



**Maine Developmental  
Disabilities Council**

## **Annual Report**

**Submitted to the 129<sup>th</sup> Legislature  
State of Maine, 2nd session**

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This information has been compiled by Maine Developmental Disabilities Council, pursuant to its duties under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, to complete and update a comprehensive review and analysis of services, supports, and other assistance for individuals with developmental disabilities (as specified in 42 United States Code, Chapter 144, Section 15024(c)(3)). The data analysis included in this report uses the most recently released data from the U.S. Census Bureau, along with information from other sources.

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## I. Maine Developmental Disabilities Council Overview

### Who We Are

Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970 to "engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose of the DD Act; and contribute to a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system of community services, individualized supports and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive and be integrated and included in all facets of community life."

Maine Developmental Disabilities Council (MDDC) is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self-determination, and independence, and acts to effect positive change. The Council has a vision that all people are included, supported, and valued in communities that provide opportunities to participate and succeed as they choose. MDDC acts to affect positive change through advocacy, capacity building, training, demonstration projects, and support for other inclusive and collaborative systems change activities.

### Mission

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

### Purpose

To **promote systems change** to ensure that all individuals with developmental and other disabilities are able to **live and fully participate** in their communities of choice. Working in partnership with people with disabilities, parents, advocates, and policy makers, MDDC works to **promote the independence, integration, and inclusion** of all people with disabilities through advocacy, capacity building, and systems change activities throughout the state of Maine and on the national level.

### Enabling Federal Legislation

Under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, MDDC is required to ensure that individuals with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all facets of family and community life.

### Council Membership

Maine Developmental Disabilities Council's specific priorities are shaped by its governing council. The Council consists of 27 members, 19 of whom are appointed by the Governor. 60% of MDDC's membership is made up of people with developmental disabilities or their representative family members. The remaining 40% of MDDC's membership is made up of representatives of State agencies administering federally-funded programs related to individuals with developmental disabilities, local non-governmental agencies/organizations that serve people with developmental disabilities, and MDDC's "sister agencies", so-called because they are also funded through the DD Act: Disability Rights Maine, Maine's Protection and Advocacy agency for people with disabilities, and the Center for Community Inclusion and Disability Studies at the University of Maine, Maine's University Center for Excellence in Developmental Disabilities.

The breakdown of membership includes:

- 5 seats designated for individuals with developmental disabilities
- 5 seats designated for parents, guardians, or family members of individuals with developmental disabilities
- 6 seats designated for *either* individuals with developmental disabilities *or* parents, guardians, or family members of individuals with developmental disabilities
- 1 seat designated for a local non-governmental agency/organization that serves people with developmental disabilities
- 1 seat for the University Center for Excellence in Developmental Disabilities
- 1 seat for the Protection and Advocacy agency for people with disabilities
- 1 seat for a statewide self-advocacy organization
- 1 seat for each of the following State Agencies:
  - Department of Health and Human Services, Office of Aging and Disability Services
  - Department of Health and Human Services, Office of Child and Family Services
  - Department of Health and Human Services, Children with Special Health Needs
  - Department of Education, Special Services
  - Department of Education, Child Development Services
  - Department of Labor, Vocational Rehabilitation

Due to its diverse membership, the Council provides opportunities for disparate perspectives to come together to work toward systems that support individuals with developmental disabilities to be fully included in their communities.

**What We Do**

Maine Developmental Disabilities Council is required to engage in advocacy, capacity building, and systems change activities that address:

- |              |  |
|--------------|--|
| ❖ Employment | ❖ Transportation                       |
| ❖ Health     | ❖ Community Supports                   |
| ❖ Child Care | ❖ Quality Assurance/Self-Determination |
| ❖ Recreation | ❖ Education and Early Intervention     |
| ❖ Housing    |  |

MDDC develops a five-year plan that best suits the needs of the community. Current strategies include:

- Promote and provide small grants for activities that expand the capacity of communities to provide opportunities for individuals with developmental disabilities to actively participate in community life
- Advocate for systems change that allow individuals with developmental disabilities to achieve full integration and to pursue meaningful and productive lives
- Increase public awareness and work to eliminate barriers that negatively impact independence, productivity, and inclusion of people with developmental disabilities
- Foster and support coalitions and other advocacy and community groups
- Support close working relationships among the various public and private service providers

**Five-Year State Plan** – See Appendix A.

## II. Defining Developmental Disability

The US Department of Health and Human Services' Administration on Intellectual and Developmental Disabilities states that:

"A *developmental disability* is a severe chronic disability of an individual that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments
- Is manifested before the individual attains age 22
- Is likely to continue indefinitely
- Results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated

An individual from birth to age 9, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life." (Developmental Disabilities Assistance and Bill of Rights Act of 2000) The federal definition is *functional*; that is, it is intended to describe the nature and scope of limitations without reference to medical diagnosis.

### How Many People Have Developmental Disabilities?

The Administration on Intellectual and Developmental Disabilities estimates the population prevalence of developmental disabilities at 1.8%. Approximately **24,000** Mainers of all ages have developmental disabilities. According to the 2015 Disability Compendium<sup>1</sup> (Institute on Disability at the University of New Hampshire):

**The prevalence of disability (any disability, by self report) among all people in the United States is 12.5%.**

**The prevalence of disability (any disability, by self report) among people in Maine is 15.9%.**

Approximately 203,400 Mainers report having one or more disabilities.

- **6.9% of Mainers have a Cognitive Disability**  
Approximately 102,000 Mainers have significant difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition.
- **2.7% of Mainers have a Self-Care Disability**  
Approximately 43,000 Mainers have difficulty dressing, bathing, or engaging in other forms of self-care.
- **6.5% of Mainers have an Independent Living Disability**  
Approximately 91,000 Mainers have difficulty doing errands such as visiting a doctor's office or shopping alone because of a physical, mental, or emotional condition.

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<sup>1</sup> Institute on Disability at the University of New Hampshire (2013) 2015 Disabilities Compendium  
<http://www.disabilitycompendium.org/> accessed 1/4/17

### III. Concerns of Maine Families Affected by Developmental Disability

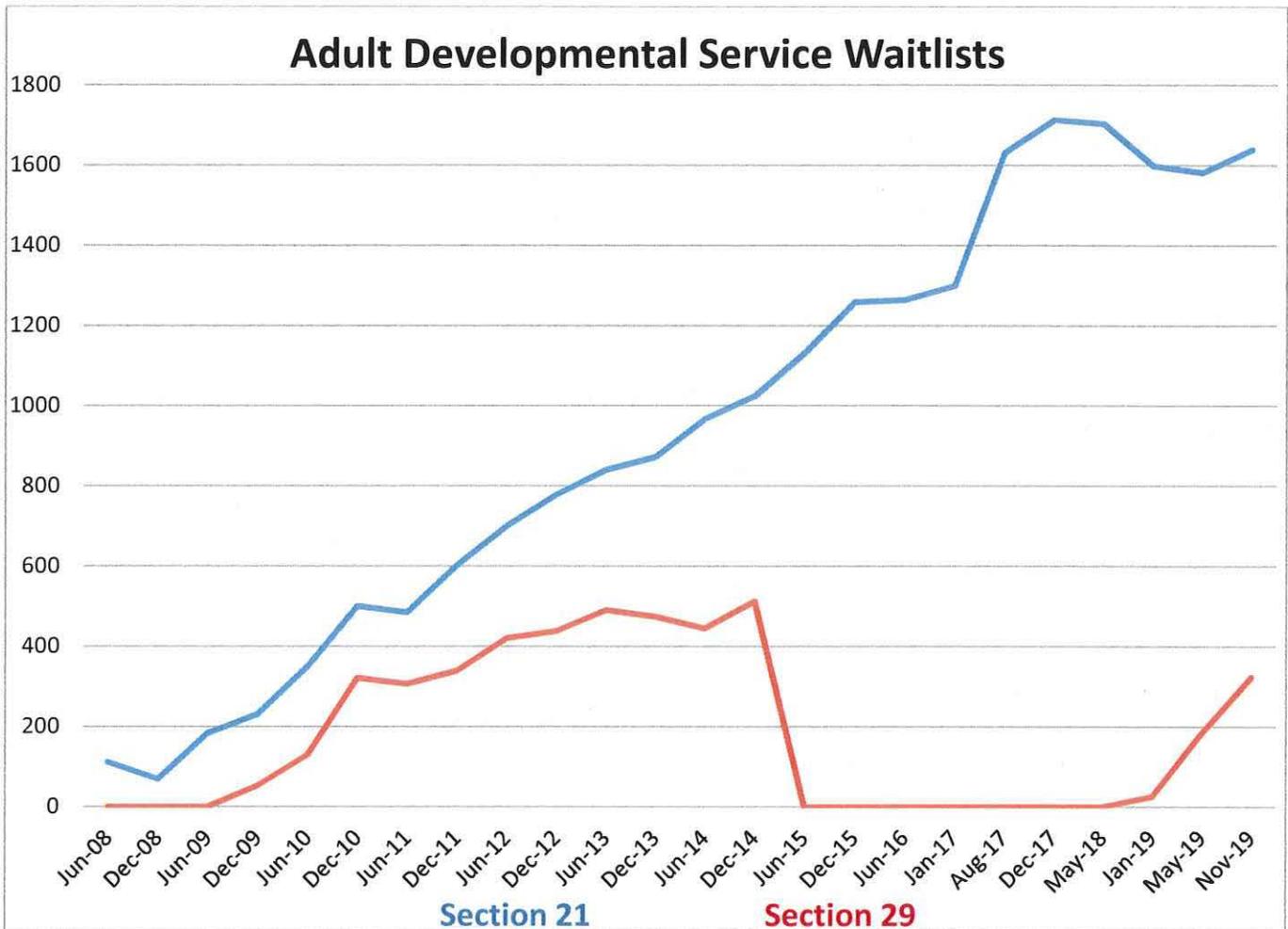
#### ***Access to Services and Supports***

Maine Developmental Disabilities Council monitors available data about services and supports available to Mainers with developmental disabilities and gathers input about gaps in the system.

#### ***Adult Developmental Services***

Upon reaching adulthood, the availability of individual and family supports changes from a model of entitlement to eligibility. To be eligible for Developmental Services, an individual must demonstrate substantial functional limitations in three (3) or more of the areas of major life activity (such as self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency).

MDDC has noted with appreciation the attention to addressing the waitlists for waiver services and appreciates the elimination of the Section 29 and the Section 21 Priority One waitlists. However, there continues to be a significant unmet need for services. MDDC also notes the challenges encountered by eligible persons in accessing those services.



### Children's Services and Special Education

Children with developmental disabilities are entitled to a fairly robust array of services and supports. However, Maine families experience very significant challenges in accessing those services, especially the areas of:

Early intervention: Young children who are at risk of developmental disabilities need early intervention services. They are not receiving timely and effective services due to waitlists, high rates of staff turnover, insufficient funding, and erosion of service delivery capacity due to systematic regulatory changes.

Obtaining community supports: At times, families do not receive needed services because qualified providers are not available. This is noteworthy in long waits for Section 28 services. One father spoke to MDDC of having to decide whether an unreliable support person was preferable to no support person and of changing holiday plans based upon the availability of support. Another spoke of having no choice but to pursue residential placement (due to the lack of availability of support). Another parent spoke of a child receiving speech therapy once every other week for a 90 minute session rather than the 20 minutes three times a week that the child needed.

Inadequate transition planning: One mother's comments reflect many other families' concerns. She said:

*"...Transition is one thing, but if there is little of quality or even adequate to transition to, the point of transitioning is completely lost. My experience and observations are that a sufficient and qualified pool of support people doesn't exist, aren't paid or supported well enough, etc. Right now, my husband and I feel like the most realistic plan for our daughter's future is that we must never become ill and must never die OR we should clone ourselves. I know that seems absurd, but it is not said necessarily in jest. I'm sure many other families relate to those kinds of sentiments, nor is it new to you."*

### Other Services

While the Office of Aging and Disability Services (OADS) provides developmental services to approximately 5000 individuals, there are thousands more Mainers who meet the federal criteria of having a developmental disability. Some receive appropriate services through another section of MaineCare such as Section 19, 20, or 50. Some have multiple diagnoses and receive services such as Section 65 or 96 which may create emphasis on alternative diagnoses, leading to less than effective/efficient care. Some do well with no services at all. Some do not, Some are in the criminal justice system. MDDC hears from/of many Mainers with significant intellectual and developmental impairments and their family members who simply do not qualify for services. They struggle to obtain and retain housing, transportation, employment, and healthcare. These people are disproportionately poor and have been impacted by such issues as Maine's response to Medicaid expansion, affordable housing policy, and income based supports such as SNAP, TANF, general assistance, and heating subsidies.

### Other Issues

Maine Developmental Disabilities Council monitors other issues that significantly impact Maine families affected by developmental disabilities.

**Poverty<sup>2</sup> 29.9% of working-age Mainers with disabilities live at or below the federal poverty level (compared to 9% for people without disabilities).**

<sup>2</sup> <http://www.disabilitystatistics.org/reports/acs.cfm?statistic=7y>

### Unemployment

According to U.S. Department of Labor statistics<sup>3</sup>, in November 2016 for Americans age 16 and older, the labor force participation of people with disabilities was 20.9% (versus 67.9% for people without disabilities) and the unemployment rate for people with disabilities was 8.4% (versus 3.7% for people without disabilities).

In Maine, the 2015 employment rate<sup>4</sup> of persons with cognitive disabilities was 21%, the employment rate of persons with self-care disabilities was 16%, and the employment rate of persons with independent living disabilities was 13%.

For individuals with developmental disabilities who do not receive waiver-level services, access to ongoing employment supports is extremely limited. This significantly limits people's ability to work. Recent Maine care data suggest a small increase in persons with autism utilizing employment supports, a positive indicator.

### Aging Caregivers

The aging of Maine's population stands to pose serious challenges in meeting the support needs of persons with developmental disabilities. Families continue to be the primary providers of care. According to national statistics, an estimated 76% of individuals with developmental disabilities live at home. In 25% of these households, the family caregiver was age 60 or older and the average age of the family member with a disability was 38 years. There are an estimated 641,000 adults over age aged 60 who have developmental and related disabilities, a number that is projected to double by 2030.<sup>5</sup> **In Maine it is estimated that approximately 4,230 persons with developmental disabilities are living at home with caregivers over the age of 60.**<sup>6</sup>

### Dental Care

Limited or lack of access to both preventative and restorative dental care is a barrier to the health of people with developmental disabilities who are not institutionalized. Lack of access is even more significant for those who do not have access to waiver-level services.

### Transportation

Most people with developmental disabilities do not drive. In a state that is largely rural with little public transit infrastructure, this severely limits the ability to travel. People with developmental disabilities rely on a patchwork of service providers, family and friends, public transit, taxis, and volunteer drivers. Individuals with developmental disabilities report that obtaining transportation to social and recreational opportunities, particularly individual activities, is especially difficult. Community transportation (public/regional and volunteer) is limited geographically, making short trips complicated and limiting vocational and social opportunities, and is essentially non-existent in the evening or on weekends. People with physical disabilities have additional difficulties with transportation in that taxis and private vehicles of family, friends, and volunteer drivers may not be accessible, public transit has limited accessible seating, and in the winter people may have difficulty negotiating icy conditions. MDDC has noted with concern the access and safety challenges of persons with developmental disabilities utilizing Non Emergency Medical Transportation.

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<sup>3</sup> U.S. Dept of Labor , Office of Disability Employment Policy <https://www.dol.gov/odep/> accessed 1/16/18

<sup>4</sup> [www.maine.gov/labor/cwri/disabilities/index.html](http://www.maine.gov/labor/cwri/disabilities/index.html)

<sup>5</sup> Heller, Tamar Ph.D. (2011) *Rehabilitation Research and Training Center on Aging with Developmental Disabilities*, Clearinghouse on Aging and Developmental Disabilities, Chicago, IL

<sup>6</sup> Braddock, et al. (2015) *The State of the States in Developmental Disabilities* Tenth Edition, The University of Colorado

#### **IV. Maine Developmental Disabilities Council Projects and Initiatives 2019 Highlights**

##### Advocacy

In accordance with its responsibilities under the federal DD Act, Maine Developmental Disabilities Council has provided ongoing information and support to legislators and other public policymakers in the development and review of proposed legislation, rules, and other policies affecting individuals with developmental disabilities and their families. MDDC has provided information and participated in the revision of statutes and rules affecting civil rights, education, healthcare, employment, housing, and other matters of concern to individuals with disabilities, parents, and other family members.

##### Early Intervention

The National Center for Disease Control and Prevention's Act Early program aims to improve early identification of children with autism and other developmental disabilities so children and families can get needed services and support to improve functional outcomes. MDDC's Executive Director is the "Learn the Signs, Act Early" Ambassador to Maine. This project distributes educational materials regarding developmental milestones to childcare workers and healthcare professionals so that young children with DD can be identified early and access appropriate services. Training was provided to WIC directors & nutritionists about how to utilize checklists and refer to appropriate services. 75% of offices have received and are satisfied with train the trainer and 50% of offices are referring as indicated through datasheets. This year the program has reached over 16,900 children. MDDC's ED, in the role of LTSAE Ambassador, was named to chair a legislative advisory committee to facilitate planning about the future of early services and was appointed by the legislature to act as chair of the Independent Advisory Review Committee on Maine's Early Childhood Special Education Services.

##### Inclusion Awards

In April of 2019, MDDC celebrated its 4<sup>th</sup> annual Inclusion Awards, an essay and artwork contest that asks Maine students to reflect on the value of inclusion for people with developmental disabilities in our schools and communities. This effort has engaged hundreds of students, as well as many educators, school administrators and parents in thinking deeply about inclusion. Council members, policymakers, and educators have been a part of the development and review process – the contest uses the Maine Learning Results statewide standards in the creation of the rubrics. The Awards ceremony, celebrated in the Hall of Flags at the Maine State House, brought awareness of this contest and the idea of inclusion to many legislators and other members of the public. This year's contest is underway.

##### Outreach and Education

MDDC presented at the Maternal Child Health (MCH) FASD conference to advocate for systemic change in that the system cannot just engage in preventative activities but also set and carry out a plan to assist people born with such issues. Multiple participants engaged in conversation about tasks that can be done to mitigate issues. 265 medical and early childhood professionals were provided information about the effects of FASD and Substance Affected Disorders on the functioning of the people born with the disorders. MDDC provided TA to 2 families of young adults with fetal alcohol spectrum disorder (FASD) Both spoke of the profound effect the condition has had on their loved ones functioning as well as the radiating impact on their families. MDDC supported them in learning to conduct outreach and start a webpage that now has 168 followers and a No-FAS chapter that now has 83 members. FASD conference Nov 2019 was standing room only full of mostly family members, individuals with FASD, and a few case managers. 133 people attended that conference and Maine NO-FAS is planning on sponsoring another.

MDDC exhibited at the Maine American Academy of Pediatrics conference to promote early intervention. 135 medical professionals, mostly pediatricians, were educated about early identification, health disparities of people with DD, and transition.

MDDC was asked to provide a presentation at Maine Children's Alliance on the multi-layer system of healthcare & services. 40 individuals attended the "Deeper Dive in Healthcare Gaps for Children w/ DD in Maine.", 10 of whom were family members of children with developmental disabilities, 5 were self-advocates, and the remainder were service providers or state agency staff.

In response to the FY18 event addressing sexual abuse, MDDC supported the development of "a comprehensive healthy relationship & sexuality curriculum as well as leadership development program, designed to increase the capacity of individuals w/ IDD in the development of healthy relationships." The grantee was a trained sexuality educator who felt that material she presented was not being well integrated due to challenges in relationships. Over the course of the grant period 20 individuals participated in workshops. 40 additional individuals were introduced to the material. Challenges included simplifying the content in response to participants' being overloaded with information that does not translate well into day to day experience; individuals may not have a sense of influence on or responsibility for their own lives or be able to articulate an awareness of the tools that would be useful to them in developing their capacity to improve the quality of their relationship to sexuality and healthy relationship practice, and, more broadly, the culture of services may not always be an optimizing environment for folks to find their voices, their choices, their contribution, or their true worth (and worthiness in relationship).

### Transition to Adulthood

*Health Care:* MDDC partnered with a group of medical, community stakeholders and family organizations to develop sample office policies around adolescent transitions, electronic medical record templates, and resource lists for families. The transition change package was completed and included; Resources, Key Driver Diagram and Measures for Success, Sample Clinic Policy on Adolescent Transition to Adult Care, Transition Information for Staff and Providers and Office Checklist, Adolescent Transition Patient Visit Checklists, Sample Adolescent Confidentiality Clinic Policy, Sample Workflows to Implement Adolescent Transition Checklist, Transitioning to Adulthood Timeline for Teens and their Families, Resources for Families and Youth in Maine with Special Healthcare Needs, and Supported Decision-Making Information Resources. While MDDC is confident that the numbers of adoptees will increase, as of the end of 2019, 17 practices have adopted policies and implemented the transition change practice. MAAP did bring together a stakeholder group to develop pilots and submitted multiple recommendations. In addition, MDDC funded the development of 3 webinars to increase understanding and capacity for care coordination. 47 professionals have taken the training thus far.

*Post-Secondary Education:* MDDC supported the Step-Up Program, a collaborative project of Vocational Rehabilitation (DVR); and the UMaine Center for Community Inclusion and Disability Studies, the College of Education and Human Development, and Student Accessibility Services and MDDC. It was developed to provide a multi-week residential living and learning experience for high school juniors or seniors with an autism spectrum diagnosis, and who may have an interest in attending a postsecondary education program. While there are certainly students with developmental disabilities, Maine has no programs with capacity to meet the needs of youth with ASDs who require specific supports to succeed in postsecondary education and increase the likelihood of their achieving positive outcomes for adulthood. The first STEP UP program for youth with ASD at the U Maine was successful. 5 students gained experience and skills that will undoubtedly facilitate their transition to post-secondary education. The program was structured to provide supports that have been shown to associated with of positive post-secondary outcomes. This included providing students with paid work experiences, participation by the

students in a college class, support for building student self-determination and self-advocacy skills, and participation in an evidence-based social skills program. In addition, the students were able to experience campus living and learn about a variety of programs at UMaine. Students rated the educational seminars highly. They left the program with knowledge about what they needed to do in order to successfully transition to post-secondary education and with the tools they need to continue planning for a successful transition to post-secondary education. Data collected on the social skills program indicated that students learned a number of important social skills as a result of their participation.

#### Reducing Restraint and Seclusion

MDDC supported the Coalition Against Restraint & Seclusion (CARS) a workgroup consisting of family members, self-advocates, & other advocates. It screened "The Kids We Lose", a documentary about the effects of R&S on children, providing an opportunity to be educated about the issue's relation to multiple pieces of legislation. CARS also assisted in the drafting of a bill to ensure that reliable information is tracked regarding the use of restraint and seclusion in schools.

MDDC planned a pilot in which a service provider who runs both a special purpose program and residential programs will engage in a quality improvement and fidelity assessment process study to determine whether Therapeutic Crisis Intervention (TCI), reduces restraints, seclusion, and isolation when staff receives increased training and technical assistance in the program. Data measures will also be used to examine the effects of increased support on staff injury, worker's compensation claims, staff turnover, and staff job satisfaction. During the planning phase a provider was found, Cornell University engaged as technical assistance to the provider, and the University of Maine at Orono, Center of Community & Disabilities Studies (Maine's AUCD) was contracted as evaluator.

#### Supported Decision Making

Mainers receiving developmental disabilities experience guardianship at nearly double the rate of their peers in the US. Supported decision-making (SDM) is a strategy by which an individual with a disability works with a trusted network of supporters to make choices about his or her own life. It can be used instead of or in conjunction with substituted decision making. In 2019, MDDC funded a pilot to develop and implement a SDM curriculum aimed at decreasing the likelihood that families will pursue guardianship of their children as they transition to adulthood. 21 parents and 13 youth participated in separate workshops and were introduced to what supported decision-making is and how it differs from guardianship, what it means to be the decider, how to create a supported decision-making team, how to determine what decisions you would like assistance with and what that assistance can look like.

Evaluations indicated that families had a much better understanding of what SDM and how it works although they continued to be unsure of the direction they will take regarding guardianship. In addition, an abbreviated version of the workshop was delivered to at a Lewiston High School family night, Family Voices National Conference, the Annual Conference for the National Symposium on Supported Decision-Making, the MACSP conference on Supported Decision-Making, the Autism Society of Maine summer family retreat, and at the Barbara Bush Grand Rounds with 195 individuals and over 100 providers informed about supported decision making.

MDDC also supported the development of a handbook about supported decision making for Maine families: <http://supportmydecision.org/assets/tools/DRM-SDM-Handbook-Rev.-01.09.19.pdf> and supports outreach and self-advocate training regarding civil rights and guardianship through its contract with Maine's statewide self-advocacy organization.

#### Supporting Self Advocacy

Speaking Up for Us (SUFU) is Maine's self-advocacy organization run by and for people with I/DD. Created in 1993 to help ensure that individuals living with I/DD in Maine are equal, thriving members of

their communities. SUFU's mission is to create new opportunities for adults living with I/DD to discover their abilities, exercise freedom and contribute to their communities. In FY19, MDCC provided funding and TA for self-advocates to develop leadership and advocacy skills, to increase understanding of and participation in policymaking and expanding awareness of and membership in self-advocacy, including youth and underserved populations. In FY18 SUFU experienced and addressed management issues that significantly impacted its activities. Additional issues unfolded during the ensuing months. Of greatest significance in terms of was the discontinuation of funding as the state moved from a direct grant to an RFP process. For 26 years, SUFU had direct funding from the state. The commitment had been longstanding and presumably relevant to past consent decrees. Losing state funding would be devastating to self-advocacy and could silence this community who already struggles for their voices to be heard. One longtime member stated that "SUFU has helped me to learn to be more assertive and to speak up for my rights and needs. It has taught me to talk to the people around me in a more, gentle manner so that I don't come across as being rude. I'm also learning patience. SUFU gives me an incentive to being more motivated." Another reported "life without SUFU would lead to our inner voices being quieted and a step in the direction of stopping self-advocacy altogether." They lamented that loss of funding would mean consideration of every option, up to and including dissolution. "Without secure funding, we will not be able to continue to get our voices involved in the conversations about services. Self-advocates work hard to be leaders of their own lives and in their communities." Challenges to the sustainability of the organization will continue into the foreseeable future.

During the course of the year, 10 self-advocates completed Leadership Development training. 7 subsequently took on leadership positions within the organization, as board members or chapter reps and were able to utilize leadership skills in action for the first time. Self-advocates demonstrated increased leadership through changes in their approach to fundraising. Participation had largely been limited to the chapter level and focused on directly benefitting participants. This year, the Board has needed to utilize unrestricted funds to pay organizational debt related to management issues. This required education regarding fiduciary responsibilities, which resulted in a desire to support SUFU itself. 2 fundraisers took place: both ideas came from leaders. 7 self-advocates took on new leadership roles in their communities to provide direct, tangible support for SUFU. 13 self-advocates are now involved with advisory boards including but not limited to the HCBS settings stakeholders, DRM Partners for Positive Change, SABE, the Coalition, and 3 who have become Council members. 79 self-advocates were provided information and resources as they prepared to vote. Several indicated that they were better prepared for the election. One self-advocate called candidates for the Legislature and Congress and asked those who responded what they thought about people living in the community or in institutions. Responses were mixed and the feedback was that many legislators are not aware of SUFU. SUFU hosted Advocacy Day in April. 47 self-advocates learned about state level policymaking and the 22 who had reached out beforehand met and directly advocated with their legislator. Since 2007, more than 600 self-advocates, parents, and provider agency staff have participated in this program. The event received media coverage <https://www.foxbangor.com/news/item/47622-speaking-up-for-us-standing-up-for-developmentally-disabled-at-state-house/> Over 70 persons with DD received education about state or federal policymaking. 24 participated in direct advocacy by testifying in person, in writing or by phone calls, or by meeting with policymakers. SUFU undertook additional education with a 31 executive and legislative policymakers about their needs and concerns, and in support of state funding for self-advocacy.

## ***Appendix A –MDDC Five-Year State Plan ✦ 2017-2021 ✦ Goals and Objectives***

October 1, 2016 marked the beginning of the implementation of MDDC's new 5 year State Plan. In 2015, MDDC undertook a comprehensive review of the status of Maine residents impacted by developmental disabilities. MDDC examined the issues identified throughout the planning process in light of state and federal policy, and the availability of resources available to address concerns that were raised. Goals were developed in several drafts to provide opportunity for and respond to public and stakeholder input, including that from persons from culturally and linguistically diverse backgrounds. Goals and objectives were informed by the mission and values of the Council through member participation, with special emphasis paid to ensuring full participation of those self-advocate and parent members less familiar with planning processes. MDDC recognizes that this Plan will not exist in a vacuum, but will be re-evaluated on an ongoing basis to assure that the Council can adjust its targets and activities as necessary to accommodate changes in the implementation environment.

### **GOAL # 1**

**MDDC will engage in advocacy, capacity building, and systems change activities that support individuals with developmental disabilities, families, and communities to have increased choices, opportunities, and self-determination.**

*Objective 1.1:* MDDC will collaborate with DD Network Partners to increase the civic engagement of individuals with developmental disabilities and family members.

*Objective 1.2:* MDDC will support diverse Maine communities to increase capacity to be fully inclusive of individuals with developmental disabilities.

*Objective 1.3:* MDDC will support the statewide self-advocacy organization to increase its effectiveness as an independent not-for-profit.

*Objective 1.4:* MDDC will partner with individuals with developmental disabilities, families, and communities to broaden the reach and increase the effectiveness of advocacy.

### **GOAL # 2**

**MDDC will engage in advocacy, capacity building, and systems change activities that support individuals with developmental disabilities and families to have greater access to their communities.**

*Objective 2.1:* MDDC will improve integration of services and supports for individuals with developmental disabilities and families.

*Objective 2.2:* MDDC will support efforts to improve quality of services and supports for individuals with developmental disabilities and families.

*Objective 2.3:* MDDC will support efforts to expand access to all aspects of community life for individuals with developmental disabilities and families.

*Objective 2.4:* MDDC will increase access to information and services for underserved persons and families with developmental disabilities.

