



**Maine Developmental
Disabilities Council**

Annual Report

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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 12.6%.

The prevalence of disability (any disability, by self report) among people in Maine is 15.7%.

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

- **7.7% 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.
- **3.3% of Mainers have a Self-Care Disability**
Approximately 43,000 Mainers have difficulty dressing, bathing, or engaging in other forms of self-care.
- **6.9% 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/> accessed 1/4/17

III. Concerns of Maine Families Affected by Developmental Disability

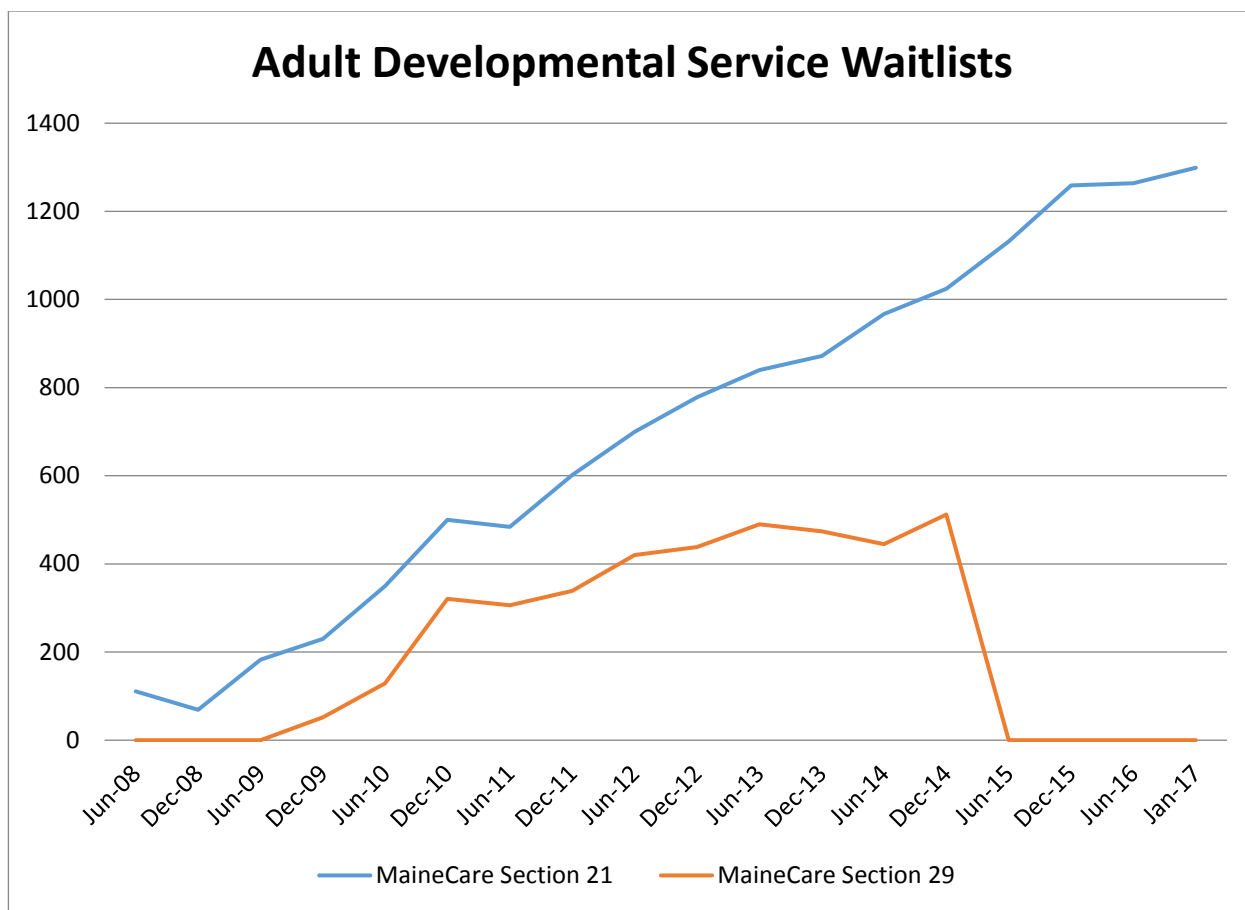
Access to Services and Supports

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 who simply do not qualify for services who 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 the Affordable Care Act, 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

36.8% of working-age persons with disabilities live at or below the federal poverty level (compared to 10.2% for people without disabilities).

² <https://www.disabilitystatistics.org/reports/2014/English/HTML/report2014.cfm?fips=2023000#poverty>

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 20.0%* (versus 68.4% for people without disabilities) and the *unemployment rate for people with disabilities was 10.0%* (versus 4.2% for people without disabilities).

In Maine, the 2014 employment rate⁴ of persons with cognitive disabilities was 21.4%, the employment rate of persons with self-care disabilities was 15.8%, and the employment rate of persons with independent living disabilities was 14.1%.

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. Because adults with developmental disabilities are living longer, families have a longer period of caregiving responsibility.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 1/4/17

⁴ U.S. Census Bureau, 2014 American Community Survey <http://www.disabilitycompendium.org/statistics/earnings> accessed 1/4/17

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. MDCC'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 2016 campaign delivered training, directly reached over 130 professionals, 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. MDCC 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. MDCC 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.

Care Coordination for Children with Developmental Disabilities

The medical home care coordination project began enrolling children in June 2012 and continued through 2016. 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 2016, 189 children had direct positive outcomes as a result of the enhanced care coordination project. 85% of these children were six years of age and younger. 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. In addition, the program reviewed 212 developmental screenings allowing physicians to provide a more comprehensive annual well child check.

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 they 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 has been added to the existing 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 2016, 243 medical providers, 510 case managers, direct support professionals, guardians, family members, and support staff received the training "Improving Care and Communication for People with Intellectual and Developmental Disabilities", focusing on pain-related behavioral changes. As a result of the training, 76% of respondents changed their communication style, 22% made changes to plans of care, 25% initiated pain assessments, and 22.7% have made other changes such as the way they treat behaviors, speak to individual, and look for signs and symptoms of pain.

In addition, an online resource manual for providers of health care, families, care givers, and case managers is being developed; practitioners and educators are collaborating to develop a standard curricula for healthcare providers and ancillary staff regarding the special healthcare needs and best practices in developmental disabilities in areas such as alternatives to pain medications, diabetes, dementia, and dual diagnoses. Finally, an ER Checklist was developed to provide attending ER personnel with accessible, relevant histories.

Care of individuals with DD is improving from the caregiver level on up to the medical practitioner. There has been overwhelming requests to have more education and training done so that medical issues are better understood.

Dementia Services and Supports

Individuals with developmental disabilities are living longer than ever before. While this is good news, there are emerging challenges to families, communities, and the health and human service systems to provide high quality supports to aging individuals with developmental disabilities.

This is particularly true in Maine, "the oldest state" in the country by median age. People with developmental disabilities develop Alzheimer's disease at rates similar to older adults in the general population. However, adults with Down syndrome develop Alzheimer's disease at greater rates and at a younger age. An effective, inclusive, systemic approach to services and supports for adults with developmental disabilities and dementia-related conditions is critical to their full inclusion. In 2015, MDDC funded a small grant to explore and document systems needs to increase access to appropriate and effective services and supports for adults with developmental disabilities and dementia-related conditions. (www.maineddc.org/resources-publications)

In 2016, MDDC funded one external grant with an Aging and Disability Resource Center to conduct outreach, training, and support among professional and informal caregivers to increase awareness of

and capacity to address dementia in persons with developmental disabilities and increase the capacity of ADRC dementia programs to accommodate this population. Project outcomes regarding education and outreach were positive, especially among professional caregivers. Over 450 individuals increased awareness and 111 participated in educational programming. 35 of these completed “train-the trainer” and went on to train an additional 30 individuals thus far.

The project had limited participation by family members. Focus groups to identify caregiving and educational needs were challenged to identify participants, suggesting that there are low numbers in catchment and, more importantly, caregivers are themselves often experiencing issues related to aging that require more intensive intervention. However, it was learned that the case managers and direct support professionals themselves knew little about aging and they were providing care to people with developmental disabilities and dementia-related conditions. Participants stated the most helpful portion was going over the basics of dementia. One family appreciated learning about what was and wasn’t considered normal behavior and shared their gratitude for learning more about how the person they were caring for experienced their surroundings differently, specifically noises in the home, and how to help them find their place in their space. On numerous occasions caregivers have shared how our services reduce their stress and the stress that the person they are caring for experiences.

Day services expanded over the period of the grant to better serve people with developmental disabilities and dementia-related conditions. Starting in one location, the program’s focus has been expanded to all four (4) sites, now meeting the needs of 21 individuals. Staff are better able to handle situations that could easily escalate without a resolution. For example, if a consumer requests to go home, they are able to redirect the attention of the client in order to keep their stress levels down and prevent them from becoming upset. They have also looked at the environment and are constantly assessing how they can improve it, such as ensuring there are clear paths that won’t confuse consumers, reducing glare on surfaces, and increasing contrast on the walls. One of the most beneficial aspects of the training has been around how they approach each consumer. They know not to assume a consumer who is becoming irate or vocal is developing dementia, they know to dig further to determine the cause of the vocalizing and keep in mind that the leading cause is typically a UTI.

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 2016, 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 funded the Independent Living Center to replicate a Danish program, Specialisterne (“The Specialists”), to match individuals on the autism spectrum with employment, especially in high tech and IT companies. The contractor planned to build, deploy, and evaluate an innovative pilot employment and internship program for young Mainers with autism. In addition, contractors planned to recruit businesses and evaluate the human resource needs that may be suited to persons with ASDs, evaluate workplaces, and provide workplace preparation and setting of expectations, transition support for placement, and ongoing support for the workplace including identifying and developing appropriate accommodations. Ultimately, eight (8) individuals received technical assistance and professional development related to employment, including leadership, self-advocacy, and self-determination (related to employment); nine (9) unpaid family members or friends engaged in training and support for employment; seven (7) job sites developed for participants; (6) individuals were placed and supported in jobs; six (6) programs and policies improved; twelve (12) policymakers were educated regarding the employment contributions of individuals with developmental disabilities, and three (3) individuals were active in systems advocacy.

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 2014-15 Maine interviews can be found at <http://www.nationalcoreindicators.org/states/ME/>

Quality Mental Health Services for Individuals with Intellectual Disabilities

Research has indicated that individuals with intellectual and developmental disabilities exhibit rates of psychiatric co-morbidity between 30 and 40 percent (two to three times greater than the general population). This challenges service delivery systems’ ability to plan, develop, operate, and monitor appropriate services and supports. Individuals with dual diagnosis (developmental disability and co-existing psychiatric disorder) present with complex challenges made more complicated by being served in both the developmental disability and mental health service delivery systems. Problems include a lack of trained staff, inadequate access to appropriate clinical assessment and treatment, and limited collaboration in service delivery between the mental health and developmental disabilities systems.

The 2014, project that directly expanded access to mental health services through mentorship, technical support and strategic assistance in the development of a Mental Health Agency (a DD service provider)

in an underserved county continues to benefit the community in that the active mental health program has continued, with additional individuals with I/DD having access to qualified mental health services. In 2015-16, MDDC contracted with an agency to test the effectiveness of national training and certification (through NADD) for direct support professionals and clinicians as a practice tool for staff retention and use of restraint, crisis, police and/or emergency department use in the pilot programs (of at risk individuals). A team of eight (8) was identified to obtain NADD certification. The consulting psychologist received the credential within one year. For participating staff, preparation supervision/groups were facilitated by an LCSW and staff had online access to learning materials. Unfortunately, at the end of the year only two (2) of the original eight (8) were still employed by the agency. The contractor reported: "The barriers are time, money and staff retention. DSP training is important but capacity for ongoing supervision is even more critical. Some of our DSP staff in the NADD track have struggled with integrating the material. In supervision they agree and understand but on a Friday night when a client is struggling using some of the interventions is challenging. It is the time to go back and review these situations that allows for the integrated practice."

Raising Expectations

In 2016, MDDC sponsored a writing contest for high school juniors and seniors that asked students to develop essays in response to the questions: "How has the Americans with Disabilities Act not yet been fully realized for people with Developmental Disabilities? If the ADA was fully implemented, how might the world look differently for people with Developmental Disabilities?" 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. Over 80 entries were received from high school students. 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. The top 14 essays have been published in a book that is included with this report.

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.

In 2016, MDDC funded a small grant that supported the development 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

In 2016, MDDC continued working with the Supported Decision Making Coalition, a partnership of advocacy, provider, and state agencies. The Coalition has developed an educational website and materials and conducted outreach to increase awareness of supported decision making.

MDDC also supports outreach and self-advocate training regarding civil rights and guardianship through its contract with Maine's statewide self-advocacy organization. In 2016, over 125 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 pursued formal changes in making decisions. Changes that have been made have generally been small and slow as people gain skills and confidence. One individual wanted more control of her finances but did not feel ready to independently manage her money. She now has a Rep Payee who is not her mother. Her relationship with her mother is improved and she now has more access to her money and more freedom of choice.

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 2016, 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.

An additional 20 individuals with developmental disabilities received additional leadership training. Outcomes included the realization that many people with developmental disabilities not only lack opportunities for self-determination, they also lack decision making skills. Thus, SUFU leaders "are challenging and attempting to understand what the term advocacy means. We have begun to think of advocacy as more than just "speaking up for yourself" but more of a problem solving process to identify what you want to change in your life, the resources needed for this change and creating the plan to make the necessary change." 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 identified community service as priority. 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 a bake sale for a Lincoln family who lost their home to fire, helping with a surfing program, and repeating a school supply drive.

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.

