Keeping the Promise

Some days I don’t have to go out. Sitting here, writing for The Independent, feels like a gift: no meetings, no noise, just my husband and I in a still house with only the wild turkeys outside our door – and an occasionally rowdy blue jay. But down the road, in our communities, and in our national and international choices, we face a call to action. Can we meet this challenge? I believe we can. Calls for a restored commitment to democratic principles, as well as for the simple and necessary local acts of helping our neighbors, feel like the social equivalent of spring sunlight that arrived in February – so unexpected and a radiant reminder of more to come.

Vermont Karen Topper was with Vice President Joe Biden recently when he discussed disability rights and self advocacy, saying, “This is a civil rights movement … There needs to be a change in policy.” We agree. Many federal policies and practices are limited by out-of-date assumptions about both aging and disability. Recent economic woes and long-standing funding needs have also challenged Vermont’s ability to maintain a remarkable safety net of both rights and services. This legacy must not be lost. Keeping the promise pays off for all of us.

– Deborah Lisi-Baker
The Independent Needs Your Help

The Independent needs your support more than ever. For several years we have gotten $10,000 from the state to help with printing, mailing and publishing costs. During the summer cuts to the state budget, this grant was cut in half and we have been told this cut will continue. Mailing costs have skyrocketed during the last 10 years: It costs us $5,000 an issue just for printing, mailing and layout costs – VCIL donates staff time to help produce and edit each issue and pays the remaining printing and mailing costs. Your donation or subscription would help us continue this paper during these challenging economic times.

We love hearing from you and love providing an independent paper for seniors and individuals with disabilities and families! Thank you for your letters, submissions and support. They all mean a great deal to us as we work to keep this paper going.

Deborah Lisi-Baker

Editor

ASL To Be Taught In Public Schools

I wanted to let you know about progress made on ASL being taught in public school as a foreign language.

As I mentioned last year at VCDR's Disability Awareness Day dinner, the requirement that ASL be taught in public schools as a foreign language [has] been sitting in the Department of Education collecting dust.

A couple of legislators came to me afterward and wanted to follow up on this with the Commissioner of Department of Education. Guess what? Department of Education got their ass kicked! Last month Department of Education finished and brought [the plan] for final approval!

It still needs some work to improve it but at least it's finally moving. Only thing missing that we want to add is the instructors must be certified by the American Sign Language Association. The Vermont Center for the Deaf and Hard of Hearing (VCDHH) has been working closely with the Department of Ed. Brattleboro Union High School now has a class.

René Pellerin

Waterbury

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**A Call To Action**

*Editor’s Note: This year the independent living movement lost Jean Mankowsky-Upham, VCIL’s second executive director and a steadfast and visionary advocate for participant-directed attendant care and a passionate and persuasive advocate for full implementation of the Americans with Disabilities Act. She also served as chairwoman of the Statewide Independent Living Council. As we celebrate the 30th anniversary of the Vermont Center for Independent Living and prepare for Disability Awareness Day 2009 at the Statehouse, it is fitting to share the message Jean sent to be read at last year’s Disability Awareness Day event:

Greetings to you from Jean and Dennis Mankowsky-Upham, mud-bound on Bliss Pond Road in Adamant, Vermont! ...Though we would much rather be with you to celebrate the advances and successes we have achieved, as well as to re-dedicate ourselves to the “fight” for equality for all, we must send our reflections to be read by someone else.

All too often citizens with disabilities are kept from participating fully with our peers and from making the impact on our communities, our state, and our nation which we desire. Sometimes it is our bodies and health which limit our involvement, other times it is a lack of resources, or transportation, or sufficient attendant care, or interpreter service that keeps us from being heard and our power as a movement felt!

And that is what makes events like this one so important and significant... For each person who is in this room tonight there are ever so many more who would be if they were able! And so tonight let us all celebrate our value both as individuals and as a community!

My coping with disability began long before the beginning of the independent living movement in the “heydays” of the Vermont State Hospital, Brandon Training School, and countless other institutions across the country where people with disabilities were warehoused, where they barely existed, and were kept apart from society as a whole. My Rheumatoid Arthritis began at age 8 and the rest of my elementary and adolescent years were spent on bed rest followed by countless long-term hospitalizations. I never knew any other disabled peers nor had any successful disabled role models who perhaps were aided by a personal care attendant, had meaningful employment, to say nothing of a romantic relationship or a family! I saw my future in a very limited way: My parents would take care of me as long as they were able, and then I would spend the rest of my life in a nursing home. Not a very happy or exciting picture for a young person in the dawn of the ’70s!

It was at this time that a very “forward thinking,” perhaps even radical vocational rehabilitation counselor came into my life. He saw more promise in my life than I did. He made sure that I had all the adaptive technology I needed for mobility and to complete coursework in college. And he put me in touch with a fledgling Independent...*
Living Center in Amherst, Mass. There I met some amazing people with severe disabilities who still had full, exciting lives full of dreams and hopes. I suddenly realized that these people were not to be pitied, but admired! And that access and services were not charity, but our rights ... our civil rights to live full, rich lives where we could strive to be as independent, successful, and fulfilled as possible!

And so for me the independent living movement was born along with a whole new way of looking at myself and others with disabilities. Accessibility and services which allow us to live as freely and independently as possible are our civil rights, not charity! I am not broken nor do I have to be “fixed,” although of course I want to be as healthy and able as possible. But any inability I may have does not make me less of a person in any way!

The past 30-plus years have seen us in the trenches of the independent living movement …

We have much to be proud of and to celebrate today. But we are also in dangerous times when all of our advances are at risk of being brought low ... due to fiscal pressures on the state and federal levels, due to competition with the medical model of delivering services where the disabled person is seen as a patient and it is believed that others know better what we need and how it should be delivered, and due to the loss of the true understanding of and belief in the independent living philosophy!

And so, whatever positions we take on various pieces of legislation, and whatever resources and services we may advocate for, we must hold tight to the independent living philosophy which says that we have the right to make the important decisions about our lives, for to accept anything less is to settle for less than our full human rights!

Fight on, my friends, together we stand, divided we fall. All for one, and one for all! Fight for adequate, participant-controlled attendant care! Fight for universal health care for all, especially for full support of hospice and palliative care! Fight for housing of all types and assure that all new housing meets full accessibility standards! Fight for transportation to allow us to participate outside of our homes! And fight for adaptive equipment and for supports for Vermonters with disabilities who want to be a contributing part of the work force.

And, above all, appreciate each other! Appreciate the work you do to make the lives of others with disabilities better and richer! Every time I attend a SILC meeting or an ASP meeting or an event like this, I go away feeling refreshed and re-energized because you are all so amazing! Very few people really understand what it takes to live, to participate when you face severe challenges just to get to a meeting. So, take strength and courage from each other, and continue the fight until we have made Vermont the most accessible place to live.

Countdown

White creams the fields and woods
and winds whip it so.

Now, the canoe’s almost buried in snow.

Transplants:
Sticks of foxglove and bee balm
(stir dreams of waving palms.)
Pine and spruce
all hold up
above snow-crusted ice.

Blue jays
and blue skies.

Our breath singing songs of cold
Six soul days
before
Solstice.

From Phyllis Rachel Larrabee’s
Winter 2008 poetry collection,
“BLOW THE SHOFAR
BLOW THE WINDS.”
**Budget** – Major cuts impacting seniors being proposed by the administration for the next fiscal year include 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, home health, supportive housing and transportation. Nursing homes would have their rates frozen and not receive their annual statutory inflation increase. The cost of living increase 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.

The budget has thus far clearly consumed the work of the 2009 Legislature. The Appropriations committees have asked for assistance from several of the substantive committees (such as Human Services and Health Care and Health and Welfare) in making recommendations for cuts and other budget policy decisions. Thus, we have found ourselves (and consumers that we have located) testifying on multiple occasions before numerous committees, and there are more to go.

While we have made a good case for continuing VPharm (some new manufacturer rebates and potential matching monies have been preliminarily identified) and have argued strongly against the 4 percent cut to caregivers and other providers, no one knows quite yet where things are going. Continuing reductions in our tax receipts combined with the massively complex stimulus act make writing a state budget a constant moving target and an incredibly challenging task.

We do know that legislative leaders think some broad-based taxes should be in the mix and believe more stimulus money may be available than the governor does. The governor relies more on cuts and transfers from the education fund to the general fund (which legislators claim will lead to increased property taxes) to balance the state budget.

The federal stimulus package is very complex and we are learning on a daily basis what strings and opportunities lie within; and with each revelation could come a significant change to our state budget needs. It was wise for the Legislature to take these two weeks off to fully digest the impact of the American Recovery and Reinvestment Act.

**Palliative Care, End-of-Life Care and Pain Management Study Committee** – The legislative study committee has presented its final report to the House Human Services Committee.

One key recommendation for seniors is for a patient’s bill of rights for end-of-life care. There was consistent testimony throughout the study committee’s work that patients with terminal conditions were not being made fully aware of available services and their choices. There were even several anecdotes of patients not being told of the availability of hospice. The Human Services Committee is struggling with the timing and detail of the information to be imparted to the terminally ill. It seems like the requirements in the bill will be somewhat general so as to give doctors more flexibility in their communication. The bill should be out of committee by mid-March.

An additional recommendation of the task force was better outreach, coordination and referral regarding end-of-life care (e.g., hospice, pain management, etc.), with a request that the state health care and long-term care ombudsman convene a small working group of stakeholders to make protocol and resource suggestions back to the Legislature this session. COVE has been asked to and will participate in this workgroup.

**Fuel Assistance (H.214)** – We have been working with Rep. Pugh and the fuel assistance task force to introduce legislation to expand program eligibility while minimizing impact on benefits going to currently eligible households.

While Vermont currently has the highest household benefits in the country, it also probably

*Continued on Page 6*
The result was a study committee which 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 naturally a high level of angst with the state supporting the sales of these long term care “partnership” policies. (There was 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. While we have made progress with the state toward standardization and other protections, COVE still has concerns with the expansion and regulation of this product. There is great interest in these policies among some lawmakers who think this will significantly reduce the need for folks to apply for Medicaid. We are skeptical and have not seen any clear evidence to prove this. Formal rules and authorizing legislation (H.202) have now been submitted. With the rules unlikely to be finalized before May, it is hard to predict what will happen with the bill this session.

Guardianship (H.308) – Another summer study we helped enact was the Guardianship Education, Improvement, and Accountability Task Force. The committee focused on making reporting forms to the probate court simpler and more uniform; providing additional training and educational materials to guardians; investigating technology improvements for the probate courts; and looking at best practices from across the country in protecting assets and improving court enforcement and oversight. We learned that the Supreme Court has access to significant grant monies to improve court technology. This could help move forward some recommendations of this task force as part of the court’s IT modernization. Due to a death in the family, the committee chairperson was not able to submit the committee report and so action on this report will probably have to wait for the 2010 session. COVE has submitted legislation for two possible legislative changes: One would require the first accounting and personal status report on the person under guardianship to be filed three months after the guardian is appointed rather than a year afterwards. Another would require counsel to stay in the case until the inventory is filed by the
Continued From Page 6

guardian. Having another set of eyes overseeing this important first filing of the guardian will result in less mistakes and/or potential for exploitation.

Colorectal Cancer (H.24) – Colorectal cancer is a leading cause of cancer deaths and the incidence of colorectal cancer increases dramatically with age. This legislation would improve individuals’ access to preventive screenings by removing cost-related barriers such as prohibitive co-payments. There is strong legislative sponsorship and support for this proposal with the opposition coming from the state’s Banking, Insurance and Health Care Administration (BISHCA) who fears the impact on rates. H.24 passed the House with a maximum co-payment of $25 and a last minute floor amendment, contingent on federal approval, which would extend the same maximum co-pay to those on Medicare.

Transparency in Rx Manufacturers Gifts to Health Care Providers (S. 48) – Vermont already restricts spending by drug companies and requires annual reporting. The bill would require a public listing of which doctors received gifts from drug companies. As recently passed by the Senate, it attempts to ban all gifts not related to education, research, samples, clinical trials, etc. According to the most recent report, pharmaceutical companies had spent $3.1 million to promote their medicines to doctors during the year ending in June 2007. That was an increase of $1 million over the previous report.

Public Transportation – We have been hearing about cutbacks in various parts of the state in such basic services as trips to kidney dialysis and cancer treatment. At the same time public transit is due to get close to $6 million in new dollars for buses and facility improvements from the stimulus package. If there is some way to use this stimulus money to free up what the state would otherwise be spending for new buses, savings could be directed toward helping public transit with their operating expenses. This is yet another example of the opportunities and challenges presented by the federal stimulus package.

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

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The Independent

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policy and that the federal stimulus package gives Vermont more time to come up with a thoughtful response to the economic situation. The governor’s 2010 budget proposes to use $107 million in federal stimulus funds, $63 million in property tax increases and $28 million in cuts to build the state budget.

In late February, House and Senate leaders rejected the governor’s budget proposal and instead proposed that the fiscal year 2010 budget include $153 million in federal stimulus money, $33 million in state revenue increases, and $28 million in cuts. Members of the House and Senate went home for a two-week break to consider these options, learn more about how the federal stimulus package can be used and hear from voters in their districts. Renewed work on the budget begins the week of March 16. By this time, Vermont should have a better handle on how the stimulus package will affect budget choices.

Much of the early testimony on the 2010 budget focused on the impact the governor’s recommended budget would have on different programs and services. Many Medicaid providers and nonprofit human service groups have been told to expect a 4 percent cut in their reimbursement or grant awards. Some providers and agencies would take significantly higher cuts as multiple funding sources or payment rates are reduced. These proposed cuts affect family support and disability service organizations and local physicians, pharmacies, home care agencies and specialty service providers. They would have a significant impact on seniors, individuals with disabilities and their families and low-income Vermonters.

Developmental and mental health agencies took significant reductions during earlier cuts in the 2009 budget. Some of these cuts are only now being felt as direct service providers in local communities lose jobs and some agencies have cut individual supports and instead offer congregate services. The governor’s recommended 2010 budget does include important increases for emergency services and for public safety, but employment and individual support services for many individuals will be cut. There are no new dollars for the June graduates in the developmental services budget; supportive employment services have been significantly cut; and flexible family funding payments will go from $1,300 to $1,000. Mental health services are facing similar reductions and a loss in preventive mental health services. In Washington County, a recovery educator position was cut. VCDR is concerned that we will see other cuts made to peer support and recovery services in regional and statewide mental health programs and to self advocacy support in developmental services.

Other respite, attendant and personal care and related flexible funding and direct support services for individuals and families are also taking significant cuts in the governor’s proposed budget. Children with Special Health Needs Respite in the Health Department would receive an 86 percent cut. These programs are administered by different state agencies but all provide essential supports to adults with disabilities and to families of children with developmental, mental health and physical disabilities.

The governor’s budget proposal also cuts the state share of individual SSI payments as a federal COLA increase is realized. In addition, $125 of a person’s SSI payment could be counted against accessing Reach Up resources that helps low-income individuals and families move out of poverty and into the work force.

Independent living services are also being affected by the 4 percent grant reduction. The Vermont Association for the Blind has been told that both their services for seniors and their volunteer transportation programs would be affected and the Vermont Center for Independent Living has been told to expect cuts in their Meals on Wheels Program, Home Access Funding and The Independent. Home Access funding is in particular jeopardy, as the governor’s proposal also calls for a 70 percent reduction in Vermont Housing Conservation Board Funding, a main sponsor of HAP.

Many believe that public transportation services will receive some protection from the federal stimulus funds; but critical care transportation (funds that help non-Medicaid-eligible Vermonters pay for transportation to critical dialysis and cancer treatments) had a projected $180,000 shortfall in early February.

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VCDR joins other Vermonters in calling for reasonable revenue strategies, careful use of the federal stimulus funds, and fairer budget reductions. We are asking the administration and the Legislature to stop the disproportionate and unfair targeting of essential health, human services, and disability programs. We believe it is wrong to make most cuts in state spending from programs upon which low-income Vermonters, seniors and individuals with disabilities depend.

Proposed Legislation: Bills to Watch

Despite the focus on budget issues, several bills are being worked on that have significant implications for individuals with disabilities and their families. Several are VCDR priorities: A bill has been crafted to move forward several recommendations in the Palliative Care Study to improve chronic pain management and end-of-life care in Vermont. S.002 addresses safety and disability accommodations in corrections and gives individuals with other disabilities that make it difficult or impossible for them to function in the corrections systems similar protections already available to offenders with serious mental illness. H.66 addresses a longtime VCDR goal of including secondary students with disabilities in senior year celebrations. Several VCDR members are part of a task force of concerned individuals and organizations working on language for a bill on use of positive behavioral interventions and supports in schools.

Vermont Protection & Advocacy provides VCDR with a regular update on bills introduced this session. A broad range of issues are addressed, including special education funding, guardianship issues, tax credits for accessibility modifications, use of mobility devices on bike paths, oversight of the State Hospital, several bills on health care reform, and workers’ comp protections. To receive a copy of this list, receive our weekly updates or help us advocate for issues that matter to you, e-mail VCDR at vcdrvt@gmail.com or call us at 802-223-6140.

Keep the Promise, Gain the Reward

Individuals with disabilities and the programs they and their families depend on are taking multiple hits. Stop the disproportionate and unfair targeting of essential health, human services and disability programs:

• Protect Vermont’s respite, personal and attendant care funding and direct support programs from drastic cuts and promote equal access to these essential services for those who need them.

• Don’t pass the governor’s proposed 4 percent grant reductions on to workers in participant and surrogate directed personal care and attendant programs. These workers already make only $10 an hour without benefits or travel stipends.

• Protect recovery education and consumer-run and staffed services in mental health and peer support programs and staffing in the developmental services budget. Make sure regional access to these services is not lost as local agencies struggle with additional contract and budget cuts.

• Protect funding for June graduates, individual and family supports and for supportive employment services in the developmental services budget; and essential long-term care services in the Choices for Care waiver.

• Protect independent living, transportation and community support services for individuals with disabilities of all ages and preserve community support for families.

• Keep health care and pharmacy benefits accessible and affordable to Vermonters who need them.

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

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More People With Disabilities Now Able To Buy Nutritious Foods

For a person with a disability, good nutrition is extremely important as it helps maintain good health and prevent sickness and hospitalization. The high costs of food, fuel and health care are making it hard for many people to put food on the table. Thanks to recent changes in 3SquaresVT, formerly the Food Stamp Program, more Vermonters with disabilities may now be able to take part. As of January 2009, people receiving disability benefits with gross incomes below 185 percent of federal poverty levels (FPL) no longer have to meet a limit on resources such as bank accounts. The 185 percent income limit is $1,604 for a single person or $2,159 for a couple.

Another important change is that retirement accounts no longer count as resources. If your income is above 185 percent FPL, you have a resource limit of $3,000, but no retirement savings will count toward that limit. If you were denied in the past because you had too many resources, now is a good time to apply again. You might also qualify for added benefits like assistance for your phone hookup and phone bill or free school meals for your children. These mean more money freed up to buy food or pay other bills. Once you are enrolled in the program, if your household income drops, it is easy and quick to request more assistance.

As a program of the U.S. Department of Agriculture, 3SquaresVT was created to help people buy food and to support local businesses and farmers. People with disabilities who take part are not taking money away from others in need. Congress made it an entitlement program to assure there would be benefits for everyone. Just like your disability benefits, 3SquaresVT is a benefit you are entitled to – there is no reason not to apply. Spending benefits in Vermont adds federal dollars to the state’s economy.

The program is also getting easier to use. The application can be sent to your home, and you can get help filling it out by calling your local Community Action Agency. You can also ask that your interview be over the phone so you don’t have to travel to the district office. If you have medical expenses of $35 a month or more (including health insurance premiums), that may mean a higher food benefit. Your benefits can be deposited as cash directly into your bank account, giving you more privacy and flexibility in how you use the benefit.

Many Vermonters are facing challenges right now. You are not alone. Everyone needs access to healthy food, and 3SquaresVT is here to help. Over 63,000 Vermonters use the program. As a person with a disability, you deserve to get the help you need. Everyone who might be eligible should apply.

For more information or an application, visit www.vermontfoodhelp.com or call Economic Services at 1-800-287-0589.
As I Sit with My Dog

As I sit in a comfy chair my dog comes over to join.

I stroke her shiny raven black fur. Her ears are like fine velvety triangles as they slide through my fingers. As I sit with my dog I feel happy. She will just pass out like a little black puddle of muddy love.

Suddenly, she is distracted. Something exciting is happening! She gets back on her four little feet and vanishes into the dark of everyone else.

I am alone. I continue on in my seemingly everlasting sit.

She will come back later.

Ash Brittenham, 11, of Montpelier, wrote this poem about his pug, Starlight. Ash has been a storyteller and writer for years and recently developed an interest in poetry. Below is a drawing he did of Starlight.

[View the image of Ash Brittenham and Starlight]

[View the drawing of Starlight]
The Governor’s Ballroom at the Capitol Plaza in Montpelier was packed on Feb. 24 to commemorate the 30th anniversary of the Vermont Center for Independent Living’s inception and to honor Deborah Lisi-Baker. She is retiring as Executive Director of the organization after almost 10 years on the job. The evening featured many tributes to Deborah, including a Deaf poem and several moving speeches. Board President Marty Roberts was first on the list of speakers, saying: “We’re proud to recognize tonight your dedication and your leadership of VCIL and the disability rights movement and your accomplishments that have helped us all in our efforts to move forward. We celebrate your work and your vision. We value your spirit, your courage, your sensitivity. We are proud to call you our leader, our inspiration, and our friend.”

PHOTO BY STEFANIE MONTE
VCIL Board Member Ed Paquin and Deborah Lisi-Baker share a moment at her retirement party on Feb. 24.

PHOTO BY ROSEMARY MILLER
Masterful master of ceremonies Nat Frothingham takes a break during the evening’s festivities on Feb. 24.
by Sarah Wendell Launderville

There is not a time in VCIL’s 30-year history when Deborah Lisi-Baker has not been associated in one way or another with VCIL. I spoke to Governor Douglas regarding Deborah’s retirement recently and he said, “It is the end of an era.” I agree – it will be interesting and awkward not having Deborah’s voice of reason at the table, or her keen insight on policy and thinking of all angles regarding disability issues.

Deborah’s connection with VCIL began in 1978 when she was interviewed by Project Outreach, a survey that was conducted indicating that hundreds of Vermonters living with varying disabilities throughout the state shared certain common desires. She was a single mom who shared her experiences, hopes and dreams, which helped shape the founding core of who we are as an organization.

Deborah had many roles in her career at VCIL, sometimes more than one. The staff was very excited when Deborah was hired as the executive director in 1999.

I was proud to attend my first ADAPT action with Deborah. We marched the streets of D.C. together. We chanted, held signs and sang songs of freedom. I still have a picture hanging in my office of Deborah and me chained and handcuffed to the fence in front of the White House.

I also traveled to an International Design conference in Rio de Janeiro with Deborah. Deborah facilitated a workshop on inclusive voting rights in America, and at the last minute filled in and read the keynote speech. We shared about disability rights in Vermont with international leaders, toured a hospital and spent time with staff from Sao Paulo Independent Living Center.

Always available, always mindful of the work. Deborah has shown her dedication to the organization and our movement.

Good luck and congratulations! We wish you all the best in your new chapter. Thank you.

Sarah Wendell Launderville becomes VCIL’s executive director on April 1. See story on Page 15.
How To Limit Risks Associated With Medication Use

by Samuel E. Liss

Editor’s Note: This is the second installment in a two-part series by VCIL Vice President Sam Liss, who has been a practicing community and hospital pharmacist and currently teaches pharmacology and human anatomy and physiology. The two-part series provides some general information regarding medication cautions and risks, particularly as they affect those of us who are elderly and have disabilities. The articles are intended for general educational purposes and do not substitute for one-on-one consultation with one’s professional caregivers.

So … how can those of us within the population of seniors and individuals with disabilities limit risks arising from the use of prescribed medication and “self-medication?”

Always, feel free to discuss any issues involving medication with your medical professionals – MD’s, pharmacists, etc. It is your body; you have a right to know!

Ask questions or rely on a trusted proxy to ask for you. If possible, do your own research; an informed patient is better able to intelligently discuss issues with one’s professional caregivers.

Otherwise:

1. Make certain that you are receiving adequate nutrition and hydration.
2. Be honest about your emotions with people whom you trust.
3. Always be open with your professionals about how you are feeling, in general; this is critically important in helping them assess how well, for example, a prescribed drug is working for you.
4. Remember, that alcohol, illicit drugs, dietary or herbal remedies and, in general, all over-the-counter drugs are indeed medications and can interact with other medications, including those prescribed by your MD. Be cautious regarding their use!
5. Remember also that drugs not only interact with other drugs; they may also interact with foods (and nicotine, etc.). Remember to discuss effects, for example, of caffeine with your professional. Certain drugs have very specific food contraindications (that is, those foods that cannot be taken with a particular medication due to risk of serious adverse reactions).
6. Try to keep track of proper medication use (generally, as prescribed) or have a trusted individual do that for you!
7. Always tell your medical professionals, including your pharmacist, of all drugs you are taking. Also make certain to tell them of all past allergic reactions and all serious past adverse reactions to drugs! Also advise as to all significant medical diagnoses!
8. Be very careful when filling prescriptions at different pharmacies or having drugs prescribed by different MD’s. Very often, drugs are unknowingly duplicated or incompatible drugs are unknowingly prescribed! Always be clear about all your medications to all of your professionals!
9. Always tell someone – a professional, if necessary – if you are experiencing any unexpected sensation(s)! It might be a result of an adverse drug reaction or an unanticipated medical condition.
Deborah Lisi-Baker Passes The Torch

The Vermont Center for Independent Living is bidding farewell to its longtime executive director and welcoming a new one. On April 1, Deborah Lisi-Baker will hand over the reins of the organization to Sarah Wendell Launderville, VCIL’s Home and Community Access Program manager.

“It has been an honor to serve as VCIL’s executive director over the past 10 years,” said Lisi-Baker, who praised her successor’s dedication and skills. “I know that both the board of directors and Sarah bring great vision and leadership to VCIL’s mission.”

Lisi-Baker may be retiring from VCIL, but she plans to stay active in the disability rights movement, doing some teaching and consulting work.

Launderville began working at VCIL in 1997 and rapidly moved up to become the Home & Community Access manager. She has completed undergraduate and masters’ level studies at Springfield College in human services, organizational management and leadership.

Launderville is excited about leading in VCIL’s top slot. “I look forward to the next 30 years and we can just celebrate this whole coming year the last 30 years that people have poured their hearts and souls into VCIL’s mission.”

While looking forward to the celebrations of VCIL’s 30th anniversary, Launderville is very aware of the hard work that lies ahead.

“There are people still sitting in nursing homes tonight,” she said. “There are people that don’t have personal care attendant services so they couldn’t get up this morning. So we have a lot of work that we still need to do to make sure that we’re moving our mission forward and our movement forward.”

VCIL’s AgrAbility Specialist Helps Farmers with Disabilities

Thomas Younkman of Hyde Park has joined the Vermont Center for Independent Living as its AgrAbility specialist.

Originally from Sarasota, Fla., Tom Younkman has farmed in Vermont for almost 20 years. He and his wife, Carole, own Stony Brook Farm, where they offer tours, produce soap from farm-raised goats and breed German shepherds. For many years Younkman was self-employed as a general contractor specializing in farm projects, including the construction of new barns. He has also worked as a landscape contractor handling projects that included irrigation systems.

Vermont AgrAbility provides education and assistance to farmers with disabilities. It is a collaborative partnership with University of Vermont Extension, Rural and Agricultural VocRehab and the Vermont Center for Independent Living. For more information, e-mail Tom at tyounkman@vcil.org or call him at 1-800-639-1522.
Karen Topper, self-advocacy coordinator for the Vermont Department of Disabilities, Aging and Independent Living (DAIL), recently participated in a presidential delegation led by Vice President Joe Biden to the Special Olympic Winter World Games in Boise, Idaho. See photo on Page 1.

Topper took the day off from work on Feb. 12 and traveled in her capacity as an adviser to the national board of Self-Advocates Becoming Empowered (SABE), providing support to Chester Finn, the president of SABE. They were invited by Kareem Dale, President Barack Obama’s Special Assistant for Disability Policy, who also traveled to Idaho.

Topper, who has been advocating for disability rights since the 1970s, said, “It was a thrill to fly on Air Force Two and have a lengthy conversation with the Vice President about the nationally recognized supports provided to Vermonters with intellectual and developmental disabilities to live real lives in Vermont communities.”

Earlier on the trip, Topper had an opportunity to talk with another delegate, U.S. Secretary of Education Arne Duncan, about the importance of including students with disabilities in regular classrooms.

Topper is back to work coordinating a wide variety of educational programs for people with developmental disabilities and members of Green Mountain Self-Advocates (GMSA), the Vermont state self-advocacy organization. But she will always remember the moment when the Vice President kissed her on the check. “It happened when I was telling him that he was my hero for writing the Violence Against Women Act.”

Topper works with members of Green Mountain Self-Advocates to collaborate with the Network Against Domestic and Sexual Violence to provide services that are accessible to people with disabilities. This is just one of the many educational projects provided by DAIL and GMSA to promote empowerment, safety and peer leadership.
Advocates Needed!

The Vermont Developmental Disabilities Council is looking for new voices! We need Vermonters with developmental disabilities and family members who want to help us make positive change in Vermont. Chances are that if you have had a disability since childhood that has a major impact on your life, you have a developmental disability. You might not meet Vermont’s definition but you probably have a developmental disability according to a number of federal laws, including Social Security and the Rehabilitation Act.

According to federal law: “A developmental disability is a severe, often lifelong disability that affects people before they reach age 22 and substantially limits functioning ability in three or more life activities such as self-care, receptive and expressive language, learning, mobility, self-direction, independent living, and employability.”

This definition looks at how the disability affects daily life, so it includes more people than the eligibility definition Vermont uses for developmental services (which is based on IQ or autism diagnosis).

**Becoming a Member of VTDDC**

One way individuals with a developmental disability and family members can advocate is to become a member of the Vermont Developmental Disabilities Council. VTDDC is a federally funded board that works on making positive change for Vermonters with developmental disabilities.

Each year VTDDC reaches out to Vermonters to find out what is happening for people with developmental disabilities. It sets goals and funds policy-making and community education, leadership training, and advocacy projects aimed at enhancing individual and family-centered supports and services. VTDDC helps fund Vermont Coalition for Disability Rights activities and is helping Green Mountain Self-Advocates to expand local chapters throughout Vermont. It funded the videos “The Apartment – Admit One to Adulthood” and “Living the Autism Maze” and the brochure “Choosing Words with Dignity.” You might have heard of our Executive Committee Fund, which helps individuals with developmental disabilities and family members attend conferences and trainings.

Consider becoming a member! Members let VTDDC know what is happening for people with developmental disabilities and families throughout Vermont, get the word out to policy-makers and the community, and decide how to use Council funds to have the greatest impact in people’s lives. Contact us to find out more about the benefits and responsibilities of membership.

Members are appointed by the governor. The first step is to submit an application to the Council for consideration. Call us at 1-802-241-2612 or toll-free at 1-888-317-2006 for more information.

You can also check our Web site at www.ddc.vermont.gov

**One Issue We Are Following: Employment Support for Graduates**

Did you know that starting July 1 there is no funding in the Department of Disabilities, Aging and Independent Living Budget for special education students completing school who need employment supports to maintain paid jobs? The recent State of Vermont Act 192 report to the Legislature estimates that 67 graduates eligible for state developmental services will need assistance. With no new funding, the priority to serve individuals who want to stay in paid employment is in danger of disappearing completely. Let us know if you want more information or are ready to advocate about graduate funding!
2008’s Outstanding Care Providers Honored

Although Vermont’s Statehouse can be a place marked by divisiveness, on an afternoon in mid-November, a spirit of caring filled the House Chamber. That’s because being honored were outstanding caregivers and those who know firsthand why they are outstanding – the grateful individuals and families for whom they provide care. Over 150 people attended the 2008 Outstanding Care Provider Awards Ceremony, which is the highlight of Professional Caregiver Appreciation Month in Vermont.

The Vermont Association of Professional Care Providers established Professional Caregiver Appreciation Month three years ago to raise public awareness about the value and importance of this critical work force. It is well known that Vermont is becoming an “older” state. This combined with the advance in medical interventions means that individuals are able to live longer at home and in the community with supports. This support is often provided by a professional direct care worker.

In 2007 VAPCP hosted its first Care Provider Award Nominations to honor those who choose this profession and do an exemplary job. Over 90 nominations were received – an impressive amount. In 2008 the number of nominations grew to nearly 160!

People gathered at the Statehouse in November to celebrate these caregivers and the countless differences that they make in lives of the elderly, individuals with disabilities, and children and their families. The impact that caregivers make every day was portrayed in the nominations that the selection committee received. There are many faces of this profession – from the individual who opens their home to support a person with a disability to the person who goes into the home of an elderly person to assist them with their daily needs, from the person who provides the critical care needed for a child to live with his or her family to the individuals who create a sense of home for people in nursing homes and residential facilities. These four examples are only snapshots that provide a glimpse of the depth and diversity of this profession.

Although this day was to honor the caregivers, nominators were also thanked for taking the time to express their appreciation for the dedicated caregivers in their lives. The heartfelt stories and expressions of gratitude that the nominators provided were truly a beautiful illustration of the importance and need for direct care workers.

Welcome and opening remarks by VAPCP Director Susan Gordon were followed by the reading of a congratulatory letter from Lt. Gov. Brian Dubie. Brendan Hogan, deputy commissioner of the Department of Disabilities, Aging, and Independent Living, and Rep. Patsy French of Randolph each related their own personal experiences and appreciation for caregivers.
Board President Suzanne Braunegg read the names of each of the nominees and presented them with a small bouquet of roses and a certificate in recognition of their outstanding work.

Although each nominee was deserving of this award, the selection committee had to narrow it down. Recognizing that it is impossible to really compare the stories from the families and recipients of the care to the supervisors and co-workers of caregivers, the selection committee formed two categories. However, the criteria of both categories still remained the same: demonstrating person-centered care, positive attitudes, strong communication skills, compassion, being advocates for the individuals receiving care, teamwork, knowledge and skills. Although all of the nominees had many of these qualities, the nominations for two caregivers stood out to the selection committee.

VAPCP Board Member Heather Merwin presented the Outstanding Care Provider of the Year award for a care provider nominated by either a supervisor or co-worker to Martha Dezotell, a licensed nursing assistant at the Visiting Nurse Association of Chittenden and Grand Isle Counties (VNA). Martha has worked as a personal care attendant for the Visiting Nurse Association for over 10 years. She was described as the saving grace in many emergencies. One of her co-workers described her as calm despite how stressful the situation may be. Thoughts from clients that she serves included: “She’s wonderful. It means that I am not going to have to tell her a thing. She knows exactly what to do. It will be effortless for me.”

Lynne Robertson, VNA director of Long-Term Care, noted, “Martha is incredibly professional. She has excellent skills that help us provide the highest quality of care to our clients. Our clients trust the care that Martha gives them.”

Suzanne Braunegg then announced that the award for Outstanding Care Provider of the Year for a care provider nominated by a care recipient or family member would go to Janelle Carter of Castleton. Janelle was nominated by her employer, Linda Clark. Janelle goes into Linda’s home to care for her ailing mother.

Linda used these words to describe the care that Janelle provides: “Janelle is my eyes and ears while I am away from my mother. As soon as I hired her I knew she must have been sent by God to help me in this time of need. She believes that everyone has a right to live as long as they want and she does everything she can to make this happen … My mother has a condition that requires frequent hospital stays. Janelle will go to the hospital and stay with my mom while I am at work to make sure her needs are met. She is not afraid to fight for my mother’s rights for appropriate care in my absence.”

Linda concluded: “I know there are many wonderful caregivers in this world. However, in my world, Janelle is number one. My mother is still alive today because of the care she receives from Janelle.”

Both Martha and Janelle received a recognition plaque and an abundant gift basket of Vermont products.

Following the presentation ceremony, VAPCP hosted a gala reception in the cafeteria which featured a number of useful resources available to direct care workers.

The event was made possible by a grant from the Department of Disabilities, Aging and Independent Living.

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)
Become a Fair Housing Tester and Help Prevent Housing Discrimination

The Housing Discrimination Law Project, a HUD-funded project of Vermont Legal Aid, is seeking fair housing testers. Testers are volunteers who can convincingly assume the role of someone seeking housing and then be neutral, objective and thorough reporters of what they observe during the process.

We particularly need testers who are in a protected class, but anyone 18 or older can be a tester. Protected classes under federal law are race, color, religion, national origin, sex, familial status and disability.

Testing is a great way to contribute to your community and make the dream of equal housing choice a reality for everyone. To become a tester you must complete a two-hour training session and a practice test. You will receive a cash stipend and mileage for each completed test.

For more information, please contact Rebecca at 1-800-747-5022.

The next tester training will be in Burlington on Tuesday, March 24, from 5:30-7:30 p.m. More trainings in other locations will follow, so please call if you are interested.

Volunteer To Stay Healthy

Many people do not realize that one road to well-being is to volunteer in your community. Numerous studies have confirmed what those of us who work with volunteers have known for decades – volunteering increases longevity. How? When a person stays involved and active in their communities, it keeps the mind and body engaged, which leads to better physical and mental health.

So, how can you become a volunteer? Here in Vermont we have many options for you through the National Senior Service Corps. This group of programs includes RSVP, Foster Grandparent Program and the Senior Companion Program. For more details about how each of these programs will work with you find the right volunteer placement to suit your needs and wants, call one of these offices in your area:

- Green Mountain RSVP (serving Bennington, Windham and Windsor counties) – phone: 802-447-1545; Web site: www.rsvptvt.org
- SVP of Chittenden County – phone: 802-860-1677; Web site: www.unitedwaycc.org
- RSVP of Central VT and the Northeast Kingdom (serving Washington, Lamoille, Orange, Orleans, Caledonia, and Essex counties) – Phone: 802-828-4770; Web site: www.volunteervt.com
- RSVP of Rutland and Addison Counties – phone: 802-775-8220; Web site: www.volunteersinvt.org
- Green Mountain Foster Grandparent (serving Rutland, Bennington and Addison Counties) – phone: 802-773-4719; Web site: www.volunteersinvt.org
- Tri-County Foster Grandparent Program (serving Chittenden, Washington, Grand Isle, and Franklin counties) – phone: 802-860-1677; Web site: www.unitedwaycc.org
- VT Senior Companion Program – phone: 802-828-4770; Web site: www.volunteervt.com
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>Talking Alarm Watch Needs Battery</td>
<td>Ericka</td>
<td>Montpelier</td>
<td>802-229-0501</td>
<td>Free</td>
</tr>
<tr>
<td>Shower/Potty Wheelchair</td>
<td>Chester</td>
<td>Jeffersonville</td>
<td>802-644-5576</td>
<td>$200</td>
</tr>
<tr>
<td>Full size hoyer lift with manual hydraulic pump with an almost new sling</td>
<td>Chester</td>
<td>Jeffersonville</td>
<td>802-644-5576</td>
<td>$800</td>
</tr>
<tr>
<td>Portable hoyer lift with manual hydraulic pump folds up and fits in almost any trunk weighs 64lbs</td>
<td>Chester</td>
<td>Jeffersonville</td>
<td>802-644-5576</td>
<td>$900</td>
</tr>
</tbody>
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### Wheelchairs and Scooters

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<th>Item</th>
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<th>Location</th>
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</thead>
<tbody>
<tr>
<td>Brand new electric wheelchair with battery and charger</td>
<td>Larry</td>
<td>North Hero</td>
<td>802-372-6625</td>
<td>$900</td>
</tr>
<tr>
<td>Manual Reclining wheelchair Excellent Condition</td>
<td>Chester</td>
<td>Jeffersonville</td>
<td>802-644-5576</td>
<td>$2500</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

Invisibility

Sometimes otherwise thoughtful friends and family consider people with disabilities and older people as “off the market” when it comes to love and romance. More than once, I’ve been with a group of people who – while discussing trying to find someone to “fix up” with a single friend – treat me as if I’m invisible. If not, they only include me by asking if I know someone their friend might date. It happens I’m “not looking right now,” but I often wonder how an older person or one with disabilities who would welcome the opportunity to meet someone “available” feels when this happens to them.

Why do people so often acquaint age or physical challenges with being “out of the running”? Just because our bodies aren’t perfect doesn’t mean we aren’t perfectly capable of love. (See “A Love-Able Couple,” in the Spring/Summer 2007 issue of this publication.) Many times, in fact, we love more deeply because we’ve experienced longer lives or developed more patience and understanding from our own limitations.

What can appear unseemly or disturbing to a non-challenged person, is often something many of us take totally in stride. For you readers who use wheelchairs or scooters, do you remember hesitating before agreeing to use that aid to help you stay mobile? I certainly do. In fact, I had to be tricked into trying one for the first time to do a favor for a friend. Then, once I discovered how wheels gave me back a whole chunk of independence, I changed my entire view toward that and other assistive equipment.

There’s another invisibility issue that often pushes people in the face when they are older or have visible physical challenges: It’s at the marketplace. Although my city is more disability friendly than many others I’ve visited of the same size, most check-out counters are still too high and many entryways are not easily accessible. I often have to wait for other customers or passers-by to open doors for me so that I can even enter a store that would gladly collect my money, same as from their non-challenged patrons. But too many times, I’ve waited in line at the register, only to be completely ignored. “Hi, there,” I say loudly and cheerfully, “looking up at the clerk. “Could you help me, please?” Sometimes the person looks right through me as if I were, yes, invisible. That’s not to say that other clerks don’t smile at me and say, “Oh, sorry I missed you. What can I do for you?”

Every time I go to my local downtown movie theater, I have to try to get through the bank-like roped off pathway to reach the ticket counter. Workers there who have come to know me, immediately help me through the maze; others who haven’t seen me before, keep on doing their work without noticing. And so it goes: Once more, invisibility.

No one likes to be out of the running. Young or old, physically able or challenged, it’s a human characteristic to want to be included. Even if we turn down an opportunity to join our friends who are going out for the evening, even
if we haven’t yet picked out what we want to purchase in a store but need help, it’s always good to be acknowledged.

One experiment I’ve been trying for several months now has made me feel visible and added a great deal of cheer to my days. Currently, I not only use an electric scooter, but also am on oxygen therapy. That means when people meet me on the street, they are aware of a wheelchair and then as I come closer, they see the oxygen canula in my nose. Many years ago, before I had these priceless aids in my life, back when I was physically able, I too treated such people as invisible. Now that I’m on the other side, I’ve come to see that only when others see our humanity, do we become real people to them.

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

No matter your age or disability, please don’t ever give up on the human race. Pray others never come to experience whatever you’re going through and that, if they do, they’ll remember a person who helped them see how to become included, no matter what is going on in their lives. Stay visible.

(K.K. Wilder is a columnist and educator. Contact her through this paper or at KKWilderg@aol.com)
Study of Cancer Survivorship Seeking Participants

The National Cancer Institute has recently funded experts at the University of Texas to study cancer survivorship among adults who had a pre-existing functional limitation or disability. The purpose of this study is to investigate factors associated with health promoting behaviors and quality of life and to modify an existing wellness intervention to promote health.

The study is recruiting individuals from throughout the United States with functional limitations that existed prior to their cancer diagnosis and who have moved beyond the active diagnosis and treatment phase of their cancer to complete a mailed survey. They will receive $25 in appreciation for the time they spend completing the survey. Please e-mail maxhealth@mail.nur.utexas.edu or call 1-800-687-8010 for more information.

Housing Discrimination Law Project Looking For Participants

Defend civil rights, pursue justice and make money. (Testers receive a stipend and mileage for each completed test.)

Become a fair housing tester/civil rights investigator. Help prevent housing discrimination. Make the dream of equal housing choice a reality for everyone in our community.

Training sessions will begin soon. For more information, please call Rebecca at 1-800-747-5022.

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 May 29, 2009