Celebrating Friends and Partners

As we were working on this issue of The Independent, I realized, with some surprise, that VCIL will be 40 years old in about two years. The Independent is not quite as old as VCIL, but it too has been around for a long time and made a lot of friends along the way. In this issue, we celebrate friends and the partnerships that make needed change possible. We thank a few of the many advocates who have helped make this change. And, as we begin this issue, we ask that we all pause and take a moment to celebrate those who have worked with us and those who will be doing so in the future. Let’s take the brightness of these partnerships with us as we prepare for the national election, a new year and a new legislative session.

In these pages, we share the work of Vermont’s Wellness Workforce Coalition, stories from VCIL, updates on COVE’s and VCDR’s legislative activities and news from Disability Rights Vermont and the Vermont Developmental Disabilities Council. Finally, we share information on voting in Vermont. We hope you enjoy this issue and we look forward to your letters and stories.

To our readers and partners — old and new — our thanks.

~ Deborah Lisi-Baker, Editor

VCIL staff members Peter Johnke and Linda Meleady chat at this year’s Disability Awareness Day.
To Our Readers

As we prepare for a new year and lots of political changes, we wanted to take a moment to thank you for your interest in and support for The Independent. Budget constraints have reduced the times we can publish this paper, but we always look forward to reaching out to all of you who read these pages and support our work. A year of political campaigning is a great reminder of how important it is to provide news as accurately as possible and to take seriously our responsibility to provide accurate information on policies and programs. We close this letter with heartfelt thanks to those who contribute information and financial support to this paper. We really wouldn’t be here without you!

We wish each of you all the best in the year ahead.

Deborah Lisi-Baker and Stefanie Monte, Editors

Take Your Passion for Disability Rights to the Polls

The disability vote is big news this election. A recent Rutgers University study on voting found that:

• A projected 35.4 million people with disabilities will be eligible to vote in the November 2016 elections, representing close to one-sixth of the total electorate.
• There will be 62.7 million eligible voters who either have a disability or have a household member with a disability, more than one-fourth of the total electorate.

Individuals with disabilities and their families have a lot of reasons to vote this election. Let the candidate of your choice know that it is time to end the high unemployment and poverty rates among Americans with disabilities. Tell them it is past time to support the policies and programs that create equal opportunity.

Never voted before? The information on page 8 of this issue lists the ways to vote in Vermont. Let Americans and Vermonters know that disability rights and our right to vote matter!

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Make checks payable to The Vermont Center for Independent Living and write “for The Independent” on the check. Audio copies available upon request.
At a hearing about 15 years ago, I spoke about the cost of prescription medication. I took those comments to the hearing at the Vermont State House because at VCIL we were hearing from people with disabilities who were choosing between food and paying for their prescription medications.

It was one of my first public advocacy moments, and I was nervous speaking the truth to the politicians. But I felt empowered at the end of the hearing, that change was in the air and that people with disabilities, advocates and lawmakers were coming together to tackle this very real problem. There was a sense of how could we as a society possibly ignore the fact that elders and people with disabilities in Vermont were choosing to eat versus taking needed medications? Solutions varied between crossing the border into Canada, stronger programs to alleviate the costs and legislation forcing the hand of large pharmaceutical companies.

But there is a problem with that day and the 5,400 days after it. There is a real disconnect about how we as a society work toward a common good and the severe reality of the power of capitalism. The sharp divide comes at the expense of people with disabilities who depend on prescription medications to live.

Heather Bresch is the CEO of Mylan Pharmaceuticals. Over the past month she has been defending to Congress and the press the increase the company chose to make to the EpiPen prescription costs. Her annual $18 million pay package was something she also defended, but as Medicare recipients saw an increase in out-of-pocket expenses and the Medicare program saw an even larger increase (from $71 to $344 per prescription between 2007 and 2014), the general public became much less sympathetic to the rising costs, and so are we. This product is essential to our brothers and sisters with disabilities, and sometimes could be the difference between someone living and dying after a severe allergic reaction.

Hearing a person say that they need to choose between food and medication has become a statement to which many have become complacent. The first time I said it in that hearing 15 years ago, I broke down crying. I remember Morgan Brown coming up to me after and helping me process the event. Today, everyone says it like it is a commonplace thing. That has got to change. I commend the actions of policymakers, including the Vermont delegation and Sen. Elizabeth Warren, who questioned and probed Heather Bresch about various concerns.

VCIL signed on as a supporter of the Healthcare is a Human Right Campaign organized by the Vermont Workers’ Center. The campaign principles include universality, equity, accountability, transparency and participation. I think of these principles as I imagine a world where someone experiencing extreme pain can access the medications they need. Or someone in the middle of an allergic reaction to shellfish can have access to a common medication that, because of the increase from large pharmaceutical companies, is now more out of reach for so many Vermonters. I imagine a world where family members no longer have to feel terror that a loved one may die because of the corporate greed allowed in our country.

We call for action and accountability for Vermonters with disabilities to ensure that we have access to affordable prescriptions. Our lives depend on these medications; they are not something that we are able to go without. When we do not have access to needed medications, it affects our ability to work, to parent, participate in our community and to live. This cannot go on any longer and we need to organize and make change happen now! We need to join in partnership with our policymakers who have made this issue a priority and stand against corporate greed that allows for the price gouging to continue.
USDA Honors Peer Advocate Counselor Coordinator

The Vermont Center for Independent Living already knew that it had a gem in peer advocate counselor coordinator Tyler Sweeten, but on Sept. 6 it got more evidence of this fact.

Sweeten, a Barre resident, was honored by the USDA with their prestigious Gold Star Partner Award. Sweeten, who has firsthand experience living with a disability, works tirelessly to ensure that peers can maintain their homes and continue to live independently within their communities. She has worked at VCIL since April of 2014.

She was drawn to her position at VCIL because she wanted to work with people in a peer-based setting — empowering people with disabilities, encouraging them and helping them live the life that they want to.

Ted Brady, USDA Rural Development Vermont and New Hampshire State Director, presented the award. He noted that USDA Rural Development has long given out Gold Star awards internally, but in recent years, staff members started nominating people outside the organization. Still, the awards are not handed out often. Brady noted that he has only seen two or three of them given out in the past three years.

“I like to think they are a thing of honor and they’re also very organic,” he said.

Dianne Drown, a rural housing specialist in USDA Rural Development’s St. Johnsbury office, nominated Sweeten for the award. VCIL has been leading Rural Development’s two-state jurisdiction in helping people access the Section 504 loan and grant program. 504 helps low-income homeowners who are unable to finance necessary repairs through other sources.

“We don’t use the program much in Vermont or New Hampshire except if you’re referred to the program by VCIL.” Brady went on to praise Tyler for directly helping the people of Vermont.

Tyler Sweeten of the Vermont Center for Independent Living was honored at a press conference on Sept. 6. From left are Gus Seelig, executive director of the Vermont Housing & Conservation Board, Sweeten, Ted Brady, USDA Rural Development Vermont and New Hampshire state director, and VCIL Executive Director Sarah Launderville.

“I’ve never been nominated for anything. This is awesome,” said Sweeten. She expressed gratitude for getting to help people she meets and for the people she works with at partner organizations. “You guys are all rock stars. This is just a testament to all of the awesome work that we do.”

VCIL Executive Director Sarah Launderville said, “We are all so proud of Tyler and the work she does to help people live independently. We could not think of a better recipient for this award.”

In other happy news, before honoring Sweeten at the press conference, USDA described over $300,000 in grant funding going to nonprofits in Vermont and New Hampshire to help homeowners preserve their homes. The money includes $26,021 for VCIL to support accessibility modifications and home repairs for Vermonters with physical disabilities.
Trip to NCIL Conference a Powerful Experience

by Michelle Grubb

EDITOR’S NOTE: Every year, VCIL Executive Director Sarah Launderville makes the trek to Washington, D.C. for the National Council on Independent Living Annual Conference. This year, she was delighted to have two other staff members also attend the conference: Finance and Operations Officer Michelle Grubb and Patricia Tedesco, Home Access Program & Sue Williams Freedom Fund coordinator. Michelle recently shared her thoughts and impressions about attending her first-ever NCIL conference.

I happily accepted the opportunity to go to this year’s NCIL Conference in Washington, D.C. and then all sorts of questions started swirling through my head. What would it be like to be part of a civil rights march to Capitol Hill? How would it feel to be part of a gathering of over 700 people in the disability rights movement from all over the country? Looking back, I can say that it was an amazing and powerful experience that I hope everyone gets to be a part of at some point in their lives.

This year’s theme was “Solidarity: Everybody In.” Conference leaders did a wonderful job of weaving “everybody in” by bringing discussion on the commonalities regarding the “fight for rights” among the disability, race and LGBTQ communities and why we should support each other. There was representation from the international community, most notably a group from Japan. We all mourned the loss of our Japanese brothers and sisters in Japan who were brutally murdered while we were at the conference that week. There were people from all over the country who shared their stories, insights and energy.

It was wonderful to see VCIL leader Sarah Launderville’s role on the national stage. She gave a powerful speech in front of Capitol Hill. One of my highlights was seeing her advocate at the Vermont congressional delegation offices for Peter Welch, Patrick Leahy and Bernie Sanders. The top three legislative priorities were as follows:

1. Disability Integration Act in which people with disabilities would have a federally protected right to their choice of housing, services and supports.

2. Stopping the ADA notification bills which would add extended notification periods 120-plus days and barriers to filing complaints under the ADA.

3. Thanking the Vermont delegation for approving an increase in funding for Centers of Independent Living for this coming year but asking them to consider funding the $200 million additional funding for next year, including CareerACCESS pilot program.

The experience that was most powerful for me was the march. It was hot and humid. It was grueling. It was loud. It was raw. It is necessary. It is empowering. It is the way we are seen and heard. It is “Solidarity: Everybody In.”
Vermonter Rocks at the Rio Paralympic Games

by Stefanie Monte

Alicia Dana of Putney did Vermont and her country proud at the 2016 Rio Paralympic Games. The former peer advocate counselor at the Vermont Center for Independent Living took home a medal.

The 47-year-old handcyclist won silver on Sept. 14 in the time trial H1-2-3. She was about 13 seconds behind the gold medalist and was the only American in the race, which featured 11 competitors.

Patrick Standen, president and founder of the Northeast Disabled Athletic Association, said, “The importance of Alicia’s silver is of historic significance for the state of Vermont. She is the first Vermonter to win a medal at the Paralympics and one of just a handful of Vermonters to capture a medal at the Olympic or international level.”

He added, “She is an excellent role model for athletes with disabilities, single moms and, indeed, for all Vermonters. The folks at the Northeast Disabled Athletic Association are especially proud because she is a past NDAA micro-grant recipient and a participant in several of our programs. We couldn’t be more excited!”

Dana has had a lifelong love for sports. In her teens, she competed at the national level in both cycling and cross-country skiing as an able-bodied athlete. Then in the late 1980s, she fell from a tree and was left paralyzed below the waist. At that time, as Dana recently mentioned to Vermont Public Radio, “handcycles were not even invented yet. So I spent a little time doing some wheelchair racing, marathons and that sort of thing, which was OK; I enjoyed it somewhat. But when handcycles came along in the mid-’90s and I got my first one, there was no looking back. It just felt great. It felt like being me again, like a part of me that had come back together again.”

She began her handcycling racing career in 2001 and competed at the national level before getting married and having a daughter, Willa. She took some time off to focus on Willa and then returned to racing in 2011.

Dana told VCIL, “My daughter Willa is the most important thing in my life. Becoming an elite athlete has helped me to be a better mother, too. I have more endurance, I have to take care of myself better and learning to push myself to achieve goals helps me know better how to help her with the same.”

The VCIL Connection

Dana worked at VCIL for a couple of years in the early 2000s. Deborah Lisi-Baker, who was executive director of VCIL at the time, said, “When I think of Alicia, I think of grace and determination. And look where these qualities have gotten her!”

For Dana’s part, while she wholeheartedly believes in the values of independent living, she found that she didn’t particularly enjoy having a desk job and felt that, in her role as a peer advocate counselor, she didn’t excel at trying to help others become
more independent. Her dreams took her in a different direction.

She said, “Ironically, focusing on myself and becoming stronger physically and mentally through athletic training and competition has greatly increased my own independence... Becoming part of the greater Paralympic movement, learning what that is, locating myself within it, having regular contact with other healthy, active, independent and often socially active people with disabilities has allowed me to more fully live and embody the values of independent living, just in a context where I can also stretch my own physical and mental limits.”

Check out VPR’s story about Alicia here: http://digital.vpr.net/post/putney-handcyclist-alicia-dana-compete-rio-paralympics-week#stream/0.

Say No to H.R. 3765

The ADA Education and Reform Act of 2016 is a national bill that rolls back the Americans with Disabilities Act. H.R. 3765 puts the responsibility of accessibility on the person with a disability, stating that a civil action may not move forward unless the “person has provided to the owner or operator of the accommodation a written notice specific enough to allow such owner or operator to identify the barrier.” It goes on to say the owner has 60 days after receiving the notice to respond in writing to the notice. It then allows the owner another 120 days to fix the access issue or “make substantial progress.”

The ADA was signed into law 26 years ago. This law is a stall tactic to businesses and will remove incentives for a business to be in compliance of the ADA. Please contact our congressional delegation and ask them to vote no to ensure the civil rights of people with disabilities is protected. Although the bill is not expected to come up for a vote until after the general election, it is important to contact lawmakers now! Also, consider joining advocacy efforts on Facebook by joining the page “Oppose the ADA Education Reform Act of 2016.”

Pass the Disability Integration Act!

The Disability Integration Act is a federal bill in Congress with four major components:

1. Public entities and insurance providers that pay for long-term supports and services (LTSS) cannot discriminate against people with disabilities when providing home and community-based services (HCBS).

2. Public entities and insurance providers that pay for LTSS must establish adequate payment structures for HCBS services.

3. Public entities and insurance providers that pay for LTSS must inform people with disabilities of their right to receive services and supports in the community.

4. Public entities must increase affordable and accessible housing options.

Vermont’s own Sen. Leahy and Sen. Sanders have signed on to cosponsor this important legislation. Major advocacy is needed to help this bill pass Congress. If you are interested in advocating in support of the bill, please check out the DIA website: www.disabilityintegrationact.org or contact VCIL at 1-800-639-1522.

PHOTO BY LINDA J. MELEADY

DINING FOR ALL — From left are Mary Alice Proffitt, Rosemary Miller, center, and Sarah Launderville. Read more on page 19.
Your Vote Is Your Voice!

Americans with disabilities are among those Americans least likely to vote. Misinformation, lack of transportation and personal assistance, as well as inaccessible voting places and services, all limit the voting participation of citizens with disabilities. Disability rights laws are changing things for the better but change is slow. Individuals with developmental and mental health conditions are still often told they do not have the right to vote. (Not true!) It has also taken a lot of legislative and local advocacy to increase the accessibility of polling places and voting equipment—a struggle that is still under way. State and federal initiatives and local action help make more voting places and equipment accessible and more citizens with disabilities understand and use their voting rights and choices.

Happily for folks in the Green Mountain State, Disability Rights Vermont is committed to making sure that people with disabilities get the information they need to vote and are not discriminated against when casting their ballots. The organization receives money from the Help America Vote Act of 2002 to help achieve these goals. DRVT has put out a Voter’s Guide for People with Disabilities that provides information about your rights as a voter and information about the people running for national and statewide offices this year. To obtain a copy of the guide, e-mail DRVT at info@disabilityrightsvt.org, call 1-800-834-7890 or access it online: [http://www.disabilityrightsvt.org/pdfs/Publications/Voting%20Guide_2016_web.pdf](http://www.disabilityrightsvt.org/pdfs/Publications/Voting%20Guide_2016_web.pdf)

The registration deadline for the general election is Nov. 8, 2016 at 5 p.m. To register to vote, you must be a U.S. citizen; be a resident of the Vermont town where you plan to vote; take, or have previously taken, the Voter’s Oath; be 18 years or older (or will be 18 on or before the day of election. To register, you need to complete the “Application for Addition to the Checklist” (voter registration form) and make sure it is returned to the town/city clerk’s office in the town or city you live.

If you are not registered to vote and need help doing so, call VCIL at 1-800-639-1533. If you experience problems with voting, you can contact VCIL, DRVT (1-800-834-7890), the Vermont Secretary of State’s Office (1-800-639-1522) or Green Mountain Self-Advocates (1-800-564-9990).

### Dates to Remember

As Election Day Approaches

- Nov. 2: Last day to register to vote for general election. You have until 5 p.m.
- Nov. 7: Early or absentee ballot request deadline due by 5 p.m. or close of your town clerk’s office.
- Nov. 8: General election and absentee ballots are due by close of polls at 7 p.m.
Equipment Distribution Program Has New Home

The state-funded Equipment Distribution Program is now housed at the Vermont Center for Independent Living. Previously the program was housed at the Vermont Center for the Deaf and Hard of Hearing, which had to close its doors due to bankruptcy. VCIL Executive Director Sarah Launderville said, “After the closing of VCDHH, we were eager to offer our support in hosting the Vermont Equipment Distribution Program. Access to the phone is critical for people who are Deaf, Hard of Hearing and have speech disabilities.”

EDP helps income-eligible Vermonters who have trouble using a telephone and need adaptive equipment. This includes people who have physical disabilities and/or speech disabilities. To qualify, applicants must provide proof that they have a disability requiring adaptive telephone equipment to use the phone service, and income that is below the federal poverty guidelines for their household size. The VTEDP will provide up to $750 of equipment for qualified individuals. The equipment is not owned by the individual who receives it through the program but is a long-term loan.

Some 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.
• TTYs (text telephones).
• Amplified phones.
• Voice-activated equipment.

To get an application or a copy of the eligibility income guidelines, please call 1-800-639-1522 or visit http://www.vcil.org/services/vermont-equipment-distribution-program.

Struggling to Get to Needed Medical Services?

People who have Medicaid coverage have the right to Non-Emergency Medical Transportation to get to medical appointments. Like all states, Vermont must make sure that those who are on Medicaid have access to transportation, so they can receive the medical care they need. In a rural state like Vermont, access to transportation is key to getting care.

Vermont Legal Aid wants to know about people with Medicaid who have trouble getting medical care because of transportation problems. If someone you know has an NEMT problem, please send an email describing the problem to medtrans@vtlegalaid.org. Or call the Office of the Health Care Advocate at 1-800-917-7787.

Benetech Delivers 10 Million Accessible E-books

Bookshare is the world’s largest online library for people who are blind, visually impaired or have a physical disability that interferes with reading, such as dyslexia. Through its extensive collection of educational and popular titles, specialized book formats, and reading tools, Bookshare offers individuals who cannot read standard print materials the same ease of access that people without disabilities enjoy. The Bookshare library is free for all U.S. students with qualifying print disabilities. For additional information, visit Bookshare’s website at http://bit.ly/2cTqD85.

Wanted: Volunteers for VLA’s Housing Discrimination Law Project

The Housing Discrimination Law Project is seeking housing discrimination testers. Testers play the role of someone trying to rent housing. Then they report what happens to the HDLP. The program is looking for people who are part of a protected class. For example, we need people with physical disabilities, African-American men and women and people with foreign accents. We also need white men (who are not part of a protected class).

Volunteers must be age 18 or older. The time commitment is very flexible, since VLA knows that most testers have full-time jobs or have other education or service commitments.
Testers receive a cash payment and gas money for each completed test. To become a tester, you must complete a two-hour training session and a practice test. Tester training sessions will begin soon! To find out more, call 1-800-889-2047 or e-mail DAyers@vtlegalaid.org.

A Round of Applause for Three VLA Advocates

This is a time of transition and change for three Vermont Legal Aid programs. VCIL celebrates the accomplishments of three passionate advocates who are retiring after decades of dedicated advocacy.

Jackie Majoros is well-known for her work as the State Long-Term Care Ombudsman for Vermont and for earlier work as an attorney in VLA’s Senior Law Project. Jackie managed a staff of six ombudsmen and a group of highly trained volunteers, who work to protect the health, welfare and rights of more than 11,000 Vermonters who receive long-term care services in licensed facilities and in community-based settings.

A strong advocate for individuals’ rights and self-direction, Jackie helped transform Vermont’s long-term care system from a nursing home-focused model to Choices for Care, a program that gives Vermonters the option of receiving long-term care services in community-based settings. Choices for Care has served as a model for many states across the country.

In addition, Jackie has helped strengthen Vermont’s home health licensing regulations, advocated to improve adult protective services, worked to reform Vermont’s guardianship system and championed the state’s advance care planning laws.

Trinka Kerr, Vermont’s Chief Health Care Advocate, has also retired. After working as a general law staff attorney at Vermont Legal Aid for 20 years, Trinka joined and later chosen to lead the Office of Health Care Ombudsman, which has been based at VLA since it was established by the Legislature in 1998. A law enacted by the Vermont Legislature in 2013 expanded the mandate of the project, renamed it the Office of the Health Care Advocate and established the title Chief Health Care Advocate.

The director and staff members in this program help individual Vermonters, regardless of their income, resources or insurance status, resolve problems with health coverage, access to services, and eligibility for programs and subsidies. The HCA has assisted approximately 50,000 callers with access to insurance and health care services since 1999.

The HCA also acts as a voice for consumers in health care policy matters before the Vermont legislature; advocates for the public before government agencies that oversee state insurance and other health care programs; and represents the public in rate review hearings and other matters before the Green Mountain Care Board.

Thomas F. Garrett, who served as the executive director of Legal Services Law Line of Vermont (Law Line) since its formation in 1996, also retired this summer. As executive director of Law Line, Tom managed a staff of attorneys who provide free representation, pro se assistance, consultation, advice, referral and education for low-income Vermonters. Law Line is funded primarily by the Legal Services Corporation. Tom also oversaw the Vermont Volunteer Lawyers Project, a cooperative effort of the Vermont Bar Association and Law Line. It is the only state-wide pro bono legal services project in the state.

Legal Aid is in the process of hiring new directors of the State Long Term Care Ombudsman and the State’s Chief Health Care Advocate. Sam Abel-Palmer, a former staff attorney at Vermont Legal Aid and the current Vermont Law Help hotline supervisor, will serve as Law Line’s interim executive director.

VCIL thanks Jackie, Trinka and Tom for their effective advocacy on behalf of Vermonters and the work they and their staff have done to establish and protect needed rights and services. We look forward to working with their successors and others at Legal Aid in the year ahead.
Working Hard But Making Time for Play

In August, the Wellness Workforce Coalition held a peer worker celebration at Branbury State Park. It included laughter yoga, swimming, good food, good conversations and a hearty game of Pictionary. There are many groups in Vermont that provide peer support, and a listing of coalition members can be found at wwcvt.org.

Peer support means sharing the power of your lived experience with others to achieve mutual goals, assess options and discover new ways of thinking and doing. It means creating a connection between two people that does not place one in the role of the helper and the other in the role of “helpee.” When we do this, both parties benefit, and both learn from the process.

Peer supporters offer a perspective that is as powerful as it is unique. That’s because peer supporters understand that all experiences, including traumatic ones, impact how we see the world and how we respond to it. Most importantly, peer support works! It’s extremely flexible, and can used either as an alternative or in addition to clinical psychiatric and substance abuse services. And it offers hope for a journey to well-being for people while managing complex mental health and recovery pathways.

VCIL Executive Director Sarah Launderville said, “We felt it was important to take a moment and celebrate the important work of peer-to-peer workers in Vermont who are a vital part of our mental health and recovery programs.”

Over the past year the WWC has spent time working on developing Core Competencies for peer workers. The coalition defines this as “the knowledge, skills, and attitudes individuals need to possess and integrate into their work in order to successfully perform a role or job. Training, on-the-job experience, mentoring, and supervision can help individuals develop necessary competencies.”

As Vermont’s peer support workforce expands and recognition of the contributions made by peer support workers increases, there is growing interest in defining what is meant by peer support, understanding the knowledge and skills needed to perform well in this role and taking steps to fully support this workforce, thereby ensuring successful employment experiences and the continued provision of meaningful and much-needed peer support. As an important step in achieving these objectives, the Wellness Workforce Coalition established a Core Competencies Workgroup to develop core competencies for its member organizations’ funded peer support workers. The core competencies resulted from several years of discussion and effort by the WWC which included review of competencies and values from several other peer organizations and oversight bodies. While the competencies were developed for use by the WWC, any program, organization or individual is welcome to use them, whether in whole or in part. Additionally, the WWC respects the autonomy of individuals and organizations that choose not to adopt them and practice peer support in a different manner.
Vermont Coalition for Disability Rights

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 Vermont Coalition for Disability Rights developed our 2016 legislative platform from the stories and concerns of Vermonters and highlighted the range of policy and budget issues affecting individuals with disabilities and their families.

We always celebrate the leadership and commitment of members of the Legislature who have helped Vermont develop and preserve policies and programs that make independence and inclusion a way of life for Vermonters with disabilities and their families.

We remember, honor and preserve the state’s legacy of support for both disability rights and community services. [The member organizations of VCDR welcome the opportunity to work with the administration and the Legislature to ensure basic rights and equal access to responsive health care, inclusive education and essential human services, including peer support services and other disability resources.]

Vermont prides itself in being ahead of the nation in many areas of disability policy. Sadly, many of the state’s past achievements and wise investments are jeopardized by recent budget and service reductions. We look to our elected officials to show their support for Vermont’s successful disability services and for policies that offer individuals with disabilities and their families equal rights and opportunities, now and in the decades to come.

Disability is a natural part of the human experience for 20 percent of Vermonters. This reality must inform our choices in health care reform, educational policy and community services. As the state addresses difficult and important funding and policy decisions in human services, education and health care reform, let us also find ways to affirm and deepen Vermont’s commitment to preserving self-determination, equal rights and community inclusion.

VCDR Legislative Activities, Public Communications and Events

During the last legislative session VCDR member organizations, persons with disabilities, their family members and advocates from other organizations testified at public hearings and in numerous legislative committees. In addition to testimony, VCDR members met outside of committee hearings with individual House and Senate legislators on various committees about budget and policy issues of importance to the disability community.

Twenty-four individuals with developmental and other disabilities, their family members, and advocates from organizations testified a total of 46 times, at public hearings and in numerous legislative committees. In addition to testimony in committees, VCDR members met individually with House and Senate Appropriations members, House Transportation, House Human Services, House Commerce, and Senate Government Operations about the FY2016 budget adjustment and FY2017 budget items and policy legislation. VCDR members held two or more press conferences on a number of issues.

Individuals with disabilities, advocates and family members participated in VCDR meetings and other related meetings, developed disability policy, monitored legislative committees, prepared testimony, testified, contacted their legislators, held press conferences, visited the State House and attended events.

In addition to weighing in to support funding for basic needs in the budget process, the coalition
advocated removing involuntary medication as a cost savings measure in the budget, restoring the Reach Up SSI benefit reduction and other proposed cuts, supporting the rate increase for disability services providers and finding appropriate funding for the National Federation of the Blind Newsline services for the blind and visually impaired that had been discontinued. We successfully supported the establishment of the Deaf, Hard of Hearing and DeafBlind Advisory Council and the Vulnerable Adult Fatality Review Team. Progress was made in the Medicaid for Working Persons with Disabilities program, the federal ABLE Act savings plan, home modification tax credits, paid sick days and the establishment of a dental therapist profession!

How can you be a part of this? VCDR maintains an email alert list, website, Facebook page and sends out weekly legislative calendars with committee agendas of interest and legislation introduced. This keeps folks informed about the Legislature, disseminates disability-related information and helps you keep up with timely communication among members and others. To sign up to receive VCDR alerts, just send a note to info@vcdr.org with “VCDR email alert list” in the subject line.

DISABILITY AWARENESS DAY 2016

The annual event Disability Awareness Day took place on March 23, 2016 at the Vermont State House in Montpelier. Over 301 people participated in the day’s activities including those with disabilities, family members, advocates, members of the administration and many allies. Over 60 distinct organizations were represented and people had the opportunity to interact with legislators and take part in legislative proceedings and events arranged at the State House for the day. We heard from the governor, attended great workshops and even held a press conference! In the evening we gathered for food, music, keynote speeches and a panel discussion —plus a good bit of socializing!

The theme of Disability Awareness Day was “Let’s Get to Work!” focusing the day on the employment of people with disabilities. The keynote speakers were Bryon MacDonald and Justin Harford, cochairs of the National Council on Independent Living’s Employment-Social Security Subcommittee. They shared their work to bring the CareerACCESS project to fruition. CareerACCESS is a community-driven proposed program to reform the current Social Security Administration’s Supplemental Security Income Program (SSI) rules so that young adults with disabilities can work and achieve their full potential without risking losing their disability benefits.


We will hold Disability Awareness Day on Thursday, March 2, next year so PLEASE save the date and join us! Get in touch at info@vcdr.org if you’d like to help us to organize the day and choose its theme!

Disability is a natural part of the human experience and your participation is a natural way for VCDR to make progress in facilitating a better community for Vermonters with disabilities!

Each year VCDR creates a Legislative Platform. We are developing our 2017 priorities now! Learn about member organizations at www.VCDR.org and give them your ideas on the directions our advocacy should take!

VCDR thanks the Vermont Developmental Disabilities Council, VCDR members and friends for their contributions and support of our work. For more information about particular bills and other VCDR advocacy activities, contact us:

e-mail: vcdrvt@gmail.com
on the web: www.VCDR.org
COVE’s 2017 Legislative Priorities

COVE’s mission is to promote and protect a higher quality of life for Vermont’s elders, through education and advocacy. The needs, concerns, safety and well-being of elders who are economically disadvantaged, physically or mentally challenged, or geographically, or socially isolated, are a central focus of our public policy work.

COVE Top Priorities (COVE Takes a Leadership Role)
1. Development of a Legislative Elder Caucus, through collaboration with aging network partners and Legislative leaders.
2. Funding for affordable senior housing for the lowest income elders (30 percent of federal poverty level or less).
3. Adequate state funding for LIHEAP (federal fuel assistance program) to ensure that beneficiaries have at least the same level of purchasing power as they did last year.
4. Transportation:
   • Advocate for expanded Elders & People with Disabilities Transportation services.
   • Monitor DVHA’s request for proposals to put Medicaid Transportation contract out to bid to ensure that services are maintained and improved.
   • Raise awareness of the connection between the availability of transportation and the quality of life for elders.
5. Protection of vulnerable adults:
   • Work with partners to develop “Improvident Transfers” legislation that will protect elders from financial exploitation in asset or property transfers.
   • Continue to work with Adult Protective Services (APS) and other partners to strengthen the APS program.
6. Choices for Care:
   • Decrease delays in eligibility determinations by 1) funding statewide the pilot that was successful at CVCOA and NEVAAA and; 2) promoting implementation of presumptive eligibility for home and community-based services.
7. Health care reform:
   • Continue to monitor All Payer Waiver and Accountable Care Organization (ACO) evolution to make sure elders continue to receive needed services to live with dignity in their homes and their communities.
   • Support and expand independent watchdog for ACO complaints and a grievance procedure that is accessible for elders (or their caregivers).
   • Monitor efforts to control/decrease prescription drug prices.
   • Promote better access to non-generics for individuals who cannot take the generic.
   • Promote better access to durable medical equipment for Dual Eligibles (individuals who are eligible for both Medicaid and Medicare).

COVE Participates in Coalitions Addressing These Issues
1. Tax credit for home modifications.
2. Affordable oral health for all Vermonters.
3. Caregiving and workforce issues:
   • Increase minimum wage to $15/hour.
   • Develop paid family leave.
   • Develop training and certification for non-medical caregivers (something like the Stars Program for children) — accomplishing this will require a clear definition of non-medical caregivers and what qualifications they should have.
4. Creation of a state retirement savings plan.
5. Efforts to release low-risk older prisoners.
COVE Volunteers Follow These Issues and Keep Policy Committee Informed

- More roundabouts in downtowns and village centers.
- SASH continuance and expansion.
- Poverty/hunger.
- Kinship care.
- Medicare rule changes and Social Security changes that impact state policy in COVE priority areas.
- Senior center and meal site needs.

COVE’s History

The Community of Vermont Elders is a group of organizations, individual elders and young people that has existed since 1981. COVE’s mission to promote a higher quality of life for the state’s elders is advanced through advocacy and education. It works with and for elder Vermonters and the organizations that serve them to identify, interpret and respond to critical issues that impact the dignity, security and well-being of elders. COVE is a well-respected advocacy and educational organization that has represented the elder population of Vermont. Our membership has grown to consist of 40 organizations, most of which provide direct service to elders and other populations needing long-term or home and community-based care.

Other member organizations have typically been fellow advocates, educators or employers who may serve a larger constituency than the elderly. Through these members we have been able to remain informed of issues which relate to the elderly. We also have a number of individual members and a substantial group of volunteers who keep us connected to the grassroots needs of Vermont elders.

Our mission continues to focus upon advocacy and education. We have educated legislators and the public about the needs of elders. Additionally, we inform elders about how to empower themselves to achieve their needs. Much of our legislative success has been our ability to engage elders to testify on their own behalf about issues that seriously affect their well-being. Legislators know that we speak for the direct recipients of program benefits and that we can readily produce real examples of problems with current systems. COVE’s strength is that we can engage those directly impacted by an issue and help them to express their concerns.

COVE’s Mission

Our mission is to promote and protect a higher quality of life for Vermont’s elders, through education and advocacy.

COVE’s Vision

COVE is committed to working toward a state in which:

- Resources, education, information and support services, key to successfully aging, are broadly available.
- Public policy is informed by, and responsive to, the aspirations and challenges of the state’s growing elder population.
- Quality health care is accessible to all residents.
- Elders continue to expand their role as active agents and resources engaged in all aspects of community life, bringing their knowledge and abilities to bear to improve the quality of life for Vermonters of all ages.
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 casework and systems change.

DRVT is once again publishing the priorities approved by our Board for the current fiscal year (Oct. 1, 2016 – Sept. 30, 2017). We would welcome your thoughts about how our unique system can best serve people with disabilities and mental health issues. DRVT’s 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 are found 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.

2017 PRIORITIES FOR PROTECTION & ADVOCACY FOR INDIVIDUALS WITH A MENTAL ILLNESS (PAIMI)

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.

2017 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 and Periodic Screening Diagnosis and Treatment (EPSDT). Priority is 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 Supplemental Security Income (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 (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).

• Increase knowledge and awareness of the civil and legal rights of people with disabilities (PADD/PAIR).
VERMONT DEVELOPMENTAL DISABILITIES COUNCIL

Five Year State Plan for 2017-21

Every five years the Vermont Developmental Disabilities Council engages in a review of the needs of people with developmental disabilities in our state. From this, the Council builds a new Five Year State Plan that will guide how the Council uses its resources -- including VTDDC’s annual allocation of federal funds -- to improve the lives of people with developmental disabilities.

VTDDC will soon announce several Requests for Proposals (RFP) to assist in meeting the Goals and Objectives of its new Five Year State Plan.

To learn more and to watch for grant opportunities, visit VTDDC’s website: www.ddc.vermont.gov/projects

GOAL 1

VTDDC will reduce barriers to competitive employment and effective health care services for people with developmental disabilities in two (2) underserved Vermont communities characterized by significant economic poverty.

GOAL 2

VTDDC will nurture and support a powerful movement of self-advocates and family members prepared to advocate for policies, programs, and funding that realize the vision of the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 [42 USC 15,001 et seq. (2000)].

GOAL 3

VTDDC will vigorously seek changes in Vermont’s many service systems so that Vermonters with developmental disabilities – including those who are currently not identified as having a developmental disability under Vermont law [18 V.S.A. §8722 (2)] – and their family members have greater and more equitable access to supports that foster the four values in the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000: community inclusion, self-determination, productivity, and independence.

Connect with VTDDC by phone 802-828-1310 or email vtddc@vermont.gov
got access?

by Stefanie Monte

Dining for All

Got access? Mary Alice Proffitt, owner of Montpelier’s Down Home Kitchen, sure does.

That’s why we here at the Vermont Center for Independent Living recognized her with the Rosemary J. Miller Dining for All Award.

The award was handed out at the restaurant on Sept. 14. Some VCIL board and staff members were in attendance. Mary Alice had done her homework on Rosie’s favorite confection, serving a delicious chocolate Coca-Cola cake that Rosie hopes will become a regular menu item.

This year’s award offered VCIL an opportunity to celebrate two passionate advocates for good food and accessibility. VCIL Executive Director Sarah Launderville said, “With this award we honor Rosemary Miller, who was on the front lines of VCIL for over 30 years, and her love of our community and good food. When Mary Alice came to town, she put her heart and soul into making sure this restaurant is accessible to all. She could easily have decided to ask for a variance or abatement from the state citing the difficulty of the space, but her character and values shined through when she made the modifications. She took a space that had never been accessible to someone with a physical disability and offered opportunity. We are honored to give her this award.”

Down Home Kitchen opened in the fall of 2015 at 100 Main St. The community-minded restaurant serves real Southern soul food and does a brisk business.

Rosie said she was surprised, prior to Down Home’s opening, to see a ramp being added to a building in Montpelier’s historic downtown. “I was impressed that the owner had the desire and the courage to fight for everyone to be able to enter the building.”

Rosie said, “Mary Alice greets everyone like an old friend and is very inclusive of her customers.” Rosie likely echoes the sentiment of many customers when she says, “I hope she stays open a long time.”

In addition to the delicious homestyle cooking and baking, there are many things to like about Down Home Kitchen, including the fact that the bathroom and entrance are accessible. But while the physical modifications that Mary Alice made to the building are admirable, it is the warm and inviting atmosphere that makes Down Home Kitchen so special. The staff is friendly and thoughtful; for example; they will gladly accommodate by reading the menu aloud for customers who are blind.

In presenting the award to Mary Alice, Sarah said, “Thank you for your vision, your commitment to this community and for going out of your way to ensure that all in this community can have access and enjoy the space you created.”

Mary Alice was touched and said she shed some serious tears upon receiving the award.

If more business owners shared Mary Alice’s vision and spirit of inclusion, the world would be a better place.

And a Thank You to Rosie

Rosie, who was born with cerebral palsy, has never let her disability slow her down. She can often be seen out and about, whether she is grabbing a bite to eat, shopping or catching a movie. Rosie’s love of community spaces and local foods make her the perfect honoree for an award to recognize accessible restaurants.

Through the years, Rosie has been and continues to be a steadfast advocate for disability rights. She once told me: “Being a person with a disability, I would love to be a role model for younger people.”

Rosie has no doubt succeeded in being a role model — I mean, how many people have an award named after them?

If you would like to nominate a Vermont restaurant for next year’s Rosemary J. Miller Dining for All Award, email smonte@vcil.org or call 1-800-639-1522.
Bulletin Board

SAVE THE DATE
Disability Awareness Day
will be
March 2, 2017, at the State House
Please plan to join the Vermont Coalition for Disability Rights in celebrating and speaking up for disability rights and services.

Include! Curriculum
The Vermont Statewide Independent Living Council has an updated disability studies curriculum for use in public schools. Include! helps students and teachers explore disability rights and the social history of disability through the voices and experiences of those who lived it.
Visit http://www.includevt.org/include.html

Self Advocates
Lead the Way
Congratulations to the national organization Self Advocates Becoming Empowered. SABE was chosen to create and operate a National Resource Center on Self Advocacy. And congratulations to all of their state partners, including Vermont’s own Green Mountain Self-Advocates, who are helping SABE develop this exciting new program. Kudos to this great partnership!

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

VCIL
Vermont Center for Independent Living

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