



**Maine Developmental
Disabilities Council**

Annual Report

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State of Maine, 1st 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)).

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Like most organizations, MDDC's activities continues to be significantly altered due to the pandemic. Timelines, roles, and plans were altered. As the medical and scientific community learned more about the virus, data became apparent that people with developmental disabilities are at higher risk both at an individual level, due to increased personal risk, and collectively, due to the way services are delivered. It also became evident that individuals and families impacted by developmental disabilities, especially those who do not receive residential services, continued challenged to access information and supports.

We appreciate the leadership of Governor Janet Mills and the Maine CDC. Their data driven response has allowed Maine, even as we are now experiencing high infection rates, to remain among the states least impacted by and most protected from the virus. This has protected the health of individuals and families impacted by developmental disability.

We thank our members and staff for their flexibility and commitment during this difficult time.

Finally, we wish the 130th Legislature our best wishes as it undertakes a difficult job in a very different way.

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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 1.58%.

Approximately 21,000 Mainers of all ages have developmental disabilities.

The overall prevalence of disability among all people in the United States is 12.6%¹; among people in Maine it is 16.3%² Approximately 217,000 Mainers report having a disability

¹ <https://www.disabilitystatistics.org/reports/acs.cfm?statistic=1>

² <https://www.disabilitystatistics.org/reports/acs.cfm?statistic=1>

III. Concerns of Maine Families Affected by Developmental Disability

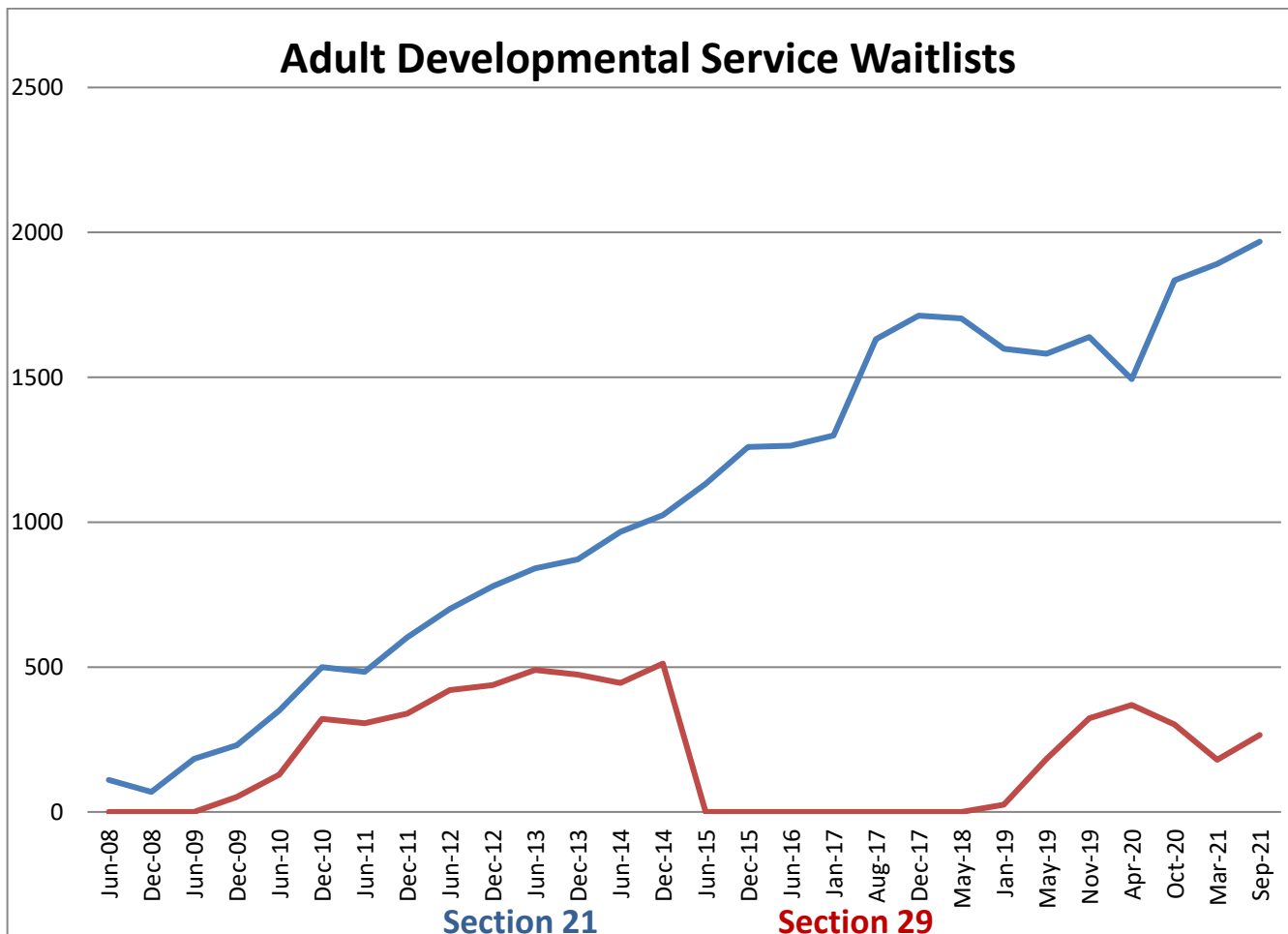
Access to Services and Supports

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 the state’s addressing the waitlists for waiver services. However, there continues to be a significant, growing, need for services. MDDC also notes the challenges encountered by eligible persons in actually accessing those services, particularly people with challenging behaviors. Waitlist data was obtained by the Office of Aging and Disability Services and its predecessors.



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 (de facto) 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 6000 individuals, there are thousands more Mainers who meet the federal criteria of having a developmental disability. Some receive appropriate services through another section of Maine Care 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.

Poverty³ **32.4% of working-age Mainers with disabilities live at or below the federal poverty level (compared to 7.7% for people without disabilities).**

Unemployment

Historically, the unemployment rate⁴ of people with disabilities is double that of the general unemployment rate. While numbers specific to people with developmental disabilities are not available, relevant data such as the National Core Indicators⁵ suggest that the numbers for people with developmental disabilities are considerably worse, with only 30% of people employed. 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.

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 2030.⁶ **In Maine it is estimated that approximately 4,230 persons with developmental disabilities are living at home with caregivers over the age of 60.**⁷

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.

³ <https://www.disabilitystatistics.org/reports/acs.cfm?statistic=7>

⁴ www.maine.gov/labor/cwri/disabilities/index.html

⁵ https://www.nationalcoreindicators.org/upload/core-indicators/ME_IPS_state_508.pdf

⁶ Heller, Tamar Ph.D. (2011) Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Clearinghouse on Aging and Developmental Disabilities, Chicago, IL

⁷ 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 2021 Highlights

Response to COVID-19

MDDC continued efforts to identify information gaps and support experienced by people with developmental disabilities and families and advocacy to ameliorate those gaps. MDDC produced educational materials for individuals with DD and collaborated to produce these PSAs about vaccination: https://youtu.be/6O_bB4sO8_8; <https://youtu.be/e0afiUvaABk>; <https://youtu.be/aht4QEx99Xw> Please see the home page of our website for survey analysis, plain language vaccine information and other materials related to the pandemic response. <https://www.maineddc.org/>

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.

Documenting our History/Telling Our Stories

The history of the treatment of people with developmental disabilities, both in Maine and elsewhere, is a story of stigmatization, isolation, and abuse – but within that tragic history live stories of perseverance, joy, and progress towards something better. In 1908, the Maine School for the Feeble-Minded opened in New Gloucester. Over the years, its name changed several times, and eventually became known as Pineland Center, but the idea behind its creation remained: that the proper place for people with developmental disabilities was in an institution, shut away from the rest of society. When the rampant abuses and neglect in Pineland and elsewhere were exposed in the middle of the 20th century, a movement for disability rights was born. Self-advocates and their allies fought to close Pineland (which finally happened in 1996) and create a system of services that would serve people with developmental disabilities in their homes and communities.

To mark the 25th anniversary of the closure of Pineland that took place in 2021, MDDC has created this online exhibit to document the history of the system’s response to people with developmental disabilities in Maine. Please visit <https://shadowsofpineland.org/>

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. MDDC’s Executive Director chaired the Independent Advisory Review Committee on Maine’s Early Childhood Special Education Services.

Health

People with developmental disabilities experience a variety of health disparities including but not limited to being more likely to report being in poor health, having shorter average life expectancy than the general population, being less likely to receive preventative care, having higher rates of undiagnosed hearing and vision impairments, higher rates of/poorly managed chronic health conditions, and being prescribed higher rates of psychotropic medication. There are a variety of contributing factors, including societal/attitudinal barriers (stigma), barriers due to disability related conditions and/or functional limitations related to his/her disability, and other barriers.

MDDC is working with Maine Primary Care Association to address these issues through a multipronged approach, including increasing understanding of adverse occurrences experienced by individuals with DD, planning and implementing a response to address adverse occurrences, increasing clinical capacity to address the needs of individuals with DD through evidence-based practices (project ECHO), and modifying typical clinical processes/practices to address specific needs of individuals with DD through evidence-based practices (project ECHO). This work is currently underway.

Reducing Restraint and Seclusion

MDDC supported the Coalition Against Restraint & Seclusion (CARS), a workgroup consisting of family members, self-advocates, & other advocates, and funded a pilot project, in which a service provider who runs both a special purpose program and residential programs engages in a quality improvement and fidelity assessment process study to determine whether restraint, seclusion, and isolation can be reduced 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. The pilot was completed and MDDC will be receiving the results in early 2022.

Efforts to impact the use of these practices on children led to concerns about the use of restraint on adults with DD. The Coalition Against Adult Restraint was formed and has continued identifying information needs and begun to review available data.

Self-Direction

CMS says: "Self-directed Medicaid services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process." Maine is one of a handful of states that do not have an option for self-directed services for people with developmental disabilities. MDDC contracted with Applied Self Direction to provide technical assistance and have worked with a coalition of advocates, service providers, and state agency representatives to create a plan forward towards a system that allows people with developmental disabilities more say and flexibility in their services. Last year, MDDC completed stakeholder recommendations for OADS; this year, we have provided technical and stakeholder support as OADS has developed and submitted policy for the introduction of this important service in Maine.

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 2021, MDCC supported a pilot to educate youth with disabilities and their families about supported decision making so that they would be better equipped to make the right decision about guardianship as youth transition to adulthood. Parents and 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 and had a much better understanding of what supported decision making is and how it works.

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. MDCC provided funding and technical assistance 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 2021 SUFU, like many organizations, SUFU continued operations on a virtual platform, overcoming very significant barriers including members limited access to and challenges in/lack of support using technology.

Appendix A –MDDC Five-Year State Plan ★ 2017-2021 ★ Goals and Objectives

The following 2017-21 goals and objectives reflects the bult of the work done in 2021.

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.

October 1, 2021 marked the beginning of MDDC’s new 5 year State Plan.

GOAL # 1 People with developmental disabilities, families, and communities will have increased opportunities for choice, self-determination, and community membership.

- *Objective 1.1:* MDDC will promote the civil rights of individuals with developmental disabilities.
- *Objective 1.2:* Support Maine’s self-advocacy organization and promote development of diverse leaders among people with developmental disabilities and families.

GOAL # 2 Improve systems of support for people with developmental disabilities and families.

- *Objective 2.1:* Decrease health and educational disparities experienced by people with developmental disabilities.
- *Objective 2.2:* Improve access, quality, and integration of services and supports for individuals with developmental disabilities and families.
- *Objective 2.3:* Support efforts to expand access to information and services for underserved individuals with developmental disabilities and families.