

THE INDEPENDENT
c/o VCIL
11 E. State St.
Montpelier, VT 05602

NON-PROFIT ORG
U.S. POSTAGE PAID
PERMIT #266
BURLINGTON, VT

Vol. 16, No. 2 Summer 2009

The Independent

A VERMONT PUBLICATION FOR ELDERS AND
PEOPLE WITH DISABILITIES

Working for Change

In this issue we share the COVE and VCDR summaries of the last legislative session and the continuing budget debates. We also celebrate the Americans with Disabilities Act and the power of individuals to make a difference. On page 3 we share Connie Curtin's thoughts on advocacy and social change. Connie founded the Vermont Parent Information Center and has been a national leader in parent advocacy and education rights and reform.

Our ability to make a real and lasting difference often comes down to whether we are willing and able to reach out to one another and do what it takes to make needed change. Connie has been a quiet and persistent change agent; it is worth taking her approach to heart as we work for a future that benefits all people.

The quality and nature of the future we are making for people of all ages depends to a great extent on how well each of us and all of us together honor this opportunity to live well together and renew our shared universe.

Do you have thoughts on what makes advocacy successful, a person or voice that has mattered to you, or a story that demonstrates why we need to be fighting for resources or for change today? We want to hear from you. Send a letter to The Independent. We will publish these Vermont stories in the next two issues of the paper.

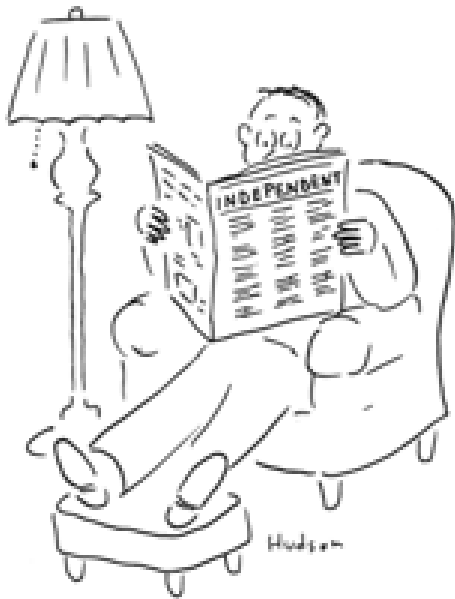
- Deborah Lisi-Baker



Photo by Kevin Plant

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Letters to the Editor

In Praise of Cats And of One in Particular

Ruben and I recently got an all-black cat with brown highlights on the outer edges of her fur. Her name is Copycat, or as Ruben puts it, Cantaster or Chowcat. She looks out through our two large windows giving our newest neighbors a devilish look at times, or so they have said.

This latest cat of ours has twice saved Ruben's life, because he has medical problems. They have happened a few moments before the cat has run in and gotten me. She'll usually track me down; that's the way she is.

People don't realize what goes on with many of us with medical problems, but dogs and cats we have can sense when a person who provides them with food is having a medical problem; they run to let others know. She has done that for us.

*Paula Mongeon and Ruben Whittemore
Winooski*

You and Your Wheelchair

The University of Connecticut is requesting help from wheelchair users. The school is conducting research on wheelchair users' opinions pertaining to wheelchair technology and services. The survey takes about 10 minutes to complete, and includes a chance to win a \$50 Amazon.com gift card. Your responses will remain confidential and will directly contribute to an increased awareness of problems faced by wheelchair users.

Call 860-728-2143 or the survey can be found online at:

[www.zoomerang.com/
Survey/?p=WEB229DYFNSVLC](http://www.zoomerang.com/Survey/?p=WEB229DYFNSVLC)

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The Power of Today: Reflections on Advocacy

(Editor's note: This essay is an excerpt from Connie Curtin's remarks at a party celebrating her work as the founding director of the Vermont Parent Information Center, which is now part of Vermont Family Network.)

Throughout my career, I have found it most rewarding to follow the starfish philosophy. When you find a bunch of starfish stranded on the beach, you toss as many of them back into the ocean as you can, even though the ocean may toss them back. Some may believe that the ocean is the problem and that trying to fix it is more important than saving the starfish. But even if the ocean could be fixed; it doesn't stay fixed. An oversimplification but you get the idea.

I remember a story I heard about Mother Teresa going to receive an award for her work fighting hunger. On the way to the ceremony, she came across a person on the street who was hungry. And instead of attending the award event, she found food to feed this hungry person. So I know I follow good teaching when I say that it is more important to first extend a helping hand to a child and family in need before trying to fix the system that has failed to meet their needs.

I am very grateful to the many families that have welcomed me into their homes and hearts and asked for my help. They have taught me more than I was ever able to teach them. Judy Heumann, a former U.S. Assistant Secretary of Special Education and a person with a disability, once said to a room full of parent advocates, "Parents of children with disabilities are changing the landscape of this country." She was right. Every parent that advocates improving their child's well-being, health, mental health, education and adult life is tearing down one brick in the barrier that limits opportunities and access for children with disabilities in society. Their efforts make the world a better place for all of us. I have learned that the greatest measure of our advocacy lies in the doing, not in the winning. While we should be confident that we can make a difference, "Our main business is not to see what lies dimly in the distance, but to do what lies clearly



Connie Curtin

at hand." (Thomas Carlyle). My hope is that VPIC played a part in helping families make a difference in their children's lives each and every day. I have learned to be patient when it comes to the future, but I do know what can be done today.

I encourage you to think of your advocacy as a stone thrown into a river. That one action creates many ripples on the water's surface, but as the stone sinks to the bottom, it becomes part of the river, changing that river forever.

Working in the disability field was an opportunity that chose me; I didn't choose it. Yet, it has become my life's work and I have become a better person because of it. This work has served as my greatest teacher. It has taught me about the true meaning of parenting, about the unlimited potential of children born with physical, emotional and learning challenges and about the importance of doing what you believe is the right thing, even when it's the unpopular thing to do.

National Health Reform: **Will It Offer What Most Americans Want?**

Health care reform hasn't had this kind of national attention since the early Clinton years, but it is too early to tell whether it will include the community long-term care services so important to seniors and individuals with disabilities and their families. Several efforts are under way to include long-term care in health reform; getting the choices and coverage most Americans want is not going to be easy.

CLASS Act Opens the Door but Raises Many Concerns

The CLASS (Community Living Assistance Services and Supports) Act would allow working adults to choose to sign up for long-term care coverage. The Older Women's League and other senior advocates are very concerned that the CLASS Act uses "age rating" to set the premiums for the new program. Individuals between 50 and 65 will be hit the hardest. They will be expected to pay a higher premium for their coverage. The CLASS Act does not address the long-term care interests and needs of individuals who are not in the work force and it does nothing to eliminate the institutional bias in long-term care. If you pay for your long-term care services under the CLASS Act, you will most likely get most of your care in a nursing home.

Americans Call for Real Change

A new survey released in July from the Lake Research Partners and the SCAN Foundation finds that seniors and individuals are not alone in wanting health care to include long-term care. Nearly eight in 10 Americans (79 percent) say they would be more likely to support a health care reform proposal that includes improved access to home and community-based long-term care. The concern is widespread and bipartisan: 67 percent of Republicans, 65 percent of independents and 91 percent of Democrats say they are more likely to support health care reform that includes long-term care. Remarkably, 78 percent say they would benefit personally from this expansion and 92 percent say it is important to have long-term care coverage pay for services in the home rather than requiring

people to go to nursing homes to get the long-term care services they need.

Community Choice Act: the Missing Piece of Health Reform

Disability and senior advocates have been advocating the inclusion of the Community Choice Act in any health care reform proposal from the administration and Congress. The CCA requires states to offer community-based supports for Medicaid-eligible consumers who want to stay in or return to their homes and communities. It will provide a real alternative to institutional care that many states lack, as well as saving Medicaid billions of dollars nationally. The House version (H.R.1670) has been referred to the House Energy and Commerce Committee and the Senate bill (S.683) has been referred to the Senate Finance Committee.

Bernie Sanders' staff tells us that the CLASS Act has been incorporated into the health reform legislation before the Senate Health, Education, Labor and Pensions (HELP) Committee but that Senate Finance has yet to determine whether they will include the Community Choice Act in their drafting of health care legislation. To date, the three House committees working on health care reform legislation have yet to include either the CLASS Act or the Community Choice Act.

Want to Help Advocate?

Vermont has been a leader in getting rid of the institutional bias in long-term care, but cuts in state programs make many people nervous. If community long-term care is incorporated into national health care reform, our community services may be less vulnerable to state revenue shortfalls.

What is your story? Do you live in a nursing home, or if community supports are cut in Vermont, will you end up in a nursing home? Please mail your story to The Independent, c/o VCIL, 11 East State St., Montpelier, VT 05602 (or e-mail it to smonte@vcil.org). You can also contact Vermont's congressional delegation directly and share your story and concerns about health care reform and long-term care options.

Promoting Participation and Rights

by Deborah Lisi-Baker

Karen Schwartz is the director of the Vermont Developmental Disabilities Council. She got involved in disability rights work through personal experience and through a desire to use her legal training to make systems work for people.

"I was trained as a lawyer, and when I came to Vermont I ran the paralegal program at Woodbury College," she said. "I had some very limited experience helping people who had to leave their jobs get Social Security Disability. Then my son had problems at birth, and it took us some time to get the information and help we needed. The thing that made the most difference was being connected to other parents where we lived in Lamoille County. Through that network I heard that VTDDC helps send family members to trainings. I also learned that there was a job available with a new program, the Family Infant Toddler Project."

Karen said she ended up working with the early intervention program for the next 11 years, first in Lamoille County and later in Washington County as a "Community Resource Parent" (later called Family Resource Consultant). In addition to helping set up learning and therapy programs for children birth to 3, she helped connect their families with other resources such as housing.

Her experience working with individual families and her own experiences as a parent advocating

for her child have convinced Karen of the importance of people sharing their stories and speaking out. "Nothing helps someone understand better than hearing concrete examples from the lives of people who are neighbors. Legislators pay attention when their constituents – voters from their community – let them know directly what is happening in their lives." Creating opportunities for individuals and families to speak out and share their experiences is an essential element of the projects supported by the Vermont Developmental Disability Council.



Karen says that both services and systems change work are important and complementary. "Both are rewarding in different ways. It felt very satisfying to be part of an early intervention system that did not exist when my son was young, and to help a child and family get off to a good start. Sometimes the systems work feels more difficult because it takes a long time for things to change, especially people's attitudes. On the other hand it is exhilarating to meet and work with advocates including people just finding their voice, and to see

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We need your voice!

We are looking for individual and family members to join the Vermont Developmental Disabilities Council.

You don't have to be eligible for developmental services in Vermont to apply.

Members let us know what is happening for people with developmental disabilities** and

decide how to use funds to have the greatest impact on people's lives.

For more information about VTDDC, what it means to be a member and how to apply, call:

802-241-2613

Toll free at 888-317-2006

e-mail: vtddc@ahs.state.vt.us

On the Web: www.ddc.vermont.gov



** A disability before the age of 22 that impacts 3 areas of daily living.

VERMONT PROTECTION & ADVOCACY SEEKS YOUR INPUT ON OUR PROPOSED FY2010 PRIORITIES

Vermont Protection & Advocacy, Inc. (VP&A) 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 14-member staff teams with the nine-member staff of the Disability Law Project of Vermont Legal Aid (DLP) to create the cross-disability legal protection and advocacy system for Vermont. ***Sneak preview: Watch for a name change coming this fall!!***

PROPOSED 2010 PRIORITIES FOR PROTECTION & ADVOCACY FOR INDIVIDUALS WITH A MENTAL ILLNESS (PAIMI)

Priority 1: Investigate individual cases of abuse, neglect, and serious rights violations in inpatient facilities (Vermont State Hospital-VSH, designated hospitals, designated agencies, emergency rooms, facilities for minors), prisons/jails, and community settings.

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.

PROPOSED 2010 PRIORITIES FOR PROTECTION & ADVOCACY FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES (PADD) and PROTECTION & ADVOCACY FOR INDIVIDUAL'S RIGHTS (PAIR – works with people with disabilities other than mental illness or developmental.)

Health Priority Area

- People with disabilities have access to needed health care/long-term care; children with mental health needs will receive needed services and supports.

Education Priority Area

- Students with disabilities are not harassed, are not subjected to Restrictive Behavior Interventions, and are not unlawfully disciplined, 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. Federal and Vermont entitlements and procedural protections are preserved.

Quality Assurance Priority Area

- Olmstead: People with disabilities have access to appropriate services/supports in the least restrictive, and most integrated, settings.
- Children in institutional and other residential and alternative educational settings will receive protection and advocacy services.
- Access to Developmental Services for children and adults with developmental disabilities.
- Guardianship: Protection of legal rights in guardianship proceedings. People with developmental disabilities do not have

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unnecessary guardianships.

- SSI: 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.
- Title II ADA: Increased accommodations for people with disabilities in government services.
- Title III ADA: Individuals with disabilities will have increased access to businesses open to the public.
- Communication Support Project (Joint priority with DDC and UCE) People with developmental disabilities receive communication support in judicial and other proceedings.
- Self Determination: People with disabilities make meaningful and informed choices about their services and supports.
- Abuse Neglect & Exploitation: Adults and children with disabilities living independently, in institutions, or in parental, family, group or developmental homes, are free from abuse, neglect or rights violations.

Housing Priority Area

- People with disabilities receive needed accommodations in housing.

Employment Priority Area

- People with disabilities will not be discriminated against in hiring, employment and advancement.

Transportation Priority Area

- People with disabilities have access to accessible transportation.

CONTACT US WITH YOUR THOUGHTS at:

Vermont Protection & Advocacy
141 Main St., Montpelier, VT 05602
1-800-834-7890 or (802) 2229-1355
Email at info@vtpa.org or visit us on the Web at
www.vtpa.org

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concrete things happen that can affect lots of lives, like funding for many more high school graduates than we thought."

Karen said the Legislature had a very difficult task creating a budget for the year starting July 1, 2009. When lawmakers convened in January there had already been two rounds of cuts, in August and again in December 2008, which she said eroded services and took away flexibility.

She highlighted some hard-won successes during this session: adding some of the funding needed for employment supports for special education students leaving schools, the preservation of funds for Children with Special Health Need's respite program, and the reduction of the proposed 4 percent cuts in developmental and mental health services and health care to 2.5 and 2 percent respectively.

"It is clear that we will need to focus attention on the need to support direct support workers, who cannot withstand any more cuts," said Karen. "What was very, very positive was the emergence of the broad-based coalition One Vermont, and recognition of the key role played by people with disabilities in its advocacy activities. Last session I also think VCDR, VTDDC and Green Mountain Self-Advocates worked very well together to effectively get the word out to people, making it simpler to contact policymakers when it was really important."

She continued, "Vermont needs to maintain its safety net in these difficult times, and continue to support community-based services. We need to get the message across that Vermonters help Vermonters, especially when times get tough, and that investing in social programs and services boosts Vermont's economy as much as any other business or the federal stimulus package."

Karen said we also need to continue to push for full community participation and rights, including special education students being able to "walk with their class" at graduation, to freedom from restraint and seclusion in our schools.

She concluded, "Right now we are focused on possible cuts that might happen even before the session starts. We need to make sure that we reach out to people with disabilities now, so that they are ready to come out and be heard."

Accessibility Moves Forward At Burlington School

by Stefanie Monte

Progress is being made in the quest to make the Edmunds school complex in Burlington accessible.

Students with limited mobility cannot attend Edmunds Middle School because it has no elevator. Therefore, once children with physical disabilities enter sixth grade, they have to be bused across town to Hunt Middle School instead of staying with their peers at Edmunds.

VCIL Executive Director Sarah Launderville said that the Burlington School District is currently in violation of the Americans with Disabilities Act, the landmark civil rights law enacted in 1990.

"The intention of the ADA is to bring people who have disabilities and people who do not have disabilities together. This allows for equal access, but also allows for us to work together as human beings. By separating children with disabilities from children without, the natural learning that takes place goes away and that is a shame."

A group of advocates calling themselves ACCESS Burlington has banded together to fight for equal access so that Edmunds, which is composed of four different buildings, will be accessible to schoolchildren and community members alike.

"I think the lack of accessibility has been a source of frustration for people in the community for a long time," said Burlington City Councilor Karen Paul, I-Ward 6. "I think the biggest stumbling blocks have been a lack of understanding of what must be done and what can be done (i.e. getting



started with compliance and not having to do everything at once) and the fact that there are many needs and naturally, never enough money to fulfill all those needs."

Recently, Paul and other advocates have seen some positive developments.

At a June 9 meeting, the school board committed to making the Edmunds complex fully accessible and ADA-compliant. This will be done as part of a \$6-8 million multi-phase plan to invest in the complex over several years. The first phase will be installing an elevator and making improvements to at least one bathroom on each floor. The plan is to follow a school committee recommendation to use \$1.09 million from the school district's capital improvement budget, \$300,000 from federal stimulus funding and \$300,000 from the city or some other viable source.

Michael Wood-Lewis is the father of an Edmunds Elementary School student who uses a wheelchair

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and is a member of ACCESS Burlington.

"I'm thrilled with the progress made to date on making Edmunds accessible for all Burlington children and community members, regardless of physical abilities," said Wood-Lewis. "That said, we have a long way to go and the groundbreaking is currently two years away. That's two more years of blocking people who use wheelchairs. That's two more years exposed to the risk of funding or political will disappearing."

School Board Chairman Fred Lane said the exact time frame for finishing the first phase of the project will depend on funding and what happens once the building walls are torn up. However, he said school officials expect that an elevator will be installed at the middle school no later than the summer of 2011.

"We're pleased that this is moving forward and we certainly look forward to making the building as accessible to as many people as possible," said Lane, whether that means teachers with injuries or elderly people with mobility issues.

The Vermont Access Board has told school officials that before they can move forward with the project, they must get approval from Ned Holt, building official for the city of Burlington. Holt said he has been in conversations with the architect hired by the school district and is reviewing the plan.

"We want to ensure that (the project) is in full compliance with the codes adopted in the state of Vermont," said Holt, adding that he expects to make the decision relatively soon, once he has enough information to move forward.

"I know it's of utmost importance to all," he said.

Got Access?

VCIL's Community Access Program is launching a public accessibility campaign with a new "got access?" bumper sticker.

"We want people in Vermont to read this sticker and consider what access means to them," said Kim Brittenham, VCIL's Community Access Coordinator. "I want people to think about how they access their community, and think about what ways they would access their community if accessibility were improved."

Access is everyone's issue, and it is different for every person. Access is not about disability. It is about each person's ability to give, participate and get what they need. Access can be a ramp on a building, a call push-button for a second-story business, an interpreter at the emergency room, or Web casting town meeting so people can participate from home. Do you have access to your community? Access to affordable housing? Public transportation? Voting? Volunteering opportunities? To work? Is your representative accessible? If not, what are you going to do about it?

"I know this sticker raises a lot of questions for folks. VCIL has a lot of answers. There are many affordable and creative solutions to barriers to accessibility. We just need people thinking about access and considering what they can do on an individual basis to improve the situations. Call me, and I'll get you going. And I will send you a sticker!" said Brittenham.

E-mail kbrittenham@vcil.org or call 1-800-639-1522 (V/TTY). A \$1 donation is suggested, but not necessary, to receive the sticker.

Leahy A “Top Champion” For Disability Rights



PHOTO COURTESY AAPD

Sarah Launderville, executive director of the Vermont Center for Independent Living, with Andrew Imparato, left, president and CEO of the American Association of People with Disabilities, and U.S. Sen. Patrick Leahy, D-Vt.

On July 22, the American Association of People with Disabilities recognized U.S. Sen. Patrick Leahy for his leadership and support for disability rights. Each year the AAPD uses the anniversary of the ADA as a time to celebrate leadership on the part of “top congressional champions for disability rights.”

Sarah Launderville, executive director of the Vermont Center for Independent Living, presented the award. She noted that Leahy was one of the early co-sponsors of the Americans with Disabilities Act, and used her own experience to highlight the importance of this groundbreaking legislation in the lives of Americans with disabilities.

“I have had a psychiatric disability since I was 5 years old. For most of my life there was little protection for me as a person living with a disability,” said Launderville. “The legislation

that Senator Leahy has helped pass over the years has made my life and the lives of people with disabilities have equal opportunity in our communities.”

Launderville said Leahy has been a vigorous supporter and sometimes a lone voice for disability rights. “He has been a leader in international efforts to ban use of anti-personnel land mines. He wrote the first law enacted by any government to prohibit the export of land mines. He established Leahy War Victims Fund which gives \$10 million annually to address the needs of people with disabilities affected by land mines. When family members return from war, he makes sure supports are available. He is supportive of mental health issues including people diagnosed with mental illness who are offenders. He is concerned about domestic and sexual violence and how violence affects people with disabilities.”

Launderville added, “Senator Leahy makes sure that Vermonters with disabilities are part of the solution to issues that face our country ... He is a true change agent and has worked in human and civil rights as well as helped push forward the disability rights movement statewide, nationally and internationally.”

The American Association of People with Disabilities (AAPD) is a national, non-partisan membership organization. Its mission is to organize the disability community to be a powerful voice for change – politically, economically and socially. It is recognized as the largest cross-disability membership organization in the country.

2009 NCIL Conference Energizes Advocates

The National Council on Independent Living held its annual conference in June. The conference titled, "Believe We are Better. Reenergize, Reorganize and Reauthorize," brought hundreds of advocates from across the country together to work on our common independent living goals.

Vermont sent a delegation of three to represent the state at the conference – Sam Liss, a member of the Vermont Statewide Independent Living Council and Vice President of the VCIL Board, Sarah Launderville, executive director of VCIL, and Janet Dermody, deputy director of VCIL.

The delegation participated in workshops including outcome measurements, working with AmeriCorps programs, recognizing and responding to violence for people with disabilities, and IL International work.

The delegation met with representatives from U.S. Sen. Patrick Leahy and Congressman Peter Welch's office and with U.S. Sen. Bernie Sanders himself. They spoke about the importance of the Community Choice Act, CLASS Act: Community Living Assistance Services and Supports, along with other acts related to civil rights of people with disabilities, employment, accessible technology, veterans' issues and transportation issues.

At the annual luncheon, Janet Dermody, deputy director of VCIL, was honored with the Region I Advocate Award "for her dedication to promoting the rights of people with disabilities and advancing the Independent Living Movement in Region I." Region I of NCIL makes up the New England region.

After receiving the award, Dermody stated, "I was so honored to receive the NCIL Region I Advocacy Award.

It's wonderful to be honored for your work in disability rights by your peers. And, a big thanks to Mary Margaret Moore, a great leader and inspiration, along with all my other colleagues and friends."

At the conference, Launderville and Dermody organized a Women's Caucus with the help of Region I representative Mary Margaret Moore. As a result, NCIL will now have a Women's Caucus as a subcommittee to the NCIL Diversity Committee.

VCIL and the Statewide Independent Living Council (SILC) are organizational members of NCIL, but individuals are encouraged to become members as well. If you are interested in becoming an individual member of NCIL, check out the NCIL Web site at www.ncil.org/membership.html, or call toll-free, 1-877-525-3400.



Janet Dermody and U.S. Sen. Bernie Sanders.



VCIL Vice President Sam Liss, left, and U.S. Sen. Bernie Sanders.

ADA Celebration Focuses On "Then and Now"

by Stefanie Monte

VCIL's annual Americans with Disabilities Act celebration was held on the Statehouse lawn July 23. Insights were shared as to what life was like before the landmark civil rights law was enacted in 1990 – and what life was like after ADA became law.

Master of ceremonies Ed Paquin, a VCIL board member and executive director of Vermont Protection & Advocacy, told the large crowd gathered for the event: "We should celebrate what we have achieved, but we also need to look at what's left to get done, and there may be no better way to do that than to get a little bit of perspective."

With the idea of perspective in mind, Paquin first introduced someone who grew up before the ADA – David Sagi, one of VCIL's founding members and current regional manager for VocRehab Vermont's Rutland and Bennington offices.

Sagi said, "On the drive up this morning, I couldn't help but reflect back to the early days pre ADA. I was injured in an accident in 1971 at 24 years old that left me paralyzed from the chest down and in this chair for the rest of my life. That was hard enough to deal with, but when I got out of rehab and went into the community, what I found was that accessibility wasn't there."

There was no transportation available to him, Sagi said – no bus system and no individual vehicles with lifts. Finding employment was far from his mind, he said. The programs and support systems that are around today to help people with vocational goals were not around then.

The only store Sagi could get into independently in Rutland in 1971 was the Grand Union. He said the Grand Union had power doors and curb cuts back in the early '70s because it was good business.

"It didn't make sense to have you take a grocery cart and bounce over a curve or try to handle doors with a cart full of groceries. That was it," said Sagi. He knew then that he had to work with other Vermonters to promote accessibility.



PHOTO BY KIM BRITTENHAM

VCIL's Ben Wimett, left connects with Aaron Tardiff at the ADA Celebration.

"Things improved, and laws came along," said Sagi. He mentioned the Rehabilitation Act of 1977, and of course, 1990's Americans with Disabilities Act.

After Sagi's speech, Paquin introduced someone who grew up after the ADA – Ben Wimett. Wimett graduated from New Hampshire's Keene State College with honors in 2008. He has mentored young people for years and is currently VCIL's Youth Leadership Program Specialist.

"To put it in a nutshell, everything that David said he couldn't do, I have the opportunity to do," said Wimett.

"I went to college. If I needed an accommodation, it was not a big deal. I didn't have to jump through hoops."

Wimett asserted, "Everything that I've wanted to do, I've been able to do, and it's because of the ADA. Without the ADA, I would literally not be here today."

Wimett was not the only young role model at the ADA Celebration. A highlight of the event was the presentation of the Deborah Lisi-Baker Leader of Tomorrow Award. The VCIL Board of Directors created this award years ago in honor of the disability rights organization's longtime executive director, who retired earlier this year, and emerging leaders in the independent living movement.

This year's award went to Aaron Tardiff of Poultney.

"Over the past couple of years, Aaron has found the advocate within himself," said Lisi-Baker. "Aaron is a highly self-motivated individual, especially when he is passionate about something. Aaron attempted to garner community support and town approval for a teen center, but hit stumbling blocks. Instead he channeled his organizing energy into successfully starting an audio-visual club at his high school this past year. Although it was slow going, he never gave up."

This year's ADA Celebration also featured performances by the Awareness Theater Company, a dynamic theatrical group composed of people with and without disabilities. Tom Rolland and Mike Bozonie of the Green Mountain Brass Band entertained attendees with their music.

Gov. Jim Douglas, John Tracy of U.S. Sen. Patrick Leahy's office, Kelly Lucci of U.S. Sen. Bernard Sanders' office, and Susan Elliot of Congressman Peter Welch's office were among the distinguished guests who attended and spoke at the celebration.

VCIL sponsored the Americans with Disabilities Act celebration. Co-sponsors included the Vermont Statewide Independent Living Council, Vermont Protection & Advocacy, VocRehab Vermont, and the Vermont Network Against Domestic and Sexual Violence. McKenzie of Vermont, Hunger Mountain Co-op, Costco, Shaw's of Berlin and Shaw's of Montpelier are among the companies that donated food for the event. The Flynn Theater donated tickets that were raffled off at the event.



From right, Harriet Hall of Newport City, Gov. Jim Douglas and Nicole LeBlanc are all ears at the ADA Celebration.



An ADA birthday cake was part of the free lunch at this year's ADA Celebration.



David Sagi spoke about what it was like to live with a disability before ADA.



Karin Nissen, VCIL's Meals on Wheels coordinator, shows off the organization's new bumper sticker.



VCIL staff members and peers march to the State-house for the ADA Celebration



Gerry and Bob Sisler of Brattleboro are all smiles at the ADA Celebration.



VCIL Board President Marty Roberts, left, and staff member Rosemary Miller catch up at the big event.



VCIL's AgrAbility Specialist Tom Younkman grills up some hot dogs for attendees to enjoy.

COVE's 2009 Legislative Summary

by Michael Sirotkin, Esq.

FY 2010 Budget (H.441) – As we all know, the biggest challenge of the 2009 legislative session was balancing the state budget. In mid-January the administration put forth its suggestions for major human service and other cuts throughout state government. Among the proposed cuts most directly impacting seniors were the elimination of VPharm; major cutbacks in Medicaid adult dental benefits; across-the-board 4 percent cuts on almost all Medicaid providers, including direct care workers, Area Agencies on Aging, adult day, home health, supportive housing, transportation, etc. Nursing homes would have had their rates frozen as opposed to receiving their annual statutory inflation increase. The cost of living adjustment (COLA) to SSI recipients given each January by the federal government would be diverted to balance the state budget, thus depriving these poorest of the poor elderly and disabled any increase in their monthly checks.

Fortunately, in February Congress passed the stimulus package which provided for some temporary fiscal relief to the states. Whether the stimulus money was viewed as a bridge to better times or temporary funds that would simply delay the inevitable became a policy debate that lasted the whole session, and continues into the summer. Ultimately, with the benefit of the stimulus funds and approximately \$25 million in new taxes the Legislature chose not to cut nearly as deeply as the administration's initial proposals. All the above cuts were restored, with the exception of \$1-2 new co-pays in VPharm (see below); a 2 percent across-the-board cut on Medicaid providers; a less than inflationary increase for nursing homes; and a possible diversion of half the SSI COLA.

The budget debate continued into a special veto session in June, where the governor's veto of the legislative budget was overridden by the narrowest of margins – one vote. Even into the summer, policymakers fear that revenue projections for next year may be downgraded, which could force a new round of program cuts in the fall.

VPharm – The elimination of the state's pharmacy assistance program, which provides comprehensive wrap-around coverage to Medicare part D, was a debate that lasted the entire session. The governor's call to shut down this 20-year-old program which addresses a major gap in Medicare coverage and now assists over 13,000 Medicare beneficiaries, was met with strong opposition. Heart-wrenching testimony from recipients in the doughnut hole energized legislators to more fully understand the program's cost and benefits and they became committed to finding a way to save it. Ultimately, through a combination of requiring more rebates from manufacturers, greater utilization of generic drugs and nominal co-pays (\$1-2), the Legislature was able to keep the program intact.

Now we are hearing from Washington that some further good news may be on the way – the major doughnut hole, out-of-pocket prescription expenses for seniors and persons with disabilities under part D, may soon be cut in half. This would save the VPharm program significant money.

Palliative Care, End-of-Life Care, and Pain Management (H.435) – This new law creates a "Patient's Bill of Rights for Palliative Care and Pain Management," designed to promote informed patient choice and control at end of life. It attaches to the individual rather than to a specific care setting and specifically provides for the following:

- a) A patient has the right to be informed of all evidence-based options for care and treatment, including palliative care, in order to make a fully informed patient choice.
- b) A patient with a terminal illness has the right to be informed by a clinician of all available options related to terminal care; to be able to request any, all, or none of these options; and to expect and receive supportive care for the specific option or options available.
- c) A patient suffering from pain has the right to request or reject the use of any or all treatments in order to relieve his or her pain.

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d) A patient suffering from a chronic condition has the right to competent and compassionate medical assistance in managing his or her physical and emotional symptoms.

When and if effectively implemented, this bill could provide a model for other states dealing with issues of terminal care and patient choice.

Fuel Assistance (H.214) – COVE led this effort to expand program eligibility while minimizing the impact on benefits going to currently eligible households.

While Vermont has one of the higher fuel benefit levels in the country, it also probably has the most restrictive eligibility guidelines. Currently our income cutoff is 125 percent of poverty and a limit on assets of \$5,000 (recently increased to \$10,000 for seniors). Most other states use 150 percent and have no asset test.

There is a strong recognition that those between 125 and 150 percent of poverty and above also need assistance. We also suggested that removing the asset test for the elderly and persons with disabilities up to at least 135 percent of poverty would be particularly important to low-income seniors who take great comfort and pride in having put aside a small nest egg for retirement, emergencies, etc.

This might have been an excellent year to pursue expanding access to the program, as the price of fuel has dropped considerably since last year. It would mean that if prices hold, the average benefit next year could be lowered and still meet the goal of covering 60 percent of a beneficiary's heating bill. This could effectively free up millions of dollars for new beneficiaries.

Unfortunately, we recently learned that the president's new budget for FY 2010 calls for a 40 percent cut in federal funding for this program (LIHEAP). This made any attempt to expand eligibility, with minimal impact on existing beneficiaries, far more challenging and while the bill passed the House, we were compelled to ask that it not become law this year until the federal funding picture became clearer. Thus, H.214 awaits action in the Senate for next session.

We were successful in making permanent the modest increases in the income and asset guidelines for seniors used last summer when oil prices were skyrocketing to over \$4 per gallon.

Long-Term Care Partnership Insurance (H.202) – This new kind of LTC insurance would allow those who buy the product to protect and retain a certain amount of their assets if they ever needed to apply for Medicaid assistance. In order for these policies to be sold in Vermont, the Legislature must first pass authorizing legislation. Last year the administration and the insurance industry fought hard for such a law, but many consumer groups had concerns about what these insurance policies would look like and how they would be marketed.

The result was a study committee that met on numerous occasions over the summer and fall. Because of bad experiences seniors have had with the marketing of Medicare supplement policies, Medicare Advantage plans, and Part D prescription drug policies, there is a high level of angst with the state supporting the sales of these long-term care "partnership" policies. (There was a very recent federal study questioning the sales practices and exploitation of seniors under Part D.)

We have raised questions of why these policies cannot be standardized down to a manageable number of plans. This would help minimize confusion in the marketplace and seniors would be better able to make apples to apples comparisons on price and service. While we have made progress with the state toward standardization and other protections, COVE still has concerns with the expansion, marketing and regulation of this product.

COVE and other consumer groups testified with the basic message of go slow. The committee, after several hearings, heard our message and had numerous questions which led them to defer any further action until next year.

Colorectal Cancer (H.24) – Colorectal cancer is a leading cause of cancer deaths, second only to lung cancer among males and lung and breast cancer among females in Vermont. The incidence of colorectal cancer increases dramatically with age with more than 90 percent

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of colorectal cancer cases diagnosed in people over age 50. Early detection screening such as a colonoscopy identifies colon cancer when it is most effectively and least expensively treated, and has demonstrated to decrease mortality from colorectal cancer.

In order to increase colorectal cancer screening rates the legislation proposed to improve individuals' access to these screenings by removing cost-related barriers such as prohibitive co-payments. The average cost for colonoscopies is \$1,684 in Vermont, ranging from \$1,100 to \$3,500 with out-of-pocket costs ranging from \$400 to \$1,800.

H.24 passed with a maximum co-payment of \$100 and, contingent on federal approval, would extend the same maximum co-pay to those on Medicare. Unfortunately, the feds have now indicated that Medicare will continue to require 20 percent co-pays on such services.

Transparency in Prescription Manufacturers Gifts to Health Care Providers (S. 48) – The bill would require a public listing of which doctors received gifts from drug companies. Moreover, it would ban all gifts not related to education, research, samples, clinical trials, etc.

Vermont already has restrictions on spending by drug companies, and an annual reporting requirement. According to the most recent accounting released in July, pharmaceutical companies had spent \$3.1 million to promote their medicines to doctors during a 12-month period ending in June 2007. That was an increase of \$1 million over the previous report. The problem was that without S.48's requirement of listing the individual doctor's name, there was less deterrent to accepting the gifts from the manufacturers.

The drug companies are already raising constitutional questions on the state's ability to ban most gifts and to require individual listing of the gifts/doctors that may be allowable. The proponents obviously think that with the doctor's name having to be listed there will be fewer acceptances of gifts and less drug company influence over prescribing habits. Apparently, such influence is most acute in the area of mental health medicines.

The bill, as ultimately passed, is probably the strongest bill in the country designed to reduce manufacturer influence on doctor prescribing habits.

The one major change in the last week of the session was the removal of the reporting requirement for doctors receiving free samples. Several doctors testified that without the samples, many of their low-income patients would suffer. The doctors said that if they had to disclose receipt of free samples from pharmaceutical companies, they would not be willing to accept them and their patients would be the ones to suffer.

Nursing Home Receivership (H. 435) – The basic focus of the bill is to put in place procedures to allow the appointment of a receiver for the protection of the residents should a nursing home be forced to close. The two concerns we had were that residents who might be injured (physically or otherwise) during a receivership might not have adequate recourse against the receiver; and that a resident or a family member should have the right to petition for receivership if they believe that a home is in danger of closing or providing for them inadequately.

Both concerns were addressed in the last week of the session and, with the support of the nursing home ombudsman, H. 435 was enacted.

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

PO Box 1276

641 Comstock Road, Suite 4

Montpelier, VT 05602

802-229-4731

cove@vermontelders.org

www.vermontelders.org

Community of Vermont Elders

VCDR's 2009 Legislative Wrap-Up

Late at night on May 8, Vermont's legislators finished their work for 2009, the first year of the biennium. They adjourned knowing that they might be called back into session should the governor veto the 2010 budget. The governor did just that and legislators returned in early June to debate the issue and vote on whether to sustain the budget as passed by the Legislature or to continue to negotiate a new budget with the governor and his administration. In the end, the Legislature had the votes to override the governor's veto. The budget that was passed reflected over two years of revenue reductions and program cuts, despite sustained effort and some success in protecting services that Vermonters depend on.

Recent Budget Changes Reflect Economic Downturn

Since January of 2008 Vermont has experienced a \$338 million revenue reduction. In addition to the revenue downgrades, General Fund spending needed to increase by \$141 million to keep up with the increasing demand on state services in fiscal years 2009 and 2010.

The FY 2010 deficit totaled \$281.5 million. The Legislature used federal stimulus funds to preserve the critical services and help keep Vermonters working. About \$250 million of federal stimulus dollars are being used to fill the FY09 and FY10 gap. This federal relief is temporary and holes in the budget still needed to be closed. The Legislature also used a combination of cutting programs and services, finding efficiencies, increasing taxes or fees, collecting unpaid taxes, adjusting transfers between funds and using the state's reserve funds. The state had already cut more than \$100 million in its spending before the 2010 budget was even proposed.

Many health and disability services have already reduced staffing and services in programs such as local mental health and developmental services, respite programs, attendant care rates, home health services and payments to a broad range of health care providers.

For FY 2010, which began July 1, the governor had proposed 4 percent across-the-board cuts in most all provider rates, and 4 percent across-the-board cuts in most Human Service Grants and

contracts in addition to line item budget cuts and / or elimination of programs.

The fiscal year 2010 budget passed by the Legislature includes an additional \$59.3 million in cuts to state programs and services. Legislative action and federal stimulus funds made it possible to protect and even enhance a few programs. The Legislature was successful in preserving, maintaining or enhancing important programs like VPharm, Reach Up, dental benefits, Children with Special Health Needs, June grads, Legal Aid funding and other program services for people with disabilities. The Home Access program was funded at the \$1 million level, almost doubling its usual appropriation to try to take care of the backlog of needed projects. Provider rate funding was cut by 2 percent instead of 4 percent, and the Human Services grants and contracts were not cut in the budget but subject to the Secretary of Human Services finding General Fund Savings of \$740,000 to be presented in a plan at the July Joint Fiscal meeting.

Cuts were still made in a number of Human Services areas including Medicaid, Department of Children and Families, the Department of Disabilities, Aging and Independent Living, most notably a reduction in Flexible Family Funding, and other areas of state government. Probably one of the ongoing impacts in the state budget cuts and rescissions will be noticed in the reductions in the state workforce, through elimination of employees, vacancies not being filled and retirement incentives.

Additional Budget Reductions Likely

The session may be over but continued threats to programs are very real. The big news out of the Joint Fiscal meeting on July 17 was the expected \$28 million deficit for the FY 2010 budget year. Vermonters face another round of possible funding reductions from the FY 2010 budget that just went into effect on July 1. The administration will present a plan to the Joint Fiscal Committee and they have a certain amount of time to approve the plan and hold public hearings. (The process is in state law and has been adjusted in H.75 passed by the Legislature and signed into law by the governor on June 1.) The 28 million represents 2.5 percent of the general fund budget (over the 1 percent which

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requires Joint Fiscal approval). So this is the “never ending” budget that just keeps going. The Joint Fiscal Committee is scheduled to meet again on Aug. 5. We will wait to see what plan is presented and most likely have to defend our programs once again.

Budget Woes Overshadow Policy Work

Public policy took a back seat to budgetary and economic concerns. Early in the session we noticed that very few bills were moving out of committees. Many of the public policy committees, like House Human Services and House Health Care, spent much of the early part of the year examining the effects of the governor’s proposed budget cuts on public policy. They looked at the proposed cuts on VPharm, regulation changes in Reach Up, cuts in dental coverage, premium increase, and what 4 percent cuts to providers and grants would do to the delivery of services. VCDR was asked to weigh in on several of the issues and worked to keep VPharm intact and to keep premiums from increasing. We also spoke constantly and to everyone about the negative effect the proposed 4 percent cuts would have on all programs and in particular, direct care services.

Bills that Passed

Disability History Week Resolution: H.R.17 and S.R.12 proclaim the third week of October of 2009 as Disability History Week, a time to recognize and celebrate Vermont work on disability rights, Deaf culture and related social change.

Palliative Care: VCDR took a leadership role in the development of this legislation, H.435. The purpose of this act to improve the quality of palliative care and pain management available to all Vermonters, to ensure that Vermonters are aware of their rights and of the care options available to them, and to expand access to palliative care services for children and adults in this state. This legislation is an offshoot of the study committee which met last summer and fall and focused on improving palliative and end-of-life care and pain management in Vermont.

The legislation adds the word “pain” in the statutes describing the responsibilities of doctors and nurses; a patient bill of rights for palliative care

and pain management; adds a definition of COLST (clinician’s orders for treatment) to the Advance Directive Statutes; and includes palliative care in the Blueprint for Health. It also asks AHS to ask for a report on the costs and effect of a waiver to allow Vermont to provide its Medicaid-eligible children who have serious medical conditions with concurrent palliative and concurrent curative care services. DAIL is asked to investigate the feasibility of allowing Vermonters to receive services under the state’s Choices for Care program while also receiving hospice benefits under Medicaid or Medicare. Finally the legislation calls for a creation of a task force on palliative care and pain management managed by Vermont Ethics Network, and a board of medical practice report on improving the knowledge and practice of health care professionals in Vermont with respect to palliative care and pain management. This last piece was in lieu of requiring continuing medical education for doctors in palliative care and pain management. VCDR and other organizations advocated for that option.

Corrections: S.2, a bill relating to prisoners with disabilities, passed the House and Senate and has been sent to the governor for signature. This bill makes important changes in identifying people in corrections who may have developmental disabilities and/or mental illness and mandates the Department of Corrections to devise and institute rules about how inmates with functional impairments will be identified, treated and segregated. The bill also requires the department to make sure trauma-related issues are considered when evaluating and treating inmates. This bill is an improvement to identifying and treating people with mental illness/functional impairments and also improves the planning process for when the inmate is about to be released from prison so that treatment services can continue in the community.

S.125 passed both the House and Senate. The bill is mostly about the sex-offender registry but it also contains a section that could have negative effects for inmates with disabilities. Nutraloaf is a food product that doesn’t taste very good and is used by prisons to “punish” inmates who have behaved badly. S.125 allows prisons in VT to serve

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Nutraloaf to an inmate who “misuses bodily waste or fluids, food, or eating utensils.” The Nutraloaf may be served to that inmate for a maximum of seven consecutive days. There is an appeal process in the law that allows the inmate to appeal the decision to prison management. Ironically, the following section of the bill states that the serving of Nutraloaf (or “special management meals” as they are called in the bill) should in no way be construed as a punishment.

Prescription Drugs: S.48, an act relating to the marketing of prescription drugs, also passed the House and Senate. The bill contains a section creating a therapeutic equivalent drug work group. Advocates successfully fought off an attempt to mandate therapeutic equivalent drug substitution laws (except for a section of the budget bill, which mandates therapeutic equivalent drug substitution for cholesterol drugs and gastric acid drugs as part of a pilot program studying the budget effects of therapeutic equivalent programs) and the workgroup was created as a compromise. This issue will need to be monitored carefully next year. Allowing pharmacies to substitute therapeutic equivalents for a patient’s prescribed medications could have severe consequences for some individuals.

Budget Authority: H.75 limits the ability of the Joint Fiscal Committee and the governor to decide on how to make large (think tens of millions of dollars) rescission cuts when the Legislature is not in session and in many cases require a public hearing before program cuts are made.

Other Policy Bills Taken Up by Committees

Graduation: H.66 is legislation that includes secondary students with disabilities in senior year activities and ceremonies. In April the committee took testimony from parents, advocates, students, legal aid, and staff from the Department of Education. The committee seemed stunned and upset that students are often not allowed to participate in these important ceremonies in Vermont. They asked very supportive and thoughtful questions. Barb Prine from Legal Aid gave the committee information on the language in the Individuals with Disabilities Education Act (IDEA) where school districts should take steps to ensure that children with disabilities have an equal opportunity for participation in these events. Witnesses from DOE testified against H.66, calling

it a mandate. House Ed eventually put it aside and moved forward on other legislation. VCDR representatives spoke to the chairman of Senate Education Committee, Bobby Starr, who expressed interest in the legislation. VCDR will work with him and with the chairman of House Education, Joey Donovan, over the summer to generate more support for passage.

Vulnerable Person: In April, House Government Operations took up H.304, which proposes to establish the missing vulnerable persons alert program that will aid in the recovery of missing persons believed to be suffering from dementia or other cognitive impairment. Nicole LeBlanc, of Green Mountain Self-Advocates, testified on the bill. The committee also heard from public safety, a mother of a child with autism, VCDR and the manager of a nursing home in Burlington.

Positive Behavior Interventions in Schools: One of several VCDR bills that was introduced but not taken up by the committee was H.400, which promotes positive behavioral intervention and supports in schools, reduces the use of physical restraint, and prohibits the use of mechanical, chemical, and prone physical restraint and seclusion as methods of addressing challenging student behavior. It currently sits in House Ed. VCDR will work toward passage of that legislation next year.

For more information about particular bills and other VCDR advocacy activities, or to share your recommendations or concerns, contact us:

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New Freedom Funds Expand Local Transportation Options

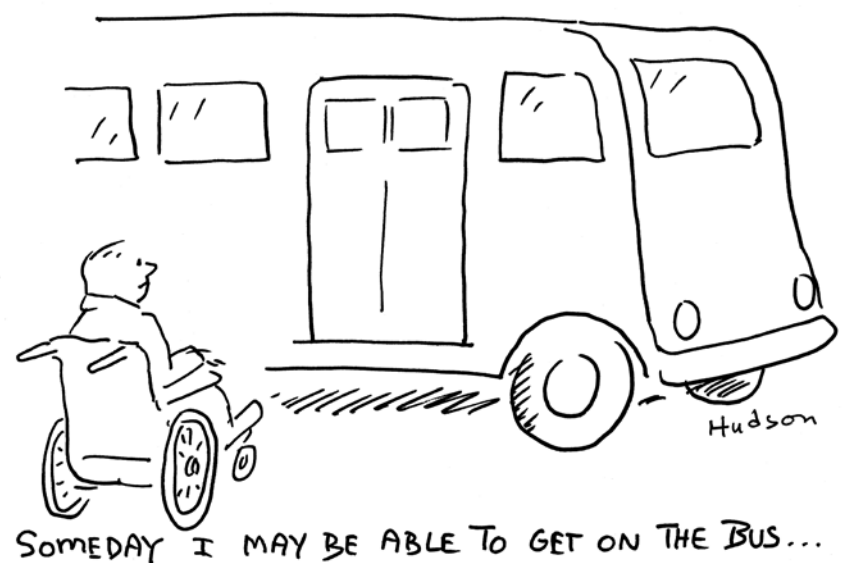
VTrans, the state agency that oversees Vermont's transportation programs, has announced the following awards to local transit providers and other partners under the Federal Transportation Administration's New Freedom program. (For more information, contact the local provider.)

- Woodstock Area Council on Aging, Thompson Senior Center – Provide transportation services to accessibility of medical and shopping in White River Junction, Vt. and West Lebanon, N.H. twice a week. Locations include Veterans Administration Hospital, Dartmouth-Hitchcock Medical Center and Lebanon Shopping Plazas. Thompson Senior Center is a recipient of 5310 vehicles and coordinates their services with the area's public transit provider. Project partners include Two Rivers Ottauquechee Regional Commission and Stagecoach Transportation Services.
- Green Mountain Community Network (GMCN) & Bennington Project Independence – Jointly working together, these two organizations will be providing door-through-door service by providing a licensed nurse assistant on a GMCN vehicle to the most frail of individuals who wouldn't otherwise be able to get out of their homes.
- Connecticut River Transit – Short-term employment transportation services for persons with disabilities while long-term or permanent transportation solutions are found. Project partners include Agency of Human Services, Department of Disabilities, Aging and Independent Living, Division of Vocational Rehabilitation, Vocational Regional Manager and Counselor in Springfield.
- Rural Community Transportation – A customer-driven, market-based mobility management program that provides customers with a wide variety of transportation options through individualized trip coordination to ensure people get to where they need to go in the most efficient and cost-

effective manner. Project partners include St. Johnsbury Area on Aging, Vermont Association for the Blind & Visually Impaired, and Agency of Human Services Field Service Director in Newport.

The New Freedom formula grant program aims to provide additional tools to overcome existing barriers facing Americans with disabilities seeking integration into the work force and full participation in society. Lack of adequate transportation is a primary barrier to work for individuals with disabilities. The New Freedom formula grant program seeks to reduce barriers to transportation services and expand the transportation mobility options available to people with disabilities beyond the requirements of the Americans with Disabilities Act (ADA) of 1990.

For more information about future New Freedom grants, contact Krista Chadwick, Public Transit Assistant Administrator, Vermont Agency of Transportation, at 802-828-5750.



ReCycle Catalog

Used Independent Living Aids for Sale

The Vermont Center for Independent Living maintains the ReCycle Catalog, a listing of used disability equipment wanted and disability equipment for sale - that can help with living independently. By using the ReCycle Catalog, you are agreeing to the conditions of the disclaimer.

Daily Living Aides

Item	Owner Name	Location	Phone Number	Price
New Invicare Infinity Chair Cushion 18 1/2 x19 1/2 x 4	Brad	South Barre	802-476-6207	BO
Contoured Comfort Mate Chair Cushion 16x16x3	Brad	South Barre	802-476-6207	BO
Comode/Shower PVC Rolling Chair	Brad	South Barre	802-476-6207	BO
Brand New Electric Scooter Chair and Car lift Warrenties transferable	Diane	St. Johnsbury	802-748-9115	\$1000
Chair Cushion Dickie Like New 17 1/2x18x2	Brad	South Barre	802-476-6207	BO

Housing

Item	Owner Name	Location	Phone Number	Price
Four bedroom accessible house for sale in Morrisville, Vermont . Ceiling track lift system in bedroom with ceiling track lift over hot tub too. Roll in shower. Located 500 feet from Copley Hospital and close to physician offices.	Dave and Debbie	Morrisville	802-888-5958	\$225,000

Wheelchairs & Scooters

Item	Owner Name	Location	Phone Number	Price
Brawn Chair Topper	Janet	W. Brattleboro	802-579-1640	Free
Quickie Manual Chair Older but still usable	Janet	W. Brattleboro	802-579-1640	Free
Power Chair in need of Batteries	Brad	South Barre	802-476-6207	BO

Ericka Reil
Vermont Center for Independent Living
802-229-0501 800-639-1522

Disability Happens -K.K.

By K.K. Wilder

Rough Patches

Older persons, and those who have serious disabilities – not to mention others who face both situations – often surprise younger and healthier people in our culture. How often have you heard someone exclaim, “You’re such an inspiration!” Many times, you’ll find they mean your attitude is a positive one, not a “poor me” presentation. You’ve reached a stage in your life where when someone asks, “How are you?” they’re not just making small talk.

One friend of mine always had the same answer to that question. “Hey!” he’d say cheerily, “I’m sitting up and taking nourishment!” His response always drew a laugh because he was far from old age and his health was perfect.

What about when we truly reach the rough patches, though? Times when we don’t want to sit up and take nourishment, at least not the kind we eat. In fact, we’re just not interested in much of anything.

Talk about bleak!

I’ve learned that those are the times we need other kinds of nourishment.

I spent several years working and living in a home for people where the median age was 90 years. Many of those residents were so spirited, they were not only inspirations, but also great mentors, conversationalists and fascinating historians. It was a true pleasure to be in their company.

But more than once I saw those same people hit rough patches. Whether their doldrums lasted several days or weeks, eventually they’d return to their old selves. How, I wondered, did they do it?

I asked an 85-year-old resident. “Why, dear,” she answered, “I try to think of what I can still do in spite of being in a difficult place in my life, and my gratitude makes everything seem better.”

“What else?” I wanted to know.

“Well, last week I was feeling stuck in here,” she said. “Useless. Something like a forgotten old pair of shoes pushed way back in the closet.”

How sad, I thought.

“Then,” she continued, “I heard someone in the sunroom playing a song on the piano. I tried to place the tune for a while, and finally it came to me: It was ‘The Blue Tango,’ a tune from the ‘50s that my younger sister and her fiancé used to dance to. That moment, I could just see them dancing around the living room, showing off, and grinning. Oh, I was so thankful for that grand memory.”

Sometimes our dreams hold wonderfully uplifting moments we can call on when the going gets tough, too. Often in mine, I’m running by the river near my family home, just as I did as a child, long before being tethered to an oxygen cannula and using a wheelchair. I run so fast I can feel the breeze on my face and the exhilaration in my entire body. I wake up smiling, no matter how I’d been feeling the night before.

As I age and my disabilities take their toll, I learn to find something in every day that brings me joy. It can be the gentleness in the wrinkled face of a loving visitor, the bright yellow flowers near the entrance of my building, or the outrageous humor of my excellent caregiver.

During the bleak times, so many day-to-day occurrences can help us if we just focus on something besides ourselves. That, and know in our hearts the rough patches will pass.

(K.K. Wilder is a columnist and educator. Contact her through this paper or at KKWilder@aol.com)



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



Community Meetings Coming Up

VCIL is having a series of community meetings over the next few months, and a portion of each of them will be a joint training with VCDR about how you can get involved in legislative advocacy.

- Montpelier – VCIL Conference room, 11 East State St., 1-3 p.m. Aug. 20.
- Barre – Tilden House, 16 South Main St., 5-7 p.m., third Monday of every month.
- Burlington – Location is changing. Two subcommittees – accessibility and transportation. Call Crystal at 985-9863 for details.
- More meetings throughout the entire state. Check the VCIL Web site from time to time for updates (see link below), or call VCIL at 1-800-639-1522.

www.vcil.org/stakeholders/PWDs/community/index.php

Be An Advocate

Contact your congressional delegation about health care reform or other policy issues:

U.S. Senator Patrick Leahy
199 Main St., 4th Floor
Burlington VT 05401
Telephone: 1-800-642-3193 (in Vt.)

U.S. Senator Bernard Sanders
1 Church St., 2nd Floor
Burlington, VT 05401
Telephone: 1-800-339-9834 (in Vt.)

U.S. Congressman Peter Welch
30 Main St.
Third Floor, Suite 350
Burlington, VT 05401
Phone: 1-888-605-7270 (in Vt.)

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 October 23, 2009