



Maine Developmental
Disabilities Council



2023 Annual Report

Empowering The Future



We are committed to creating a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included. To do this, we create and support policy advocacy for individuals with developmental disabilities.



The Maine Developmental Disabilities Council (MDDC) does a lot with just a little.

Part of a national network of state developmental disabilities councils established under federal law, the MDDC protects the rights of people with developmental disabilities (DD) to live as they choose in their own communities while expanding their opportunities. We advocate for policies that empower people with DD, help them address the barriers they face, and cultivate communities that are supportive and welcoming to all.

Our annual budget, mostly from the federal government with some state funding, is about \$660,000—well below the salaries of many professional athletes. But, while small, we are nimble and responsive. Over the years, we have become a trusted resource for people with DD and their families, as well as a driver of innovative solutions.

This past year has been about moving forward from the COVID-19 pandemic—not “returning to business as usual,” because that’s changed forever, but adjusting to change and forging ahead.

Fostering Healthy Relationships

Some of the most important and exciting work we’re doing right now is around sexual health and healthy relationships. We began this effort a year ago with a groundbreaking event featuring experts from around the country who spoke about providing care for people with DD who have been sexually abused.

Fast forward to 2023: We have expanded beyond recognition and treatment of sexual abuse to launch a two-pronged sexual health and healthy relationships education program that engages clinicians and people with DD.

In June, we held a two-day intensive training with six self-advocates with disabilities and about a dozen professionals, including people from Maine Family Planning, Maine Parent Federation, and Speaking Up for Us. Our curriculum, “Empowered Together,” co-led and co-taught by a self-advocate and a health professional, covered a range of issues, from healthy relationships to sexual health, birth control, reproduction, and pregnancy.



Why is it important to learn about healthy relationships?

“It’s important because I feel like a lot of folks with disabilities are usually left out of those discussions. It doesn’t really seem fair. It’s almost like the prevailing attitude is that people seem to think that they don’t need to know this stuff, or this stuff shouldn’t interest them. But we all have the same unique needs and desires. We’re all human. We all want to love and be loved and be able to express those things in healthy ways.”

Marco Orlando
Self-Advocate

We also did a debrief with the self-advocates who attended to explore their feelings and reactions. The discussions we had were powerful and healing, and several participants expressed interest in becoming instructors for the programs themselves.

One thing we're particularly proud of is that we're paying self-advocates who participate in the program for their time—for coming to the training, for speaking, and for training to become teachers.

The program is continuing with a series of webinars geared toward parents and caregivers of people with DD to strengthen their understanding of this issue. Some of these sessions are being led by trained self-advocates.



Empowering Young Learners

Just like everyone else, young people with disabilities need others to recognize and acknowledge their potential. Too often, though, the messages they receive from their families and schools are ones of low expectations. And when that happens, kids don't challenge themselves. Their gifts frequently go unrecognized and are wasted.

Brody

When Brody's mom was asked to name one strength her child has, she drew a blank. She couldn't think of one.

Two weeks later, Brody, who is non-verbal, had completed his own 20-page learner profile book, using photos and videos and his own words, as part of Empower the Learner, a project of the Maine Parent Federation supported by the Council.

You can learn a lot about Brody through this book: his strengths, challenges, his interests, who's important in his life, how he learns, what makes him nervous, and what soothes him. You'd see that he's a polite, sociable boy who loves music, singing, and making people laugh. He uses sign language, has a great memory for people and motor vehicles, and wants to learn how to drive.



Sami

Sami is an active, energetic high school freshman who likes listening to music, reading, playing softball, and skiing. She has Down's syndrome, which she says helps her make people laugh by being fun. At school, she sometimes has difficulty focusing and gets distracted easily, but she's working on "having more rock star days."

The Empower the Learner books give young people with DD an opportunity to show how they see themselves—and how they want others to see them. They're also useful tools for parents to share during IEP meetings and for teachers trying to understand how best to interact with their students and help them learn. They can also help transition students from one school to another.



So far, we have had two full Empower the Learner trainings with 11 parents interested in working with their kids on these books—and more ahead. Our goal is to empower young people to share not only their stories but their gifts with their communities.

Expanding Self-Advocacy

People with DD are their own best advocates and their own best decisionmakers. That’s why, since 2015, the Council has funded the Self-Advocacy Leadership Program in partnership with Speaking Up for Us, an organization run for and by people who identify as self-advocates. The goal of the program is to instill learners with the confidence and skills to be leaders in their own lives and in their communities. The training they receive is the same kind and level of training that people learning to lead boards of nonprofits receive.

Designed for in-person training, the program went on hiatus during the COVID-19 pandemic but returned in 2022 and again in 2023. Speaking Up for Us trained nine new self-advocates this spring and summer who were enthusiastic about learning and exploring their opportunities together. Many of them have applied to be members of the Speaking Up for Us board, which is often a next step for people after completing the training. We’re also starting to see people branch out to participate in more leadership opportunities, such as board seats with the Council. We want people to serve on more boards and groups as their interests and passions take them. If we are to build a truly inclusive society, then we have to show what that means from the viewpoint of people with DD.



“I enjoyed being on the board, mingling with other peers and people trying to make a difference. [The Self-Advocacy Leadership Program] has helped me become a stronger advocate for myself by not being so shy. It’s helped me be more confident and speak out more.”

Stephanie Pelletier
former board member
Speaking Up for Us

Looking Ahead

There is always more work to be done, and the Council will continue to explore how we can protect and expand opportunities for people with DD while promoting communities that are inclusive and welcoming. We are grateful to have such creative and hard-working partners who are passionate about improving life for people with DD.

Special thanks to Autism Society of Maine, Empower the Learner, Mad Hatter Wellness, Maine Family Planning, Maine Parent Federation, Speaking Up for Us, and all our program participants.

To stay up to date on our work, visit our website at www.maineddc.org.

FY 2022-2023 MDDC Expenditures

