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**Maine Developmental
Disabilities Council**

Annual Report

**Submitted to the 128th Legislature
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)). 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 effect 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 Compendium¹ (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.

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

III. Concerns of Maine Families Affected by Developmental Disability

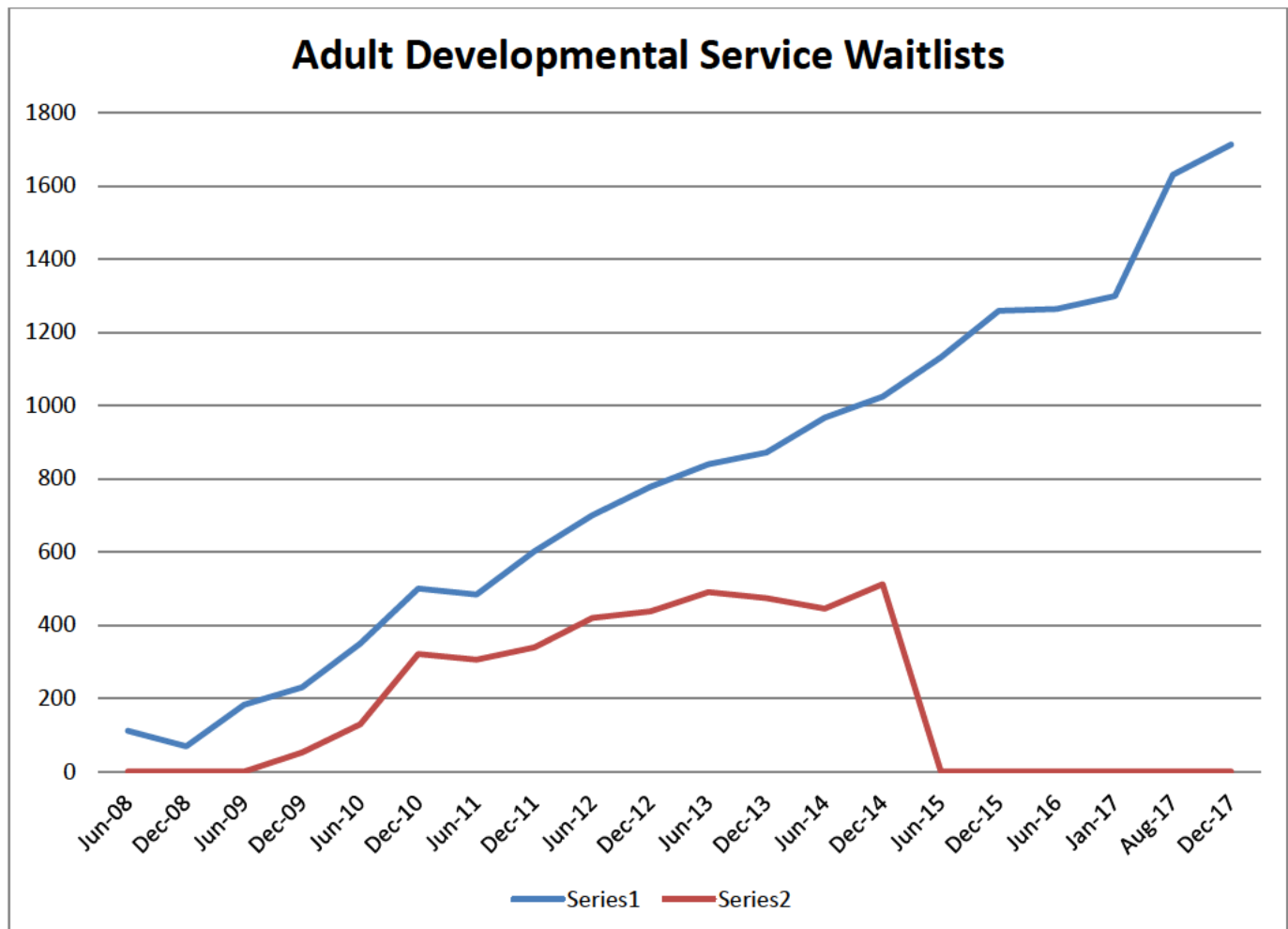
Access to Services and Supports

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 waitlist for Section 29. While there is no longer a Priority One waitlist for Section 21, there continues to be a significant unmet need for services.



Children's Services and Special Education

Maine has a fairly robust array of services and supports available to children with developmental disabilities. Challenges are noted in the areas of:

Obtaining needed services: At times, families do not receive needed services because qualified providers are not available. This is noteworthy in accessing 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 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. 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 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.

Poverty²

29.9% of working-age Mainers with disabilities live at or below the federal poverty level (compared to 9% for people without disabilities).

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

Unemployment

According to U.S. Department of Labor statistics³, 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 rate⁴ 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 2030.⁵ **In Maine it is estimated that approximately 4,230 persons with developmental disabilities are living at home with caregivers over the age of 60.**⁶

Dental Care

Limited or lack of access to preventative and restorative dental care is a barrier to the health of people with developmental disabilities who are not institutionalized. Lack of access is 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.

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

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

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

⁶ 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 2016

Act Early Campaign

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. The 2017 campaign delivered materials and information directly to several hundred early childhood professionals and parents through meetings, conferences, and other events and reached several hundred additional members of the public indirectly, through social media and exposure to educational materials.

Advocacy and Education for Public Policymakers

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.

Disability Advocacy Day provides an opportunity for individuals with developmental disabilities, family members, and other interested parties to become familiar with the legislative process and to take an active role in communicating their concerns to their elected officials in the Legislature. MDDC provides advocacy training and makes arrangements for participants to meet with their senators and representatives personally at the State House and in their local communities. Individual participants in turn become mentors for others who wish to speak up for themselves about current issues affecting individuals with disabilities and organize ongoing connections with policymakers. Since 2007, more than 550 self-advocates, parents, and provider agency staff have participated in this program.

Autism Awareness

New Mainers Public Health Initiative, a grass roots organization that is actively working to improve individual and community health in the Lewiston and Auburn community, serves a diverse population of "new Mainers" that includes men, women and children from Somalia, Ethiopia, Yemen, Sierra Leone, South Sudan, Sudan, Burundi, Rwanda, Iraq, Syria, Chad, Darfur, Uganda, Angola, and Tunisia and other countries. New Mainers observed that many of its constituency lacked awareness and understanding of and experienced stigma related to developmental disability. New Mainers felt that increasing awareness of autism was important to the health of the entire community, as misunderstanding can impact public health behaviors such as vaccination compliance.

New Mainers created accurate, culturally and linguistically appropriate outreach and training materials, including educational videos in which members of the community participated <https://vimeo.com/195655710> and presented educational materials to over 90 people. Evaluating effectiveness of efforts using standard tools was challenging not just because of limited literacy but "Because talking about a word that does not exist in the Somali language was extremely hard. Nonetheless, the actions, behaviors, and developmental problems that were visual things made the topic much easier to tackle and to discuss. At the end of the workshop the participants could relate on behaviors and developmental problem that they see in their child". Participants engaged with

presenters, come forward with questions, and referred family members and friends to additional workshops.

Care Coordination for Children with Developmental Disabilities

The medical home care coordination project began enrolling children in June 2012 and continued through 2017. The goal of the project is to evaluate the effectiveness of coordination of services for children with developmental disabilities, identify barriers to effective intervention, and generate possible solutions. The care coordinator contacts the family by phone within 24 hours of the receipt of a referral from the pediatrician to enroll the child in the pilot and begin the care coordination process. The care coordinator then continues to interact with the family over time.

In 2017, 206 children had developmental screenings reviewed or enhanced care coordination as a result of the project. Most of the children benefited from accessing needed services and/or needed intensity of health care services. The care coordinator also advocated, when appropriate, for children to receive more effective services through the educational model. Other work included reducing duplication of services, providing consultation to community case managers, and doing research for the pediatricians.

The medical practice attempted to pilot a transition to adult healthcare program. Twelve (12) youth were enrolled. Significant challenges occurred including finding adult practitioners who believed that they were competent to take the youth into adult care. Two of the most common concerns of adult medical providers were being unfamiliar with the type of developmental disability or unfamiliar with the medications that the youth was prescribed. Perhaps the most surprising barrier found was by pediatricians. There was resistance to acknowledge that transitioning to adult practices was really a problem. Most of the pediatricians believed that the family was responsible for finding the adult practitioner and didn't realize that many were unable to do so and, as a result, the young adult either went without medical care or had high usage of emergency room visits.

DD Health Project

Healthcare for adults with developmental disabilities was included in the recently completed State Improvement of Medicaid System (SIMS) project. SIMS contracted with MDDC to develop and deliver a curriculum for case managers, direct support professionals, and healthcare providers targeting information regarding how behaviors change in response to pain, how to interact with the healthcare system, and understanding the multitude of systems and strategies for effective medical care coordination; to embed information regarding health and individuals with DD to medical professionals into the existing learning collaborative, and to develop evaluation plans for each of the tasks.

In 2017, 240 healthcare providers, case managers, direct support professionals, guardians, family members, and support staff received training addressing one of several topics, including: "Improving Care and Communication for People with Intellectual and Developmental Disabilities", focusing on pain-related behavioral changes; "Dual Diagnosis", focusing on the persons with DD who also experience mental illness; "Alternatives to Pain Medication"; "Diabetes and the Person with a Developmental Disability".

The DD Health Project also developed an online resource manual for providers of health care, families, care givers, and case managers. It can be found at <https://www.maineddc.org/index.php/for-caregivers> Finally, an ER Checklist was developed to provide attending ER personnel with accessible, relevant histories.

Developmental Screening Initiative

MDDC supports Maine efforts to ensure that all infants and toddlers receive timely developmental screenings according to the American Academy of Pediatrics (AAP) Periodicity Schedule.

<https://www.mainequalitycounts.org/page/896-1097/improving-childrens-health>

In 2017, efforts focused on investigating the Help Me Grow Model for Maine, focusing on enhancing access to developmental, education and family support services for children ages 0-8. This investigation was primarily guided by the findings from the Developmental Screening Integration Initiative, which illustrated varying practices, philosophies and “intensities” of care coordination across sectors which could, untowardly, interrupt or fragment the referral and information-sharing process.

Four workgroups spent several months studying and applying the HMG principles to Maine’s early care and community-based services system. This cross-sector work involved additional stakeholders in four inquiry groups: Child Health Care Provider Outreach, Community & Family Engagement Outreach, Centralized Access Point and Data Collection & Analysis.

Maine became an affiliate state with Help Me Grow Model (HMG), formalizing a partnership with Maine 2-1-1 to further investigate the integration of the HMG model through the establishment of HMG Resource Specialists, expansion of 2-1-1 to include significantly more early child and education statewide resources, and discussions of marketing and ways in which the 2-1-1 information would be kept “current” and expanded over time.

The DSI noted variations in practice across Maine’s various early care and education coordination systems and the need to embed high quality standards of practice into policies and procedures, training and performance measures at both the State and local program/agency levels – across sectors and populations served. Having a consistent, cross-sector framework for coordination practice would help to reduce the opportunities for duplication, at a minimum. At a maximum, this framework would enhance quality and promote increased opportunities to strengthen client strengths and self-advocacy. The DSI recommends that in order to HMG to function effectively, a more expansive approach to coordination as a system’s issue given its importance in supporting clients, some throughout the lifespan. The DSI discussed the significant opportunity that appears to present itself now to bring partners together who provide service coordination and engage them in the development of shared, common modules that would be accessible by all entities to serve as a foundation for service coordination training. Individual agencies or programs would augment this foundation with topical-specific modules unique to their entity. This approach to collaboration and communication has helped to articulate a series of existing supports and structures at both levels that should be marshalled in any continued development towards HMG implementation and expanding the statewide development screening activities.

Employment

Participation in integrated community employment is strongly correlated with positive outcomes: being a homeowner, having strong social supports, being engaged in community life, and utilizing fewer paid supports. Significant progress has been made in the clinical understanding of the technical aspects of accessing and maintaining integrated community based employment for individuals with disabilities. Despite this progress, **employment rates of individuals with developmental disabilities continue to be very low** and systems of support have not systemically institutionalized this understanding.

In 2017, MDDC funded two projects to test novel approaches to supporting individuals with developmental disabilities in obtaining and retaining competitive employment.

MDDC funded a replication of the successful Summer Work for ME Project, designed to provide youth with developmental disabilities with a range of work experiences to increase their understanding of work as a first step in identifying possible careers and provide instruction and practice in identifying strengths and interests, setting goals, and identifying the steps necessary to achieve those goals. These strategies promote self-determination, independence, productivity and integration into community living. The project involved collaboration of multiple organizations including Maine's UCEDD CCIDS, Community Rehabilitation Provider KFI, the Maine Bureau of Rehabilitation Services, and Bangor area school districts. Total time in the project each week for the students was approximately 19 hours. This schedule provided "instruction with practice" which current research indicates is good practice.

Feedback from both students and parents was very positive with all students reporting increased knowledge and understanding about work. Comments included "We are learning a lot in the process of operating the project." "Positive piece has been good communication among collaborating partners throughout." During its second year there was a wider variety of work sites available and funding was contributed through VR. Subsequent to the project one participant is attending community college, one is seeking employment (working with VR) and four (4) are currently finishing their 4th or 5th year of high school.

MDDC also funded a project to explore an approach to employment directly utilizing the self-advocacy organization and community resources (an employment agency) for people who had not been successfully employed through the service system. This project was unfortunately unsuccessful, with significant barriers encountered that could not be resolved within available resources.

National Core Indicators (NCI)

NCI is a national, voluntary effort by public developmental disabilities agencies to measure and track their own performance. This effort supports the development of standardized quality measures in adult developmental services. The Maine Department of Health and Human Services contracted with MDDC to conduct in-person interviews with 400 adults with developmental disabilities throughout Maine.

The interviews address individuals' experiences with the services that they receive, measure person-centered outcomes, and assess system-level indicators related to employment, choice, relationships, case management, inclusion, and health. Qualitative feedback from the interviewers suggested that those who work in integrated settings and live more independently seem happier and that many participants seemed to have limited awareness about the availability of choices in services and supports. The Human Services Research Institute's (HSRI) report of the results from the Maine interviews can be found at <http://www.nationalcoreindicators.org/states/ME/>

Raising Expectations

In 2017, MDDC sponsored a writing contest for high school juniors and seniors that asked students to develop essays in response to the question "How does the full inclusion of individuals with developmental disabilities in all aspects of community life benefit the community and its members?" This was a large-scale effort which engaged many Council members, educators, policymakers and other interested parties in the development and review of the contest. Entries were received from high school students from across the state. Each essay was reviewed by three (3) independent evaluators and measured with a standardized rubric. The winners of the essay received their awards at a ceremony in Maine's State House in the Hall of Flags. Well over 40 legislators and 50 additional members of the public were exposed to the idea of inclusion.

Small Grants Program

The Small Grants Program provides funding to support individual or community activities and/or short-term research, demonstration, or other projects that help realize the goals and objectives of MDDC's Five-Year State Plan and demonstrate the potential to positively impact the lives of individuals with developmental disabilities and their families by increasing opportunities to be contributing members of their communities, fostering new and different ways to address barriers or challenges facing people with developmental disabilities, improving quality of services, and/or improving quality of life. Small Grants supported the following initiatives:

- MDDC co-sponsored the Maine Resilience Building Network to implement the "Reaching Teens" toolkit, evidence informed communication strategies for improving health outcomes for teens of all abilities. This project was important because it looked at how care providers learn, plan and implement change in a dynamic and challenging employment environment.
<http://maineaces.org/wp/>
- Dissemination of a "toolkit" for choosing a community service provider for the community supports waiver which is the service most available to families.
(<http://www.maineddc.org/section-29-toolkit/>) An accompanying video was created by Maine's statewide self-advocacy organization <https://www.youtube.com/watch?v=AEhWIYSMLR8&t=13s>

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 make choices about his or her own life. It can be used instead of or in conjunction with substituted decision making.

In 2017, MDDC helped to support the evaluation of a pilot that developed and executed a curriculum aimed at increasing individual's and families' capacity for decision making so that they could consider terminating guardianships.

MDDC also supports outreach and self-advocate training regarding civil rights and guardianship through its contract with Maine's statewide self-advocacy organization. In 2017, over 85 adults with developmental disabilities learned about decision making and civil rights. Participants have expressed increased understanding of their rights and options in day-to-day activities and many have expressed a desire for more independence in making decisions and respect for their decisions. Few participants have initiated formal changes in making decisions.

Supporting Self Advocacy

Through an ongoing contract and collaboration with Maine's statewide self-advocacy organization, Speaking Up for Us (SUFU), MDDC provides resources and technical assistance to support individuals with developmental disabilities to have real, self-determined lives in the community.

In 2017, over 200 individuals with developmental disabilities participated in education about self-determination, accomplished through a wide array of activities including educating the public about community inclusion, encouraging and providing support to individuals with developmental disabilities to actively seek competitive employment, educating individuals with developmental disabilities on ways to be a valued part of their community, working with providers to support individuals with developmental disabilities to be in the community with the least amount of support necessary, and engaging in systems advocacy through leadership and policy making roles at the state level.

11 persons with developmental disabilities participated in the leadership development program and an additional 15 received additional leadership training. Many people with developmental disabilities not only lack opportunities for self-determination, they also lack practice with decision making skills. Chapters have developed and participated in targeted leadership training that (so far) has led to more autonomy of those chapters (less reliance upon paid staff). Plans are being developed with Lift 360 to replicate the leadership program with other states.

SUFU has continued to focus on “giving back” to its communities. Chapters were asked to go out and complete one community project. Projects support members in undertaking valued roles of leader and volunteer. Projects vary greatly (as the communities do) and are undertaken in partnership with other organizations and people. Some examples have been helping with a surfing program, undertaking a successful school supply drive and volunteering with local animal shelters, food drives, and community meals.

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.