Lead On!

This year we celebrate 25 years of the Americans with Disabilities Act (ADA) and 40 years of the Individuals with Disabilities Education Act (IDEA), the law that recognizes and protects the rights of children with disabilities to participate in and benefit from public education with other children. This year also saw the long-awaited reauthorization of the Older Americans Act, the law that created and continues to preserve key resources for seniors. Many of us who were young when the IDEA and the ADA were passed are now old enough to look to the Older Americans Act programs for information and services.

In this issue we celebrate these laws and the lives and advocacy of many individuals and groups who helped establish these rights and resources. We also recognize the many changes that are still required. New voices are joining past voices as individuals, families and other allies work to bring democratic ideas and legislative promises to full expression in our homes, job sites, schools and communities. Keep speaking out, keep making change happen, and remember, you are not alone! The individuals and organizations represented in this issue and our allies around the world are with you.

~ Deborah Lisi-Baker, Editor
Letters to the Editor

Thoughts on the ADA

Back in the early ‘70s, when the Vietnam War was at its height, the Kent State shootings had recently occurred, and the civil rights movement was just beginning to heat up for both the race component and the people with disabilities sector, a number of persons, including myself, gathered together to begin the formation of what became the Vermont Center for Independent Living.

Over the years, since the early days, the passion for the rights of all people, including PWD, has remained and grown stronger, leading to the enactment in 1991 of the Americans with Disabilities Act, under President George H.W. Bush.

Progress has been made to improve both accessibility and the civil rights of people with disabilities thanks to the hard work of the peers, advocates, members of the disability community and representative groups statewide and nationwide, but a great deal of work remains to educate the public and the business community in particular regarding rights and responsibilities under the Americans With Disabilities Act and how to best comply with the law.

I strongly encourage everyone to become aware of your rights and responsibilities as people with disabilities or as providers of goods and services to people with disabilities under the Americans with Disabilities Act and to work toward the day when full compliance with this important civil rights law will be reached!

For more information about the ADA and how it affects you, please contact the Community Access Program at the Vermont Center for Independent Living, 1-800-639-1522.

Mike Charron
Northfield

Mike Charron is VCIL’s civil rights specialist.

Reason to Celebrate

I had the opportunity to spend the 25th anniversary of the passing of the ADA in Washington, D.C. and participated in a march down Pennsylvania Avenue, alongside over a thousand other advocates. The energy I felt from others who are actively engaged in the disability rights movement energizes me to keep pushing for equality!

As a member of Generation ADA, I have seen the effects of the hard work of those who fought for the ADA all around me. I see access to physical, employment, education and communication barriers being eliminated. Though we have a long way to go, we have come so far, and that is worth celebrating!

Alaina Clements
Montpelier

Alaina Clements is VCIL’s assistive technology specialist.
Happy Birthday, ADA!

by Nicole LeBlanc

As we celebrate the 25th anniversary of the Americans with Disabilities Act, I would like to share some thoughts on what the ADA means to me as a person with autism. I want to say first off that I feel very lucky and privileged to have grown up with the ADA. I was only five years old when the ADA passed in 1990 and I was attending the Easter Seals preschool program in Manchester, N.H. Being part of the ADA generation has allowed people like myself to access the supports and accommodations needed to be successful in this world.

In my view, ADA is like the Declaration of Independence for people with disabilities. The ADA has done a lot to help move society to a place where there is a level playing field in all aspects of community life. For instance, the ADA has made it illegal to discriminate against someone with a disability in areas such as community services and employment. Another big thing is that the ADA has made it easier for people with disabilities to come out of the closet about their disability and be proud of who they are as a person. One thing we say at Green Mountain Self-Advocates is that there are two closets: the first closet is the LGBTQ (Lesbian Gay, Bisexual, Transgender, Questioning) closet and the second closet is the disability closet.

The Americans with Disabilities Act has made the lives of people with developmental disabilities better because it has helped to shift America away from the medical model of disability toward the civil rights viewpoint. Before the ADA was passed, disability was thought of as a medical problem. This meant that disabilities were treated as a disease or a deficit. With the signing of the ADA on July 26, 1990, it was the beginning of a new era where disability is seen as a natural part of the human experience and as another form of human diversity that makes America so great. When society makes diversity of all kinds a part of its community fabric, everybody is a winner!

As we look toward the next five to 25 years of the ADA, there is still much more work to do and progress to make. I hope that in my lifetime to see a world where everyone with a disability is fully included in the community to the greatest extent possible. I hope that everyone is living in integrated housing and working real jobs for real pay, not just the food and filth department. Another important aspect of integrating people with disabilities into the community is encouraging active participation in community activities alongside people without disabilities. Lastly, I hope to live in a nation where nobody with a disability is living in an institution or working in a sheltered workshop at subminimum wage.

To conclude, I want to say that I am ever so grateful for all the veteran disability rights activist leaders who have fought tooth and nail to get the ADA and many other import civil rights laws like IDEA and the Social Security act passed for us. Thank you all to all the advocates and allies that have helped to level the playing field for the disability community over the last 25 to 50 years.

Nicole LeBlanc is advocacy director at Green Mountain Self-Advocates. LeBlanc has a keen ability and interest in public policy and excels at communicating about the needs of people with developmental disabilities to public officials. She travels around Vermont visiting local Self-Advocacy groups supporting her peers to feel comfortable talking to their elected officials about what they need. LeBlanc is a natural leader chosen by her peers due to her unwavering commitment to speaking truth to power.
Reflections on a Post-ADA World
A Conversation with Kim and Ash Brittenham

by Deborah Lisi-Baker

Young people growing up today, as well as their parents, are part of the post-ADA Generation. How has disability rights changed their world and their expectations of the world? I decided to ask Kim and Ash Brittenham, two individuals who have been speaking up and speaking out for disability rights and awareness for quite a while.

Ash just turned 18. I met him when he was about nine years old (“just a naive kid,” Ash tells me today). He was already using his art and his ideas to speak out for funding for muscular dystrophy research and disability awareness. Earnings from his children’s book, “Max the Super Dog,” were donated to muscular dystrophy research. VCIL gave Ash VCIL’s first Deborah Lisi-Baker Leader of Tomorrow Award because of his creative vision and because he was already making changes in the world.

Through Ash I met his mother, Kim, who later came to work at VCIL and was eventually promoted to civil rights manager. Feisty, indomitable, passionate about the rights of women and social justice movements, Kim brought her own rights-bearing viewpoint, her passion and her creativity to parenting three children and to VCIL’s community access work.

Today, Ash says, “When I got the award was the first time I realized that what I do and say matters, that my voice makes a difference. Today I am not thinking just about muscular dystrophy research but about being part of a movement. It’s the judgments and attitudes coming from others that are disabling. It wouldn’t be so bad if disability was recognized as just one of those normal things, which it sort of is — but people still don’t see it that way. I am still figuring out a lot about how I can use my voice to advocate.”

If he could change anything, what would it be?

“Schools,” Ash says. “Nowhere in education in school is there anything about disability or the ADA. How are people supposed to make it better when everybody is oblivious to the existence and the experiences of people with disabilities?”

Another thing he advocates for is access. Ash knows inaccessibility and accessibility firsthand. He remembers the field trips he could not participate in, the accessible school entrance that was always locked, the everyday barriers to restaurants and other community spaces, the joy of wheeling on an accessible trail in Waterbury Center, working with a restaurant owner who was delighted to make her new business more accessible and sailing an accessible sailboat with the Northeast Disabled Athletic Association (NDAA). He says he learned about the
ADA through his mom’s work at VCIL.

Kim said, “For me, it was just necessity. Before, I was just oblivious. Suddenly, through Ash, I realized there is a whole other world I had been oblivious to. I did not want to go back to where I had been. Now I look at all the buildings built over the centuries, designed with stairs instead of ramps; and I wonder: what were we thinking? Why didn’t we ramp everything?”

Ash graduated from Montpelier High School this year, and he and his family are making a new home in North Carolina, where Kim fantasizes about doing something to support divorced women. (“A friend and I fantasize about creating an after-hours drinking club for divorced women,” she says, smiling.) Ash also plans to work in design and to explore transforming and shaking up what we mean when we say “normal.”

“I want disability to be normal, but not too normal,” he says. Ash wants the ordinary to make room for radicals, self-identified dorks and other human diversities, for taking comic books and Legos and creative media into his future work as an artist, designer and activist. Kim plans to do her own work in design, women’s rights and community organizing. I can just imagine the family gatherings in North Carolina ...

I know that — singly and together — Kim, Ash and their family will be helping to move the independent living movement forward, taking on access barriers in new communities, making new spaces for conversations that help people understand and respect people with hidden and visible disabilities and that allow for the power of people coming together to change the world. They are part of a community of young people and families who continue to transform what disability means and how it is experienced.

When I was Ash’s age or a little younger, I had a powerful dream — one that I carry with me. I was walking in a thick tropical forest, surrounded by people of all races and cultures, from different times. We were walking on a hidden road that travels though all places and times. In the dream I knew it was the Underground Railroad that black slaves traveled; and I was perhaps there because of my disability, or because I was a young woman, and because I did not need to travel alone. Others there, each with their own stories and history, surrounded me but we were all walking a shared history and a shared journey toward equality and human rights. It was a hidden march but a joyous one. Talking to Kim and Ash, and thinking of all the others I have met in disability rights and social justice work, is like reaching over in that dream and touching a few of the people that walk beside me ...

VCIL Honors Allies of Accessibility

During this 25th anniversary year of the ADA, Kim Brittenham was instrumental in making sure that various entities were recognized for their commitment to VCIL’s work of promoting accessibility.

Waterbury Center State Park, the city of Burlington and the Vermont Institute of Natural Science all received plaques from VCIL at ADA celebrations over the course of the summer.

VCIL Executive Director Sarah Launderville said, “All three of these entities, along with Lake Shaftsbury State Park, are superstars for what they have done recently to improve access for people with disabilities. We are so grateful and proud to have partnered with them during what we are calling the Year of Outdoor Recreation.”

Lake Shaftsbury added a ramp/walkway and purchased a beach wheelchair prior to their ADA Celebration on July 24. The staff at Waterbury Center State Park went above and beyond to make sure that their accessible trail was ready to go after rainstorms compromised it prior to their ADA event in June. At Burlington’s ADA Celebration on July 10, Mayor Miro Weinberger and others highlighted steps that have been taken to make the city more accessible, including modifications to city buildings and infrastructure and providing interpretive services to allow Deaf residents to participate more fully in city events.
VCIL Salutes Former Employee

by Stefanie Monte

In December, longtime VCIL employee Joyce Werntgen retired, but she will always remain part of the disability rights movement. For example, she volunteers on a regular basis at VCIL, much to the delight of her former coworkers.

VCIL Executive Director Sarah Launderville has known Joyce for many years. “She was my first supervisor at VCIL and is a warm and wonderful woman. Her sense of humor and incredible work ethic has allowed VCIL to grow to the organization it is today, and she leaves a great legacy in her retirement.”

Joyce has been a fixture at VCIL since 1993, when she was hired as the executive director’s assistant. She served in that role, working under four different directors, for about 10 years, till she began working in the Home Access Program in 2003. Joyce retired as coordinator of the program, which provides home entrance and bathroom modifications for people with disabilities.

Working at VCIL has fulfilled Joyce’s career goals of doing something that matters in people’s lives, and she has particularly enjoyed her work in the Home Access Program.

As with any job, Joyce’s work at VCIL has come with its struggles, including trying to do a lot with not a lot of money.

Joyce has not always worked in a mission-driven environment. “In my life in New York, I was a legal secretary,” she noted.

She grew up in Brooklyn and lived for awhile on Long Island.

“I’m always excited when I hear a New York or a Long Island accent. It took me awhile to get my language understood in Vermont because I had such a New York accent.”

Today, no trace of a Big Apple accent can be found in her speech. Instead, Joyce is known for her kind heart and remarkable ability to lighten the mood of any meeting or gathering with her dry and quick sense of humor — always managing to come up with the perfect quip for any occasion.

In 1967, Joyce moved from New York City to Vermont and found work at a law firm in Burlington. In 1971, she stopped working outside the home to focus on raising her three sons. She returned to work in 1981, running a special religious education program in Burlington for people with developmental disabilities from age 8 to adults.

After that, Joyce got a job doing administrative work at COTS, a nonprofit that provides emergency shelter, services, and housing for people who are homeless in Vermont. While working at COTS, Joyce was able to go back to school, obtaining her associate’s degree in women’s studies from Burlington College. She took a lot of writing courses, which would prove to be very helpful in her work at VCIL.

During her 21 years working in the movement, Joyce has witnessed a shift in people’s attitudes toward people with disabilities.

She explained, “A disability now is not something we need to hide away, and make sure somebody’s taken care of. That’s changed a lot. Instead it’s ‘how do we get folks with a disability to be able to fully participate?’"
Ed Paquin Honored in Washington, D.C.

The executive director of Disability Rights Vermont, Vermont’s protection and advocacy system, was honored at a national civil rights conference recently.

Ed Paquin is the recipient of the National Council on Independent Living Region 1 Advocacy Award for his dedication to promoting the rights of people with disabilities and advancing the independent living movement in New England (which comprises NCIL’s Region I). The award was presented on July 29 at a banquet in Washington, D.C.

Paquin said, “It was a real surprise and an honor to receive the NCIL Region I Advocacy Award. It has given me an opportunity to step back and think about how lucky I am to be able to work with some of the best people and organizations around to make the world a better place.”

He added, “It was a joy to be at the NCIL conference celebrating the ADA surrounded by hundreds of people whose very presence was proof that disability is a foolish reason for any sort of discrimination — they were sharp, good-willed, motivated, funny and ABLE! We don’t get this work done alone and when I feel frustrated that I am not making the impact I should, I will think about this award and realize that I am a part of something truly greater than the sum of its parts!”

Kim Brittenham, the Vermont Center for Independent Living’s civil rights manager, said she nominated Paquin for the award because he is the type of man she would like her sons to become. “Ed is a tireless, yet graceful, warrior for civil rights who has put his shoulder to improving lives of people with disabilities no matter what role he has filled.”

Paquin is a well-known leader in the Green Mountain State. He served six terms in the Vermont House of Representatives. A longtime board member of the Vermont Center for Independent Living (where he has served as both president and treasurer), he is also president of the Vermont Coalition for Disability Rights.

Sarah Launderville is executive director of VCIL and represents New England on the NCIL Board. She said, “I was so excited to present this award to Ed. He is so humble and it was fun to see the surprise in his face that he was being honored. It was particularly special because we were celebrating the 25th anniversary of the signing of the Americans with Disabilities Act and there were so many young people at the conference who are motivated by what he has helped create here in Vermont.”

She added, “Ed always makes time to listen, think about how to improve a situation and advocate against injustice. He is a wonderful man and champion of disability rights.”

The Vermont Center for Independent Living, a nonprofit organization directed and staffed by individuals with disabilities, works to promote the dignity, independence and civil rights of Vermonters with disabilities. VCIL is committed to cross-disability services, the promotion of active citizenship and working with others to create services that support self-determination and full participation in community life. For more information, visit www.vcil.org.
Vermont Vermonter Recognized as Champion of Change

Max Barrows of Montpelier was honored at the White House on July 27 as a Champion of Change. The event was held as part of the 25th anniversary of the Americans with Disabilities Act (ADA). The July celebration honored both longtime disability advocates and young Americans with disabilities who are working to uphold and expand the spirit of the ADA. The Champions of Change program was created to feature individuals doing extraordinary things to empower and inspire members of their communities. This year the program honored nine disability advocates.

“It means a lot to have the work I do be recognized because it’s so important for people with disabilities to be included in every aspect of society,” said Barrows.

Barrows works as the outreach director for Green Mountain Self-Advocates, a disability rights organization in Vermont. In that role he mentors youth and adults with developmental disabilities to speak up for themselves and become leaders. Max connects with people on all levels advocating for true inclusion of people with developmental disabilities. In his work, he advances the message that when you meet an individual with a disability, presume competence. Max is currently on the board of Self-Advocates Becoming Empowered (SABE), the national self-advocacy organization, and co-chair of the Community Advisory Council at the University of Vermont’s Center on Disability and Community Inclusion. His goal is to travel internationally to spread his messages of true inclusion and self-advocacy.

Barrows said, “It’s so easy for a disability to be viewed as an automatic weakness, when really it’s the perception that society has of us! Being selected by the White House as a Champion of Change means that we have made so much progress in what we are striving toward. But, there still is a lot of work to be done.”

Max was interviewed and filmed for the CDCI Life History Project earlier this year. To see Max’s Life History video, go to:

http://www.uvm.edu/~cdci/lifehistories/?Page=stirlingscorner.html
Advocates Reflect on Landmark Laws

A couple years before the ADA was passed, I “joined” the disability community. My level of awareness of disability issues was negligible — and that’s still true of many folks — and I was thrust into a world of challenges. As I experienced the preconceptions and barriers around me, I also learned it was a time of transition. Year by year, physical access has improved and other forward leaps, like the Supreme Court ruling in Olmstead v. L.C., have reinforced the positive effects of the ADA. So let’s not stop with getting through the door — let’s STAY in a time of transition!

~ Ed Paquin

I’m very glad we have the ADA now. I wish we’d had it when I was younger. Now that I’m in a wheelchair, I really notice if I can’t get into certain shops and restaurants. It is upsetting that nowadays there are still places that treat people with disabilities like second-class citizens.

~ Rosemary Miller

“But my doctor told me I need to be in a nursing home and I trust my doctor.” This statement was more present and common 20 years ago. Today, many more people are saying, “I want a ramp/bathroom, personal attendant services,” and they are being heard by medical professionals and case managers. The Olmstead decision made a huge impact in upholding the ADA, and advocates have insisted on a tone and culture change and we are seeing the difference.

~ Sarah Launderville

Living with a disability post-ADA is in some ways a challenge, in other ways not a challenge. It’s what you make of it. Most people don’t think about disability till it really affects you. I have found that when I first became disabled, I was very distraught knowing that my life had changed and I would never again be able to do the things I had done prior. That takes a lot to get over. But overcoming these obstacles I have met people I probably would have never met, become friends with a lot of people I wasn’t friends with prior and have come to learn to respect individuals with disabilities. I hope that it has made me a better person.

~ Henry Demar

On July 25, 1990, I was at home with a baby and two toddlers. Our mode of transportation often included strollers. While using a stroller to cart around three cute, active, sometimes noisy, sweet boys, I quickly learned how difficult it was to gain access to places with stairs. Now those same cute, active, sometimes noisy, sweet kiddos are 25, 27 and 29. Because of the work and advocacy of folks in the disability rights movement, much progress has been made in access and many other areas; my sons grew up in a world of change without knowing it. Today, I’m proud to work with VCIL’s Home Access Program, building ramps and other home modifications to help Vermonters with disabilities have better access to their homes and communities.

~ Patricia Tedesco

I am thankful to work with VCL for 10 years. I have learned so much about ADA rights and Vermont advocacy for Deaf rights. I am thrilled to have Vermont Interpreter Referral Service to participate with VCIL to support our Deaf community in Vermont.

~ Missy Boothroyd
State Agrees to Delay Planned Cuts in Reach Up Benefits

Vermont Legal Aid brought a class action lawsuit against the state following a policy change that targets adults with disabilities and their families. If implemented, the policy would reduce monthly Reach Up benefits by $125 for families that include an adult with a disability. The policy change, which was expected to take place in August, has been delayed at least through November. Legal Aid has been posting updates on its website: http://www.vtlegalaid.org/news.

Creative Cooking on $4 a Day

A lot of people are living on fixed incomes these days. Leanne Brown was frustrated by the lack of good cookbooks for people who use food stamps and have to manage a food budget of $4 a day. Her book, “Good and Cheap: Eat Well on $4/Day,” makes it easier for people with limited money for food to eat well and enjoy cooking. Free copies of her book can be downloaded from the Internet. Supporters are also helping her get free print copies to people who cannot afford to buy it. Check out http://www.leannebrown.com/ for more information.

A New Door to Nutrition and Tips for Cooking Accessibility

The World Institute on Disability (WID) brings people with disabilities’ stories and concerns to the world stage. Recently they created a new web resource, New Door/Disability FEAST, intended to bring disability accommodations to seniors and people with disabilities who are looking for accessible cooking tools, tips on cooking with different disabilities and information on new research and resources on nutrition and health. The site is primarily intended for beginners (and their allies) in the world of nutrition, health promotion, aging and disability. Their site includes creative links to tools for individuals with limited mobility, one-handed cooks, cooks who are blind or partially sighted and Little People. Check out their site at http://wid.org/access-to-health-care/health-access-and-long-term-services/new-door/FEAST.

Want some local help? In Vermont, area agencies on aging and both the Vermont Center for Independent Living and the Vermont Association of the Blind and Visually Impaired can also provide tips and information.

New Leaders at DMH and DAIL

In June, Monica Caserta Hutt became commissioner of the Department of Disabilities, Aging and Independent Living, replacing Susan Wehry who had served in this role for four and a half years. In her final press statement, Wehry spoke about the importance of both the ABLE Act and work incentive initiatives that were recently endorsed by the Vermont Legislature. Hutt comes to the role of commissioner after 25 years of work in human services and disability programs, including leadership roles at the Sara Holbrook Center, the Howard Center, and the Agency of Human Services.

Frank Reed, a longtime employee of the Department of Mental Health, serves as the interim commissioner there.

Help in an Emergency — One Form Can Help

United Way organizations, Vermont 211 and Enhanced 9-1-1 want to make sure that Vermonters who need help during an emergency have filled out the E911 CARE form that helps first responders be ready to assist individuals with disabilities in an emergency. If a person uses a wheelchair, has a service animal or uses oxygen or needs communication aids or devices or other supports, the first responder will be prepared to help. The form must be filled out each year so that your contact information and service needs are up to date. For more information or help getting the form, contact your Area Agency on Aging, VCIL or other service agencies or call your local United Way office or Vermont 211.
State Plan for Independent Living:
Join us for a Public Meeting and Working Lunch

Every 3 years, the Statewide Independent Living Council (SILC), The Vermont Center for Independent Living (VCIL) and The VT Department of Disabilities, Aging and Independent Living (DAIL) create a plan, using input from Vermonters, that guides spending in programs and services for people with disabilities. As we start the process, we need your input on these key objectives: Housing, Transportation, Education, Youth Transition and others.

We need your input!

We are holding a public meeting to hear from you! Tell us: How are people with disabilities treated? What do you wish was better? What would Vermont look like if all people with disabilities were included? To give feedback in advance of this meeting, please go to VCIL.org after October 15th.

Join us for a Working Lunch on November 17th

On Tuesday, November 17th at 10 AM at the Holiday Inn in Rutland, we are inviting advocates and people with disabilities to come give input on important joint objectives for this 3 year plan. Lunch will be served. Please let us know of any accommodations that you may need. Please RSVP to Stefanie Monte of VCIL at 800-639-1522 or smonte@vcil.org. Please let us know of dietary restrictions you may have if you plan to join us for lunch. We hope to see you there!!
Disability Awareness Day: Progress Made, Miles to Go

VCDR’s annual Disability Awareness Day took place on March 18 at the Statehouse in Montpelier. Over 318 people participated in the day’s activities, including those with disabilities, family members, advocates, members of the administration and many allies.

The theme of the day was a celebration and recognition of Disability Milestones: Progress Made; Miles to Go. Andrew Imparato, executive director of the Association of University Centers on Disabilities, was the keynote speaker for the day.

Disability Awareness Day visitors had a choice of attending a number of workshops in the morning, or sitting in on the testimony held by the House Commerce and Economic Development Committee on two pieces of legislation focusing on economic savings incentives and Medicaid for people with disabilities in the workforce.

Gov. Peter Shumlin welcomed the standing room only crowd in the morning and spent time answering questions from attendees.

A number of additional workshop and trainings were held, including storytelling circles about people’s struggles with their civil rights and disability milestones that meant something in their lives. The stories were documented with recordings and pictures to be displayed in different parts of the state.

Thirteen organizations displayed their work in the Statehouse “card room” and interacted with legislators there. A press conference was attended by over 100 individuals including legislators and was covered by numerous news outlets. Our keynote speaker spoke along with advocates from the Vermont Association of the Deaf, Vermont Center for Independent Living and individual members about the disability milestones met nationally and in the state of Vermont throughout the years, and the miles we still need to go.

A House resolution recognizing important legal milestones in the protection of the rights of persons with disabilities and designating March 18, 2015 as Disability Awareness Day at the Statehouse was read and disability folks were introduced on the floor of the House and applauded by the 150-member House of Representatives. The Senate took up S.66, an act relating to persons who are Deaf, Deafblind, or Hard of Hearing and voted to read it for a third time to its eventual passages in the Senate.

The day culminated with a well-attended evening gathering where participants got to enjoy appetizers and entertainment from the Me2/Organization. The evening program was the keynote address from Andrew Imparato followed by a panel presentation and a lively discussion focusing on the Americans with Disabilities Act and the Individuals with Disabilities Education Act with a Green Mountain Self-Advocate member, a representative from the Americans with Disabilities Act Title II, and Citizens.

The day was made possible by the planning, staffing, logistical and financial support of the Vermont Developmental Disabilities Council, the Vermont Coalition for Disability Rights and their member organizations, especially VCIL, the Vermont Statewide Independent Living Council, the Center on Disability and Community Inclusion at UVM, Vermont Registry of Interpreters for the Deaf and VCDR legislative advocate Karen Lafayette.
COVE’s 2016 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.

Highest COVE Priorities

1. Choices for Care (CFC): CFC is Vermont’s long-term care (LTC) program for low-to moderate-income elders and adults with disabilities. It provides for both nursing home and home-and community-based care for those with financial and clinical needs for the same. The program has been very successful in giving Vermonters a choice as to where to receive services and in saving the state significant dollars. The biggest problem CFC has repeatedly encountered is how to use those savings — whether to reinvest the savings in an improved home and community based services program, as required by the federal waiver, or to offset other pressures and priorities in the state budget. COVE’s priorities for this program in 2016 are:
   • No cuts in home- and community-based services (HCBS).
   • More reinvestment of savings in HCBS.
   • Elimination of delays in eligibility determination.
   • Restoration of funding for case management in Enhanced Residential Care & Adult Family Care.
   • Consideration of how the new global commitment will affect HCBS.
   • Housing for elders who need LTC and other services and are homeless.
   • Comprehensive study of LTC needs of aging population and the related economic opportunities for the workforce needed to support aging at home.

2. Low-Income Home Energy Assistance Program (LIHEAP): The federal LIHEAP provides assistance paying for home heating for people of all ages, including many elders whose household income does not exceed 185 percent of the federal poverty level. COVE’s priorities for this program in 2015 are:
   • Restore baseline funding in the budget.
   • Maintain or increase benefits.

   • Work to coordinate weatherization and fuel assistance advocacy and to engage legislators and interested parties in a broad policy discussion on the relationship between the two.

3. Protection for Vulnerable Adults:
   • Work for passage of H.46, Adult Fatality Review Team.
   • Get bill introduced and passed to deal with “improvident transfer of titles.”
   • Adult Protective Services: APS investigates reports of abuse, neglect and exploitation of vulnerable adults. When reports are substantiated, APS can take steps to protect the victim and can put the perpetrator on the adult abuse registry to ensure that person cannot get another job working with vulnerable adults. There are statutory requirements as to how much time is allowed for opening an investigation and notifying the reporter and victim of progress, etc. COVE’s priorities for this program in 2016 are:
     ~ Strengthen the system, support positive changes.
     ~ Monitor issues around Division of Licensing and Protection and APS and how they interact to ensure that cases are being routed to the correct division.
     ~ Support the administration to ensure they have the tools necessary to conduct proper investigations.

4. Transportation: There is significant unmet need for transportation in Vermont, rooted in our state’s rural demographic, a growing elder population, and people choosing not to use cars. COVE will continue to work collaboratively with service providers, advocates, lawmakers, administration officials and other interested parties to address those needs in a comprehensive way. The discussion will focus on need and must be broader than medical transportation, to address an across-the-board desire for more non-medical transportation throughout the

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Update on VCDR Budget and Policy Priorities

STATE BUDGET FOR FISCAL YEAR 2016 (H.490)

Reach Up Grant Reduction for Families Receiving an SSI Disability Benefit ($1.6 Million): This reduction, which was approved by the Legislature, counts the first $125 a month of Supplemental Security Income received by an adult family member with a disability against the Reach Up grant amount. Vermont Legal Aid has introduced a class action lawsuit to stop implementation of this discriminatory policy, which will affect up to 1,106 households. (See News & Views, page 10.) If the state does implement this cut, it will occur after November 2015.

Vermont Association for the Blind and Visually Impaired (VABVI) Grant Reduction ($42,000) Proposed) — Funding Restored: A proposed cut in the VABVI Older Blind Grant would have only saved about $9,000 in general fund dollars, but had a 4-to-1 federal match, representing an actual loss of $42,000 in service funds. Those dollars serve about 40 people, making it possible for them to stay in their homes. This funding was restored.

Cut in Legal Aid Services ($47,415) — Funding Restored: The administration proposed a significant cut to Vermont Legal Aid and since services in certain kinds of cases are required by law, primarily mental health commitment and guardianship, the impact would have fallen on their legal services to low-income people. Thankfully, this cut was restored.

Choices for Care (CFC) Enhanced Residential Care and Adult Day Programs Grant — Reductions: CFC is Vermont’s long-term care (LTC) program for low-to moderate-income elders and adults with disabilities. It provides for both nursing home and home- and community-based care for Vermonters who meet financial and clinical eligibility. The program has been very successful in giving Vermonters a choice in where they receive services and in saving the state significant dollars. The final budget bill eliminated a grant for adult day programs and funding for case management for individuals in Enhanced Residential Care. The bill directs the administration to examine the delays in CFC eligibility determinations and requires an interim report to the Legislature addressing the likelihood of reductions in adult day services.

VCIL-Vocational Rehabilitation Assistive Technology, Peer Advocacy and Adaptive Van Funding — Reduced or Eliminated: Reductions in the Assistive Technology Reuse Program ($70,000) and independent living peer advocacy ($51,250) will result in loss of services for a number of people. Peer counseling allows one person who has a disability to help others work together toward independent living goals. Although the van modification funding only paid for a few modifications a year, the general fund dollars were matched 4-to-1 with federal monies, resulting in a total loss of $100,000 for this essential service.

VCIL-Mental Health Wellness Workforce Coalition — Reduced: The budget bill includes a reduction of $20,000 in the Wellness Workforce Coalition. The WWC provides peer-to-peer supports for mental health and recovery communities.

Developmental Services New Caseload Funding Increased — $1.9 Million in “Savings” Targeted, Reduction Taken: The budget bill cuts $1.9 million as a “savings reduction” recommended by the administration which claimed that this could be met without negatively affecting individuals and families. Advocates were outspoken in their concern that this reduction would instead cause hardships. On the positive side, the budget does include funding for anticipated caseload increases, though funding priorities remain narrow and only 21 percent of those eligible under the state definition of developmental disability are served. Strong advocacy after the session persuaded the Agency of Human Services to release $600,000 (same as FY14) as “one-time” assistance that had been threatened.

LIHEAP Proposed Reduction ) — $6 Million Out of the Base Fuel Assistance Budget — Commitment to Fund: This cut would have reduced heating assistance from covering 34 percent of...
average fuel costs to about 21 percent. The average benefit would drop from $783 to about $545. This cut passed, but the bill included language that approved $5 million in funding if enough tax revenue comes in. Thankfully, it looks as though this money will in fact be available.

**Affordable Housing — Reductions in VHCB and Mental Health Vouchers:** Most of the housing and homeless programs maintain level funding, with the exception of Vermont Housing and Conservation Board ($850,000 reduction) and mental health housing vouchers ($500,000 in cuts).

**Community High School of Vermont Correctional Education Program — 50 Percent Proposed Reduction Restored:** The Community High School of Vermont (CHSVT) is a program that provides educational and vocational training to Vermont’s prisons. The governor had proposed to cut the funding for a high-school completion program in half. In the final deliberations, the Legislature fully funded the correctional high school education program and compromised on allowing anyone over 23 to participate with the commissioner’s approval.

$3.2 Million Investment in Health Care Reform Passes: The governor proposed a plan to raise $90 million from a 0.7 percent payroll tax to fund modest health care reform that would have increased Medicaid reimbursement rates to all providers after deciding not to go forward with single payer before the session began. The Legislature did not accept the payroll tax and instead used a 33 cent increase in the cigarette tax and increases in taxes on other tobacco products to level-fund exchange subsidies for out-of-pocket costs, modestly increase Medicaid rates and to invest in initiatives to strengthen the primary care system.

**POLICY LEGISLATION**

**H.333, an Act relating to Enhancing Eligibility and Work Incentives for the Medicaid for Working Persons with Disabilities Program:** The legislation provides incentives for persons with disabilities to work, while being able maintain their Medicaid coverage. The legislation directs the state to seek federal permission to amend the state plan and to raise the entry level asset threshold, institute individual and spousal income disregards, and have disability benefit counselors to inform potential applicants. Passed in the economic development bill (S.138). Signed into law.

**H.402, an Act Relating to Authorizing the Vermont ABLE (Achieving a Better Life Experience) Savings Program:** This legislation authorizes Vermont to implement the federal ABLE act to create tax-free savings accounts for persons with disabilities to help finance disability-related needs. A task force, with representatives from the disability community, will be created to execute this process. Passed in the economic development bill (S.138). Signed into law.

**S.66, An Act Relating to Persons who are Deaf, Deafblind, or Hard of Hearing:** This proposed legislation would have set up a task force to examine all of the issues regarding Deaf education and services in the state after the closing of the Vermont Center for the Deaf and Hard of Hearing. S.66 passed the Senate following powerful testimony by Deaf Vermonters and families. Rather than wait for the House to act next year, the Senate Government Operations Committee and House members agreed with the administration to expand an existing commission into a comprehensive task force. It will have a broad mandate and should begin to meet this fall.

**S. 20, an Act Relating to Establishing and Regulating Licensed Dental Practitioners:** This legislation would improve access to dental care for thousands of Vermonters who currently don’t receive oral health services, especially Medicaid recipients. The bill would allow licensed dental therapists, working under the general supervision of a dentist, to offer preventative and restorative care throughout the state: in clinics; nursing homes and schools. This legislation passed the Senate with a strong vote and is currently in House Human Services.

**H.187, an Act Relating to Absence from Work for Health Care and Safety:** The Healthy Workplaces bill establishes a minimum standard of earned sick time for working Vermonters. Eighty percent

*Continued on next page*
of the Vermont workforce currently has access to paid time in Vermont. The 20 percent that don’t — roughly 60,000 working Vermonters — are disproportionately women earning low wages and working multiple jobs. This legislation passed the House and is currently in the Senate Rules Committee. The bill will be taken up next year.

S.73, an Act Relating to State Regulation of Rent-to-Own Agreements for Merchandise: Many Vermonters who lease or purchase household or consumer goods through these transactions are low-income Vermonters or Vermonters with limited or no credit history. S.73 provides Vermonters with reasonable limits on what the industry may charge for its products, with information about the real costs of “rent-to-own” transactions, and protection from harassing or unethical collections practices. This bill also includes a “Financial Literacy Commission.” The governor has signed this bill into law.

H.488 (Act 40), an Act relating to the State’s Transportation Program — Language in the Bill to Review Elder and Disabilities Transportation Programs: The legislation requires the Agency of Transportation in consultation with the Agency of Human Services, the Joint Fiscal Office, and interested stakeholders, to review the Elders and Persons with Disability Transportation Program (E&D Program). This review must include examining gaps in service, delivery models, opportunities to achievable efficiencies, challenges in raising funds; issues relating to the Medicaid waiver and emerging technology. A written report is due to the House and Senate Committees on Transportation on or before January 2016.

Vermont Coalition for Disability Rights 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:

11 East State St., Montpelier, VT 05602
e-mail: vcdrvt@gmail.com
on the web: www.VCDR.org

COVE, continued from page 13

state and across generations. This endeavor is a multi-year effort. COVE also recognizes and appreciates the important work of other advocates pursuing healthy transportation options that will make Vermont downtowns and village centers safe and accessible for people of all abilities across the age spectrum to walk, bike, drive and ride public transit. COVE participates in several coalitions and will work with coalition partners on the following issues:

1. Medicare coverage in universal primary care.
2. Accountable care organizations and long-term care issues.
3. Access to oral health care, including S.20, the dental therapist bill.
4. Eyeglasses/dentures for Medicaid recipients.
5. Kinship caregivers.
6. Earned time off.
7. Affordable housing for elders, with adequate support services for those who need it and a streamlined application process.
9. 3SquaresVT participation rate for elders: needs to be increased through appropriate, effective state outreach.
10. H.238, state income tax credit to mitigate the expense of home modifications required by a disability of physical hardship.

Other Issues of Concern to Elders and COVE:
1. COVE opposes vision and road testing for older drivers.

Advocating for a Safe Harbor for Vermont Seniors
P.O. Box 1276
Montpelier, VT 05602
802-229-4731; cove@vermontelders.org
www.vermontelders.org
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, 2015 – Sept. 30, 2016.) 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, the Protection & Advocacy for Developmental Disabilities (PADD), and the Protection & Advocacy for Individual Rights (PAIR) programs on the next page. These priorities serve to focus the work of the agency and are developed by our board and our advisory councils, who get input from the community and staff. Your input is appreciated! We strive to do as much as we can with the resources we have … and we can do that best when folks in the community let us know their greatest advocacy needs!

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

info@disabilityrightsvt.org
or to DRVT, 141 Main Street, Suite 7, Montpelier, VT 05602
Or by phone: 1-800-834-7890 or, locally, (802) 229-1355
And please visit our website at www.disabilityrightsvt.org

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

1) the client meets the federal definition of an individual with a disability as defined by the grant;
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.
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.

2016 PRIORITIES FOR PROTECTION & ADVOCACY FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES (PADD) & PROTECTION & ADVOCACY FOR INDIVIDUAL RIGHTS (PAIR)

(DRVT & 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 revising 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 please visit www.disabilityrightsvt.org/Programs or contact us at 1-800-834-7890 and request a copy be sent to you.

2016 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.
• 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.
• Advocate to improve access to Developmental Services for children and adults with intellectual and developmental disabilities.
• Provide advocacy to ensure people with intellectual and developmental disabilities do not have unnecessary or unnecessarily restrictive guardianships.
• Access to and preservation of SSI benefits for income eligible children under age 18 or turning 18 whose benefits are terminated on the basis of disability. Maintain maximum SS benefits for adults who are disabled and working.
• 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.
• 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.
• Increase knowledge and awareness of the civil and legal rights of people with disabilities.
New HCBS Rules Shine Spotlight on Services

by Kirsten Murphy

The short history of deinstitutionalization and community living for people with disabilities is full of examples where individuals and families had to build a bike while riding it. Their can-do approach said, “Let’s move ahead, even if we are not quite sure how we’ll get there.”

It should not come as a surprise, then, that home and community-based services (HCBS) have only recently been given a legal definition by the Centers for Medicare and Medicaid (CMS). Formally adopted in early 2014, the HCBS rules provide new guideposts on the journey toward full inclusion and self-determination for people with disabilities.

Although Vermont differs from most states in the type of contract they have negotiated with the federal government, CMS has made it clear that the standards still apply. As required by CMS, Vermont recently filed its plan to address the HCBS rules as part of Vermont’s Comprehensive Quality Strategy. It proposes a phased-in approach, starting with a review of Choices for Care and gradually rolling in other programs that provide HCBS — specifically, Developmental Services, Traumatic Brain Injury and Community Rehabilitation and Treatment Services by the end of 2016, and children’s mental health services by the end of 2017.

What are these new standards? CMS guidance describes the HCBS rules as falling into three broad categories:

- **HCBS Settings Requirements:** CMS is clear that gated communities, isolated farmsteads, and facilities located on or next to former institutions are not community-based. However, full community integration is about far more than the number of people or the size of a building. The settings requirements speak to the quality of the life an individual leads in their home. HCBS settings provide opportunities to seek employment, engage in community life and control personal resources. HCBS settings must ensure privacy, the right to invite friends over at any time and the freedom and support to control one’s own schedule.

- **Person-Centered Planning Requirements:** HCBS must be individualized through a person-centered process driven by the individual and including people selected by the individual. People must be offered choices about their services and about who delivers those services. Their service plan must be written in plain language and reflect their specific goals, strengths and service needs.

- **Conflict-Free Case Management Requirements:** To protect people from coercion or artificially narrow choices, the HCBS rule requires a clear separation with eligibility and service design on one side, and service delivery on the other. Whether state oversight and a “firewall” within an agency will provide sufficient protection to meet this standard is still under discussion.

The HCBS Rules provide an opportunity to take a hard look at the quality of Vermont’s services. Are individuals offered authentic choices about where they will live and how they will spend their time? Is there a need for greater separation between those who support the person-centered planning process and the entities that ultimately deliver services?

Individuals and families should keep an eye out for action alerts from the Vermont Coalition for Disability Rights letting them know about opportunities to express how they want to see these new rules guide services here in Vermont.

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Or sign up for our newsletter, Council Connections: [http://www.ddc.vermont.gov](http://www.ddc.vermont.gov)
B u l l e t i n  B o a r d

Get AT Stuff

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White Cane Safety Awareness Day

11 a.m. Oct. 15, 2015, at the Manchester Community Library

Join the Vermont Association for the Blind & Visually Impaired and the Division for the Blind & Visually Impaired to show support for those who depend on the white cane for mobility and independence. RSVP to Carol Wood: 802-786-5822 or carol.wood@vermont.gov

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

Accessible Adventures Await

Do you know of a local business with great wheelchair access or Brailled menus? Let your peers know about it on Accessible Adventures. Thanks to the Vermont Statewide Independent Living Council, anyone can submit their own reviews of restaurants, stores, theaters and recreation areas by visiting www.accessibleadventuresvt.org.

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