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A VERMONT PUBLICATION FOR ELDERS AND
PEOPLE WITH DISABILITIES

After The Storm

In this issue we highlight some resources for individuals and families coping with the aftermath of Irene, share legislative reports from both the Community of Vermont Elders and the Vermont Coalition for Disability Rights, share some highlights from VCIL's summer celebration of the Americans with Disabilities Act and profile two women involved in disability advocacy. We also revisit the words and wisdom of K.K. Wilder, a longtime friend of The Independent, whose column inspired us for so many years.

The day after Irene hit, I listened to two community members talking about the destruction of their workplaces and surrounding homes. I saw an older woman, someone I have long admired for her advocacy for others, filmed by reporters as she was helped out of a damaged home in the Bethel area. Stories poured out from all over Vermont: words of fear, sorrow, caring and love for this state and its people. The days pass and the stories continue. The Independent sends our best wishes to all who are coping with flood losses and our appreciation to individuals and organizations who are reaching out to offer needed help and the gift of community.

Deborah Lisi-Baker, Editor



PHOTO BY MARK COLLIER

This covered bridge in Quechee was left in ruins after Tropical Storm Irene tore through Vermont.

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Letter to the Editor



Close Vermont State Hospital

Although the number of beds is said to still remain in question, Gov. Peter Shumlin, Agency of Human Services Secretary Doug Racine and Department of Mental Health Commissioner Christine Oliver have each declared their firm commitment to replacing the embattled Vermont State Hospital with a brand-new version of the same old thing.

Besides building along these lines, the administration's plan also includes providing an additional 16 to 24 beds elsewhere as well.

This all to the tune of millions and millions of state taxpayer dollars in remaining dependent on an outdated institutional treatment model sure to follow wherever the facility or such other beds would be located.

This is much like had been done in New

Hampshire to the detriment of the community mental health system there and, as a result, the neighboring state came under scrutiny by the U.S. Department of Justice, who issued a scathing report earlier this year.

Such monies, as Gov. Shumlin is recommending be put aside to replace the state hospital in this fashion, could be better used to build the holistic community system needed in closing VSH and, not replacing it, save for a small forensic facility to be located somewhere within the state.

If we could close the former Brandon Training School without building a new version of the same old thing, creatively putting in place a more robust community system instead, we can indeed close VSH and, although there might be differences in such a system, do much of the same for our fellow citizens currently forced to languish at the state hospital, in prison, in homeless shelters or on the street.

Morgan W. Brown
Montpelier

EDITOR'S NOTE: The Vermont State Hospital is currently unoccupied due to flooding from Tropical Storm Irene. This letter was received before the flooding.

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Nothing And A Whole Lot More

by Deborah Lisi-Baker

"The right people stepped up at the right time at the right place. It was so grass-roots and organic. I don't know how you would plan for that."

-- Don Schneider, quoted by reporter Chris Preston, Waterbury Record, Sept. 8, 2011

Before the flood of 1927, the road past my house was the road to the next village. Waterbury was very hard hit by the rising waters; and after the flood, national Civilian Conservation Corps members came to Vermont. They built the Waterbury reservoir, a new construction, designed to reduce the impact of future flooding on the town below. Now my road ends at the reservoir. Similar construction happened in other towns and villages in Vermont, dams built to hold back water. I was glad to hear recently that these structures did indeed hold back Irene's waters: The waters rose again; but not to the heights they reached in the storm of '27.

I can't help but wonder: What new structures will rise out of our response to Irene? How will this new construction shape our streets and bridges, our communications systems, our ways of living together? When rebuilding starts, the destruction will offer opportunities. Throughout Vermont we have the opportunity to create shared spaces that work for more Vermonters, now and in the future: rebuilding streets and homes and community spaces to be more accessible and creating more inclusive ways to serve individuals who have been housed in the Vermont State Hospital.

Meanwhile, the storm images and losses from Irene are overwhelming: We see tumbled earth and stone that used to be roads; houses gutted; businesses and families scraping mud off their floors;

streets lost to floodwaters; and, tragically, Rutland residents learning of two deaths. Next to these images, there are many others -- of people reaching out to one another, honoring one another and restoring hope and community. Vermont history and experience also teaches us that humor and determination helps. We see it here, now, in our own communities. Chris Preston, writing for the Waterbury Record, remembers a sign he saw in a hard-hit second hand shop's window. It says, "I started with nothing, and I still have most of it left."



This story is echoed in the spirit and response of other hard-hit communities. People have been amazing. The Vermont story continues and shows us the unexpected, the possible. The response to Irene has made us remember what we cherish about living here: Community makes all the difference. School Principal Don Schneider is right in saying that the kind of response we have seen may not be something that can be planned. Certainly we need planning but planning is not enough. I hope we continue to live together in ways that prompt this kind of generous response and make room for it.

VCIL and The Independent team have been thinking about Vermont seniors and individuals with disabilities and their families: How have things been for you during and after the storm? What worked and what could be improved if this should happen again? We would love to hear from our readers and also wanted to share the information in the FEMA article on page 9 of this issue.

From Survivor To Social Change Advocate: One Woman's Story

by Maureen Mayo

EDITOR'S NOTE: Maureen Mayo has worked at VCIL since 1995. In recent years she has helped represent VCIL in the Vermont Coalition for Disability Rights and has also been part of national campaigns with ADAPT, a powerful grass-roots organization fighting for alternatives to institutions.

She retires from her legislative and policy work this month. The Independent asked Maureen to tell us how she got involved in independent living and her journey from individual survivor of a traumatic brain injury to legislative advocate. Here is her story, along with her tips for how you can get involved.

In December of 1985, I was in a nearly fatal car accident on the access road in Berlin which caused a traumatic brain injury. I was in a coma for nine months. During this time I was transferred from the Mary Fletcher Intensive Care Unit in Burlington to another ICU and then to a TBI rehab hospital in Boston where I spent the next three years. I am told that I was not expected to survive the coma. I feel that those expectations to a large extent overshadowed my lengthy recovery process. I have little memory of those three years; which I later realized was mainly because of the number of drugs that I was made to take each day - many of which were intended to keep me quiet and under control!

About halfway through my second year there, the hospital informed my brother and me (my brother became my guardian after the accident) that my insurance would stop coverage at the end of the year; but that they were very willing to transfer me to a nearby nursing home. Lucky for me, my brother is a lawyer. After negotiations with the hospital, they agreed to begin taking me off all of my meds - something that they had never done for anyone before. It took the full six months to safely remove all of the drugs from my system.

During those six months, I went through all sorts of mood shifts; and I can actually remember waking up one day, not long before my discharge, and realizing who I was! This means that I had been more than two and a half years with little awareness



of who I was. In the end, I was discharged into an apartment and became the first person ever to be discharged from that hospital to live alone without a guardian, supervisor or caregiver on site.

Somehow, I survived - although I did manage to get on a first name basis with many of the workers in the Boston emergency room during 1986! Trial and error and physical therapy, which I scheduled myself before leaving the hospital, were the only tools that I had at my disposal. Imagine being placed in an independent living situation at the age of 33 in an unknown city with little or no memory of your prior life. Granted, the rehab did provide me with lessons in some of the activities of daily living that I might encounter. With little memory of life outside the hospital, it was a bit like sending someone to live and survive in France after a few hours of French lessons!

I got a job with Professional Nurses, working with other TBI survivors served by Vermont's TBI Waiver. Then, at the end of 1995, I took a job at VCIL where I worked with peers as a Peer Advocate Counselor. During those years I was working with peers on numerous issues (including but not limited to housing, obtaining benefits, access to durable medical equipment, food stamps or jobs).

Continued on next page

I began to more fully realize the gaps that exist in everything: from knowing what services one is eligible for, to knowing where to go to obtain services, to jumping through the hoops to apply for services, to waiting and wondering if you will get your needs fulfilled.

I became active in ADAPT in those years and learned that there is strength in numbers. At the same time, I also became more aware of how the legislative processes, both federal and state, worked. I began to realize that systems change could address many of my peers' problems better than always attempting to solve issues one person at a time.

Ultimately, this systems advocacy for peers led me to legislative advocacy - where the policies are made and funds that address peer needs are dispersed - and where I felt I could better serve my peers. In 1997 I switched to my current position as Advocacy Specialist. I work on systems advocacy and spend much of my time advocating for disability issues at the state Legislature. When the Legislature is not in session, I am involved with various state disability committees. I also do research on disability systems in other states to help us prepare for current and upcoming Vermont and national issues.

I have been involved with the Legislature directly for about 13 years and I have enjoyed testifying on the needs and concerns of VCIL peers as well as forming meaningful relationships with legislators who recognize the importance of our advocacy work to those we represent. I think that our legislative presence is important and I plan to support whoever is hired to continue this work.

If you have an interest in an issue that the Legislature is acting on, just go over to the Statehouse. You can go to the Sergeant at Arms office, which is to the door to the right of the main entrance, and ask where the committee you are interested in meets. Go and listen. Don't be overwhelmed by the building or the hearing rooms. This is "the people's house." All Vermonters are welcome to listen and have input on the decisions made by our legislators. Your first few visits may be a bit overwhelming; but once you figure out where things are, you can be as much, or as little, a part of the legislative and rulemaking process as you wish!



COURTESY PHOTO

From left, Statewide Independent Living Executive Director Peter Kriff, U.S. Sen. Bernie Sanders, and VCIL's Kim Brittenham and Sarah Launderville.

Marching On Washington

VCIL Executive Director Sarah Launderville and Community Access Coordinator Kim Brittenham represented VCIL at the National Council on Independent Living's 2011 Annual Conference in Washington, D.C. in July. Peter Kriff, executive director of the Vermont Statewide Independent Living Council, rounded out the Vermont contingent "marching on Washington." While in D.C., the three met with Vermont's congressional delegates to talk about the impact of then-looming budget cuts on people with disabilities. Staff from U.S. Rep. Peter Welch and U.S. Sen. Patrick Leahy's offices - as well as U.S. Sen. Bernie Sanders and his staff - shared similar concerns for the future of social services. Sanders, who believes our country is in its biggest ideological battle yet, gave a rousing address to the NCIL Rally attendees on the Washington Mall.

During the NCIL Conference, Launderville presented a workshop on physician-assisted suicide and Brittenham co-presented a panel workshop "Responding to Violence in the Lives of People with Disabilities" with state CIL directors from West Virginia, Illinois, and Idaho. New friends were also made with individuals from Domestic Workers Union in town for their "Care Congress" with mutual hopes of benefitting domestic workers and care providers and the people with disabilities who employ them.



got access?

by Kim Brittenham

New ADA Regulations

The Americans with Disabilities Act was updated by the United States Department of Justice in 2010. As compliance dates come into effect this year and next, the result is improved access for people with disabilities.

Programs and Services

State and local government, and any place the public goes, are now required, as of March 15, 2011, to comply with these updated requirements for:

- Service animals.
- Event ticketing.
- Wheelchairs including other power-driven mobility devices.
- Providing auxiliary devices.
- Examinations and education courses.

Here are some examples of what this means to you:

A sports arena must now tell a person with a disability and their companions about the features of accessible seating. If seating maps or brochures are provided to the general public, similar information showing accessible seating must be provided.

Service animals are now defined as dogs, not monkeys, birds, snakes or cats. Miniature horses can, in some circumstances, be considered a service animal as part of a reasonable accommodation request.

Wheelchairs can go anywhere pedestrians go. However, other power-driven mobility devices, like

golf carts or Segways, used by persons with a disabilities may be restricted

A wider variety of auxiliary devices is available. Primary consideration must be given to individual's preference when accommodations are granted. Entities must use Sign language interpreters rather than rely on a Deaf person's minor child, adult friend or family member. People who are Deaf, but not the primary service recipient, are entitled to a sign language interpreter. TTYs are still required for outgoing calls in public phone banks and to receive incoming TTY calls.

Buildings

New construction and alterations to buildings will need to comply with new standards for facilities, called the "2010 ADA Standards for Accessible Design" or "2010 Standards" as of March 15, 2012.

The 2010 Standards include guidance on types of buildings that were not originally included in the 1991 ADA Standards. These buildings must remove barriers to access and come into compliance with the 2010 Standards. Examples of these facilities are:

- Amusement rides.
- Bowling lanes.
- Court sports facilities.
- Exercise machines and equipment.
- Fishing piers and platforms.
- Golf facilities and miniature golf facilities.
- Play areas.
- Recreational boating facilities.
- Saunas and steam rooms.
- Swimming pools, wading pools, spas.
- Shooting facilities with firing positions.
- Team or player seating.

Buildings which already comply with the old 1991 ADA Accessibility Guidelines (ADAAG) do not need to make changes to comply with the new 2010 Standards, unless there is an alteration made after

Continued on next page

March 15, 2012.

What does this mean to you? After March 15 of this coming year, you can now expect all new buildings to have accessible parking and an accessible main entrance. You can expect an accessible bathroom if bathrooms are provided. A portion of all elements available for use by the public – counters, phones, computers, drinking fountains, tables – are accessible to people who use wheelchairs. You can expect accessible elements to be within reach ranges rather than be at fixed heights. You can expect elements, including protruding fixtures, to be detectable to people who are blind.

At the gym, you can find an accessible locker, a path to exercise equipment, a lift into the swimming pool. You have the right to equal access to saunas, spas, tennis courts and bowling lanes. Those accused of crimes can also expect equal access to courtrooms, the witness stand, as well as detention and correctional facility cells.

You can bring your service animal with you on the bus, to meetings, while shopping, and into restaurants. You can buy tickets (on phone, in person, online) to accessible seating in a range of locations, have your companion/s sit with you, and be guaranteed a line of sight to the stage.

Basically, you can expect all programs, goods, and services provided to the public be made accessible to you. You may need to request a specific format or an accommodation (an interpreter, or reader, or object from a high shelf), but if the request is reasonable it should be provided. If it is not, you are protected by the ADA and you can file a discrimination complaint to demand the law be enforced.

To find more information on these new updated regulations, you can visit www.ada.gov or contact VCIL.

VCIL's Community Access Program works to improve access to buildings, services and programs in the state of Vermont – and is supported by the regional DBTAC ADA Technical Assistance provider: New England ADA Center from the National Institute of Rehabilitation and Research (NIDRR). For more information, contact the Community Access Program: 1-800-639-1522 (Voice/TTY) or visit: www.vcil.org.



Rosie Miller

Landmark Anniversary Celebrated

This is a banner year for a familiar and beloved face at the Vermont Center for Independent Living. On Feb. 17, Rosemary Miller marked 30 years of working as a receptionist at the disability rights organization. She is the first person visitors see when they enter VCIL's door on East State Street in Montpelier.

Miller, who was born with cerebral palsy, has never let her disability slow her down. She grew up expecting to find a job, buy a home and pay her own bills. And that is exactly what she has done.

"Rosie is a hard worker and cares deeply for VCIL and the disability rights movement," said Executive Director Sarah Launderville. "We are proud that she is celebrating 30 years at VCIL."

Miller has witnessed many changes at VCIL, over the years, including branch offices opening around the state – in Bennington, Chittenden, Orleans, Rutland and Windham counties.

She also has many happy memories of working with people who were not only colleagues but close friends.

"I love VCIL," said Miller. "It's my family. It's my job. It's my life."

ADA Celebration Features Surprises And Sizzling Temperatures

The 21st anniversary of the signing of the Americans with Disabilities Act was held on the State-house lawn July 21. People's spirits soared, even as temperatures climbed well into the 90s, thanks to the inspirational speeches, tasty lunch, music and camaraderie that the event offered.

The Inaccessibles, VCIL house band, played a variety of inclusive dance tunes, and René Pellerin, a Vermont storyteller and comedian, gave an amusing keynote address. Long recognized by his Deaf peers as an amazing entertainer, Pellerin has dedicated his professional life to the Deaf community. He has been instrumental in the passage of laws supporting the needs of members of the Deaf community and sign language interpreters throughout the state.

Surprises were the order of the day as two VCIL employees became unexpected honorees. Alaina Clements received the Deborah Lisi-Baker Leader of Tomorrow Award. Clements has worked at VCIL since August of 2009. She has done great work for both the Home Access Program and the Sue Williams Freedom Fund. Clements, a graduate of Johnson State College, enjoys writing and has used this talent to educate people by writing a monthly column about her disability.

Launderville said, "Alaina has faced struggles in her personal journey with disability and has used the energy, learned from her experiences and this has made her the amazing woman she is. Her willingness to learn and take on new projects shows maturity beyond her years."

AgrAbility Specialist Thomas Younkman received the VCIL Advocacy Award at the celebration. Susan Elliot from Congressman Peter Welch's office helped present the award, which was an American flag flown over the U.S. Capitol June 9 on Younkman's behalf.

Launderville lauded Younkman, saying, "He has changed the way VCIL interacts with farmers who

have disabilities. He outreaches to farmers, connecting them to our movement. He organizes and connects farmers to the equipment and services available to them to help them continue to farm."

VCIL sponsored the celebration. Co-sponsors included Disability Rights Vermont, the Division for the Blind and Visually Impaired, Vermont Workers' Center, the Vermont Human Rights Commission, the Center on Disability and Community Inclusion, Vermont Statewide Independent Living Council, Vermont Developmental Disabilities Council, Green Mountain Self-Advocates, Vermont Psychiatric Survivors, VocRehab Vermont and Sorenson Communications.



PHOTO BY STEFANIE MONTE
Alaina Clements, front center, smiles after receiving the Deborah Lisi-Baker Leader of Tomorrow Award. From left are VCIL Direct Services Manager Harold Nadeau, VCIL Executive Director Sarah Launderville, and Lisi-Baker.

Post Emergency Relief For Individuals With Disabilities And Their Families

FEMA Wants To Know If You Are Getting The Help You Need

In the wake of devastating flooding from Tropical Storm Irene, VCIL is partnering with disability specialists at the Federal Emergency Management Agency to improve outreach and services to individuals with disabilities, including seniors. We want to know how emergency shelters and services are working for individuals with disabilities of all ages. Please call VCIL and let us know how emergency services are working for you. We want to know what has worked well and whether you have experienced difficulties accessing emergency information or services. FEMA and VCIL are hosting teleconferences with disability organizations each week to help disability and senior service organizations share the successes and the needs of Vermonters with diverse disabilities and FEMA is committed to addressing the problems quickly.

Are telephone lines and news coverage in your area accessible to you? Do you need pharmacy assistance, specialized equipment or health related services following the flood? Do you know how to get the disability services or FEMA support you need for yourself, a family member, or someone you work with? If you are having difficulty getting needed help with these and other issues, please let us know.

To report a problem and/or ask for assistance, please contact VCIL at 1-800-639-1522 (V/TTY). For a list of updates and resources, please visit VCIL's Web site at www.vcil.org.

Vermonters who experienced damage and losses because of Tropical Storm Irene and called Vermont's 2-1-1 line must still register with FEMA to receive federal disaster assistance. Registering with voluntary agencies or with 2-1-1 does NOT register anyone with FEMA. The phone number to register

with FEMA is 800-621-FEMA (3362).

To register with FEMA, call 800-621-FEMA (3362), go online to www.DisasterAssistance.gov or a web-enabled mobile device at m.fema.gov. Those with a speech disability or hearing loss who use a TTY can call 800-462-7585 directly; or 800-621-3362 if using 711 or Video Relay Service. Phone lines are open from 7 a.m. to 10 p.m. seven days a week until further notice.

Individual assistance to homeowners and renters includes grants to cover expenses for temporary housing, home repair, and other serious disaster-related needs and expenses, such as replacement of personal property and medical, dental or transportation costs that are not covered by insurance or other assistance programs.

FEMA's temporary housing assistance and grants for public transportation expenses, medical and dental expenses, and funeral and burial expenses do not require individuals to apply for an SBA loan. However, applicants who receive SBA loan applications must submit them to SBA loan officers to be eligible for assistance that covers personal property, vehicle repair or replacement, and moving and storage expenses.

SBA disaster loan information and application forms may be obtained by calling the SBA's Customer Service Center at 800-659-2955 (800-877-8339 for people with speech or hearing disabilities) Monday through Friday from 8 a.m. to 6 p.m. ET or by sending an e-mail to disastercustomerservice@sba.gov. Applications can also be downloaded from www.sba.gov or completed online at

<https://disasterloan.sba.gov/ela/>.

Are You Eligible For Both Medicaid And Medicare?

The state of Vermont has a planning grant to look at ways to improve services to individuals who are "dually eligible" for both Medicaid and Medicare. Upcoming issues of The Independent will be looking at health care reform and we would love to hear from you about what works ... and what doesn't. How does being on both programs affect your access to things like doctors' appointments, equipment, or prescriptions? What services and supports help you stay healthy and independent? What is important to you in your health care and in disability-related services you receive?

Share your story! We will include quotes and stories from our readers in the next issue. Write us at The Independent, c/o VCIL, 11 East State St., Montpelier, VT 05602 or email us at smonte@vcil.org

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Vermont AAAs Offer News & Resources

Here is a sampling of resources offered on the Web sites of Vermont's Area Agencies on Aging. Some listings are local but here are a few of their listings of statewide or national services available to seniors, caregivers, and in some cases, younger individuals with disabilities

Transportation Services

For those without a car, or who can no longer drive, getting around can be a challenge. Transportation programs are available for seniors (age 60-plus) and people with disabilities who need individual rides to local medical appointments and for essential shopping. For complete information on transportation options call the Senior Helpline at 802-786-5991.

HHS Launches New Web Site Promoting Long-Term Care Planning

This new Web site, www.longtermcare.gov, will make it easier for consumers to get the information they need to plan for long-term care. The Na-

tional Clearinghouse for Long-Term Care Information Web site provides comprehensive information about long-term care planning, services and financing options, along with tools to help people begin the planning process.

Low- or No-Cost Educational Opportunity For Seniors

The Vermont State College System recently amended their policy on senior students. Anyone who is 65 or older can attend any of the VSC schools (Community College of Vermont, Lyndon State, Johnson State, Castleton State and Vermont Technical College) tuition free. Students must be non-degree, meaning that they are not earning a degree. Students are still responsible for the \$50 registration fee, and for any other fees that may be associated with the specific course that they elect to take. For example, art and drawing classes sometimes have a small fee for supplies.

* * * * *

VSA Vermont Puts Out Call To Artists

VSA Vermont seeks artwork that is of high artistic quality, demonstrating originality, imagination, skillful use of materials and quality of craft. VSA Vermont invites established and emerging Vermont artists to participate in Engage, a touring juried exhibition showcasing works of art by Vermont artists with various disabilities. The premiere exhibit will be held at the Amy E. Tarrant Gallery of the Flynn Center for the Performing Arts on Feb. 26, 2012.

Artists 18 and older with various disabilities, regardless of experience or formal training, are invited to apply. Detailed application form and instructions are available at www.vsavt.org/engage.

The application postmark deadline is Sept. 31, 2011. For more information, please contact Judith Chalmer at judy@vsavt.org or 802-655-7772. Voice and relay calls are welcome.

Complete Streets Bill Becomes Law

Safe Access For All The Goal

After a two-year campaign of outreach, public education and statewide advocacy, AARP applauds the Vermont Legislature for its passage of a Complete Streets bill. Vermont and 45 other state organizations worked together for passage of the bill.

Complete Streets policies ensure that transportation agencies and municipalities routinely design and operate the right of ways to enable safe access for everyone on the road. Complete Streets guidelines make community and roadway planners think about how people can access the community without a car. The design considerations apply to new roads and those being redesigned or rebuilt.

"Thanks to the action of our lawmakers, Vermonters can look ahead to roadways that are designed for safe and convenient travel by all users and all ages," said Greg Marchildon, AARP Vermont state director. "We believe this is how Vermont should plan its streets, town centers, cities and suburbs, so that people who cannot drive or want to drive less have more ways to get around. Many current road and sidewalk designs create barriers and discourage people from walking and biking," he said. "We need to make it easier for people to leave the car at home and to be active and fit."

Pedestrians, cyclists and public transit users will benefit from this important change in how roads are designed and rebuilt. Recent street and intersection surveys conducted by AARP in Brattleboro, Rutland, Burlington and St. Johnsbury revealed a host of problem areas in these communities – many of which could be addressed for little or no funds.

The statistics on this issue paint a compelling picture. A recent AARP report found that two in five Americans age 50-plus say their neighborhood sidewalks are inadequate. Incomplete streets include anything from no sidewalks or bike lanes to

broken sidewalks and unsafe crossings. Some 47 percent of Americans over the age of 50 reported not being able to safely cross a main road near their home. This is a key reason why 65 percent of non-driving seniors make fewer trips to visit family, friends, shop or attend community events. It is unacceptable that so many older Vermonters are staying home and missing out on activities that are so vital to mental and physical health due to inadequate pedestrian access or safety concerns. By 2025, people age 65-plus will comprise nearly 20 percent of the population. Yet two-thirds of transportation planners and engineers say they have yet to begin addressing older people in their street planning.

"AARP Vermont and our partners especially thank Rep. Mollie Burke of Brattleboro who sponsored this bill and helped move it through to passage," said Marchildon. "Her support was critical in this campaign."

Advocates also expressed appreciation to transportation committee chairmen in both the House and Senate – Rep. Patrick Brennan and Senator Richard Mazza – as well as all members of those committees.



2011 COVE Legislative Summary

by Michael Sirotkin, Esq.

As predicted, the 2011 session of the Vermont Legislature ended on time in early May. With one party strongly in charge of both chambers and the executive branch, it was clearly the most orderly adjournment in recent memory. Budget issues and health care reform dominated the session. Fortunately for COVE and the Vermont seniors we represent, threatened budget cuts to Choices for Care were, at the last minute, totally averted.

Progress was also made on the issues of Adult Protective Services, transportation, hospice and palliative care, and home heating and energy assistance. Several of the above issues were also accompanied by requirements for further study over the summer and fall, which will require our careful attention and participation over the next few months.

Choices for Care: Far and away the biggest challenge faced this year were the proposed cuts to Choices for Care. For the approximate 1,500 recipients who would have been impacted, they could have lost on average over \$3,000 each in critical supportive home and community-based services. Being low income, most would have had no means to afford to replace these services. The overall proposed cut would have amounted to a 40 percent (\$5.2 million reduction to the current \$13 million) reduction in respite/companionship services and assistance with IADLs.

While the size and impact of these cuts should have been self evident, the administration initially downplayed any resulting hardship – saying that they could adjust the services in individual households so that no one would have to enter an institution, and no one would even need to see any significant loss in support or quality of life. COVE did our own informal, unscientific survey of all case managers and found that roughly 15 percent or more of these Choices for Care participants would

need to go into nursing homes, which could easily wipe out entirely the \$5.2 million in savings projected by the state. While ultimately the state acknowledged that these cuts would diminish the quality of life for the vulnerable Vermonters dependent on these services, they never wavered from their savings figure of \$5.2 million. We looked at the possibility of a legal challenge to set this massive cut apart, but ultimately focused on Statehouse and grassroots lobbying.

We started using individual stories with individual senators and worked the press hard. We also looked at other sources of funding, including rainy day funds and new tax revenues. Just before the budget moved to the Senate floor, it looked like we were clearly facing a committee vote which would have sustained the House's position of only restoring half (\$2.6 million of the \$5.2 million) of the cuts. Fortunately, with some digging we found that the overall Choices for Care budget was running a \$7- to \$10-million surplus for FY 2011. We were able to argue that the money to avoid these cuts was clearly available and the Senate Appropriations Committee, the full Senate, and then the House, all agreed to avoid the cuts.

Fuel and Energy Assistance: The need for fuel assistance hit record highs last winter and unexpected increases in fuel prices made the winter a particularly challenging one for many Vermonters. Fortunately, in December the federal government increased our block grant from \$14 million to \$25 million. Without that last minute bailout, benefits would have had to be severely reduced.

Though we survived this heating season, the same ominous factors face us for next year – with prices showing no sign of abating and the federal government (including the president's proposed budget) calling for a 40 percent reduction in federal help.

The most telling numbers given to us on the task force is that next year's worst-case scenario could see an average benefit of just \$400 (which could be less than what some companies require to pay for a minimum delivery of 100 gallons). The average home will cost \$2,800 to heat. So our fuel program could wind up paying just 15 percent of the average heating cost, as opposed to the programmatic goal of 60 percent.

Next year's potential crisis in fuel assistance has already been flagged by legislators as a major problem area for next year's budget. In fact, many of the pleas this year for use of rainy day and other reserve funds were denied using the potential crisis in LIHEAP as to why cuts this year could not be restored. Hopefully, these same legislators will remember their reasoning if and when we need them to appropriate significant state funds to backfill federal reductions to LIHEAP come next winter.

One piece of very good news that could help with our fuel assistance problems was the just-released decision by the Public Service Board. The petition by AARP to establish a low-income electric assistance program has now been preliminarily approved. While all the details have yet to be finalized, the program will apply to all Central Vermont and Green Mountain Power (about 90 percent of all electric customers) who have incomes below 150 percent of poverty. Those qualifying will have a 25 percent subsidy on their bills and can receive a one-time arrearage waiver when first applying. This new program can take significant pressure off of our fuel program as folks who heat with electricity can also qualify for fuel assistance and the fuel assistance crisis program currently pays to avert electrical disconnects (so furnaces can keep running). With the new low-income electrical assistance program, we believe there will be far fewer disconnects and, thus, less pressure on the fuel assistance program.

Transportation (H.198): "Complete Streets" was a two-year legislative effort led by AARP, with the support of COVE and many other environmental

and consumer groups. It passed in the final days of the session and will serve to ensure all future road projects take into consideration the transportation needs of mobility-impaired Vermonters and the promotion of alternative means of transportation. It will promote walking, biking, public transportation, etc. in the future design of new roads, as well as in the existing road improvements and expansions. It does have the flexibility of towns getting waivers from its requirements under special circumstances.

Health Care (H.202): As mentioned above, health care reform dominated the Statehouse. Most of the new law sets out a road map for getting to a single-payer plan in 2017 (or 2014 with a federal waiver). Many of the details are left to a powerful five-member board appointed by the governor. The board is charged with making more detailed recommendations on the single payer reform proposal for the Legislature to review and approve next year and into the future. The controversial issue of how to pay for the system – Dr. Hsiao recommended a payroll tax on employees and employers - is deferred for this year and not part of the legislation.

Marge Power put together excellent comments regarding senior citizen concerns with the original Hsiao study and highlighted two major omissions – long-term care as a covered benefit and non-inclusion of Medicare in the single-payer model – as well as the proposal to subject working seniors to a payroll tax for which they will get nothing in return. The payroll tax issue will not be addressed this year, as no financing proposal is included in the bill. How Medicare will ultimately be treated under Green Mountain Care is still unclear and will be the subject of further study by the five-member board and future sessions and possible waiver requests. We were successful in getting mention of long-term care as a benefit that should be studied, if affordable, for future inclusion in the benefit structure of Green Mountain Care.

H.202 would also repeal the Medicaid Advisory Board, upon which COVE currently has a statutory

seat, effective this July; and would replace it with a new Consumer and Health Care Exchange Advisory Board. It is very possible that COVE will retain its seat on the new board, as the new board's required composition will be similar to the old.

Adult Protective Services (APS): Vermont's APS program has deteriorated over the last few years with less staff and resources protecting elders and other vulnerable adults from abuse, neglect and exploitation. We find our state inexplicably ranked near the bottom of the states in the numbers of investigations and substantiated cases, as well as seeing too many cases being unreasonably delayed in their resolution. We need to treat these cases every bit as seriously as cases of child abuse, and need to do a full review of why the program is not functioning as well as other states' programs.

COVE has been meeting with AHS and DAIL since last fall to address the multiple challenges/violations in this program. We had asked Vermont Legal Aid to explore the possibility of litigation to bring the state into compliance. On the eve of VLA filing a complaint, DAIL agreed to work collaboratively with advocates establishing written protocols and benchmarks to address the shortcomings and delays in APS.

One of the areas where disagreement still exists is the need for formal rules to govern the future operation of the APS program. At the very end of the session, COVE and others tried to pass legislation (H.290) which would have mandated such rules. It passed the House; but because it was offered just a week before adjournment, the Senate rules prohibited its consideration.

Hospice and Palliative Care (H.201): Despite some road bumps late in the session, the bill was signed by the governor in early May and is mostly the same as what passed the House in March. While the Senate's review was less detailed than the House's, the administration weighed in with a greater level of concern about several provisions,

which resulted in a somewhat weaker bill.

In particular, the Department of Vermont Health Access (DVHA) indicated that seeking a waiver for enhanced Medicaid and Medicare services (whereby by one could receive hospice care and curative care simultaneously, and with a 12-month versus the current six-month life expectancy) would be prohibitively expensive. Despite unified opposition from the full group of advocates (hospitals, medical society, Vermont Ethics Network, VCDR, COVE, etc), the Senate Health & Welfare Committee elected to let DVHA pare back the waiver to include it only in a waiver for those dually eligible for both Medicare and Medicaid (as opposed to all Medicare beneficiaries) by July 2013.

H.201 begins with a set of comprehensive findings establishing the rationale for the bill, citing the gap between the desires of Vermonters at the end of life and the care they actually receive. The findings focus largely on the benefits of hospice and barriers to access.

The bill encourages Vermont health insurers to offer plans that include enhanced hospice access, and gives detail as to what this terminal care management program should include. These are based largely on a heralded Aetna study on the patient benefits and cost savings of integrating hospice. The bill also mandates the inclusion of palliative care, hospice and end-of-life pain management in the Blueprint for Health.

The bill requires DAIL to revise its current policies to allow individuals who have been admitted to hospice to apply for Choices for Care, and to ensure that these individuals are treated no differently than individuals who first enroll in Choices for Care and then enroll in hospice. This change will be in effect for a trial 12-month period, during which DAIL will monitor specified evaluative measures to determine the effects and cost of the change.

H.201 mandates that the Medical Practice Board

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VCDR's 2011 End-Of-Session Legislative Report

by Deborah Lisi-Baker and Karen Lafayette

The Vermont Legislature adjourned the 2011 legislative session on May 6. This was the first legislative session under the administration of Gov. Peter Shumlin. This summary highlights action taken on VCDR priorities and on other budget and policy issues that VCDR monitored on behalf of the disability community.

VCDR members, other advocates, and many members of the disability community spent time at the Statehouse testifying in the House and Senate Appropriations committees, the Senate Health and Welfare Committee, and the House Human Services Committee on budgetary issues, telling their stories about the impact of budget cuts on people's lives in Vermont. The 2011 session began with a \$176 million budget shortfall for fiscal year 2012. The Legislature closed the gap through \$88 million in cuts, \$60 million in one-time funding transfers, \$24 million in new taxes and \$9 million in new revenues. About \$4 million of one-time money was put into the Agency of Human Services caseload reserve fund.

The governor had proposed over \$43.8 million in cuts to Human Services programs in January. Overall the Legislature scaled back the Human Service proposed cuts from \$43.8 million to \$38.7 adding back \$5.1 million in state spending. That change brings in \$5.1 million in additional federal funds.

This is the fourth budget year in succession that Vermont has made significant cuts to Human Service programs. Language in the Appropriations bill looks at the consequences of the budget reductions and directs the administration to minimize impact on individuals and to search for cost saving measures in Choices for Care and other programs.

BUDGET HIGHLIGHTS

Mental health and developmental services: The governor had proposed a 5 percent reduction in mental health and developmental disability services. The governor's recommended budget included a reduction of over \$3.2 million in the Department

of Mental Health and a proposed reduction of over \$7.6 million in Developmental Disability Services. The reduction in developmental services would have required the department to absorb the expected increases in general caseload, high school graduates, and Public Safety. The 2012 budget passed by the Legislature reduced these proposed cuts by 50 percent.

The Budget Bill also requires providers to "include developmental service program participants in decisions regarding changes in their service plans."

Choices for Care: The governor's proposed reductions in the Choices for Care Respite and Companion Services Program would have reduced state and federal funds for this program by over \$3 million. This reduction would have resulted in a 50 percent reduction in service hours for people who need help with incidental activities of daily living (IADL). These are activities such as shopping, meal preparation and light housekeeping. Fortunately, the Legislature restored 60 percent of the funding in the IADL Respite and Companion Services and approved the use of expected savings to fully fund these services.

Attendant Care Services Program – Medicaid PDAC: ASP participants will receive reduced assistance with household tasks such as help with shopping and housework. Funds for these services were cut by \$165,000, half of what the administration had proposed.

Non-Medicaid PDAC (Participant Directed Attendant Care): The governor's proposed budget was supposed to realize \$1 million in savings by freezing the list of applicants eligible for this program. The final budget for this program includes funding to serve four additional individuals and two additional slots for "new" applicants for these personal assistance needs. This represents \$40,000 in additional general fund dollars, a 6 percent increase in the budget.

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Area Agencies on Aging - Triple "A"s: Funds are used by the AAAs to support a variety of services including case management, information/referral/assistance, home-delivered meals and congregate meals and family caregiver support services. The governor's proposed budget would have cut the program by \$200,000. The Legislature restored \$50,000 for nutrition and meal services.

Autism Insurance Language Implementation Delayed: The administration was concerned about the date set for implementing this new coverage. The section of the bill delays coverage by private insurers to Oct. 1, 2011, and for Medicaid to July 1, 2012.

Children's Palliative and Curative Care: The Department of Vermont Health Access (DVHA) will apply to the federal Centers for Medicare and Medicaid Services (CMS) for a waiver that would allow Vermont Medicaid programs to provide concurrent palliative and curative care. The DVHA proposal goes further than the federal reform. Under this proposal, children with life limiting illnesses who are not expected to live until adulthood could receive palliative care without stopping curative Medicaid services.

POLICY LEGISLATION

The following is a summary of legislative or administrative action on bills that were VCDR platform priorities and other legislation followed by VCDR:

Respectful Language Act 24 (S.90): The "Respectful Language" bill was signed into law by the governor at a ceremony on May 11 of this year. Green Mountain Self-Advocates took the lead on testifying and promoting this legislation. The bill creates a working "study" group to identify words that should not be used in Vermont statutes and regulations, and suggest words that reflect a positive view of people with disabilities. The committee membership includes members from the Vermont Coalition for Disability Rights, Green Mountain Self-Advocates, the Vermont Center for Independent Living, Vermont Psychiatric Survivors and others. The report is due to go to the Legislature by Nov. 1.

Non-Driver ID Notification in Act 46 (S.94): This

bill contains the House amendment to instruct motor vehicles to send out first-class mail notices 30 days in advance for non-driver ID renewals.

Student Athletes and Concussions Bill (H.46): The bill as introduced passed the House and was added to S.100, an act updating education law. This legislation includes language changes to the state's Special Education Advisory Council. The H.46 amendment to the education bill puts in place some safety precautions for schools when there are concerns about youth athletes suffering or suspected to be suffering from a concussion or other head injury. The bill prohibits a coach from allowing a student who was removed from a sports activity because of a concussion from being able to participate again until he or she has been examined by a health professional and receives written permission. It includes development of guidelines and training requirements.

Palliative Care - Act 60 (H.201): The palliative care legislation was signed into law on June 1, 2011. The bill as introduced was based on the recommendations from the Palliative Care and Pain Management Task Force. The Vermont Center for Independent Living serves on the task force. The law encourages insurance companies to offer enhanced hospice benefits, including an expansion of the standard six-months benefit to 12 months while also allowing individuals to continue to receive curative care. The law asks the state to implement a one-year expansion of services, allowing individuals on hospice to also receive Choices for Care services. Other sections address Do Not Resuscitate orders (DNR), license renewal and medical education.

Challenges for Change Outcomes - Act 2 (H.1): This bill restates the desired outcomes for individuals with disabilities, mental health needs or substance abuse that were included in last year's Challenges for Change legislation.

Transporting Patients with Mental Illness - Act 19 (H.427): This is an act extending the state reporting concerning transportation of children in state custody and transportation of individuals in the custody of the commissioner of mental health. This bill extends the deadline to collect the data

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about the transportation of individuals with mental health concerns.

Complete Streets - Act 34 (H.198): The purpose of this bill is to ensure that the needs of all users of Vermont's transportation system - including motorists, bicyclists, public transportation users, and pedestrians of all ages and abilities - are considered in all state and municipally managed transportation projects and project phases, including planning, development, construction, and maintenance, except in the case of projects or project components involving unpaved highways.

Health Care Professional Regulation (Hearing Aid Dispensaries) - Act 66 (H.420): Section 10a of this legislation amends the professional regulation law and puts a member of the public who is an individual with significant hearing impairment and who uses a hearing aid regularly, to sit on the advisory panel for hearing dispensaries.

Change in Disability Parking - Act 62 (H.443): VCDR opposed language in this legislation, which includes a change in policy in parking for people with disabilities in municipal and state parking facilities. The legislation "clarifies" the law pertaining to the length of time that allows for 10 days "free" parking, but also reduces the time from 10 days to "24 continuous hours" in state and municipal operated parking garage facilities (including airports). Legislators on the House side are willing to review this change in policy next session as the amendment (to reduce the number of days) was presented late in the process and changed - with little formal discussion.

Universal and Unified Health System - Act 48 (H.202): This bill sets up the process to ensure universal access to and coverage to all Vermonters. It is the intent of the General Assembly to create Green Mountain Care to contain costs and to provide, as a public good, comprehensive, affordable, high-quality, publicly financed health care coverage for all Vermont residents in a seamless manner regardless of income, assets, health status, or availability of other health coverage. It is the intent of the General Assembly to achieve health care reform through the coordinated efforts of an independent board, state government, and the citizens of Vermont, with input from health care professionals, businesses and

members of the public.

Adult Protective Services (H.290): This bill proposes to require the secretary of the Agency of Human Services to adopt rules governing the implementation of the statutory responsibilities of the Department of Disabilities, Aging, and Independent Living, Division of Licensing and Protection, with respect to adult protective services. This bill was passed by the House and is pending in the Senate.

Medicaid for Working Persons with Disabilities "Work Incentives" (H.422/S.89): The bill promotes additional work incentives and access to health coverage for individuals receiving Medicaid for Working Persons with Disabilities and would make it easier for these individuals and eligible spouses to access health coverage. Legislation was not passed, but the administration agreed to proceed with plans to implement some proposals in the legislation as introduced. Vermont recently received a federal grant which provides funds to hire a subcontractor to do the cost analyses and write the Medicaid waiver requests entailed in the legislation. In addition, the prospective grant would also entail exploration of work incentive aspects within the Affordable Health Care Act, dual eligible waiver and other state health care reform.

Positive Behavioral Intervention/Prohibition of Restraint and Seclusion (H.204): This bill proposed to promote positive behavioral intervention and supports in schools, reduce the use of physical restraint, and prohibit the use of mechanical, chemical, and prone physical restraint and seclusion as methods of addressing challenging student behavior. Testimony was taken last year in House Education and the committee chairperson urged the Department of Education and advocates to pursue adoption of rules. Legislation was introduced again this year while rules were still being proposed.

New rules have now been adopted by the Department of Education. VCDR members participated in the rulemaking process and support most of the rule changes because they provided needed and consistent policies to guide schools throughout the state. However the new rules allow continued use of harmful restraints in certain situations, practices which VCDR would prefer to see prohibited. VCDR will continue to monitor this issue.

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OTHER LEGISLATION

Two bills that VCDR supports did not see action this year. These were H.308, which proposes to require health insurance coverage for medically necessary supplements and modified foods for individuals with the metabolic disorder phenylketonuria, and H.235, Van Modification, which authorizes funding for grants to make vehicles wheelchair accessible.

Legislation that VCDR opposed, Involuntary Medication and Physician-Assisted Suicide, did not move forward this year, but are expected to be up for discussion again next session.

NEXT SESSION

There were few opportunities this legislative year to pursue any increases in funding, or new programs. Many challenges are ahead as budget reductions take effect, healthcare reform progresses, and federal budget reductions are expected to widen the state's budget deficit next year.

VCDR thanks the Vermont Developmental Disabilities Council and our member organizations and friends for their ongoing support and shared advocacy to improve policies and services for individuals with disabilities in Vermont. We can only do this work well by doing it together.

"Nothing About Us Without Us"

For more information, or to get involved in VCDR's legislative and policy work, contact VCDR at:

11 East State St., Suite 2
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or visit our Web site:
www.vcdr.org

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(MPB) institute by rule a 10-hour CME requirement by 2014. In particular, the MPB shall require evidence of physician competence in recognizing the need for timely consultations and referrals to assure fully informed patient choice of treatment options, including hospice, palliative care, and pain management services.

H.201 also implements comprehensive changes to the Clinician Order for Life Sustaining Treatment (COLST) statutes. The bill calls for a unified COLST and Do Not Resuscitate (DNR) form to be developed by the Department of Health. It also establishes specific DNR identification jewelry as only necklaces, bracelets, or anklets. This is to assist first responders in knowing what to look for when arriving at a scene. The bill enhances the procedures and obligations on providers, health care facilities, residential care facilities and health insurers.



To share your concerns or for more information on how you can get involved, contact COVE:

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Words for the Journey

EDITOR'S NOTE: Much to our disappointment, K.K. Wilder is no longer writing for The Independent. In her final "Disability Happens" column, K.K. wrote, "Plans and results, like life, have a way of taking on their own paths. Perhaps one of the main things to remember is to be guided by our faith, not our fear." Like so many of K.K.'s messages, this one is a source of strength, rippling out from the still center of K.K.'s prose. It has particular meaning for me now; as I watch so many Vermonters recreate their communities after Tropical Storm Irene. K.K. has a way of reminding us that it is OK to step back, take stock, and hold the moment in our hands like a living promise. We send this bouquet of K.K.'s words as company during this time of change and renewal. And to K.K. we send our love and thanks.



K.K. On Keeping The Blues Away

We were talking about what we disabled or elderly people can do when we hit the rough patches. You know – those times when we're feeling just plain bleak. We talked about calling on good memories or dreams, about looking for at least one joyful moment in every day, and thinking of what we're still able to do in spite of our age or disabilities. I'm fortunate to have some other items in my bag o' tricks for blue or discouraged days and can guarantee I find them totally useful.

K.K. On Staying Visible

First I make sure there's a pleasant expression on my face, then I look straight into the eyes of the person approaching me, and say a very friendly, "Good morning!" Their reactions are very educational for me and, I hope, for them. Some of them put their heads down, remain silent, and keep on walking. Some look at me out of the corners of their eyes and mumble, "Hi." Some look up and smile, nodding their heads. But most, and I'm not kidding you, the great majority, smile at me face-on and say, "Yes! Good morning!" in the most welcoming and inclusive way. If I am fortunate enough to see the person again on some of my more familiar routes, they speak first! Hallelujah!

K.K. On Growing Old

As far as I know, disabilities and/or aging can make us bitter or better. I believe the choice is up to each of us ... We don't have much of a choice of the happenings in life ... the losses, the sorrows, the need to let go of previous abilities. But, luckily, we do have the choice of how we decide to face such things. When we allow them to make us better people, we've been given a priceless gift. And *growing old* is one of them.



B u l l e t i n B o a r d



Looking For Information And Resources On Hearing Loss?

The Hearing Loss Association of America has posted its newly designed and reformatted Web site. Check it out at: www.hearingloss.org

HAAA is working to eradicate the stigma associated with hearing loss and raise public awareness about the need for prevention, treatment, and regular hearing screenings throughout life.

ReCycle Catalog

The Vermont Center for Independent Living maintains a ReCycle Catalog, a listing of used disability equipment that people are seeking and disability equipment that is for sale. To receive a copy of the ReCycle Catalog or to list an item, contact Ericka Reil at 802-229-0501, or visit us online at www.vcil.org/resources/recycle-catalog

Got PRIDE?

The PRIDE curriculum was developed by the Vermont Statewide Independent Living Council. The purpose of the program is to bring disability pride and awareness to students with and without disabilities. PRIDE materials are available free to interested schools. PRIDE's resources include K-12 lesson plans that meet Vermont Learning Standards, a network of participating schools and community ambassadors, and updated listings of books and learning tools. The Vermont SILC is partnering with the Center on Disability and Community Inclusion at UVM to bring PRIDE materials to more Vermont classrooms. To learn more about the program and materials, call the PRIDE Outreach Project at 802-656-1334 or visit CDCI's PRIDE Web page at

www.uvm.edu/~cdci/pride

To find out about other disability or senior programs, activities, and services, contact the Senior Helpline (1-800-642-5119) or the I-Line at the Vermont Center for Independent Living (1-800-639-1522)

SUBMISSION DEADLINE

Submissions for the next issue must be received by Nov. 18, 2011