms and ask for hands.

~ Deborah Lisi-Baker
Lead On!

Nicole LeBlanc, Ash Brittenham and Stephanie Woodward were among the thousands of Americans who marched for health care and disability services this summer. (Some of you will remember Stephanie as the keynote speaker at this year’s Disability Awareness Day.) Our thanks for their voices and leadership, and our thanks to all who are using their voices, their experiences and their lives to protect disability and health services provided by Medicaid and the Affordable Care Act, as well as rights established under disability and civil rights laws. As Justin Dart, father of the ADA, said during earlier disability rights and social justice campaigns, “Lead on!”

Former Vermonter Nicole LeBlanc, a self-advocate, attends a march and rally to the Capitol during the National Council on Independent Living Annual Conference on July 25.

On June 22, Stephanie Woodward of ADAPT protests cuts to Medicaid.

Ash Brittenham, center, at an action in Portland, Maine, on June 28. Also pictured, from left, are Zoe Lasden-Lyman (Ash’s PCA), Kim (Brittenham Ash’s mother) and Isa Rhynfield (Ash’s cousin).
In late June, scrolling through my social media, I started to see posts and pictures of ADAPT activists sitting in at Senate Majority Leader McConnell’s office in Washington, D.C. Many of the activists are people I look up to and got to meet when I went to the 25th ADA anniversary march and rally two years ago. A video was circulating of ADAPT leader Stephanie Woodward being carried out of her chair by police down the hallway shouting “no cuts to Medicaid!” Among the people I also recognized were Kings Floyd, Bruce Darling and Clifton Perez. I watched Rachel Maddow cover the “die-in” action and how people with disabilities have saved this country before.

I was happy to see my friends defending the Affordable Care Act, and I wanted to do so as well. So when Sarah Launderville of VCIL texted me that an action in Maine was being planned, of course I had to say yes.

On Wednesday, June 28, I joined 50-plus activists and advocates at a park across the street from the office of Sen. Susan Collins, R-Maine, to show approval for her announcement to vote against repealing and replacing the Affordable Care Act (Obamacare). People held signs that said “Healthcare Not Wealthcare,” “Life or Death: Don’t Cut Medicaid” and “You Can’t Get Rich Off the Backs of Dead People.” After passing around the megaphone for sharing statements about the importance of national health care and Medicaid, our group crossed the street to meet with Sen. Collins’ staff. We lined the office hallway waiting to be let into the reception area. We left messages of thanks for the senator’s support and encouraged her to keep her word and vote no. The staff gave us sincere confirmation that indeed no was final and that she cared about our issues. Nobody was arrested, much to the chagrin of some of the more rambunctious activists. I had pondered the possibility myself, but was satisfied with the outcome.

In July the Senate finally brought its “repeal and replace” to a vote in a sketchy middle of the night session with activists outside the building screaming all the while, “Kill the Bill; Don’t Kill Us.” Collins kept her word and voted no alongside seven other Republican senators. You can thank the senators, but I think the real heroes are the activists and ADAPT.

The Portland Free Press published a photo in June of me and my brother with my sign, “If I’m Dead Who Will Inspire You?” I’d wanted to be a part of an ADAPT action for some time, and I was happy when this photo was shared across the country by other activists. While this activism was a pretty great way to spend a summer, I know I will continue to ADAPT & RESIST all year long.

ADAPT is a national grass-roots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom. Vermont has its own chapter: Green Mountain ADAPT. If you would like more information, please contact Ericka at Ericka@vcil.org
SAVE THE DATE!
Disability Awareness Day
will be
Feb. 28, 2018, at the State House

Kudos!
During the last year, the Vermont Department of Disabilities, Aging and Independent Living received two prestigious awards for disability initiatives. In February, DAIL staff and community partners traveled to Vienna, where they received the international Zero Project Award for early leadership and innovation in supportive employment. In August, DAIL was awarded the first-ever Pacesetter prize from the Scan Foundation for improvements in long-term services and supports. The award highlights Vermont’s innovative practices and improvements in providing accessible and affordable health and long-term services and supports.

Call to Artists
VSA Vermont and the Flynn Center for the Performing Arts invite established and emerging Vermont artists to participate in FLOURISH, an exhibition showcasing works of art by Vermont artists with various disabilities. The exhibition is to be held at the Amy E. Tarrant Gallery at the Flynn Center for the Performing Arts, April 7 – June 30, 2018.

Submissions must be postmarked or emailed on or before Sept. 29. To request a paper or large print format of the complete application and instructions, contact VSA Vermont or visit their website, http://www.vsavt.org/flourish/

Artists who cannot provide digital photographs of their artwork can attend a sessions where photographers will be available to take digital images of artwork. These will be Sept. 18, from 3:30 to 6 p.m. at the Brooks Memorial Library in Brattleboro and Sept. 19, from 3:30 to 7:30 p.m. at the Generator in Burlington.

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