

Hello, Neighbor!

Learn how
Vermont is
making our
state a more
welcoming place

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The Importance of Good Neighbors

A strong network of support starts at home and in the community

by Debbie Arrington

Now, maybe more than ever, it's time to be a good neighbor. Neighbors make up our support network. They help us during good times and bad. They help make everybody in the community feel welcome and part of the whole.

Among many things, the coronavirus crisis demonstrated the power of having good neighbors – especially for Vermont residents with developmental disabilities.

Kirsten Murphy, Executive Director of the Vermont Developmental Disabilities Council, saw many examples of what a difference neighbors and strong networks can make.

"This crisis has highlighted for me how friends and neighbors are so important," Murphy said during the coronavirus restrictions. "For a lot of people with disabilities, there were fewer paid caregivers available through state programs. But peer groups and neighbors really stepped up."

A statewide public board, the Council is a voice for the people it serves. By law, at least 60% of its members are individuals with disabilities or family caregivers. The Council focuses on public policy, with an eye toward ensuring that Vermonters with developmental disabilities are well-supported and fully included in their communities. Council members come from every corner of our state – from Bennington to Derby Line, from Swanton to Brattleboro.

VTDDC is currently in the fourth year of a five-year plan. "I feel really great about the progress we've

made," Murphy said. "Most plans are by design ambitious, and ours certainly was. But it all starts with investing in people and building strong networks of self-advocates and families."

"One thing I'm really proud of," continued Murphy, "is how we've really grown our annual Leadership Series. We've trained over 140 Vermonters with lived experience of disability."

"Neighbors provide a critical safety net. You don't build those networks after the crisis has started. You need them in place before the crisis hits."

Kirsten Murphy
Executive Director, VTDDC

"Another program we invest heavily in is Green Mountain Self-Advocates, where people who have disabilities run the organization and deliver training and peer support to more than 20 local self-advocacy groups."

All those advocates have become an important resource for the Council



Council members come from every corner of our state — from Bennington to Derby Line, from Swanton to Brattleboro.

Photo courtesy of Vermont Developmental Disabilities Council

and the people of Vermont, she added. "We have this group of people with stories that really resonate with legislators and state officials."

How do those stories translate into lasting change? "Good policy makes good sense," explained Murphy. "And the best people to explain what makes sense are the people directly impacted."

For example, the Council heard from self-advocates and families that many healthcare facilities were not welcoming to people with disabilities. "We have worked for years on raising awareness about how to respectfully engage people with developmental disabilities in talking about their

health," said Murphy. "That really paid off during the recent crisis. We weren't starting at square one."

"But what keeps people healthy," said Murphy, "isn't hospitals. It's long-term community support." And that comes back to neighbors.

"Neighbors provide a critical safety net," Murphy noted. "You don't build those networks after the crisis has started. You need them in place before the crisis hits. That's why we want to get the message out: Build your networks. Connect with neighbors. That's what makes Vermont communities strong."



Who is the VTDDC?

The Vermont Developmental Disabilities Council (VTDDC) is a statewide board that identifies and addresses critical issues affecting people with developmental disabilities and their families.

At least 60% of its members must be self-advocates or family caregivers. Currently, 16 board members are among that group. Other members represent agencies in state government or partner organizations in Vermont.

VTDDC serves a significant segment of the state's population.

Among the state's 620,000 residents, about 5,000 have a developmental disability that qualifies them to receive support in order to live in the community. But the majority of people with disabilities — 1 in 5 Americans — do not have special services. They rely on friends, family, and neighbors when they need help, just like the rest of us.

The main goal of the VTDDC is to improve people's lives. As Executive Director Kirsten Murphy says, "A rising tide helps everyone."

Living Life Her Way

Thanks to Home- and Community-Based Services, she has the support she needs

by Elizabeth Morabito

Living in a family home, seeing friends, being out in the community and participating in activities; those are all part of daily life. Unfortunately for people with disabilities, these things are too often unavailable or can be difficult to access.

But for roughly 3,200 Vermonters, a modest package of Home- and Community-Based Services (HCBS) can make a world of difference.

Meet Jessica Sanville. She leads a very full and active life, surrounded by love.

Since 2000, Sanville has lived in the Northeast Kingdom with a home provider hired through the designated agency system. It's a busy household, with the provider's three children, as well as a second individual with disabilities who has lived there for the past 20 years.

Sanville spends about 25 to 30 hours a week volunteering for causes she cares about and helping others. She spends several days a week at the United Community Church in St. Johnsbury, preparing activities for children to do during services and assisting with midweek community lunches. In addition, she helps out other congregation

members by cleaning for those who rent apartments from the church, assisting with grocery shopping, or just keeping folks company.

As a member of the Vermont Workers' Center, Sanville also engages in advocacy, a skill she has been developing over many years. Sanville is a former member of the

"(I have) a normal, happy, loving family life."

Jessica Sanville
HCBS recipient

Vermont Developmental Disabilities Council and, this fall, she tackled the Council's challenging Leadership Training Series.

Workers' Center community organizer Eliza Hale explains, "Jessica's willingness to help with all aspects of the work we do illustrates the kind of world we are trying to create — one based on unity across differences, equality and participation."

Sanville is passionate about securing healthcare for all Vermonters as a basic human right — a message she has even taken to the State House.

Sanville has a steady boyfriend, William, who also has developmental disabilities. They enjoy going out to eat or doing activities like bowling. They see each other about every other week and spend a lot of time chatting when they are apart.

Sanville has been able to create this life for herself because of the Home-and Community-Based Services she receives through Vermont Medicaid. Her package includes case management, respite, and assistance from a direct support professional who helps her with shopping and other chores. It also funds her home provider, and that's what Sanville values most. She's treated like one of the family, with plenty of encouragement to try new things and a little bit of help when life gets challenging.

In her words, she has "a normal, happy, loving family life."



Jessica Sanville, who participated in the Council's Leadership Training Series, spoke at the State House.

Photo courtesy of Vermont Developmental Disabilities Council

How HCBS Can Help

When Vermont closed the Brandon Training School, its state-run institution for people with developmental disabilities in 1993, it was only the second state in the country to do so. In fact, even today only 11 states have entirely shuttered large, congregate facilities for people with intellectual and developmental disabilities.

Vermont's secret to success has been the strong values that have guided the creation of its home- and community-based system. From the beginning,

policymakers embraced the idea that — regardless of the severity of their disability — adults can make decisions for themselves, can live in typical homes, and can contribute as citizens to the communities where they live.

In building its Developmental Services System, Vermont adopted an individualized approach that tailors support to the capacities, needs, and values of each person. Delivered through one of 15 local agencies, people with developmental disabilities receive a

customized package of assistance that can include case management, support to work or volunteer, help with activities of daily living, crisis intervention, and respite. They may live with their own family or with a home provider who shares their living space and their community connections. Some live independently in their own apartment.

The advantages are many. Research has shown that HCBS are not only better for the individual served, they also cost far less than care in a large institution.



The Vermont's Developmental Disabilities Act reads:

"When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community."

His Secret Ingredient: Himself

Purely Patrick specialty foods give purpose with plenty of joy

by Allen Pierleoni

Whenever Patrick Lewis and his mother, Mary Anne Lewis, set up their tent and table of Purely Patrick-brand specialty foods at a farmers market, crafts fair, festival or other public event, she prominently displays a poster that gives context to who her son is.

In Patrick's "voice," it reads, "I have cerebral palsy and even though I don't talk, I always get my point across. My hands 'see' what my eyes can't."

Lewis proves this at home, where as the company president, he fills Ball Mason jars with layers of dry ingredients for 20-some products, from cornbread and cookies to soups and brownies. Customers add the liquid ingredients to his dry mixes.

Lewis, 28, does this in his workshop by maneuvering a switch

linked to a movable metal arm, in turn hooked to a measuring cup and pouring device. He gets help from two local developmental services specialists.

"The business gives him meaningful purpose and enjoyment," says Mary Anne Lewis, an occupational therapist by training. She and her architect husband, George, left their previous lives in Baltimore in 2009 to open the nine-room Brass Lantern Inn in Stowe, Vermont, a four-season destination located at the foot of Mount Mansfield.

"All his life, I thought, 'What is Patrick going to do ongoing that will give him some joy and self-worth?'" Mary Anne says. "A lot of people in his position (with multiple disabilities) would be in a medical



Patrick Lewis (above) has built his own brand, Purely Patrick. He lives at a country inn run by his parents, including dad George, shown with Patrick (below left).

Photos by Mary Anne Lewis

day-care center, and I was hell bent not to have him there."

While he was growing up, one of Lewis' repetitive hand motions allowed him to use switches and buttons to turn his beloved music on and off and to control his pouring device to help make breakfast. In 2008, his mother put that skill set to work and Lewis was soon putting bath salts into plastic baggies to be sold at the inn.

The Lewises moved beyond that to dog cookies, but Patrick didn't like the feel of the wet, gooey dough.

both at events and online at www.purelypatrick.com. Still, most sales are at the inn itself.

Though he does as much of the product assembly as he can, "Obviously he can't distinguish a quarter-teaspoon from a quarter-cup, so that's where his job coach comes in," Mary Anne says. "But there are a lot of pieces he can do. As his job coach says, 'If it's in the jar, Patrick put it there.'"

Though Lewis isn't verbal, "he is very communicative," his mother says. "He has an amazing repertoire of songs he sings. One time, he kept singing the same phrase over and over and we couldn't figure it out." The song turned out to be "Under the Bridge" by the Red Hot Chili Peppers, with the refrain "Take me to the place I love."

As Mary Anne sees it, "Part of my mission — especially when we're at shows and the farmers market — is advocacy and helping other parents (of people with developmental disabilities) by showing them what's possible and guiding them to resources," she says.

"Everywhere we go, Patrick goes, so he meets a lot of people and loves unconditionally," she adds. "He's just pure and simple. I think he's the epitome of what we should all be a little more like."

"I think he's the epitome of what we should all be a little more like."

Mary Anne Lewis
Mother of Patrick Lewis

"Someone suggested he make baggies of dog cookie ingredients so people could make them at home," Mary Anne says. "That's how it started, then it took off. It's been an evolution. We don't do things in an 'A to B' pattern. We kind of zigzag."

Lewis began with five products in 2011 and now sells an array,



Finding the Right Spot

He's independently working at the job he loves best

by Allen Pierleoni

Patrick Ball has worked on a goat farm and in a dairy barn, among other gigs, but his current job as a dishwasher at the North Woods Café in Bradford tops them all.

"I love this one the best," he says. "My favorite part is meeting new people and seeing all my friends who stop by."



Patrick Ball recently attended the Vermont Leadership Series, which teaches legislative advocacy skills.

Photo courtesy of Vermont Developmental Disabilities Council

For Ball, it's all about staying engaged in his community. When he's not in the North Woods kitchen or dining room, he can often be found volunteering at the Bradford Food Shelf. "It's a nonprofit for people who don't have enough food, and I help out there," he says. "I'm a very caring guy, and I'm a nice-looking guy, too."

Ball, 35, recently attended the Vermont Leadership Series, which is underwritten by the Vermont Developmental Disabilities Council and other partners. The three-month program teaches people with developmental disabilities and family caregivers legislative-advocacy skills. The Series emphasizes techniques to "promote inclusive practices and positive attitudes about disability." Ball is looking forward to his graduation ceremony at the Vermont State House in Montpelier.

"Never give up on your dreams."

Patrick Ball
Work Unlimited client

Ball receives supported employment through Work Unlimited, a division of Upper Valley Services. UVS offers a lengthy menu of support services, including – as in Ball's case – shared-living providers who reside with clients.

UVS maintains offices in three counties, including Orange, and serves 200 people. The staff help clients search for work, apply and interview for jobs, and learn the ropes of their new positions.

"The idea is to provide services so they can be successful in the long term," says UVS Director of Employment Lisa Culbertson.

Ball works independently, meaning he does not have a one-on-one support provider at his job site, she says. Instead, he relies on co-workers to help him out if he needs assistance, just like any other staff member. "He will reach out to Work Unlimited staff for anything he's concerned about," Culbertson says. "We follow up with him monthly to see how things are going. We also meet with his work supervisor to offer any support that will keep things going on a positive basis."

How is Ball doing so far? "He's done very well," Culbertson says. "He has a triangle of support – himself, his employer, and his Work Unlimited team."

As for Ball, he says, "(Support services) have been very much beneficial to me."

When not on the job, Ball likes to visit his girlfriend in a neighboring county, and he loves hiking in Franconia Notch, a valley in New Hampshire's White Mountains. He also likes to read suspenseful mystery novels and is close to finishing "L.A. Outlaws" by T. Jefferson Parker.

What's his best advice to other people with developmental disabilities?

"Never give up on your dreams," he says. "If you want to try something, go on and try it."

Does he have a special dream himself?

"Yes, I want to travel the world someday."

Employment First makes a difference

Vermont was an early leader in the movement to close segregated employment sites — also known as "sheltered workshops" — for people with developmental disabilities and adopt an "Employment First" mindset. A national movement, Employment First is centered on the idea that **all** citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life.

Beginning in the late 1980s, that philosophy found a voice in the Association of People Supporting Employment First. **APSE is a professional association** with chapters in 39 states, including Vermont. It provides training and technical assistance to employers, employment support professionals, self-advocates, and family members. For 50 years, APSE has advocated for public policies that address the gap in employment rates for people with disabilities.

Although Vermont was an early adopter of supported employment and other best practices, people with disabilities remain underemployed: **While 80% of Vermonters without disabilities work, only 28% of Vermonters with a cognitive disability are employed.**

"APSE is rooted in the value that people with disabilities have the right to work in an inclusive workplace and to earn a fair and competitive wage," says APSE's national Executive Director Jenny Stonemeier. "Our work is guided by the simple principle of 'Real Work for Real Pay.'"

For more information on APSE, visit <https://apse.org>.

Opening Classrooms and Possibilities

Signed into law in 1975 by President Gerald Ford, what's known today as the Individuals with Disabilities Education Act (IDEA) has opened classroom doors to millions of children with disabilities.

IDEA guarantees access to a free, appropriate public education in the least restrictive environment to prepare students for future employment and independent living.

Overseen by the U.S. Department of Education and administered by the Office of Special Education, grants are provided by the federal government to states, state educational agencies, institutions of higher learning, and nonprofit organizations to support:

- Early intervention services for children with disabilities from birth through age 2
- Special education and related services for children with disabilities up to age 21
- Technical assistance
- Technology development
- Teacher training
- Parent training and information centers such as Vermont Family Network

Today, nearly **14,000** Vermont students are served under the IDEA; **more than three quarters** of these students are in general education classrooms for at least **80%** of their school day.

For more information about the IDEA, visit <https://sites.ed.gov/idea>.

For more information about Vermont resources for special education, go to www.vermontfamilynetwork.org.

'If you don't know what to ask for, you're not going to get it'

Vermont Developmental Disabilities Council helps families advocate for their rights

by Anne Stokes

Terry Holden describes her 18-year-old son Graham as an outgoing and gregarious curiosity seeker. He's a seven-time Special Olympics athlete and likes helping out around the family's farm. He's also nonverbal and has autism.

"He's pretty active and likes to keep moving, he likes to learn by doing," Holden says. "He's autistic, but he breaks the stereotype; he likes to be included in social activities. ... He doesn't want to be the center of attention, but he wants to be part of it."

By age 3, Graham showed significant language delays. Since then, Holden says she's faced a steep learning curve, navigating the complex public education and social services bureaucracies. From early on, she says, it was clear she would have to be her son's advocate.

"As a parent, if you don't know what to ask for, you're not going to get it," she says. "We didn't know there could have been adaptive spelling, there could have been adaptive counting, there were different ways to present these concepts to him."

"One of the things I wish we had done more was teach the other kids how to include Graham. He

wanted to go to Senior Prom, so we went shopping for styling apparel. He practiced wearing it. His speech teacher helped him prepare. We did everything to ensure he would be a good guest. He so wanted to dance, but no one spoke to him, complimented him on his handsome turnout, or asked him to dance. Then I realized; we prepared Graham to be there, but we never taught his schoolmates how to make him part of the gala."

"My goal is that my son be a contributor to his community."

Terry Holden
Council Member and parent

Holden got involved with the Vermont Developmental Disabilities Council when Graham was 13. Through the Council, she was connected to education and resources that helped her navigate Vermont's special education and local

agency systems. She notes that the Council's Leadership Series — which teaches self-advocates and their families how to effectively impact public policy — has been particularly helpful.

"It teaches you how to get your point across without getting emotional, without screaming, without threatening, without sobbing," she says. "These are your points, this is how you want to make them ... so that you're reasonable and people want to listen to you."

She says the Council connects parents like her to support and resources that help them advocate for their child's rights and future goals. In the end, Holden wants what any other parent wants for their child.

"Graham's a doer," she says. "He's volunteered at Valley Dream Farm. He runs track. At our farmers market, everybody knows him. My goal is that my son be a contributor to his community; not just be present, but that he has something to give back."

For more information on the Vermont Developmental Disabilities Council's Leadership Series, call 1-802-828-1310 or visit www.ddc.vermont.gov.



Graham Silman poses with some of his artwork that fills a cabinet.
Photo courtesy of Terry Holden

'Nothing about us without us'

He helps others learn how to speak up for themselves

by Allen Pierleoni



Leading by example, Randy Lizotte teaches self-advocacy to others.
Photo courtesy of Green Mountain Self-Advocates

Randy Lizotte has more than his share of responsibilities. First, as a husband; he and wife Jana Weber Lizotte have been married for 5-1/2 years.

Secondly, he's a peer educator at Northwestern Counseling & Support Services, where he helps other people with developmental disabilities find ways to depend less on clinical services and more on peer support.

And thirdly, he's Board President of Green Mountain Self-Advocates. It's run by and for those with developmental disabilities, with the mission of educating peers to take control of their own lives – including being in charge of their own services.

"I do a lot of teaching self-advocacy and I help facilitate (programs)," Lizotte says. "Currently, a co-worker and I are teaching a sex education course and one on basic self-advocacy – everything from how to speak up for yourself, to speaking up to legislators."

Lizotte has addressed Vermont decision makers numerous times, advocating for the rights of people with developmental disabilities.

One theme he emphasizes is the spirit of the slogan, "Nothing about us without us." It's a key component in the civil rights movement of people with developmental disabilities, he says.

"It means don't make any decisions that will affect me without me being present. I get the final say," he says. "We're people, too, and don't want to be known for our specific disabilities. We want to be known by our names."

Because of his achievements and his work with so many people, Lizotte

"We see ourselves as normal people who need help in certain areas. But everybody needs help at some point in their lives."

Randy Lizotte
President, Green Mountain Self-Advocates

is considered something of a hero in Vermont. "I guess I am," he says. "Especially when people have said, 'He isn't going to amount to anything, he'll wind up in an institution.'"

After high school, Lizotte found his way into the role of facilitator-teacher for several groups, including Speak Up, Addison County. "The members said I had natural leadership ability and elected me as their president," he recalls. "I had no idea I had the skills, but that's where my (advocacy career) started."

Lizotte met his wife at a Green Mountain Self-Advocates meeting. Now, they advocate for marriage for people with intellectual disabilities.

"We do a workshop where we talk about the challenges we faced, and tell people they have the right to get married," he says. "There are a lot of 'normal' people out there who think, 'Oh, well, they're disabled, they don't need to get married. It's going to be too hard on them.'"

"But that's not true," he says. "We see ourselves as normal people who need help in certain areas. But everybody needs help at some point in their lives."

What's the best advice he gives in his role of peer mentor?

"Tell people what you want," he says. "If you can't do it alone, find somebody you trust to go with you."



Self-Advocacy Leads to Inclusion

For more than 600 members, Green Mountain Self-Advocates (GMSA) is a source of peer-to-peer connection, education and pride — a path to taking control of their own lives.

That path is focused on self-advocacy, which Outreach Director Max Barrows emphasizes is a "civil rights movement, not a program."

"It encourages people with disabilities to speak up for themselves, take responsibility for their actions, and thrive in the community with the support and accommodation they need and deserve," he says. "The truth comes from us when we speak up, because who knows us better than ourselves?"

Barrows, who has testified many times before the Vermont Legislature on behalf of people with developmental disabilities, says GMSA encourages its members not to shy away from society, but to "be proud of who you are and stand up for what you believe in. It's a way of combating a world that looks at a disability as a burden. We say it's not. It's the negative attitudes of others that's the real burden."

People with disabilities "want to be seen as people like everybody else," he adds. "We have the same goals and dreams, and we want to be included."

For more information on Green Mountain Self-Advocates, visit www.gmsavt.org.



The 2019 graduating class of the Vermont Leadership Series poses at the State House on Disability Awareness Day.
Photo courtesy of Vermont Developmental Disabilities Council

Help Your Neighbors

Vermont Developmental Disabilities Council needs everyone to take part

Vermont strives to be the best state in the country in which to live with a disability. Beginning with the closing of the Brandon Training School in 1993, we have made tremendous progress toward building inclusive communities.

Still, many Vermonters who have a developmental disability experience isolation and a lack of opportunity. With your help, we can draw each and every Vermonter into the heart of our communities.

Cover photo of Graham Silman by Mike Longren, case manager, Sd Associates

Our mission

The mission of the Vermont Developmental Disabilities Council is to help build connections and supports that bring people with developmental disabilities and their families into the heart of Vermont communities.

Be an ally

Speak up when you see barriers to inclusion wherever you live, work, learn or play.

Be an employer

Vermonters with developmental disabilities can be part of the solution to Vermont's workforce shortage.

Be a good neighbor

Reach out and get to know people with developmental disabilities and their families who live in your town.



Find out more

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