



Life Well Lived



Maine Developmental
Disabilities Council
Annual Report

Community Inclusion

Members from across the state focus on advocacy, self-determination and independence

BY THEA MARIE ROOD

The Maine Developmental Disabilities Council exists to improve the lives of people with disabilities and their families. With its unique mix of experts and people with lived experience, it has successfully filled that mission for nearly 50 years.

The Developmental Disabilities Act of 1970 paved the way for state councils, and Maine's was established by the governor's office in 1971. "It was developed as a bridge between individuals and the government — moving people from institutions to community life," said Nancy Cronin, executive director of the Council. "The Developmental Disabilities Councils work with government to implement policy and make systemic change, making sure individuals with disabilities and their families are part of those decisions. We are bringing government to people and making sure policy will reflect real lives in positive ways."

One example of that is the Council's focus on restraint and seclusion policies, which particularly affect youth with developmental disabilities in both educational and community living settings. "Professionals don't know what else to do," said Cronin, "but they are often not picking up on communication." Agitated kids may be in physical pain, for example.

The Council is working on policy, coalition-building, increasing public awareness, and other strategies around reducing and eliminating the use of restraint and seclusion across the lifespan of people with developmental disabilities. "There are models using alternative de-escalation techniques that show great

promise in helping to mitigate behaviors, and we are hoping to see them tested and implemented in schools and group homes in the near future," said Cronin.

After recent changes in the probate code, the Council took on another project: funding a parent organization that educates families about supported decision-making, where friends and family provide support to a person with developmental disabilities in making decisions.

"Parents have heard from professionals they must consider guardianship ... so we bring them and [their] teenagers in ... to help people understand what supported decision-making is and how it can be used," said Rachel Dyer, the Council's associate director. "We want this to not just be the law, but to make it real for families."

The Council is also proud of its ongoing history project: documenting the history of self-advocates throughout the state who have lived in the community after years in institutions.

"Finally, the single biggest investment we make is self-advocacy," said Cronin. "Much of our work is improving people's capacity to advocate

for their needs. Inclusion is important for everyone, because everyone has gifts. If you forget an entire group of people, you are missing those gifts."

"Everyone has gifts. If you forget an entire group of people, you are missing those gifts."

Nancy Cronin

Executive director, Maine Developmental Disabilities Council



Changing the Way We See, winning artwork from MDDC's 2018 Inclusion Awards
PHOTO BY SOPHIA ANN DESCHIFFART

DEFINING THE TERMS

Self-determination means having control over one's own life. By law, students should be served in the **least restrictive** school environment — and the Maine Developmental Disabilities Council believes that should be true across the lifespan.

But Maine leads the nation in the number of individuals with developmental disabilities who are under full guardianship, the **most restrictive** lifestyle option. As a result, the Council is engaging in a number of initiatives to consider alternatives to full guardianship.

Self-advocacy is the act of speaking up for oneself and the things that are important to you. Being able to use one's voice is a right for all people, including people with developmental disabilities.

Ready to Learn

Integration into mainstream classrooms benefits all children

BY ANNE STOKES



The Woodcock family has seen the difference inclusion makes for daughter Samantha.

PHOTO COURTESY OF THE WOODCOCK FAMILY

Like many sixth graders, Samantha Woodcock loves music, horseback riding, skiing and spending time with friends.

“Sami is very bubbly, very friendly, easy to get along with,” said her mother, Carrie Woodcock, executive director of the Maine Parent Federation. “She’s totally driven by peer involvement and peer inclusion.”

Now 12 years old, Sami was born with Down syndrome. After an early intervention preschool program, she was integrated into a mainstream kindergarten classroom. In first grade, however, she ended up repeating a year and was separated for parts of the day into the school’s special education program. According to Woodcock, Sami was being pulled out of class too often and during integral parts of the day when she would otherwise be able to fully participate with her classmates. Even during the time she was in the regular classroom, she was still being given a different curriculum than her peers.

“She regressed in every single academic area,” Woodcock said. “But it gave us the data we needed to push the district for full inclusion and give her what she needed within the mainstream classroom. From that day forward, she’s been in a mainstream classroom. Every year, we were able to gather data to prove that is her least restrictive environment. ... When you have the report

cards and the tests, you can’t argue with data.”

For Sami, that least restrictive environment means being in a mainstream classroom with her peers for the whole day. She receives accommodations and modifications so that she’s able to access the same curriculum as her typically-developing classmates.

Woodcock says that while Sami’s transition from elementary to middle school was tough — new teachers, new schedules and more difficult curriculum — it was made easier by her earlier efforts to ensure her daughter’s right to a free and appropriate public education.

“I was preparing for middle school at the end of fourth grade. What I’m doing now in middle school is thinking and preparing for high school because I don’t want Sami to be in a living skills room in high school, I want her to be in academic classes,” she said.

“What I’m doing overall is preparing Sami for the real world.”

What Woodcock says she wants for

Sami’s future is independence, including being employed and leading a fulfilling life.

“Our expectations for Sami are no different than our expectations for our typically-developing son; how we get there is different,” she said. “Everything I’m doing currently is being done with purpose for her future.”

“Everything I’m doing currently is being done with purpose for her future.”

Carrie Woodcock
Mother and executive director, Maine Parent Federation

INCLUSIVE EDUCATION

The Maine Developmental Disabilities Council believes early intervention and education services for all students should be inclusive, accessible, comprehensive, high quality and student/family centered.

Inclusion means that students with disabilities learn, play, and work in the same schools, classrooms and other educational sites with their peers, siblings and neighbors who do not have disabilities.

This type of inclusive education prepares youth with developmental disabilities for:

- ✓ **Employment**
- ✓ **Independent living**
- ✓ **Full participation in civic and community life**

Bridge to Adulthood

Young adults and their families need support to figure out what comes next

BY THEA MARIE ROOD



With the help of his parents, Evan Youde found the support he needed to transition into an adult program.

PHOTO BY NIKOLAS HAMPLE

Any parent will tell you the final years of high school are nerve-racking, trying to balance costs and logistics for a teen’s move to a new stage of life. But this is particularly acute for parents whose children have developmental disabilities.

“Evan’s transition was very stressful because of the unknowns,” recalled Jean Youde, who lives in Hallowell, Maine — a small town near Augusta — with her husband Jon, their 22-year-old son, and a 1-year-old Labrador retriever. “What if there’s no local program? Are we willing to move? Reduce our work hours? Stop working?” Evan’s funding was also initially only four hours a day and we both work full-time.”

Evan, who is on the autism spectrum and has intellectual disabilities, graduated in 2017; and the Youdes had already spent a year looking at day programs. “I’m on the Developmental Disabilities Council, which has a wonderful publication

(‘Selecting a Community Support Provider’)* by parents and providers on how to select a community program,”

Jean said. “I took the questions everywhere we went.”

“Our greatest wish is to have him living in his own place, and know that he is happy and safe.”

Jean Youde
Council member, Maine
Developmental
Disabilities Council

They ultimately found a day program for Evan that was under the umbrella of his former school system, a real advantage as they moved into adult services. “There’s often no bridge between pediatric and adult services, and you have to figure out health care, a program, transportation,” she said. “It can be like starting all over in a system you don’t understand.”

The Youdes persevered, however, and initially paid out-of-pocket for Evan’s extra hours so they could stay in their jobs. “We couldn’t sustain that, but we knew the Governor’s budget had a big increase in the [Section 29 funding] cap,” said

Jean, adding that she actively lobbied for its passage in 2018. With the funding increase, Evan was able to get more service hours.

Evan recently moved to another program, one even closer to home, where Jean says he enjoys a peer group and many community activities. He also completed his vocational training and the Youdes are hopeful he will soon have a job.

“He has good skills, likes being with people, likes learning new things,” she said. “I also think he would enjoy living away from home with the right supports, in a community apartment with a roommate. Our greatest wish is to have him living in his own place, and know that he is happy and safe.”

*To find this toolkit, visit <https://maineddc.org/index.php/resources-publications/community-support-toolkit>.

TRANSITION CHALLENGES

It is called “the cliff” — a young person with developmental disabilities has a birthday, turns 21, and on that day, graduates from the children service sector to the adult service sector. Unfortunately, these young adults are often falling into an abyss.

Across the lifespan, there are wait lists for almost all MaineCare service sections — services that are necessary to provide

support and treatment for individuals so they can live the most successful and independent lives in their community. And wait lists are getting longer, not shorter: Some young people are waiting months and years for appropriate home- and community-based services — leaving their families with limited options.

Children/Youth Services

Policy Section	Number of People Waiting*
Section 28 (Community Support)	410
Section 65 (Community Treatment)	457

Adult Waiver Services

Section 29 (Supports Waiver)	323
Section 21 (Comprehensive Waiver)	1,639

*As of October 2019

Building an Independent Life

Finding happiness (and love) through work

BY ANNE STOKES

These days, Kile Pelletier has a career he loves, lives independently and is engaged to be married. But things haven't always been so great. In the past, he's lived in a group home and a shared living home. For 10 years, he was employed at a nursing home kitchen, but it didn't feel fulfilling.

"I was thinking, 'What am I going to do with my life?'" he said. "I was going around in circles. It was not what I really wanted to do, I felt like I was not succeeding in what I really wanted to do in life."

He first heard about Speaking Up For Us (SUFU) — an advocacy group run by adults with developmental disabilities — through a day program he was in. He says it was eye opening to find other individuals like himself who were working to create opportunities for themselves and others.

"There were a whole bunch of self-advocates out there like me," he recalled. "Yes they have barriers, but they're trying to work to get those walls broken so they can go through them."

When a staff position became available in 2017, it was a perfect opportunity to earn a living while continuing his advocacy work. Today, Pelletier is a program associate and helps board members coordinate schedules and stay on task.

"I thought, this would be perfect for me because I'm a person who likes to speak out; I'm a self advocate ... just now, I get paid for it," he said. "I love it, it's my passion. I love speaking up for other people, and trying



Kile Pelletier and Stephanie Tardiff plan to marry in August.
PHOTO COURTESY OF KILE PELLETIER

to help point people in the right direction to break [down] those walls that need to be broken."

Eight years ago, he met Stephanie Tardiff, a SUFU board member. They hit it off so well that he proposed to her last year at the beach. They're planning on getting married in August, after which they plan on living independently ... together.

"I have my own place, my own car, I come and go as I please, I cook my own meals, I do my own laundry," Pelletier said. "I love coming and going as I please, not having anyone tell me, 'You can't do this' or 'You can't do that' because there's not enough funding.

I go ahead and I do it. If I want to go somewhere, I go somewhere. If I have the money to go somewhere, I go."

For more information on Speaking Up For Us, visit www.sufumaine.org or call 207-956-1004.

"I'm a person who likes to speak out; I'm a self advocate ... just now, I get paid for it."

Kile Pelletier
Self-advocate and program associate with Speaking Up For Us

A LEVEL PLAYING FIELD

Most of us hope to grow up, have a job where we are valued, and engage in a healthy, loving, romantic relationship. But there are built-in challenges for people with disabilities.

Marriage SSI

Many individuals with developmental disabilities rely on Social Security Insurance (SSI) or Social Security Disability Insurance (SSDI) to get access to support necessary to live. But if you rely on SSI/SSDI income, marriage may quickly become unaffordable or a choice between love and survival. Here's why: If an individual and her partner both receive SSI/SSDI and they marry, there is a marriage penalty in which they will lose 25% of their income.

Employer SSI

Employment can be just as tricky for people with developmental disabilities, juggling lots of items in small print trying to keep their SSI/SSDI benefits. Accessing supports for competitive employment can be time consuming and complicated.



For more information, check out these links:

Social Security and SSI for People with I/DD and Their Families:

thearc.org/wp-content/uploads/forchapters/NPM-SocialSecurity_SSI_4.pdf

People with Disabilities and the Federal Marriage Penalties:

ici.umn.edu/products/impact/232/22.html

Understanding Supplemental Security Income SSI Work Incentives:

www.ssa.gov/ssi/text-work-ussi.htm

Fighting Fires with Spirit

Christopher DuPont is focused on a primary goal – helping others

BY ALLEN PIERLEONI

“Look at your abilities, not your disabilities.” That’s Christopher DuPont’s best advice for people living with disabilities, and he’s taken it as a blueprint for his own life.

DuPont, 27, was born in Sanford, Maine. He was removed from his home at a young age and, until age 18, lived in various foster care and group homes, ultimately ending up in Washington County. There Chris found a community who supported him, and a community to which he wanted to give back.

Today, he’s a graduate of the Hancock County Fire Academy and a certified Levels 1 and 2 firefighter at the Addison Volunteer Fire Company in Washington County. He’s also a board member of the self-advocacy group Speaking Up For Us.

“He’s not willing to let other people define how it’s going to be for him,” said Rachel Dyer, associate director of the Maine Developmental Disabilities Council. “He’s clear about what he wants and makes his own decisions.”

“When people tell me no, I go even harder,” he said. For instance, he recently obtained his driver’s license and hopes to buy a car sooner rather than later. “I take things one step at a time,” he said.

To help things along, DuPont is transitioning from one support organization to another, where he will regularly meet with others for support. On a broader scale, the MDDC is “the first place I call when I need some advice. They’ve really helped me a lot.”

But it’s his involvement with the Addison fire department – a place he was first drawn to at age 16 – that helps define who he is.

“As firefighters, we’re one big family and we all take care of each other,” he said. “Any time tones go off, we respond to the station and get into a truck. Usually I have all my gear on by the time we’re at the scene, where I wait for further instructions from my chief.”

“It’s a great feeling knowing I’m on the front line when people are in trouble.”

Christopher DuPont
Volunteer firefighter

DuPont is “interior technician-qualified,” which allows him to enter unsafe areas for fire suppression. Additionally, he is at the operations level when it comes to hazardous materials, “which means I can go to HAZMAT scenes,” he said.

Working as a volunteer fireman is “very important to me,” he said, as it’s his way of giving back to the community.

“It’s a great feeling knowing I’m on the front line when people are in trouble,” he said. “When we go to a serious scene, I put in the back of my mind that we’re helping somebody’s family and we have to take great care of them.”



Volunteer firefighter Christopher DuPont sees his work as a way to give back to his community,
PHOTO BY FIRE CHICKS PHOTOGRAPHY

VITAL ASSET TO RURAL COUNTY

Washington County experiences challenges common to rural communities, with limited access to employment, education, transportation, healthcare and other services. It also has unique demographic challenges:

Aging

The percent of the population in Washington County over 65 is much higher than that in Maine, already the oldest state.

Poverty

Washington County is the state’s poorest county.

Disability

People in Washington County experience a high rate of disability.

Health

Health outcomes for people in Washington County are worse than that of other Mainers and they have the state’s highest rate of premature death.

Washington County is also rich in natural resources, noted for blueberries, its stunning coastline, and especially its cohesive, resilient communities. People with intellectual and developmental disabilities live in rural areas for the same quality of life that is valued by others in the community. And, they often face challenges in accessing that quality of life. In particular, individuals and families report having difficulty securing needed specialty services and supports throughout the lifespan. Adults with developmental disabilities, who are often unable to drive, face barriers to transportation and employment.

Communities are stronger when all members are able to use their gifts.

Long Battle to Independence

Institutionalized at age 10, she's now one of Maine's leading advocates for Mainers with developmental disabilities

BY ALLEN PIERLEONI

When Maryann Preble's mother died, her father committed his daughter to the notorious Pineland Hospital and Training Center in New Gloucester. It opened in 1908 as the Maine School for the Feeble-Minded.

Maryann Preble was 10 years old.

Today, 60 years of self-determination later, Preble is a highly respected advocate for people with developmental disabilities, a pioneer in her field who has lived independently for years.

Her accomplishments have been remarkable. For instance, she's a leader in the self-advocacy group Speaking Up For Us, serves on the consumer advocacy board of the University of Maine's Community Inclusion and Disability Studies department, and has testified multiple times before the Maine State Legislature, advocating for those with developmental disabilities. Preble is a member of the executive committee of the Maine Developmental Disabilities Council.

"A lot of people in group homes want to be out on their own, to have an apartment, to get married," she said. "When I testify at the state house and tell them about [other people with developmental disabilities], I'm taking their voices with me. [Advocates] wouldn't be on committees if it wasn't for me speaking up. It makes me feel good to do that."

"Maryann's life embodies possibilities," MDDC Executive Director Nancy Cronin said. "The system was

willing to throw her away, but the fact that she was able to continue on and speak for people who often can't speak for themselves, is amazing."

Preble was 16 and still in Pineland when an aide took her to lunch at a local restaurant. Incredibly, she ran into her brother, who soon engineered her release and moved her in with him and his wife.

"I thought, 'Good, I'm out in the community and with my family,'" Preble recalled.

"I made up my mind after I got out of Pineland that I was going to get my own place and be out on my own," she said. "I went from my brother's home to a group home. We would cook (as a group) and make our own menus and meals. It was like being on our own. And once I was there, I was able to see my family quite a bit."

Preble left the group home when she was about 30. "I said I was going to find my own apartment and get a job, which I did. I wanted to meet people and earn some money. I worked at a preschool and it was fun working with kids. But they let me go because they couldn't pay me anymore."

"You know what you want, but other people aren't going to know if you don't tell them."

Maryann Preble
Self-advocate and MDDC
executive committee
member



Maryann Preble continues to speak up for herself and other Mainers with developmental disabilities.

PHOTO BY NIKOLAS HAMPLE

Then, she met "a companion." They married and moved to Litchfield. When her husband had a stroke and was moved into a nursing home, she got an apartment in Augusta to be near him. She commuted from there to Hallowell to visit her husband until he passed away.

Ever ambitious, she got a job as activities director at the nursing home and began advocating for herself and others. "I'd advocate for people who couldn't advocate for themselves," she said. "It brought me closer to doing something for other people, and I felt good about that."

Preble has lived in her apartment for "about 20 years now," she said. "I'm a different person from who I was. I make my own decisions and go where I want, when I want. It's like, 'I'm free, I'm out on my own. What am I going to do next?' I volunteer and it makes me feel good doing things for other people."

What advice does Preble offer those who struggle with their developmental disabilities?

"Speak up, don't keep it in," she said. "You know what you want, but other people aren't going to know if you don't tell them."

PREVENTING A STEP BACKWARDS

The Maine Developmental Disability Council is very concerned at the current trend to open larger congregate settings for people with disabilities. The Council believes firmly that Maine has "been there, done that, and it didn't work."

That doesn't mean our community services system is working perfectly — wait lists are growing for services, in addition to a housing crisis and a direct workforce crisis — but the

solution must not be opening large institutions.

Some who support institutional living point to people's safety, but the statistics are clear: People are safer in the community and they have better lives.

It is critical that we learn from our history and fix the problems in our systems without repeating the mistakes of the past because we have forgotten the terrible consequences.



Check our website for more information:

www.maineddc.org.



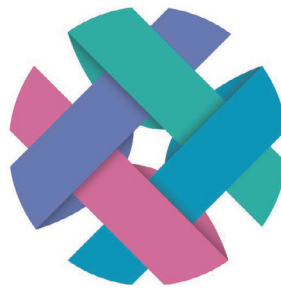
Who We Are & What We Do

The Maine Developmental Disabilities Council (MDDC) is a partnership of people with disabilities, their families, and agencies that identifies barriers to community inclusion, self determination and independence.

The Council acts to effect positive change through advocacy, training, demonstration projects, and support for other inclusive and collaborative systemic change activities.

Our Mission

MDDC is committed to creating a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included.



Maine Developmental Disabilities Council

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OUR IMPACT

These are just some of the accomplishments of the Maine Developmental Disabilities Council in the last year:



Self-Advocacy

Over 500 people with developmental disabilities had their voices heard and over 160 participated in trainings to help them build their leadership and advocacy skills.



Professional Development

600+ medical, education, and service professionals received trainings to help them better serve people with developmental disabilities.



Legislative Advocacy

MDDC staff and members were actively involved on 24 bills, built coalitions to positively impact public policy, and our members increased their advocacy skills to take their own action.



Public Awareness

17,000 parents of at-risk children received information on early intervention and more than 13,000 people engaged with MDDC's website and social media.



Education

Over 200 people with developmental disabilities, parents, students, and community members participated in projects that helped them better understand the needs and issues of those with developmental disabilities.

Learn more about our work at [maineddc.org](https://www.maineddc.org)



Facebook: <https://www.facebook.com/MaineDevelopmentalDisabilitiesCouncil>



Twitter: @MaineDDC



Instagram: <https://www.instagram.com/maineddcouncil/>