Arts, Advocacy and Community

We open this issue with the image of Vermont puppeteer Sarah Frechette stitching Snowflake Bentley back to life and move on to social change. Advocacy and the arts join hands as we visit writers, puppeteers and a film project and also present the legislative agendas of the Community of Vermont Elders and the Vermont Coalition for Disability Rights. One of our best writers is K.K. Wilder whose work has graced these pages for many years. Thank you, K.K., for your vision and clarity and thanks to all of the artists and performers whose work is mentioned in these pages.

We want to make sure everyone knows that we will be publishing an Early Spring edition of The Independent before the legislative session ends and will publish updated information on both budget issues and policy bills. There are difficult choices ahead. We hope that you will share your stories and concerns and take time to reach out to your Legislature and to groups like COVE, VCDR and One Vermont (see pages 4, 6 and 21) as the session moves forward.

One of our greatest tools for change is our ability to speak up and share our story: in words, through technology, in paintings and drawings and in theater. Today we need these stories to keep our democracy and our daily life in tune with and reflective of the lives that make up Vermont’s community. Thanks to our many readers for speaking out for social justice and understanding.

-- Deborah Lisi-Baker, Editor
Letters to the Editor

Reverse VSH Canteen Closure Decision

While the Vermont State Hospital remains open, I have come down on the side of opposing the closure of the hospital canteen out of respect for those currently as well as formerly incarcerated at VSH who have indicated the canteen is needed for the time being as their one small bright light at the end of the tunnel, even if only a glimmer of hope is provided by such.

That said, I am also among those who have long been working to have VSH closed down as well as at the same time working to have put into place a very different system of providing for the actual needs of those either currently or previously incarcerated there as well as those who could be in the future and, will not shy away from continuing to do so at all.

These needs include real, safe, decent and affordable housing, income, training, employment, transportation and other such supports and services that allow one to live independently where and how they may choose to reside.

This of course runs contrary to what has basically been the sole focus of the commissioner of mental health to chiefly replace the role or functions of VSH and merely move what is done there in the form of institutionalization in one fashion or another to other places elsewhere, while mostly providing poor lip service to providing truly community-based opportunities and real inclusion for people whom too many within our society would rather keep out of sight out of mind.

The fact is that dumping people without their being offered basic housing as well as independent living opportunities and supports or services they can freely choose from when they are without such is no solution either.

The commissioner and his supporters have mixed up priorities and, as such, have been headed in the wrong direction for quite some time.

Even though closing VSH is highly desirable and sorely needed in order to move ahead with what will be required, the closure of the canteen while the current facility remains open is not desired, certainly not among those incarcerated or employed there, nor by those of us who stand in solidarity with them either.

Morgan W. Brown
Montpelier

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Make checks payable to The Vermont Center for Independent Living and write “for the Independent” on the check. Audiotape copies available upon request.
An executive received some complimentary tickets to a performance of Schubert’s “Unfinished Symphony.” Since she was unable to attend, she passed the invitation along to an accountability manager on her Tiger Team. The next morning, she asked him how he enjoyed it. Instead of a few plausible comments, she was handed a memo which read as follows:

1. For a considerable period, the oboe players had nothing to do. Their number should be reduced and their work spread over the entire orchestra, thus avoiding peaks of inactivity.

2. All 12 violins played identical notes. This seems unnecessary duplication. The staff of this section should be drastically cut. If more volume is desired, this could be obtained through use of amplification.

3. Considerable effort was involved in playing 16th notes. This seems an excessive refinement. It is recommended that all notes should be rounded up to the nearest eighth notes. This would make it possible to use amateurs and paraprofessionals rather than experienced musicians.

4. No useful purpose is served by repeating with horns the passage that has already been played by the strings. If all such redundancies were eliminated, the concert could have been reduced from two hours to 40 minutes.

5. This symphony had two movements. If Schubert did not achieve his musical goals by the end of the first movement, then he should have stopped there. This would further reduce the concert to 20 minutes.

6. In light of the above, one can only conclude that had Schubert given attention to these matters, he probably would have had the time to finish his symphony.

We can find great amusement in this parable, but it is no laughing matter when we consider the parallels to the state’s budget cutting frenzy and the Government Accountability Committee report: Challenges for Change. Folks who support this report are being framed as “champions of change” and those of us who raise legitimate questions or reservations are being labeled as “forces for the status quo.” Critical analysis, ideological differences and reasonable cautions should not be discarded as unenlightened, or dismissed as resistance.

Our quality of life is directly connected to the public structures and supports we have created over many decades. These investments have made Vermont a good place to live. In times like these when elders and families are struggling, we need to ensure that fundamental structures, services and supports are working to promote and protect the dignity, security and well-being of Vermonters. Now is the time for government to step up, not away, from its role and responsibilities.

Cuts to state government and human services have already had significant, negative impact for vulnerable Vermonters, especially those who are medically frail, geographically isolated and economically disadvantaged. Efficiencies and cuts alone will not meet the needs of Vermonters, and additional cuts will end up creating hardship and suffering and costing us so much more in the long-term.

It has been said that the budget is a moral document. Let us hope and demand that it reflects our values and is not balanced on the backs of folks who need and deserve a responsive government.

Dolly Fleming is the executive director of the Community of Vermont Elders.
The quality of life we enjoy is directly connected to the public structures and supports we have created over many decades. These investments have made Vermont a good place to live for the most part. In times like these when elders and families are struggling, we need to make sure the fundamental structures, programs, services and supports are working to promote and protect the dignity, security and well-being of older Vermonters.

Now is the time for government to step up, not away from its role and commitment, and:

- Build and protect public structures and supports that create quality of life.
- Foster the common good.
- Provide responsible management and stewardship of resources.
- Protect public health and safety.

Cuts to state government and human services and supports for elders have already had a significant, negative impact on the quality of life and safety for many older Vermonters, especially those who are medically frail, geographically isolated and economically disadvantaged. Efficiency is important and something the state and providers should be looking for all the time, not just in tough times. Cuts alone will not meet the needs of Vermonters, and additional cuts to essential supports will end up costing us more.

We need a balanced approach to this crisis – one that examines expenditures, measures impact and includes revenue increases. We need assurances and evidence that the budget promotes the dignity and security of older Vermonters and vulnerable citizens and does not further erode and dismantle policies, critical services and essential supports. Additional cuts will undermine the systems we rely upon every day, create suffering and hardship and result in greater long-term financial costs.

COVE recognizes the importance of taking a stand for a state that works for all Vermonters. Toward this end, we work in collaboration and partnership with a broad base of organizations, coalitions and stakeholders and citizens.

Legislative and policy issues COVE will be monitoring include:

- Promotion of legislative oversight, accountability, transparency and evidence of social and programmatic and long-term financial impact when relevant cuts are proposed.
- Ongoing identification, review and response to emerging issues and bills that impact the dignity, security and well-being of seniors.
- Funding and reimbursement to aging and long-term care service providers and their ability to meet the needs of older Vermonters.
- Adult Protective Services – legislation that calls for an independent, comprehensive

Continued on Next Page
evaluation of APS; that all Vermont residential care homes and assisted living facilities are surveyed annually; assurances that potential Elder Justice funds are appropriately and wisely applied; credible and effective emergency response system and capacity for responding to abuse, neglect and exploitation of vulnerable adults

- Choices For Care – prevention of further funding and service erosion; maintenance of federal match resources; scrutiny regarding high needs frozen list and moderate needs wait list; and monitoring stated goals of serving more, offering choice and reinvesting in home and community-based services.

- Elder Care Clinician program – this already underfunded program is at serious risk of erosion or elimination. We need to ensure that the mental health needs of elders are adequately addressed and that effective outreach and access are preserved.

- Public transportation – reinvigorating and expanding consumer representation on public transit advisory boards; promotion of Complete Streets – enabling safe access to public roads for all users using complete street design principles; protect volunteer drivers from being required to have commercial coverage by their insurance companies; strengthening transportation to ensure access and mobility for seniors.

- Public pension preservation – support for principles of a good public pension system and preservation of retirement security for retired teachers and other Vermonters in public service careers.

- Affordable hearing aids – promotion of insurance coverage.

- Court reorganization – ensure that any changes do not result in erosion of access and supports for seniors or community justice concept, especially grandparents as kin and guardianships.

- Health care – inclusion of long-term care in health care reform efforts; preservation of premium assistance to Catamount; preservation of VPharm and VHAP; prevention of increased Medicaid co-pays, etc.

- Direct care worker support – recognizing that most recommendations from the legislative study require funding, COVE wants at a minimum to ensure that state-funded direct care workers do not experience another wage reduction; strength of this workforce is essential to well-being of elders and people with disabilities.

- Energy support program for low-income Vermonters - ongoing support for AARP’s petition to the PSB for reduced rates with the state’s two large electric utilities.

For 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 2010 Legislative Platform
Budget and Policy Priorities

by Deborah Lisi-Baker

Policy commitments that have been built over the last two decades must be preserved. Programs and policies with long-term financial and social benefits must not be sacrificed to reduce temporary budget shortfalls. Approaches that make self-determination, health, independence, safety, work and community participation possible are good investments.

We believe that Vermont lawmakers need to find a more balanced approach to the budget crisis – one that will address the very real and immediate revenue concerns while maintaining Vermont’s commitment to policies and programs that work for Vermont.

VCDR will be advocating for maintaining current Medicaid benefits and the Medicaid long-term care services that individuals with disabilities of all ages depend on to maintain their health and independence. We will also advocate for successful state-funded programs that make health, independence, community participation and work possible.

Cuts in budgets and staff positions have already lessened the ability of state and nonprofit agencies to operate essential programs and maintain both policy and service commitments to Vermonters with disabilities. We will continue to monitor the impact of existing cuts and oppose those that reduce the quality, effectiveness and availability of disability services.

Vermont’s peer-run programs and services must be protected. Programs and services run by Vermonters with disabilities offer resources and support that cannot be found elsewhere. These programs (which include Vermont Psychiatric Survivors, Green Mountain Self-Advocates, and Another Way Drop-In Center), as well as peer-run newspapers The Independent and Counterpoint, are dependent on state support for their survival. As the state budget crisis escalates we cannot afford a reduction in Vermont’s commitment to self determination and to peer-run recovery services.

**Policy Bills**

**TBI Trust Fund:** VCDR supports legislation to establish a trust fund, as 20 other states have, to provide a source of revenue dedicated to filling the gaps in services and support for people with brain injuries and to develop programs designed to reduce the incidence of brain injury in Vermont. The proposed trust fund would be financed either by a $1 surcharge on motor vehicle registrations or by dedicating a portion of penalties for violation of motor vehicle safety statutes, including DUI (in recognition that a substantial percentage of brain injuries in Vermont result from negligent operation of motor vehicles, especially drunken driving). A TBI Fund was set up at the end of the 2008 legislative session with onetime funding but without ongoing funds. BIA and VCDR are also asking for state funds to help support a successful pilot program for injured veterans.

Continued on Next Page
Protection of Service Animals: VCDR supports legislation to (1) prohibit a person from interfering with any service animal in training or performance of its duties; (2) establish penalties for cruelty to a service animal or for killing of a service animal; and (3) permit an owner or user of a service animal that has been harmed to obtain restitution from or file a civil action against the person who carried out such violations.

Respectful Language Legislation: VCDR supports legislation to make sure that the Vermont Legislature and state agencies use respectful language when referring to individuals with disabilities in the preparation of legislation and rules. Such legislation will promote use of “people first” language and prohibit use of outdated and disrespectful terms, such as “mental retardation.”

Positive Behavioral Supports: VCDR supports legislation or strong regulation promoting the use of positive behavioral supports and restricting and carefully regulating any use of restrictive behavioral interventions (restraint, seclusion, or aversives) in all of Vermont’s primary and secondary educational settings.

“Walk with Your Class” Legislation: VCDR supports legislation to allow students with disabilities who will be continuing their secondary school activities to join their classmates in the graduation ceremony and other senior year celebrations and activities.

Preservation of Rights of Individuals with Mental Health Issues: VCDR will monitor proposed legislation that may diminish the civil rights of people with mental health issues. With the emphasis on movement of services from the Vermont State Hospital to community settings, it is important that due process in involuntary treatment and other rights to self-determination are not compromised.

Pain Management and End-of-Life Care: VCDR supports legislative initiatives to improve pain management services available to Vermonters throughout life and the improvement of end-of-life care and pain management in Vermont. VCDR opposes any legislation legalizing physician-assisted suicide (sometimes called “End of Life Choices” or “Death with Dignity” legislation). We would prefer to see Vermont policy and legislative efforts focus on making real improvements in and increasing and equalizing access to needed end-of-life and chronic pain services. (No PAS legislation has been introduced for fiscal year 2010 but proponents have said that they will be reintroducing legislation in the future.)

Disability Parking Fines: VCDR supports legislation to increase the fine for illegally using parking spaces that are reserved for individuals with disabilities.

Transportation Funding: VCDR supports legislative initiatives to preserve and increase community transportation and public transit funding, including state and federal funds for both critical care transportation and for senior and disability transportation.

Work Incentives: VCDR supports and will monitor efforts by the administration and/or the Legislature to expand Vermont’s work incentive benefits, including expanding eligibility and asset protections in Vermont’s Medicaid for Working People with Disabilities Program.

Continued on Next Page
Other Budget Concerns and Priorities

Communication Support Project: VCDR supports funding for the administration of the Vermont Communication Support Project. The program provides communication supports to individuals with cognitive and other disabilities during court and administrative procedures. Without this service, individuals with cognitive disabilities are not able to understand and fully participate in legal and judicial activities that impact their lives.

Peer Navigators/Family Support Initiative: VCDR supports an appropriation of $250,000 for Vermont’s Peer Navigators (PN). PNs have been working with families with parents with disabilities and with children with disabilities to connect them to appropriate services and supports. Grant funding will run out at the end of June, 2010.

Vehicle Modification Funds: VCDR supports Vermont Family Network’s request for an allocation of $318,000 to assist families with expenses relating to modifying a van or other vehicle required to make the vehicle accessible to children whose medical condition requires adaptive equipment and/or a wheelchair.

CSHN Respite: VCDR supports a $55,000 increase in the Vermont Department of Health’s current budget for the Children with Special Health Needs Respite Program: first, adding an estimated $55,000 to restore the program to 2008 funding levels of $350,000; and also adding an additional $130,000 to bring this program funding parity with the Developmental Services Flexible Family Funding program. Internal transfers have been hard to track, but these numbers will be updated as new budget figures emerge.

Early Periodic Screening, Diagnosis and Treatment: VCDR calls for careful monitoring of the use of the $2.4 million in the SFY 2008-2009 budget and funds included in the 2009-2010 budget (amounts unclear) which were intended to support full implementation of EPSDT services (especially case management and rehabilitative therapies) for Vermont’s Medicaid-eligible children. The request for monitoring is intended to address two issues: assurance that the funds will be allocated to their intended purposes and to assess whether this funding is adequate to cover mandated EPSDT services.

Other Issues We Are Following

VCDR will continue to monitor and support any efforts to expand S.271 to allow family court to consider requests to extend child support for an individual with physical, mental, or developmental disabilities beyond the age of 22.

VCDR will continue to monitor education finance and reform initiatives and appropriations to ensure that the rights and interests of students with disabilities and their families are protected.

VCDR will monitor legislation or initiatives emerging from recent reports, summer studies and administrative or legislative task forces such as the guardianship study, continued efforts to enhance and support Vermont’s direct care workers, and sustaining long-term care services for individuals with disabilities and seniors and transition services for youth with disabilities that create equal opportunities for independence, self determination, community participation and work.

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

VCDR
11 East State St., Suite 2
Montpelier, VT 05602
Phone: 802-223-6140
E-mail: vcdrvt@gmail.com
We Shall Overcome!

by Max Barrows

Green Mountain Self-Advocates was asked to speak at the People First of Alabama conference. Randy Lizotte and I taught a sexuality workshop along with the dating game. When we started teaching the workshop on sex, we had an activity on asking the audience about what messages did you get about sex when you were growing up. Ninety percent of the responses we got back were: “I have never talked about sex at all.” It was a shock to me.

Alabama has a great civil rights history. In Birmingham, we went to the Civil Rights Institute. It was located on 16th Street, the same street as the Baptist Church where four girls were murdered while the church was bombed by the Ku Klux Klan in 1964. We went in the institute to look around and examine the exhibits. It was very powerful.

While we were in the institute, I met a man named James Armstrong. James Armstrong is a volunteer at the institute. During the civil rights movement, he had two boys who sued the city of Birmingham to integrate the all-white schools. He also told us about how he worked with Martin Luther King Jr. and about not fighting back while protesting even when being physically attacked. He told me how he was in a little diner and sometimes white folks used to put out their cigarettes on his neck, but even though it was painful and hard not to react (like nowadays), he had the courage not to. Overall, it was a great experience to be in Alabama and to get a taste of the South and its history and hospitality.

Max Barrows is outreach coordinator for Green Mountain Self-Advocates.

Thank You!

In December, the state of Vermont eliminated funding for the only full-time employee of Green Mountain Self-Advocates. GMSA is a nationally recognized organization that has helped Vermont earn a reputation as a role model for serving citizens with developmental disabilities in the community. GMSA is a statewide network of more than 600 youths and adults with developmental disabilities. This grassroots organization provides technical assistance to 18 thriving local groups in every corner of Vermont, from Bennington and Brattleboro to Newport, and more groups are added every year. GMSA goes to the heart of the quality of life for Vermonters with developmental disabilities. GMSA wants to thank all of our allies for your ongoing support during this tough time. We shall overcome!
Vermont Caregiver Champion Honored

Although the Vermont Association of Professional Care Providers (VAPCP) closed its doors last spring, the Community of Vermont Elders is continuing its commitment to supporting professional caregivers while expanding support to family caregivers as part of its Caregiver Initiative.

Good things are already happening. This year the Governor’s Healthy Aging Awards has included the new category of Caregiver Champion to celebrate these professional caregivers. This award honors those outstanding caregivers who exemplify the profession in the field of caregiving.

Lucinda “Cindy” Vandenburgh, a licensed nursing assistant (LNA) of 30 years, was honored with this award at a ceremony held at the Vermont Statehouse on Nov. 24.

Cindy works at Mountain View Center, a Genesis Healthcare Facility, in Rutland. Mountain View Center is a Gold Star facility. The Gold Star employer program was implemented in Vermont in 2004 by the Vermont Department of Disabilities, Aging and Independent Living in partnership with the Vermont Health Care Association to foster and support best practices for recruitment and retention of caregivers, particularly direct care staff. The program recognizes nursing homes that employ best practices.

Want to learn more about COVE’s work to improve care and support direct care workers? Susan can be reached at:

Susan Gordon, Caregiver Initiative Director
COVE
PO Box 1276
Montpelier, VT 05602
802-229-4731
susan@vermontelders.org
Work and Benefits
FEARS AND FIXES

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<th>I’m not going to work because:</th>
<th>I can go to work now because:</th>
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<tr>
<td>I am afraid to lose my health care.</td>
<td>One of several Vermont programs that protect my health care is Medicaid for Working People with Disabilities. I can keep Medicaid coverage if I have countable income up to $27,180 a year (for one person), after allowable deductions from my gross income. If I have Medicare coverage and I go to work, my coverage will continue at least 93 months after the Trial Work Period. (See a benefits specialist about the Trial Work Period.)</td>
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<td>I am afraid of losing my benefits and then finding out I can no longer work. I’ve always heard that it is so hard to get back on benefits.</td>
<td>There is a new Social Security program called Expedited Reinstatement where I may be able to quickly get back on SSI or SSDI benefits, without a new application as long as it is within five years since my benefits were stopped.</td>
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<td>I am afraid to lose my subsidized housing.</td>
<td>There’s a new work incentive where I may be able to freeze my rent for one year if I go to work.</td>
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<td>I don’t trust that I am getting accurate information about what will happen to all of my benefits if I go to work.</td>
<td>Through the VCIL Benefits to Work Program, I have access to specially trained and certified benefits specialists who will tell me exactly what will happen to all of my state federal benefits when I go to work. This will help me make an informed decision about going back to work.</td>
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For more information, contact the Benefits to Work Program at the Vermont Center for Independent Living:
1-800-639-1522
802-229-0501
Whether they know it or not, all Vermont municipalities must comply with the Americans with Disabilities Act. Specific administrative requirements for designating ADA coordinators, adopting grievance procedures and providing accommodations, help ensure that the needs of people with disabilities are addressed in the programs, activities and services operated by a public entity. Having these requirements in place will not prevent all problems, but it will help to efficiently address many problems.

If your municipality has less than 50 employees, it is required to:

- adopt and distribute a public notice about the relevant provisions of the ADA to all people who may be interested in its programs, activities and services.

If your municipality has 50 employees (includes all full- and part-time employees of all departments) or more, it is required to:

- adopt and distribute a public notice about the relevant provisions of the ADA to all persons who may be interested in its programs, activities and services;
- designate at least one employee responsible for coordinating compliance with the ADA and investigating ADA complaints; and;
- develop and publish grievance procedures to provide fair and prompt resolution of complaints under Title II of the ADA at the local level.

**ADA Committees in Vermont**

Vermont’s capital city, Montpelier, has a newly formed ADA Advisory Committee led by the city manager, temporarily serving as the acting ADA coordinator. The eight-member committee is made up of community members, the director of public works, school superintendent, and chaired by an active city council member. The committee has enacted a grievance procedure and distributed a notice of nondiscrimination against people with disabilities. The committee has secured capital campaign funding to begin updating its ADA transition plan. Vermont’s ADA state affiliate, VCIL, played a key role in organizing the advisory committee and providing ADA technical assistance to its members and the city.

Brattleboro has an ADA Advisory Committee as well, and so does Barre City. (See related story.) Efforts to establish committees elsewhere are under way.

If you have questions about issues relating to ADA compliance, call your town clerk or manager and ask to speak to the ADA coordinator. If your town needs help understanding how to meet its responsibility to the ADA, the person to contact is Kim Brittenham, VCIL Community Access Coordinator: 802-229-0501 or kbrittenham@vcil.org

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**How An ADA Committee Was Formed: One City’s Story**

*by Ericka Reil*

In April of 2008, the Vermont Center for Independent Living (VCIL) went to talk to the residents of Tilden House about getting ideas on making Barre City a better place to live for people with disabilities and the elderly.

It took awhile for everyone to open up to each other but soon the conversation was flowing.

*Continued on Next Page*
People talked about the sidewalks being in ill repair, lights at the crosswalks not being long enough and that cars did not stop for people at the Tilden House crosswalk. During the next few meetings VCIL held at Tilden House, people really tried hard to find solutions to these problems. But it seemed we went around and around on how. Many times people asked if they thought anything could be done. The answer was always yes. Finally we decided to invite the mayor of Barre to hear us. We also invited a reporter from the Times Argus. Both the mayor and the reporter came to the next meeting. The mayor said that he would look into the problems.

Time went on and nothing happened. We did not see changes and the group became more and more frustrated. So we wrote a letter to the Barre City Council and were invited to their next meeting. In June, we went to read our letter and the mayor and city manager said they would attend our next meeting.

They did not come to the next meeting but hope was not lost. We then decided to invite the city manager and everyone from the city council and mayor’s office. The mayor, city manager and a council member came to a meeting in September. The mayor agreed that Barre needed some help with accessibility but that he could not do it all himself. That’s when the idea was born to have a group of concerned residents walk around and look at what needs improvements. The mayor agreed and Barre City’s ADA Committee was formed.

Continued From Previous Page

Representatives from VCIL and several other organizations filled a large meeting room at the Statehouse on Jan. 6, urging lawmakers to fix a broken system and pass health reform.

The rally was organized by the Vermont Workers’ Center and it was one of a series of events held across the state in recent months. It is all part of the Workers’ Center’s “Healthcare is a Human Right” campaign, an effort to promote the two single-payer bills that are currently before the Legislature. While VCIL has not taken a position that specifically backs a single-payer system, it has long been a proponent of universal health care and adequate health care for people with disabilities.

“It is time for change!” said Sarah Launderville, executive director of the Vermont Center for Independent Living. “We all understand the system is broken. We are here to invest our dollars in a new system in which people are treated with full respect and dignity. ‘Healthcare is a Human Right’ is not just a catchy phrase; it is the truest form of investing in and protecting ourselves so that we and our children can live with the decency that we deserve.”

Another advocate, Susan Lucas, president of the nurses union at Copley Hospital, said, “We believe that health care is not a commodity but a public good shared by all. The time is now to make health care a basic fundamental right for every single person.”

Lawmakers are considering a number of approaches but make no promises about taking action on health care reform this session.

PHOTO BY BEKAH MANDELL
At the Statehouse on Jan. 6, Sarah Launderville of VCIL, center, talks about the importance of fixing Vermont’s health care system.
Sexual and Domestic Violence Programs Move Forward

Access to violence and abuse hot lines and shelters is improving in Vermont due to work through a federal grant partnership between the Vermont Center for Independent Living, Green Mountain Self-Advocates and the Network Against Domestic and Sexual Violence, a coalition of 15 local domestic and sexual violence programs around the state. VCIL is celebrating three years of work supporting two new local collaborations – one in Barre and one in Burlington.

Barre

In Barre, the local domestic violence shelter, Battered Women's Services and Shelter, and Deaf Vermonter Advocacy Services have worked to improve hot line and shelter services for people who are Deaf and Hard of Hearing. A spiral-bound resource guide was created to assist staff in using communication equipment (videophones, vibrating alarm, flashing door signal, TTY). This collaboration was celebrated during a recent press event with community partners attending from local law enforcement departments, social service providers and the community. This pilot program is unique and a first of its kind, not only in Vermont, but in the rest of the country. Lessons learned and the resources created in Barre are being shared with programs throughout Vermont and the rest of the country.

Burlington

In Burlington, access to sexual violence programs has improved due to collaboration between the Women's Race Crisis Center (WRCC) and HowardCenter's Developmental Services. HowardCenter has created a new “Safe Face” program where staff and clients are receiving ongoing trauma sensitivity training to become “safe people” who can better support people with developmental disabilities who experience violence. WRCC is tailoring training curriculum and services to be more cognitively accessible. In testament to the long-term value of this work, WRCC recently presented its 2009 Community Ally Award to HowardCenter.

Access Improves Statewide

In addition to supporting the Barre and Burlington collaborations, VCIL, GMSA and the Network have improved the way their organizations support people with disabilities experiencing violence and abuse. VCIL maintains a violence-free workplace, supports peers experiencing and recovering from abuse and violence and works closely with community partners to end violence and abuse. GMSA has a new guide for communicating effectively and running accessible meetings for people with developmental disabilities. The Vermont Network is training staff and programs on scheduling and conducting accessible meetings – and launching a new Web site to support its programs when working with people with disabilities.

People with disabilities experience violence and abuse at a higher rate than people without disabilities. VCIL and NCIL (National Council on Independent Living) take this reality seriously and are working to improve access to the services necessary for support and healing. VCIL sits on the NCIL Task Force Against Violence Committee and co-chairs NCIL's newly formed women's caucus.

This work to improve access to domestic and sexual violence programs has been funded by a federal grant through the Department of Justice's Office of Violence Against Women. For more information, contact VCIL's Community Access Coordinator, Kim Brittenham at 802-229-0501 or kbrittenham@vcil.org
Snowflake Bentley Returns!

Vermont History and Ingenuity Inspire Local Puppeteer

by Deborah Lisi-Baker

Wilson Bentley, the Vermont farmer and self-taught scientist who first discovered that each snowflake is unique, returns to Vermont through the work of Sarah Frechette and her creative circle of family and friends. You can meet him in her show, “The Snowflake Man,” which opened in Georgia, Vt., and Boston a few weeks ago.

Sarah’s interest in Snowflake Bentley is a family affair. Meeting Snowflake Bentley triggered her grandfather’s lifelong interest in science. Years later he shared Snowflake Bentley’s story with his granddaughter. When she grew up and become a puppeteer Sarah had the idea of creating a puppet show of Snowflake Bentley’s life; in part to honor his life and work, but also to celebrate her grandfather and her Vermont heritage.

Friends and family helped bring Sarah’s vision to life. The puppets and stage sets were built in part at her great-uncle Don’s workshop where she and a friend worked together creating puppet bodies. And behind this show – and every show Sarah does – is the memory of her Vermont heritage, of grandparents and relatives who work with their hands and with their hearts, and a great love of community life in a small northern Vermont town – Georgia.

Sarah has another play about her grandfather, “Papa Walt,” that shows him using a walker.

“I carved the marionette while in Buoch, Germany, at the Studio of master puppeteer Albrecht Roser,” said Sarah. “When I returned home I showed my Papa Walt the puppet. ‘Look Gramp. I made a puppet of you.’ He replied, ‘Why, you did not make a puppet of me – you made one of you and me together!’ Oh, the grandfather is very wise …” (You can see what he meant if you follow the strings of the Papa Walt marionette to the sometimes hidden – but extremely talented hands, heart and mind – of his granddaughter.)

Sarah teaches puppet making and performs her shows at schools, theaters and community groups in Vermont and out of state. Once she taught a workshop in a segregated residential school for adults with disabilities in the Midwest, an experience that left her in tears. Her show about Papa Walt shows someone in old age moving toward death while also celebrating every moment of life. “The Snowflake Man” show is sponsored in part by grants from the Vermont Arts Council and the National Endowment for the Arts.

For more information on Snowflake Bentley and the work of Sarah Frechette, visit her Web site at www.puppetkabob.com or e-mail her at puppetkabob@gmail.com
Vermont Protection & Advocacy Has a New Name

On Oct. 16, 2009, Vermont Protection & Advocacy celebrated its new name, Disability Rights Vermont, with a celebration and live performances showcasing disability rights and Deaf culture.

One Viewer’s Response: A Night of Change and Celebration

by Jerome Lipani

Awareness Theater Co: “The Life of Edward”

Awareness Theater Company performed the “The Life of Edward”… one person’s life story from birth trauma to system trauma and beyond. The company, an enthusiastic and accomplished ensemble of six actors, uses mime, storyboards and highly innovative props to tell the silent but outspoken story of the life of one of its own actors. Awareness Theater’s telling of one person’s life irrevocably changes the audience’s view of lives that all too often go unnoticed and forgotten.

The youngest actor among them made his debut performance both tender and sharp. The company’s use of props and costumes made from almost nothing bespeak more than perfectly the innocence, openness and highly intuitive intelligence of the actors, who had collaborated on the play’s script.

Deaf Performer Rene Pellerin

This was a remarkable venture of the evening, with the sign language interpreter providing immediate translation into spoken English. Pellerin’s natural use of mime and gesture in ASL, pitch-perfect timing of the many jokes, and simple and direct retelling of his impossibly complicated adventures allowed us to see him traveling alone through airports to his hotel in a world designed for those who are sighted and hearing. This was a tragically-comic retelling of almost any modern American airport nightmare of the first order. This culturally Deaf and visually-impaired performer of

Continued on Next Page
French-Canadian and Vermont heritage told us of his voyage through a darkening and sound-free emptiness – Pellerin’s own physical environment – and his experiences with the usual, sudden and interminable travel horrors and the insane interactions and miscommunications with the professionals who were supposed to be able to help him. What was there to do – what could we do – but laugh?

Gail Marlene Schwarz in her play, “Crazy”

Three stars to Gail Marlene Schwarz for her marvelously intense performance! Revealing some terribly anti-HIPPA-esque moments, Schwarz regaled us with poignant and hilarious reenactments of her experiences of modern American psychology as seen through her own revolutionary perspective and the unmistakably rigid viewpoints of some 18 psychiatrists she has seen from the age of 5 to the present. From her point of view, it would appear that acting out in a psychiatrist’s office is one’s actual mission; one’s Jeffersonian Duty, actually.

After having (literally and figuratively) swept the stage, she slowly unrolled a long, long list (from her forehead to the floor) of the numerous psychological diagnoses, mid-diagnoses, and clearly misdiagnoses that she has been forced to live among since the age of 5. She mentioned that she had finally been forced to purchase her own (very expensive) copy of the DSM-IV. Then she calmly sat down and proceeded to very slowly rip the seemingly endless list of some 24 different diagnoses in half. I wanted to applaud this brilliant piece of stage business, which totally transcended its own symbolic meaning. Socrates observed in fifth-century B.C. Athens that “physicians” prey on a sick society. It doesn’t really seem that much has changed since that particular Golden Age!

Congratulations to Gail Schwarz for her outlandish courage and non-relative truthfulness! Her freely anarchic and yet somehow emotionally accessible presentation – which would put off guard most watchdogs that might be in the vicinity – would present well in any professional or semi-professional comedy club.

In fact, all three pieces were brilliant in their Otherness. The effect was compounded by each and through each, almost as if the actors were in fact an ensemble company. The high professionalism, self-discipline and genius-level hard work of these actors was a stupendous high for its highly enthusiastic audience, other members of the disability community in Vermont, assembled in the Main Street Landing Performing Arts Center Black Box Theatre, a wonderfully-architected Community Cultural Center on Burlington’s waterfront. And all of this to celebrate a “mere” name change from Vermont Protection & Advocacy to Disability Rights Vermont! Hip hip hooray!!

Jerome Lipani is a writer and art correspondent who lives in Calais. You can write to him directly at jerome@vtlink.net
Most of us live many lives in one lifetime. Janet Schmidt is no exception. She has been a woman struggling to find herself and celebrating each gain; a respected educator and psychologist; a citizen advocate for Vermonters who are blind or visually impaired; a person struggling with depression; a truth teller; and a board member on the Vermont Developmental Disabilities Council. In the process of doing all these things she also found her way into a good marriage and discovered her love of writing. Two of her autobiographical essays are included in the anthology “Behind Our Eyes” and she is now looking for a publisher for her memoir, “An Ordinary Madness: Self Against Self.”

Asked to describe herself, Janet said: “I have congenital Optic Nerve Atrophy which contributed to my drive to achieve at the highest level possible to be competitive in the job market, education, and life in general. My struggle with depression has also contributed to my character. Struggling under too many years of inclusion without accommodations probably contributed to my sometimes ironic sense of humor and my ongoing struggle with depression. Nonetheless I love life and have caught the brass ring many times. People, travel, education, reading and writing are among my passions.”

Her life today includes caring for her husband who has been very ill, enjoying time with her extended family, participating in the Northeast Kingdom PALS group (a peer support group for individuals who are blind or partially sighted) and “cherishing moments of solitude.”

Living in the Northeast Kingdom is a choice that still brings delight. “We are surrounded by breath-taking beauty and the terrific people who fill our lives outweigh the negative of ‘you can’t get there from here.’ She credits good friends and the right disability services and supports for making it possible for her to both give to others and live a rich and rewarding life. She has just the right quote to share: “Freud held, ‘The good life is ‘lieben and arbeiten’ – to love and to work – love others and work for the common good.”

Janet Schmidt: A Writer’s Tale

Janet Schmidt

Janet’s writing style is an interesting combination of a survivor’s wry “straight from the hip” style interspersed with more lyrical lines of quiet introspection. In her memoir, she writes about outer marriage but also the hidden marriage of learning to live holistically with oneself. “My thesis concerns the importance of the marriage of: our soul, our spirit, our mortal being. When these are fragmented we do not function as whole human beings who experience reasonable contentedness, joy and sadness. Rather we splinter into pieces as a fine crystal goblet flung to the floor.” She goes on to tell the reader, “To quote e. e. cummings, ‘We do not believe in ourselves until someone reveals that deep inside us is valuable, worth listening to, worthy of our trust, sacred to our touch. Once we believe in ourselves we can risk curiosity, wonder, spontaneous delight or any experience that reveals the human spirit.’”

Good thoughts to hold onto; both in a winter of hard knocks and in the more peaceful moments of our lives.
Transforming Schools Through Story and Film

by Deborah Lisi-Baker

Harwood students and faculty continue to take on disability stereotypes through their groundbreaking film project, “Speak Out for Understanding.”

Students and advisers created a film record of the voices, experiences and dreams of Harwood students with learning disabilities and another student film is in the works. The discussions in their school and community made the students, faculty and families want to take on other projects and other disability issues.

Maureen Charron-Shea, faculty adviser for the project, wrote us recently, “Speak Out for Understanding has been going strong at Harwood. Steve Rand, an English teacher at Harwood, has picked up the cause and his Creative Writing class at Harwood just self-published children's books that are phenomenal! We love to share our work because we have seen the positive impact in our community. Emma Wade is home on break from college and came back to help get the next movie started. The support and interest is amazing.”

In 2008, the student and faculty advisers received VCIL's Leader of Tomorrow Award for their innovative use of film to create attitudinal and cultural change. The story was picked up by Teaching Tolerance, a project at the Southern Poverty Law Center that highlights successful approaches to teaching about diversity and inclusion. In writing their story about the Harwood project, they interviewed one of the advisers, Greg Sharrow of the Vermont Folklife Center, who talked with Teaching Tolerance about the power of storytelling.

“The interview process wasn’t just about collecting information,” Sharrow said. “It was about helping student develop their own stories ‘until they arrived at a place of strength.’”

The Harwood filmmakers who have seen the negative power of labels have created a positive

PHOTO BY STEFANIE MONTE
In 2008, Deborah Lisi-Baker, front left, presented VCIL's Leader of Tomorrow Award to participants in the SOFU project. Accepting the award are, front right, project guru Maureen Charron-Shea and, back row, from left, students Grace Kirpan, Emma Wade, Abby Zarotny and Tucker Sargent.

one for their project: SOFU, or Speak Out for Understanding, is what they want to inspire others to do.

So, when I told a friend from another school district about this project she passed the story on to a young woman with disabilities who talked it over with her grandfather. They went shopping the next day and got a video camera. Is Speak Out for Understanding coming to a school near you?
2002. A doctor found a piece of glass in Sarah Collins’ stomach.
“How did it get there?” he asked.
Sarah knew.

It was the Sunday in September 1963 that she lost her eye
and her sister Addie Mae and friends Carole, Cynthia and Denise
were killed by a bomb
exploding
in church.

It could have happened in New York or Iraq.
It could have happened in the Congo, in Vietnam or Afghanistan
It could have happened in Israel or Palestine.
It happened in a church in Birmingham, Ala, USA 1963
Four young girls slain while they prayed.

Said Sarah: “I can’t feel it. Glass is nothing.
Some people have demons inside them.”

In spite of the demons Sarah lived on with her losses.
The children carried on.

Though their mothers and fathers, grandmothers and grandfathers
who adored them, warned them,
the African American children of the South said:
“If we die, we die. We will not live in humiliation, fear and
cringing and they filled the jails, singing.

They knew they were made of the same stuff
--the same stuff as the stars.

Phyllis Rachel Larrabee is a poet who lives in Woodbury. She was
an information and referral specialist at VCIL for nine years. She
credits this experience in “giving her a PhD in how to live with a
disability.”
Counting Up the Losses

by Deborah Lisi-Baker
VCDR President

It is Jan. 22, 2010. The governor gave his budget address earlier this week. It calls for $150 million of savings. It also endorses the recent “Challenges for Change” report, which anticipates finding about $38 million in savings from restructuring how state government works. Like others, I think that administrative efficiency is needed. I remain skeptical about many of the proposals in the report, in part because it lacks the detail necessary to help policy-makers assess whether and how these savings will be achieved.

But the plain truth is that most of the proposed savings will be made by denying help to Vermonters: $48 million through program eliminations and eligibility and service reductions in human services and equally catastrophic reductions proposed to health, housing, education and other services. Most of the hardship and pain is once again going to be borne first and foremost by those Vermonters who have fewer resources, many of whom will no longer be eligible to turn to the state for help. We are talking about: working families, low-income Vermonters, individuals with disabilities and seniors and their families.

The details of various proposed budget cuts are beginning to emerge. Numbers so big as to be hard to believe: a cut of $147,000 in state funds to Area Agencies on Aging; $1 million cut from the Attendant Services Program; $127,000 from the Long Term Care Ombudsman Program; $692,000 from home health personal care; cuts of up to $357,000 from the Children with Special Health Care Needs’ respite programs, clinics and individual support services; similar cuts in mental health and developmental services programs.

These are just a few early numbers from a growing list. It takes lots of large and small cuts to reach $100 million. When I start counting the totals, I do not see numbers, but Vermonters being turned away, jobs denied, paychecks cut, health care lost, respite and community services disappearing …

We need to talk with each other and with our legislators about whether cutting so much, and so deeply, is the best way to build a budget for hard times. Meanwhile the Public Assets Institute has just published, “It’s Raining Hard: Tap the Fund.” It describes what other states are doing with their rainy day funds and highlighting Vermont’s 120 million of unspent reserves. They suggest looking for ways to help Vermonters today and building long-range solutions to prevent this from happening again. Isn’t it time to look at the rainy day fund and at some reasonable short-term approaches to tax revenue?

Want to help protect the public structures that work for Vermonters?

One Vermont is a network of citizens, organizations and businesses committed to state policies, systems and public structures that help build a society that works for all Vermonters. One Vermont invites participation of all citizens and organizations that support its mission.

For more information on One Vermont, contact:
Barbara Postman, Coalition Chair
One Vermont Coalition
c/o Voices for Vermont’s Children
PO Box 261
Montpelier, VT 05601
bpostman@voicesforvtkids.org
802-229-6377
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

<table>
<thead>
<tr>
<th>Item</th>
<th>Owner Name</th>
<th>Location</th>
<th>Phone Number</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathmaster Sonaris automatic showerchair, gently used</td>
<td>Laurie</td>
<td>Brandon</td>
<td>802-247-6891</td>
<td>$800 OBO</td>
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### Wheelchairs & Scooters

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<th>Item</th>
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<th>Location</th>
<th>Phone Number</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td>Used Electric Wheelchair</td>
<td>Mike</td>
<td>Derby Line</td>
<td>802-873-3525</td>
<td>$345</td>
</tr>
<tr>
<td>Electric power 3 Wheelchair. Very good condition</td>
<td>David</td>
<td>Rutland</td>
<td>802-747-0293</td>
<td>$2000 OBO</td>
</tr>
<tr>
<td>2 manual wheelchairs 175.00 for one 300.00 for the pair</td>
<td>Betty</td>
<td>St. Albans</td>
<td>802-524-1139</td>
<td>$175 each</td>
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### Vans & Automobiles

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<tr>
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<th>Phone Number</th>
<th>Price</th>
</tr>
</thead>
<tbody>
<tr>
<td>97 Ford 150, wheelchair lift. Needs some work</td>
<td>Laura</td>
<td>Williston</td>
<td>802-658-3640</td>
<td>$1000</td>
</tr>
</tbody>
</table>

Ericka Reil  
Vermont Center for Independent Living  
802-229-0501  800-639-1522
Disability Happens -K.K.

By K.K. Wilder

Rough Patches
(Part Two of Two)

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. First, is my elderly gentleman cat, Uncle Edson. Edson’s human companions moved to New Zealand and left him with me. He’s a big gray and white boy, 13 years old, about 16 pounds, has seven digits on each paw, never bites or scratches, and lets me know in no uncertain terms when he wants his food … NOW. He sits on my lap, looking up at me as if I’m Athena, purrs so you can hear him across the room, and lets me brush him backward or forward for as long as I want. Remember, if you live in any HUD or government-sponsored senior housing, you’re allowed a cat or small dog. It’s been proven animals are good for our mental and physical health.

Another great assist to those of us who need them can be a homemaker or caregiver. Such help can come through professional nursing organizations, such as VNA or ARIS Solutions; they can also be hired privately or through health care agencies. A homemaker does housework, prepares easy meals, and takes care of your laundry. A caregiver does the same, except also helps with showers, dressing, visits to the doctors, and reminds you to take your medications on time. If you are ever as lucky as I have been to get help from anyone with a great amount of efficiency, a wild sense of humor, and who knows how to cook well, you will find your mind taken off yourself daily.

Very special, often found in senior, nursing, or assisted living homes are the lovely men and women who find each other –sometimes becoming a couple. One woman tells me having a very close friend means there’s somebody who accepts you for whoever you are, listens, and if in the same generation, shares the same music. “I can put on a Glenn Miller album,” she says, “and he wants to dance. Or sometimes we’ll just start singing old songs like, ‘Put your arms around me, honey, hold me tight. Cuddle up and cuddle up with all your might.’” And it means being touched … holding hands by the TV, when they walk, and other times.

Such gentlemen don’t mind if you slip up now and then and use your deceased husband’s name instead of his. My friend’s particular male friend walks with her because she can’t go alone with her poor balance. She can tell him stories over and over again because he has short-term memory loss. She quotes a saying her mother had on the wall. “A friend is not a feller who is taken in by sham; a friend is one who knows our faults and doesn’t give a damn.” Neither of them would want a 24/7 situation, but they love shopping, walking, attending movies, and watching TV as a twosome.

All this is not to say you can’t ever just close out the world for a few hours and have yourself a pity party. That’s totally OK; we just suggested you put a time limit on it.

(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

SAVE the DATE !!!!

Disability Awareness Day
Wednesday, Feb. 17, 2010
Join Us at the Statehouse
8:30 a.m. to 7:30 p.m.
Room 11 - 10 a.m. to noon
Supper in the Cafeteria

Disability Awareness Day is co-sponsored by the Vermont Developmental Disabilities Council and the 27 member organizations of the Vermont Coalition for Disability Rights. For more information or to register, call: the Vermont Center for Independent Living at 1-800-639-1522 (V/TTY) or VCDR at 802-223-6140, e-mail vcdrvt@gmail.com, or visit our Web site:

www.vcdr.org

VCIL would like to thank EverBank for its very generous donation.
More information to follow.

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 March 12, 2010