

The Independent

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A VERMONT CENTER FOR INDEPENDENT LIVING
PUBLICATION FOR
ELDERS AND PEOPLE WITH DISABILITIES

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Making Room for Grace

We send our best wishes to all the readers of this issue. It has been such a hard year for so many communities, and now we are entering a new wave of this pandemic. Many of us are turning to the natural beauty of Vermont, connections with loved ones, the gifts of art and literature and whatever it is that helps each of us experience and make room for grace in our lives.

In this issue, we share resources and moments of celebration. Morgan Brown reminds us to remember and appreciate “the essential growth and thriving of both individuals and all of humankind.” This is what has shaped so much of the creativity, community building and caring that has helped so many during this pandemic. And it can help us continue to create shared solutions. Thank you for what you do to cultivate hope and grace in a challenging time.

~ Deborah Lisi-Baker, Coeditor



*Sefakor Komabu-Pomeyie, VCIL's Independent Living Coordinator, had a great time kayaking for the first time at Silver Lake State Park this summer, thanks to the Northeast Disabled Athletic Association. **See story on page 6.***

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Letter to the Editor

Finding Accessible Trails

I am so happy to see wheelchair access to the outdoors is improving in Vermont!

Vermont State Parks now has a search feature for universal access on the map page and I found over 40 parks my family can visit using a wheelchair. I encourage you to check out <https://vtstateparks.com/>.

This summer, I am going to check out Camp Smith Trail through the 1930s-era Conservation Corps Camp in Waterbury, Brighton State Park’s audio interpreted trail in Island Pond and the new Barnes Camp boardwalk at Smugglers’ Notch!

These trails and others are also listed on the wicked cool TrailFinder.info; look for the access symbol to find many wheelchair-accessible trails. (Read more about Smugglers’ Notch hiking trails at <https://www.trailfinder.info/trails/trail/smugglers-notch-mount-mansfield-east>.)

I want to thank Mike Charron for his work with

VCIL and state parks to see so many access improvements realized in his lifetime. Please join me this summer finding a stream or a trail to honor my friend Mike.

Kim Rae Brittenham

Editor’s Note: Mike Charron was VCIL’s longtime civil rights specialist. He passed away in September 2020, but his legacy of fighting for access in Vermont continues.



PHOTO BY MARY CLAIRE CARROLL
Mike Charron did some fishing at Waterbury Center State Park during a Vermont Center for Independent Living picnic several years ago. He and Kim Brittenham, who at the time was VCIL’s civil rights manager, shared a moment in the sunshine.

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Finding Our Way

by Deborah Lisi-Baker



Some people were fiercely critical when Simone Biles chose to withdraw from Olympic events due to concerns about her mental health and what she described as an inability to sense her body's position in space. I was glad to read different responses,

including this Facebook reflection by Byron Heath, who was reminded of another athlete who was bullied past her own instincts and best interests by a domineering coach:

"This realization I had about Simone Biles is gonna make some people mad, but oh well. Yesterday I was excited to show my daughters Kerri Strug's famous one-leg vault. It was a defining Olympic moment that I watched live as a kid, and my girls watched raptly as Strug fell, and then limped back to leap again. But for some reason I wasn't as inspired watching it this time. In fact, I felt a little sick. Maybe being a father and teacher has made me soft, but all I could see was how Kerri Strug looked at her coach, Bela Karolyi, with pleading, terrified eyes, while he shouted back "You can do it!" over and over again. My daughters didn't cheer when Strug landed her second vault. Instead they frowned in concern as she collapsed in agony and frantic tears. "Why did she jump again if she was hurt?" one of my girls asked. I made some inane reply about the heart of a champion or Olympic spirit, but in the back of my mind a thought was festering: She shouldn't have jumped again.

"The more the thought echoed, the stronger my realization became. Coach Karolyi should have gotten his visibly injured athlete medical help immediately! Now that I have two young daughters in gymnastics, I expect their safety to be the coach's

number one priority. Instead, Bela Karolyi told Strug to vault again. And he got what he wanted; a gold medal that was more important to him than his athlete's health."

This public conversation brought to mind damaging expectations received by people with disabilities — deeply rooted messages that we are flawed and that we must hide or to overcome our disability. But we can't do either really. If we are lucky, or wise or have great advice and support, we learn to live well with our disability, to experience it as part of who we are, as part of being human. What we have to overcome are all the barriers to acceptance: stigma, pity, rejection, inaccessible and exclusive design, our own fear and the mixed message that we are so often offered: to either accept low expectations or to strive beyond what is reasonable.

Simone Biles and Byron Heath's daughters ask us to consider a more realistic response: No one is perfect; we are often remarkably gifted in some ways, and have a right to develop and use our gifts. But we are also — like everyone else — vulnerable and in need of respect, self-care and kindness from those who are supposed to care. And, finally, we are more than what can be seen by the relentless public eye.

It's about finding our own life balance. This past year I listened as several middle and high school students with different disabilities talked about how it feels when teachers and "helping" professionals only offer low expectations. Simone Biles reminds us that the pendulum can also swing too far the other way. We need to let people learn how to discover their own boundaries, which are sometimes different than anyone expects. As she said, "The outpouring [of] love & support I've received has made me realize I'm more than my accomplishments and gymnastics."

Tribute and Farewell to a Poet

The Vermont Center for Independent Living pays tribute to Phyllis Rachel Larrabee, an amazing poet, sublime storyteller and fierce activist for human rights. She died at home in April after a short period of declining health. Larrabee leaves behind two sons (Frederick Emile Sawyer and Malcolm Sawyer) and three grandchildren.

The spunky 82-year-old retired from VCIL in the 1990s after becoming severely disabled by cigarette smoke, petroleum-based fragrances and molds and mites. Retired VCIL Executive Director Deborah Lisi-Baker fondly recalled Larrabee's time at the organization helping people who called to find resources or support.

Lisi-Baker said, "Some days it was so hard to do the work—she would sometimes head outdoors for a primal scream—but she was good at listening and connecting people to resources. She said how much VCIL transformed her attitude about her own experiences of disability. Helping others and sharing stories, she uncovered her own strength and found the deep roots we all need to reach when society sends so many negative messages."

But social equality had been on Larrabee's mind long before she started working at VCIL. Her son Frederick Sawyer recalls, "At 14, horrified by the Holocaust and the intolerance within her own society, she was already a radical feminist." She would go on to spend her life fighting not only for women's rights and disability rights but for environmental justice, Abenaki

rights and racial justice. She even attended the March on Washington for Jobs and Freedom in 1963, where Martin Luther King Jr. gave his stirring "I Have a Dream" speech.

Through the power of her pen, she skillfully highlighted important social issues and brought nature, which she so loved, vividly to life. She began taking poetry very seriously in the early 1970s, and it was a passion for the rest of her life. She was prolific, always writing and composing poetry in her final years, many unpublished. In fact, she was attempting to write a poem up until the very last minute, holding a pen on her deathbed though unable to get the words down.

VCIL is proud to have had some of Larrabee's poems grace the pages of *The Independent* over the years. As Lisi-Baker noted, "What beauty she put into her poetry and her life: color, life, exuberance and an unfailing gaze, sheer celebration and a wry sense of humor."

The Phyllis Rachel Larrabee Foundation has been formed to oversee the final collection of her works and make them available to the public.

Floating

© *Phyllis Rachel Larrabee*

One loon circles another
in the green mirror

their white dazzling
with their black
designs over and over

floating together
and apart
the mystery of this dance

how they share
a lake
a marriage
without war.



PHOTO BY SUZY NORRIS

Phyllis strikes a pose during a trip to California.

Needed: Space for Equity in Vermont Schools

Sarah Shine provides speech language services to children in a public school in southern Vermont. One morning she found that she no longer had a room to work in. Instead she was given a corner of the library and a room divider. There was not a lot of privacy and no place to store the materials she used to help students engage in the speech therapy she did every day.

She began to wonder how many students with disabilities were being asked to learn in inadequate “found” space in Vermont’s school buildings and how much the lack of light, air quality, privacy and quiet affect student learning and even self-esteem. How did the spaces they were in affect the teachers and other professionals who are expected to teach in poor spaces for learning?

Sarah’s question became the focus of her academic research as a student in the Culture of Disability class taught by Professor Winnie Looby of the University of Vermont’s Center on Disability and Community Inclusion. In a unique partnership with VCIL, Professor Looby offers a few students the opportunity for one-on-one collaboration with VCIL’s Independent Living Coordinator Sefakor Komabu-Pomeyie, a Ph.D. graduate from UVM.

The experience was transformative. As Sarah explains, “When Sefakor offered to work with any students from the Culture of Disabilities class on a project of their choosing I knew I couldn’t let the opportunity go by. I had a project in mind, a situation in my public school that had been weighing on me for months. As I explained my ideas to Sefakor she listened intently, taking notes, asking questions, and then fed me back my thoughts with the labels and terminology that would start me on my research path. Throughout this process I was struck by the generosity shown to me by Sefakor, who devoted so much of her personal time and energy into this project.

“As I began surveying educators across the state of Vermont, I found many colleagues were walking in my shoes. It was a mixed feeling of camaraderie

and sadness, that so many educators were working in poor conditions. That so many children were receiving their education in uncomfortable spaces. As I worked my way through the existing research on the impacts of the physical environment on learning outcomes and compiled the data I collected from Vermont educators I felt validated. The most important piece of this work came when I interviewed students and gained their perspective on the services they receive and the classrooms they are taught in.

“This process demonstrated for me how important it is that we tell our stories, even those that are ugly, and maybe create feelings of shame or inadequacy. In creating my survey, I invited other educators to share their stories of the workspaces they are assigned and the challenges they face in their classrooms. In interviewing my students, I offered them a platform on which they could share their experiences, and say what is working and not working for their education. The other lesson I took away from this experience is the importance of creating and sharing audiences, so that our stories can be heard by people who can help us make changes. VCIL gave me both a platform to share my story and an audience who listened and joined the conversation. I am so grateful to Sefakor and VCIL for the opportunity to create and share this project.”



Accessible Kayaking a Big Hit at VCIL Picnic

by Stefanie Monte

Ah, Vermont in summer. The sparkling lakes. The beaches. The endless outdoor recreational activities. Vermont Center for Independent Living staff members were able to enjoy all of these things at a staff picnic held at Silver Lake on an idyllic day in late July.

Silver Lake State Park, located in the picturesque town of Barnard, is popular for its picnic grounds and sandy swimming area. VCIL rented the park's pavilion for the picnic, allowing staff members to relax in the shade.

Picnickers enjoyed brown-bag lunches, a delicious dessert of doughnuts, and the chance to reconnect with each other. (Some folks had not seen each other in person since before the pandemic began!) A few people went for a swim, but for many, a highlight of the day was a chance to go kayaking. This opportunity was thanks to Cathy Webster, director of the Northeast Disabled Athletic Association's Adaptive Kayaking program.

VCIL Executive Director Sarah Launderville said, "It was really wonderful to connect with everyone. Our gratitude goes out to NDAA and their team who set up an amazing day of kayaking. We hope to work with them in the future to connect our peers with their wonderful program!"



PHOTO BY SUE BOOTH
Jake Lavigne, left, and Khol Hitchcock reconnect at VCIL's staff picnic on July 28.

Nate Besio, VCIL peer advocate counselor coordinator, has been a board member of the NDAA since 2011 and is also coordinator of the



organization's adaptive sailing program and power soccer team. He said, "It was exciting to see so many people from VCIL get on the kayaks and get out into the water. Many of the people I talked to had never been kayaking before and didn't think it was even possible. This is exactly how I felt when I went kayaking for the very first time three years ago. It is an incredibly liberating feeling. Cathy and the NDAA have done an incredible job allowing many people with disabilities to get out on the water and experience this great feeling."

Independent Living Coordinator Sefakor Kombu-Pomeyie was one of the VCIL staff members who thoroughly enjoyed the chance to make some waves at the picnic. Since Ghana, the country where she grew up, is close to the Atlantic Ocean, being by the shores of Silver Lake made her feel right at home. She said, "I used to see the sea roaring from my grandma's bedroom. We love the water so seeing the lake was very refreshing and rejuvenating. I think kayaking wasn't any difficult task at all but rather easy and fun. It involves just a little effort to paddle and make yourself happy."

To learn more about NDAA's Adaptive

Kayaking program, visit

<https://disabledathletics.org/>

or call (802) 862-6322

Need Health Insurance?

Many Americans are struggling with health care costs. The state of Vermont announced a COVID-19 Special Enrollment Period (SEP) from Feb. 16 to Oct. 1, 2021. It is for Vermonters who do not have health insurance. You can enroll in a qualified health plan (QHP) and get financial help with premiums and cost-sharing if you are eligible. For this Special Enrollment Period, you need to apply by phone. Call the Customer Support Center at 1-855-899-9600 Monday through Friday from 8 a.m. to 4:30 p.m. (except on holidays). You can get a Vermont Health Connect plan from Blue Cross and Blue Shield of Vermont, MVP Health Care or Northeast Delta Dental.

Vermonters can continue to apply for Medicaid at any time of the year. If you've lost some income, you may now be eligible for Medicaid or financial help for a qualified health plan.

Vermont Emergency Rental Assistance

This Vermont Housing Finance Agency program has already helped 2,492 households and will be accepting applications for rental assistance through Dec. 31 or until the funds are gone. It is also possible that the federal government will offer additional funding for VERAP through Sept. 30, 2022. Please check the VERAP website (<https://erap.vsha.org/>) for updates.

Looking for Rights and Benefit Information?

Many COVID-related emergency services were scheduled to end in July and we are just beginning to learn what services are continuing and what new services are about to start. Vermont Legal Aid continues to update their web page on COVID/coronavirus rights and benefits to keep Vermonters informed of changes in how court practices, legal services, and state and local benefit programs will operate during this new wave of the COVID-19 pandemic. Much of their information is offered in sev-

eral different languages. For more information, visit <https://vtlawhelp.org/coronavirus-updates>.

Affordable Housing on the Way

The Vermont Housing & Conservation Board (VHCB) has received state and federal funds to address homelessness related to the COVID-19 public health emergency and an underlying shortage of affordable homes. VHCB's longtime Executive Director Gus Seelig said that because of "unprecedented need and rising prices, VHCB will invest these funds to create and rehabilitate 288 apartments, 50 shelter beds and 51 homeownership opportunities in communities around the state, both for households experiencing homelessness that have been living in motels during the pandemic and for moderate-income Vermonters struggling to find housing they can afford." VHCB is granting funds to community organizations soon and will make additional awards to housing developments in the coming months.

COVID Relief Funds Go to VABVI's SMART Program

This \$100,000 makes it possible for the Vermont Association for the Blind and Visually Impaired (VABVI) to continue their SMART Training program. The trainings help Vermonters who are blind or visually impaired understand how to use devices like iPads, iPhones and other Android, Kindle and Google products to stay connected with their community. VABVI's Director Steve Pouliot explains the program's past success: "We did it by training participants to use features that connected them to medical services, support groups and social outlets with family, friends and clubs. Through this training, VABVI clients were able to keep up with their medical professionals, send emails, text messages, listen to audiobooks and more. Over 90 percent of our clients who received this training reported feeling less socially isolated and were better off for having received this service." For more information, call your local VABVI office or their toll-free number, 1-800-639-5861.

VCDR Report on 2021 Legislative Session



The 2021 legislative session was the first year of the new biennium with newly elected

representatives and senators along with those returning to the Legislature, new leadership in the House and Senate and a new lieutenant governor.

The Legislature continued to meet remotely for the entire session, as they had since March of 2020. Although there certainly were some technology and access issues, many Vermonters listened to committee discussions and were able to testify via Zoom.

COVID relief funding and related concerns dominated the session and shaped the state budget and the final versions of bills to address racial equity in health care, expand broadband access, provide housing and homelessness resources, respond to the pandemic's impact on education and increase resources for infrastructure initiatives and other challenges. A number of social justice and equity issues shaped the final language of budget and policy bills.

The following paragraphs summarize some of the budget decisions and policy bills that are important to Vermonters with disabilities and their families. For a more detailed legislative report, please visit www.vcdr.org. It includes links to the full budget and to the final versions of different bills. Readers of this paper can find additional policy and resource news in the News & Views section.

Selected Funding in the FY 2022 Budget

Increase in Funds for Community Service Agencies: The budget funds a 3 percent increase to mental health, developmental disabilities and Choice for Care providers and an increase to Vermont Assistive Care Services (ACCS) rates to ad-

dress increased wage and operating costs.)

VABVI Technology Training Funds: Vermont Association for the Blind and Visually Impaired received \$100,000 to help individuals with vision disabilities increase their ability to use information technology to lessen the isolation experienced by so many people with vision loss. (See News & Views page for details.)

Reach Up Program: Adds \$2.7 million from the general fund to increase the Reach Up benefit to the 2019 standard of need, increasing the average benefit by \$111 a month. Additionally, the bill eliminates the inclusion of any SSI benefit in the calculation of the Reach Up benefit. VCDR applauds this decision to get rid of the \$77 a month deduction that was charged against Reach Up grants when an adult in the home receives Supplemental Security Income (SSI).

Housing: The budget includes increased funding for the Vermont Housing and Conservation Board (\$12 million), the Agency of Commerce and Community Development (\$5 million) and \$15 million of federal American Rescue Act funds to supplement, continue or extend the Rental Assistance Program for Reach Up families as permissible by the Emergency Rental Assistance Program.

Selected Policy Legislation Passed

Act 33, an act relating to addressing disparities and promoting equity in the health care system, responds to significant health inequities experienced by groups of Vermonters. The law sets four strategies to address disparities in health status based on race, ethnicity, disability and LGBTQ status: establishing better and more consistent collection and access to data; enhancing the full range of available and accessible culturally appropriate health care and public services across Vermont; ensuring the early and equitable inclusion of Vermonters who experience health inequities because of race, ethnicity, disability and LGBTQ status in efforts to

eliminate such inequities; and addressing social determinants of health, particularly social, economic and environmental factors that influence health.

Eugenics Apology Resolution with Amendment (J.R.H.2): The House and Senate passed this resolution, which states “that the General Assembly sincerely apologizes and expresses sorrow and regret to all individual Vermonters and their families and descendants who were harmed as a result of State-sanctioned eugenics policies and practices; that the General Assembly continues to work to eradicate the lasting legacy of its prior actions by listening to and working with the affected individuals and communities; and that the General Assembly recognizes that further legislative action should be taken to address the continuing impact of State-sanctioned eugenics policies and related practices of disenfranchisement, ethnocide, and genocide.”

Task Force on Equitable and Inclusive School Environments (Act 35): This law bans most suspensions and expulsions of students under age 8 and creates the Task Force on Equitable and Inclusive School Environments to address the broader issue of suspensions and expulsions of students in Vermont schools. The Task Force membership includes designees of Vermont education associations, two high school students, a teacher and a school counselor and representatives from a cross section of restorative practice programs and advocacy organizations, including the Vermont Family Network and the Disability Law Project of Legal Aid. This group is charged with several tasks including assessing the behavioral supports and in-school services available to students who would otherwise face exclusionary discipline, recommend additional services and better and more responsive interventions including use of positive behavioral supports, trauma-informed practices and restorative practices.

DISABILITY AWARENESS DAY(S) 2021

**“Justice & Access for All,
More Important Now Than Ever!”**

Legislators, youth leaders, federal and state of-

ficials and people from all over Vermont helped us celebrate VCDR’s motto, “Nothing About Us Without Us.” Because of the pandemic, VCDR’s annual Disability Awareness Day Statehouse event became a series of online events. We want to thank everyone who participated and give a particular cheer to the Vermont Developmental Disabilities Council for sponsoring these forums and the other work of VCDR.

Each session was recorded and captioned and they are now posted for online viewing:

Legislative Panel: On March 17, Ed Paquin moderated a remarkable conversation with Sen. Anthony Polina and Reps. Kevin “Coach” Christie, John Killackey and Anne Donahue. Panelists shared their personal experiences with disabilities as it relates to their legislative work, and responded to questions about the legislative process.

<https://www.youtube.com/watch?v=ttJUIYB1mc>

Keynote on Disability Resources for COVID: On April 19, Sean Barrett of the federal Administration for Community Living and Monica White, now the commissioner of Vermont’s Department of Disabilities, Aging & Independent living (DAIL), addressed questions relating to COVID issues and concerns of people with disabilities and spoke about vaccine rollout in Vermont.

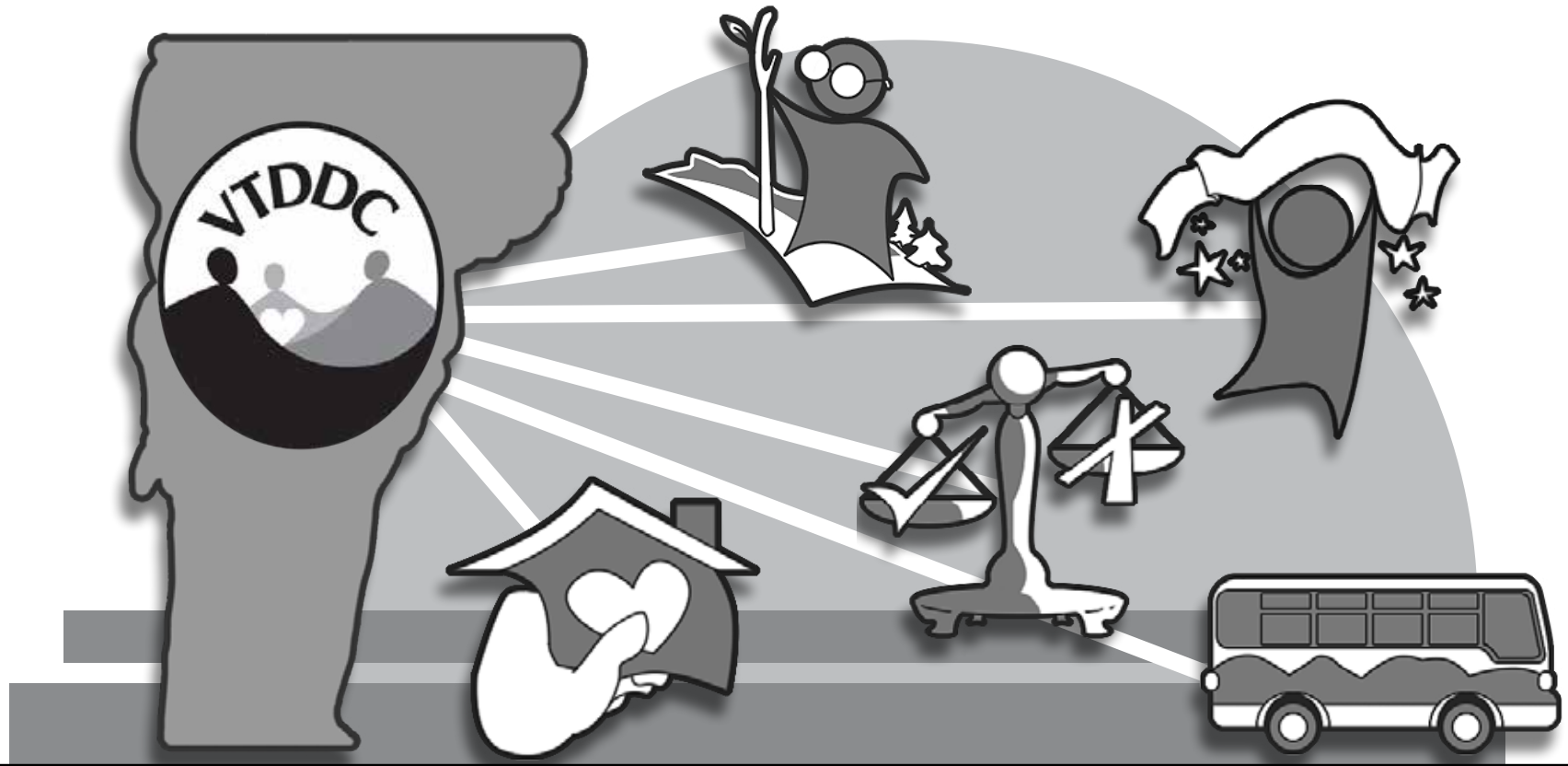
<https://www.youtube.com/watch?v=40gdcM6U2Ro>

“Stronger Standing Together” Workshop: On May 13, Sefakor Komabu-Pomeyie, VCIL’s Independent Living Coordinator, opened an interactive workshop “Stronger Standing Together” that was led by student leaders who shared their lived social experience of disability and called for respect, rights and education justice in our schools. Other students, families, allies, educators and policy makers joined the conversation, adding their recommendations and concerns. VCDR thanks Education Justice Coalition of Vermont for cosponsoring this event.

<https://www.youtube.com/watch?v=---00qlaPNk>

The Vermont Developmental Disabilities Council is proud to announce...

THE NEXT FIVE-YEAR STATE PLAN



Every five years the Vermont Developmental Disabilities Council (VTDDC) drafts a new State Plan to steer Vermont toward positive, social and economic change for people with disabilities.

Created by the federal DD Act more than 50 years ago, the Council is made up of Vermont citizen from every corner of our state – Bennington to Derby Line, Brattleboro to Swanton, and everything in between. These Vermonters know first-hand what it is like to live with an intellectual or developmental disability.

We also have members from state government and agencies that serve people with disabilities.

The DD Act is a remarkable law. It envisions a country where people with disabilities and their families have all the supports and services they need to live, learn, work, and play in whatever community they choose. The Act requires that every five years, Councils measure how well their state is doing in achieving that vision. Based on that review, Councils must write a plan that addresses the most urgent needs.

The VTDDC began building their next State Plan last fall. Self-advocates and family members shared their lived experience in small group conversations around the State. Council staff also collected lots of information about services in many different arenas, including healthcare, education, transportation, and housing.

In early 2021, the self-advocates and family members on the Council began meeting in small teams to sift through all this information. Where, they asked, are the best opportunities for change? They wrestled with setting priorities so that VTDDC could use the money it receives from Congress for the greatest impact. The Council shared its draft plan last April. Based on public comments, they revised the Plan one more time and adopted the goals you see on the next page.

The Five-Year State Plan is a living document. It guides VTDDC's work but leaves room for unforeseen challenges and opportunities. Do you have a good idea to help us implement our Plan? Please be in touch. Our contact information is below.

To learn more about VTDDC and the Five-Year State Plan, visit the website at: <https://ddc.vermont.gov/>

Or contact VTDDC directly by phone (802) 828-1310 or by email: vtddc@vermont.gov



VTDDC members at our 2019 retreat, pre-covid.

What are VTDDC's Goals and Objectives for 2022-2027?



Goal 1, Empowering People

All Vermonters with developmental disabilities and their family caregivers are empowered to make personally meaningful, culturally appropriate choices about their services, education, employment, guardianship status, healthcare, living situation, and relationships.

1.1, Leadership Development

The VTDDC will support self-advocates and family members to become leaders in the disability rights movement.

1.2, Support for Self-Advocacy

The VTDDC will support the expansion and long-term sustainability of the self-advocacy movement in Vermont.

1.3, Guardianship

Working with community partners, the VTDDC will promote a range of alternatives to full guardianship, including supported decision making.

1.4, Peer Support

The VTDDC will ensure that trained peers are available to support those who need help with their Home and Community-Based Services (HCBS) and other supports.

1.5, Family Caregivers of Adults

The Council will support and connect family caregivers of adults with developmental disabilities.



Goal 2, Gaps in Services

Working with community partners, the VTDDC will address three (3) gaps in critical services for people with developmental disabilities and their family members.

2.1, Universal Design

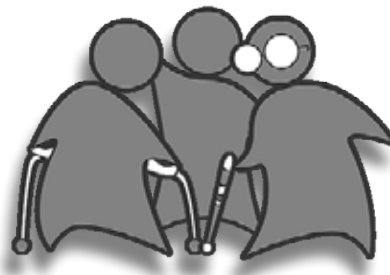
Working with community partners, the VTDDC will advocate that spaces and programs for recreation, health, and wellness are fully accessible and follow the principles of universal design.

2.2, Housing

Working with community partners, the VTDDC will develop and promote housing options for adults with developmental disabilities. These living options must be affordable, foster independence, ensure necessary support, and assist in the development of friendships and other community connections.

2.3, Transportation

Working with community partners, the VTDDC will develop and promote more affordable, convenient and flexible transportation options for people with developmental disabilities.



GOAL 3, Addressing the Needs of an Underserved Group

The VTDDC will advocate that individuals with complex disabilities and/or substantial support needs have equitable access to, and appropriate supports to realize, opportunities for employment, social engagement, and personal development.

3.1, Customized Employment

Working with community partners, the VTDDC will develop and promote customized, integrated employment opportunities for individuals with complex disabilities and/or substantial support needs.

3.2, Adult Services

Working with community partners, the VTDDC will develop and promote opportunities for adults with complex disabilities and/or substantial support needs to increase social engagement and independence.



Goal 4, Systems Change

The VTDDC will support policies and practices that promote self-determination, full community inclusion, and equitable access to high quality services and supports, including special education.

4.1, Raise Awareness

The VTDDC will conduct outreach and public awareness campaigns that change perceptions about the abilities and contributions of people with developmental and other disabilities.

4.2, Ongoing Policy Advocacy

The VTDDC will monitor state and federal legislation and policy, educating decision-makers and building strategic partnerships as needed. Working through its Policy Committee, the VTDDC will be able to address issue that were not foreseen or that have grown to be a priority.

4.3, Systems of Care

The VTDDC will advocate that Vermont adequately fund Home and Community-Based Services (HCBS). Vermont will have stable, strong, and equitable service delivery systems that protect the right to person-centered planning, emphasize prevention over crisis care, and provide individualized, flexible supports rather than adhering to rigid service categories.

4.4, Direct Support Workforce

The VTDDC will advocate for the professionalization and stabilization of the direct care workforce.

DISABILITY RIGHTS VERMONT ANNOUNCES FY22 PRIORITIES



Disability Rights Vermont (DRVT) is a private nonprofit agency dedicated to defending and advancing the rights of people with mental health and disability issues. We are empowered and funded by the federal government to investigate abuse, neglect and serious rights violations. Our staff team combined with the staff of the Disability Law Project of Vermont Legal Aid (DLP) creates the cross-disability legal protection and advocacy system for Vermont. This past year we have continued to try to help people with the challenges that the COVID-19 pandemic presented. Ordinary difficulties, isolation and hardship have become even greater for people with disabilities.

DRVT is once again looking for comments on our priorities to be approved by our Board for the upcoming fiscal year (Oct. 1, 2021 – Sept. 30, 2022.) We would welcome your thoughts about how our unique system can best serve people with disabilities and mental health issues. DRVT is publishing our current priorities for the Protection & Advocacy for Individuals with Mental Illness (PAIMI) program, for the Protection & Advocacy for Developmental Disabilities (PADD), and the Protection & Advocacy for Individual Rights (PAIR) programs on the adjoining pages. These priorities serve to focus the work of the agency and are developed by our Board and our advisory councils, who get input from the community and staff. Your input is appreciated! We strive to do as much as we can with the resources we have...and we can do that best when folks in the community let us know their greatest advocacy needs!

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

info@disabilityrightsvt.org or to DRVT, 141 Main St., Suite 7, Montpelier, VT 05602

Or by phone: 1-800-834-7890 or, locally, at (802) 229-1355

And please visit our website at www.disabilityrightsvt.org – there you will find more particular objectives within the general priorities below.

CURRENT PRIORITIES FOR PROTECTION & ADVOCACY FOR INDIVIDUALS WITH A MENTAL ILLNESS

Priority 1: Investigate individual cases of abuse, neglect and serious rights violations in inpatient facilities (hospitals, any state run facilities, emergency departments and facilities for minors), prisons/jails and community settings, including peer services and designated agencies.

Priority 2: Reduce the use of seclusion, restraint, coercion, involuntary procedures and inpatient confinement when not warranted by patient treatment needs through systemic efforts. Continue systemic work to create culturally competent, trauma-informed, violence free and coercion-free mental health treatment environments.

Priority 3: Reach out to community settings, designated facilities and hospitals, emergency rooms, prisons/jails, residential and therapeutic care homes. Monitor conditions and educate residents, patients and providers about rights, self-advocacy, and DRVT services, with emphasis on the integration mandate of the ADA.

Priority 4: Advocate for self-determination, access to alternative treatment options and community integration. DRVT will advocate for designated agencies to establish relationships with individuals in inpatient settings during discharge planning in order to support people to seek their full potential in the community.

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

(DRVT and DLP work together to serve across ALL disabilities! PADD and PAIR come from different sources.)

CURRENT GOALS & PRIORITIES

- People with disabilities have access to needed health care/long term care; children with developmental disabilities and/or mental health needs will receive needed services and supports. Represent individuals seeking access to needed health care/long term care when issue is disability, duration of services, covered services, due process or EPSDT. Priority given to cases involving: access to COVID-19 related health care including vaccination when available; children and youth inappropriately placed or held in emergency departments due to lack of mental health services; and services and discharge planning for children and youth transitioning from residential placements (PADD/PAIR).
- Students with disabilities are identified, evaluated and receive a free and appropriate public education and related services during the COVID-19 pandemic. They are educated in the most integrated appropriate educational setting, are not harassed, are not unlawfully disciplined and are not unlawfully suspended or expelled from their educational program; they receive an appropriate transition from school to employment and independent living, and use of truancy proceedings is eliminated. Federal and Vermont entitlements and procedural protections are preserved. Federal COVID-related funds are used to increase equity in Vermont's education system (PADD).
- Ensure access to appropriate services/supports in the least restrictive and most integrated settings. Advocate for people with disabilities in nursing homes, long-term care homes, correctional facilities, inpatient hospital settings and other restrictive settings for whom appropriate services/supports may be available in more integrated settings (PADD/PAIR).
- Advocate to improve access to developmental services for children and adults with intellectual and developmental disabilities (PADD).
- Provide advocacy to ensure people with intellectual and developmental disabilities do not have unnecessary or unnecessarily restrictive guardianships (PADD).
- Access to public benefits (SSI, Unemployment Insurance and COVID-related state and federal payment programs). Access to and preservation of SSI benefits for income-eligible children under age 18 or turning 18 whose benefits are terminated on the basis of disability. Maintain maximum SS benefits for adults who are disabled and working. Ensure access to Unemployment Insurance and COVID-related state and federal payment programs (PADD/PAIR).
- Provide advocacy to ensure individuals with disabilities will have increased access to businesses open to the public as written in Title III of the ADA (PAIR).
- Provide advocacy for improved access to government services and programs as provided in Title II of the ADA (PADD/PAIR).
- Ensure that individuals with intellectual and developmental disabilities are not discriminated against in hiring, employment and advancement.
- Ensure that individuals with intellectual and developmental disabilities are not discriminated against in businesses open to the public under Title III of the ADA, including not discriminated against in housing.
- Ensure that adults and children with intellectual and developmental disabilities living independently, in institutions, in juvenile treatment facilities or in parental, family, group or developmental homes, are free from abuse, neglect or rights violations (PADD).
- Increase knowledge and awareness of the civil and legal rights of people with disabilities (PADD/PAIR).

A Shot of Hope: All About the Vaccine

What is COVID-19?

It is a virus making people sick all around the world. Fortunately, there are things people can do to protect themselves and others. The best way to protect yourself and others is to get the vaccine! You can also wear a mask and follow social distance rules.

What is the delta variant I am hearing so much about?

Viruses constantly change. Some changes help the virus spread to more people. The delta variant is the latest version of COVID-19. More people are catching this version of COVID-19.

What is a vaccine?

A shot that helps your body fight a virus. Getting the vaccine is the best way to protect yourself and others from getting the delta variant of the virus that causes COVID-19.

Is it safe?

Millions of people in the United States have received COVID-19 vaccines, and these vaccines have been through the most careful safety tests in U.S. history. Getting the vaccine will not give you COVID-19. The vaccine is the best way to protect yourself and others from getting a bad case of the virus.

Which vaccine is best?

The best COVID-19 vaccine is the first one that is available to you. Do not wait for a specific brand. All currently authorized and recommended COVID-19 vaccines are safe, effective and reduce your risk of severe illness.

How much does it cost?

The vaccinations are free for anyone living in the United States

If I've already had COVID-19, do I still need a vaccine?

Yes. You can get COVID-19 again even if you've already had it. The vaccine is the best way to protect yourself and others from getting it again or from getting really sick if you do get the virus a second time.

How will I feel after a shot?

Your arm may be sore, you might get a headache, fever, sore muscles or be tired for a couple days. These side effects are normal and mean that your body is building up protection to the virus. Sometimes people worry about feeling sick when they get a shot, but side effects from a shot are less dangerous and uncomfortable than getting sick from the virus.

How long will it take to work?

It takes two weeks to build up protection, or immunity. You can still get sick or make someone else sick during that time so it's important to wear your mask, wash your hands and stay at least six feet away from others until doctors tell you it is safe.

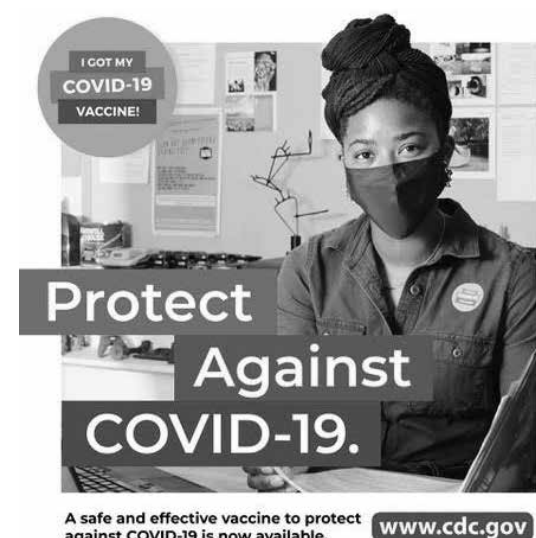
What if I am unsure about the vaccine?

Talk with your doctor or health care provider if you are worried about getting the vaccine. They are the best people to help you with your medical and safety concerns.

Help with COVID-19 vaccinations for people with disabilities

Need help finding out where to go, how to sign up or finding accessible transportation? The Disability Information and Access Line (DIAL) is now available to help people with disabilities get vaccinated. **Call 888-677-1199 Monday-Friday from 9 a.m. to 8 p.m. or email DIAL@n4a.org.**

For questions about your civil rights as a person with a disability, you can also call Disability Rights Vermont at 1-800-834-7890.



Concerns About School Safety

The delta form of COVID-19 is causing the governor and the Agency of Education to reconsider masks. They now recommend that students, teachers and staff wear masks when schools open. Sadly, it is just a recommendation. School districts may choose not to require masking and all schools are preparing for in-person learning, without offering any online learning options. Without masks, online learning options and other safeguards, public education isn't safe or accessible for thousands of Vermont students. As one Vermonter responded, "Wittingly or unwittingly, AOE has created a situation where families of students with medical disabilities are now having to decide if they are going to attend public meetings to attempt to convince school board members to grant kids their civil rights already provided for in federal law."

The current surge highlights the need for vaccination. COVID vaccines provide a great deal of protection from severe illness for most people. Though about 78 percent of eligible Vermonters are fully vaccinated, children under 12 are not yet eligible and young people over 12 are significantly undervaccinated.

Pam McCarthy, vice president of the Vermont Coalition for Disability Rights and CEO of the Vermont Family Network, shared plans to help families and students access vaccines this fall. "VFN is collaborating with the Vermont Developmental Disabilities Council, the Vermont Department of Health, the American Academy of Pediatrics VT and other health and education partners to make sure that families of children and youth with disabilities or special health needs have timely, accurate and helpful information about COVID-19, especially with regard to vaccines. We have heard from families and medical homes that sensory-friendly options would be very welcome, not only for COVID vaccination, but for other doctors' visits, as well. We hope to make a lasting positive impact on accessibility and health equity."

To learn more about VFN's vaccine activities, call 1-800-800-4005.

Never Take For Granted

by Morgan W. Brown

Ever take notice about how,
when the blessing
warmth of sunshine
as well as either morning
blanket of dew or shower of rain drops
caresses and nourishes the earth,
flowers and leaves slowly
bud forth and eventually blossom;
life in various forms then venture forth,
essentially in gratitude for being provided
another glorious opportunity to grow
as well as to also thrive?
Although this is something that
one can easily grow accustomed
to experiencing on a regular basis,
this is something that never
should be taken for granted.
Hope and faith are much the same;
which, as such, one should
never take these for granted either.
Both should be carefully nourished,
conscientiously, on a regular basis as well;
otherwise, there could be severe
drought conditions, where hope and faith
could potentially languish and perish
from the gentle and tender
soul of humankind, which is always
needing outward growth while
hungrily seeking to thrive.
Once again, this too, the essential
growth and thriving of both
individuals and all of humankind,
is something never to be taken
for granted for that matter either;
because, absolutely, none of these
happen on their own.

Vermonters Call for Boldness and Change

by Deborah Lisi-Baker

Section 9817 of the American Rescue Plan provides significant funding and opportunities for innovation in how and what Medicaid home- and community-based services (HCBS) are provided, though there is no promise that this flexibility will continue beyond 2024. Vermont's preliminary plan highlights planned uses for the funds, including funding alternative services that respond to the mental health needs of school-age children who have been going to emergency rooms, improving provider training and pay and increased access to peer support services and social programs that promote health. This first plan was only the beginning of figuring out how to spend the money, as the ARP requires strong public engagement and quarterly updates.

Vermonters spoke at a public hearing in July, at least one Vermonter has written to newspapers, and others are submitting public comment by the state's Aug. 16 deadline. Pam McCarthy of Vermont Family Network shared some of the comments and recommendations from the public hearing, "Big themes were more housing options for people with disabilities, and parents as paid caregivers. We also heard peer support as a focus. Max Barrows of Green Mountain Self-Advocates made a powerful statement on this. Strong points were made for better supports for DeafBlind individuals and transportation. (Mike Gruteke said, 'Being well is tied to being able to get out.')

The importance of adequately supporting and paying family members who are providing essential services is a concern shared across HCBS programs. Difficulties accessing agency caregivers during COVID has made the problem worse. As one parent said, "I'm old. I'm exhausted. I had to retire to do care."

Charlie Murphy wrote to the Bennington Banner to say, "Funds from the American Jobs Plan could make needed improvements to Vermont's Choices

for Care program. Currently Vermont caregivers are paid a wage just above the minimum wage, which reduces the pool of people willing to do this vital work and, consequently, the quality of the care given. The program also requires that applicants be impoverished; they must shed assets that could be used to maintain a home, a car, an accessible van, or the purchase of food for a specialized diet. Income from work can result in loss of Medicaid eligibility, hence eligibility for the program. I hope the American Jobs Plan funds could also be used here in Vermont to bolster and revitalize the Participant Directed Attendant Care program. It's not Medicaid based, does not require that assets be shed, and does not discourage employment."

So many of the ideas about use of these funds for improved community-based disability services remind me of sitting at the United Nations years ago, listening to disabled delegates from around the world talk about what approaches to disability should be embedded in the U.N.'s Convention on the Rights of Persons with Disabilities. They spoke about the fact that people with disabilities, of all ages and with diverse disabilities, were often the first to go without help in an emergency; and one delegate said, "We don't want to do what the United States did, and tie disability services to health insurance. Disability is a social issue more than a medical one." So it did not surprise me to read the letter from Charlie Murphy or this comment from Steve Kieselstein: "I want my child to be included, not cured... I don't want words anymore. We need BOLDNESS and CHANGE!...The problem is a service delivery problem. There is a tyranny of low expectations. We need REAL inclusion."

Updates on HCBS Enhanced Funding will be posted to the Global Commitment Register (GCR). You can email AHS.MedicaidPolicy@vermont.gov if you would like more information.

Hearing Loss: A Silent Danger to Older Adults

by Mara Brooks



Hearing loss affects tens of millions of people in the United States and can be brought on by aging, noise, damage, ear-wax or heredity. Some issues attributed to aging are common side effects of hearing loss:

higher risk of falling, trouble following a conversation and increased risk of dementia. Approximately one in three people between the ages of 65 and 74 is living with some form of hearing loss, generally caused by a combination of age and exposure to noise.

When hearing loss is caused by aging it usually occurs slowly over time, and in both ears. For that reason, it might go undetected until it reaches an advanced state and interferes with basic activities. While some dangers of hearing loss are obvious (difficulty hearing smoke alarms, doorbells, warnings, etc.), others are more ambiguous. If an older person finds they increasingly struggle to make out what friends and family are saying, they might start to withdraw from social events and lead a more isolated lifestyle.

Isolation is a serious issue affecting older adults and has been associated with a 50 percent increased risk of dementia. It was also found to significantly increase the risk of both heart disease and stroke. Isolation can also lead to depression, anxiety and suicide in older adults.

There is currently no cure for hearing loss, but there are many treatment options, with new advances in technology all the time. Of course, an ounce of prevention is worth a pound of cure, so remember to always protect your ears from loud, pro-

longed noises. Earplugs and earmuffs can help by placing a buffer between your ear and the source of loud, external noise.

But if you are already living with hearing loss, several strategies are available to help you reclaim your life, health and social confidence.

Hearing aids, which are electronic devices worn in or behind the ear, are among the most popular treatment options. Unfortunately, they can also be expensive and are not always covered by insurance. In recent years, legislation has been introduced in many states compelling insurance companies to cover the cost of hearing aids but mandates still vary from state to state.

Hearing aids can be life changing but finding the right one can take a little effort. Audiologists can help to diagnose hearing loss and find the right hearing aid to suit your needs.

Another option involves surgically implanted ear devices known as cochlear implants. These are helpful to provide sound for those with profound hearing loss or deafness. Unless your hearing loss is very severe, this might not be your doctor's first course of action.

There are also over-the-counter listening and amplifying devices, as well as apps where a user can upload their personal hearing profile so that sounds filtered through their headphones are customized to their specific hearing needs.

The first and most important thing to do is to have your hearing tested by a medical professional. With the right treatment, you or your loved one might find you are again able to participate in robust conversations, enjoy family and social events, land on a sure foot and take in the full range of sounds that life has to offer.

Join the Vermont Statewide Independent Living Council!

Be part of the conversation concerning the issues facing people with disabilities in Vermont.

The VT Statewide Independent Living Council (VT SILC) and its partners are working to address issues in the state of Vermont, such as accessible housing, supporting special education and youth in transition, increasing access to public transportation, reinvigorating the state's Olmstead Plan and much more.

Our Goals

1. Hear from individuals and organizations in our community about the issues they are facing around Vermont.
2. Identify key issues to be addressed to eliminate barriers to independent living in Vermont through our Transportation, Housing and Education committees, as well as other advocacy initiatives.
3. Contribute to and help implement the VT State Plan for Independent Living, a guideline to help direct service organizations better serve people living with disabilities in Vermont.

How to Join

If you are interested in being a part of the discussion, or would like to learn more, you can reach out to Tom at the email below for more information. We hope to talk to you soon!

Contact:

Tom Hamilton, SILC ED: vtzilcdir@gmail.com
www.vermontsilc.org





got access?

by Ash Brittenham

On the Road

Recently my mom, brother and I drove to Florida to visit family. And my beloved Chihuahua came too. Traveling is not an easy task. Before attempting the long drive, we made a trial overnight run closer to home. We discovered the impracticality of bringing our own support equipment with us. My wheelchair weighs 400 pounds; the additional weight of my Hoyer lift, breathing machines and luggage caused our modified Honda Element to sit dangerously low over the rear axle.

So we set off without my lift or shower chair, expecting to rely on people to transfer me, but we had no idea how I was going to shower or use the toilet! Luckily we found Hotel Indigo, a Holiday Inn family hotel, with good wheelchair access that welcomed my dog. The room was great with wide open space, not cluttered with furniture and had a roll-in shower. There were enough outlets to plug in my BiPAP, cough assist and feeding pump and charge my wheelchair and machines. Had we been able to bring the rolling lift, it would have fit perfectly under the raised bed!

My dog B loved the big bed!

The hotel staff even brought up a comfortable chair when my grandma visited, and B loved that too. The blue was a perfect contrast to her fox-red fur.

While the room setup was ideal, it did not fully work for my needs as I still needed a safe way to transfer and shower.

As many travelers would agree, the fold-down shower benches in most accessible hotel rooms are death traps. Mom's leg was sliced open by one when it collapsed under me on a previous trip to Washington, D.C. This trip, the shower solution was actually a loan from someone with the same condition I have, who lived a 40-minute drive from the hotel. Moms on Facebook sure know how to network.

I think more people could travel if hotels provided assistive equipment such as lifts and supportive shower chairs, similar to the visual and tactile devices they provide for travelers who are Deaf or Hard of Hearing. One hotel we stayed in on the way down had a cleverly ramped pool, but no manual chair a person could borrow to actually roll in.

Another thing that makes traveling hard is the inaccessibility of airplanes. Many people who use wheelchairs and dare to attempt air travel risk injury transferring into airplane seats and their wheelchairs are either damaged in cargo holds or left behind.

I hope that one day people will be able to drive onto airplanes and tie down their power or manual chair. A group called All Wheels Up is working to make this happen. They are currently crash testing with the Federal Aviation Administration. Founder Michele Erwin has a Tedx Talk: "Funding Accessible Airline Travel." It's worth a Google.

I signed up for their August Accessible Air Travel Event on Aviation Day this Aug. 19. You can find them online if you want to join me.

Ash Brittenham is a poet and activist born and raised in Montpelier. He now lives with his Chihuahua in their own apartment in the city of Charlotte, N.C. He likes ducks.

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



Youth Advocacy Council Seeks Members

Are you a youth on an IEP/504 plan (between ages 14 to 24) who wants to make a change in your school or in your community?

Please register or share the application for the Youth Advocacy Council with other youth, peers, and young adults.

<https://www.surveymonkey.com/r/B67PKJQ>

Create Resources in Plain Language

The Autistic Self-Advocacy Network has released a new toolkit to help write in Easy Read, an accessible format that uses images and easy-to-understand language. "One Idea Per Line: A Guide to Making Easy Read Resources" can be downloaded for free at <https://bit.ly/3AbIPll>

Get Involved with Disability Rights Vermont

Become a member and a mover! Disability Rights Vermont is looking for individuals to serve on their Board of Directors or on their PAIMI Advisory Council. Come join either of these great groups of people who are helping steer the ship in the continued fight for disability rights in Vermont. For more information, please contact Lindsey at DRVT (Lindsey@disabilityrightsvt.org or 1-800-834-7890) or Sarah at VCIL (slaunderville@vcil.org or 802-224-1817).

To find out about other disability or senior programs and activities, contact VCIL at 1-800-639-1522 or the Senior Helpline at 1-800-642-5119



For information on the
next issue, call
1-800-639-1522