



# 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

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 (also funded through the DD Act) the Disability Rights Center and the Center for Community Inclusion and Disability Studies at the University of Maine.

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
- 2 seats designated for local non-governmental agencies/organizations that serve people with developmental disabilities
- 1 seat for the Center for Community Inclusion and Disability Studies
- 1 seat for the Disability Rights Center
- 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 (pending)
  - 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 2013 Disability Compendium<sup>1</sup> (Institute on Disability at the University of New Hampshire):

**The prevalence of disability (any disability, by self report) among all people in the United States is 12.2%.**

**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.

- **6.4% of Mainers have an Intellectual Disability**  
Approximately 93,000 Mainers (*ages 5 or older*) have significant difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition.
- **2.1% of Mainers have a Self-Care Disability**  
Approximately 31,800 Mainers (*ages 5 or older*) have difficulty dressing, bathing, or engaging in other forms of self-care.
- **4.5% of Mainers have an Independent Living Disability**  
Approximately 83,700 Mainers (*ages 18 or older*) have difficulty doing errands such as visiting a doctor's office or shopping alone because of a physical, mental, or emotional condition.

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<sup>1</sup> Institute on Disability at the University of New Hampshire (2013) [2013 Disabilities Compendium](http://www.disabilitycompendium.org/)  
<http://www.disabilitycompendium.org/> accessed January 31, 2014

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

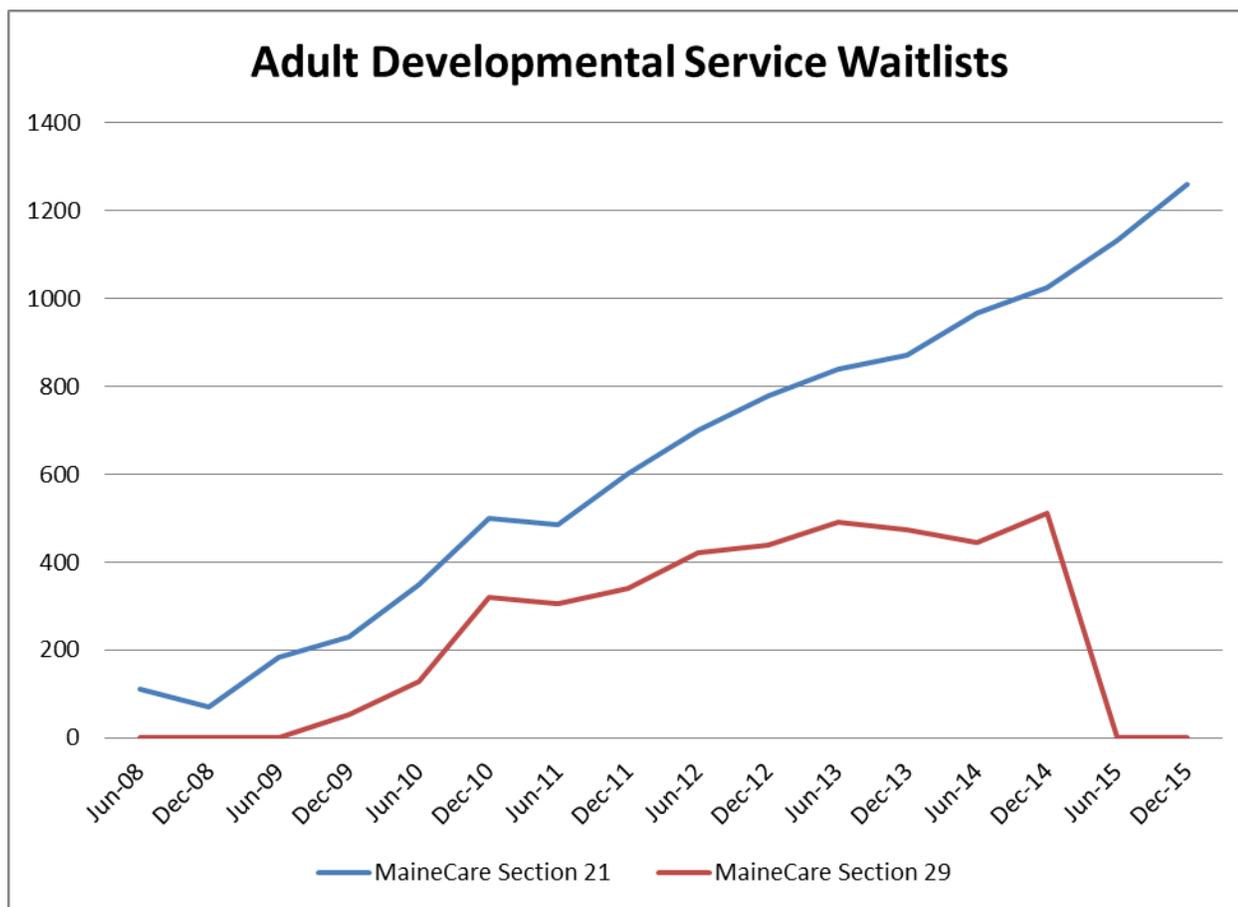
#### ***Access to Services and Supports***

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, overall numbers have continued to increase.



## 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. 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 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.

## Poverty

**32.7% of working-age persons with disabilities live at or below the federal poverty level (compared to 11.6% for people without disabilities).**

## Unemployment

According to U.S. Census Bureau statistics<sup>2</sup>, in 2012, 33.2% of working-age persons with disabilities were employed (compared to 78% percent of persons without disabilities). The employment rate of persons with intellectual disabilities was 22.6%. The employment rate of persons with self-care disabilities was 17.5%. The employment rate of persons with independent living disabilities was 14.1%.

- **Percentage Working Full-time:** 22.6% of persons with disabilities age 21 to 64 years employed full-time (compared to 50.9% of working-age people without disabilities who were working full-time/full-year).
- **Mean Annual Earnings** of working-age people with any disability was \$16,753 in 2012. Mean Annual Earnings of persons without disabilities was \$28,379.

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.<sup>3</sup> **In Maine it is estimated that approximately 4,350 persons with developmental disabilities are living at home with caregivers over the age of 60.**<sup>4</sup>

## 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.

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<sup>2</sup> U.S. Census Bureau, 2011 American Community Survey 1-Year Estimates <http://www.census.gov> accessed January 30, 2014

<sup>3</sup> Heller, Tamar Ph.D. (2011) Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Clearinghouse on Aging and Developmental Disabilities, , Chicago, IL

<sup>4</sup> Braddock, et al. (2011) The State of the States in Developmental Disabilities Second Printing, Revised, The University of Colorado

## **IV. Maine Developmental Disabilities Council Projects and Initiatives 2015**

### *Accessing Healthcare: The Experience of Individuals with ASD in Maine*

Individuals with Autism Spectrum Disorders (ASD) are significantly more likely to have unmet healthcare needs and difficulty accessing healthcare services than those with other disabilities. Minority status, living in a rural location, and low income can exacerbate these disparities. Other obstacles to effective healthcare for individuals with ASD include the following: (1) severity of symptoms associated with ASD; (2) lack of knowledge or skill of medical practitioners; (3) lack of access to comprehensive healthcare supports or a medical home; and (4) lack of access to health insurance for needed supports and services. Individuals with ASD of all ages are likely to have a range of comorbid medical and psychological conditions, making the need for comprehensive healthcare imperative.

MDDC funded a research activity to collect information about the experience of accessing healthcare from 85 parents of children with ASD and 22 adults with ASD or their guardian who live in Maine in comparison to the recommendations for medical best practices for the general population and existing research. A consultant conducted structured in-person interviews to collect information and the Center for Community Inclusion and Disabilities Studies analyzed the method and data collected then reported on the results. Significant findings include an improved earlier mean age of diagnosis of ASD, indicating that systems change efforts conducted to improve early identification of ASD have been successful. The report from this project was distributed to over 360 medical professionals and policy makers. *(Report available on MDDC's website at [www.maineddc.org/resources-publications](http://www.maineddc.org/resources-publications))*

Additional activities included collaboration with a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) fellow to conduct a small focus group of eight families of children with complex health conditions to assess any barriers or gaps of healthcare and presenting to second year medical students at the University of New England where 160 students received information about providing healthcare to individuals with developmental disabilities in a meaningful and respectful way.

### *Act Early Campaign*

The National Center for Disease Control and Prevention's "Learn the Signs, Act Early" program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and support they need. MDDC took the lead in a New England Act Early summit. Nine representatives from medical practices, families, MaineCare, the AUCD, early childhood educators, and Children and Youth with Special Health Care Needs met to renew Maine's state plan for early intervention. In addition to developing a plan, Maine representatives were exposed to other ideas like the HelpMeGrow model. Upon return from the trip, attendees organized a conference in which 125 State professionals engaged in active discussion to adopt HelpMeGrow or similar program.

MDDC staff represented Maine on a national panel to plan for ways to allocate Autism CARES Act of 2014 funding. In addition, the MDDC participated in an effort to train professionals on how to provide multicultural sensitive developmental screenings to children.

### *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 500 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 2015. 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 2015, 106 children had direct positive outcomes from the enhanced care coordination project. 84% of these children were six years of age and younger. Most of the children benefited from accessing needed services and/or needed intensity of services through the medical model. 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 426 developmental screenings allowing physicians to provide a more comprehensive annual well child check. This year the project began hosting groups of youth with autism spectrum disorders to practice skills such as checking in and making appointments at the doctor's office prior to transitioning to adult practitioners. The cost effectiveness and overall value of this project is clearly being demonstrated by virtue of the number of young children accessing services and time being saved by pediatricians. To attempt to generate interest in replicating the enhanced coordination, the medical practice has been presenting at multiple conferences and has reached 370 medical practitioners. For the last year of the project the medical office will be working with the health system to solidify long term funding. In addition, they are adding a focus of improving transition to adult healthcare.

### *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 include information regarding health and individuals with developmental disabilities within the existing learning collaborative managed by Quality Counts; and to develop evaluation plans for each of the tasks. A DD nurse was hired to develop curriculum and provide training and technical assistance to ensure that individuals with developmental disabilities receive appropriate medical care. One focus of the work is to increase appropriate diagnosis of pain and decrease misuse of psychotropic medications that may be prescribed to control behaviors. 301 individuals including healthcare providers (physicians, physician

extenders, nurses, and medical practice managers), developmental disabilities case managers, administrators, and direct support professionals, as well as one congressional staffer, from all regions of the state have received training. The evaluation and sustainability portion of this work is expected to be available in FY16.

In addition to the DD Health Project, MDDC addresses healthcare for individuals with developmental disabilities by collaborating with a Leadership Education in Neurodevelopmental and Related Disabilities (LEND) fellow to conduct a small focus group of eight families of children with complex health conditions to assess any barriers or gaps of healthcare and by presenting to second-year medical students at the University of New England where 160 students received information about providing healthcare to individuals with developmental disabilities in a meaningful and respectful way.

### *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 full inclusion of individuals with developmental disabilities. 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. (*Report available on MDDC’s website at [www.maineddc.org/resources-publications](http://www.maineddc.org/resources-publications)*). The material in this report was presented to over 500 professionals in Maine and nationwide through in-person and conference presentations.

MDDC sponsored a pilot training of the new national model training curriculum developed by the National Task Group on Intellectual Disabilities and Dementia Practices. 41 people from aging and developmental services learned to recognize when changes in functioning in individuals with developmental disabilities may signal the onset of dementia, how dementia impacts an individual’s ability to function, and key triggers of challenging behaviors.

### *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 2015, MDDC funded two projects to test novel approaches to supporting individuals with developmental disabilities in obtaining and retaining competitive employment.

Summer Work for ME provided six Bangor area youth with developmental disabilities with education, support, and paid work experience as a first step in identifying career related interests and skills. The project involved collaboration of multiple organizations including the University of Maine, the Maine Bureau of Rehabilitation Services, Bangor area schools, service providers, and local employers. The project was well received by participants and initial evaluation suggests that the project was successful.

A second project is underway that proposes to replicate a Danish program, Specialisterne (“The Specialists”), to match individuals with Autism Spectrum Disorders (ASD) with employment, especially in high tech and IT companies. Individuals with ASD are unemployed at even higher rates than those with other types of developmental disabilities. Contractors agreed to build, deploy, and evaluate an innovative pilot employment and internship program to address disability-specific barriers specific to social pragmatics. Project outcomes are expected in 2016.

### 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 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.

In FFY14, MDDC funded two projects to test innovative approaches to building capacity to enable adults with developmental disabilities to obtain high-quality behavioral health services and supports. These projects continued to benefit individuals with developmental disabilities in 2015.

24 professionals received education regarding Psychopharmacology for Medical and Behavioral Health Professionals - Focus on Intellectual Disabilities and Autism Spectrum Disorders.

A Clinical Rounds program was expanded to include the agency’s Children’s Services and 16 individuals benefitted from clinical rounds regarding individuals with developmental disabilities and co-occurring physical and mental health issues. Licensed mental health services have reached additional individuals with dual diagnoses.

Finally, MDDC is funding a pilot project to implement a specialty training and certification program developed by the National Association on Dual Diagnosis for direct support professionals and clinicians. This pilot will assess the effectiveness of the program’s use as a practice tool for staff retention to address use of restraint, crisis, and police and/or emergency department programs for at risk individuals.

### *Raising Expectations*

Too often, families, as well as members of the general public, are not encouraged to expect more of a child with a disability's future than moving into a group home and engaging in a day program. MDDC believes that while there is a need for these services, children with developmental disabilities should expect and be expected to grow up to be active, valued members of their community. MDDC completed a public outreach campaign to raise the expectations of and for individuals with developmental disabilities, their families, and the general public by engaging with the Civil Rights Teams at two Maine high schools. Initial focus groups with students at these schools were held to document their perception of individuals with disabilities and opinions about what lives are like for individuals with developmental disabilities after high school. Posters with messages aimed at raising the expectations and perceived value of individuals with developmental disabilities were hung throughout each school. At the end of the school year, a follow-up focus group was held with the students to determine whether the posters had effected a change in attitudes and perceptions. Outcomes were mixed regarding the posters as they were perceived to be an anti-bullying campaign. On the other hand, over 1,000 high school students and faculty were exposed to the pro-inclusion messages.

### *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 2015, this program supported 10 family members of adult individuals with developmental disabilities to increase their engagement in state-level legislative advocacy. Activities were organized by the applicant and education provided by a qualified consultant. The project was enormously successful in term of increasing public awareness and engaging family members of adults receiving developmental services, a group that has limited formal organization.

### *Supported Decision Making*

In 2015, MDDC joined and provided funding for the Supported Decision Making Coalition, a partnership of advocacy, provider, and state agencies. The Coalition is working to examine policy, practices, and resources that address the use of guardianship of Maine residents with developmental disabilities. MDDC also supports outreach and self-advocate training regarding civil rights and guardianship through its contract with Maine's statewide self-advocacy organization.

### *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 2015, **over 200 individuals with developmental disabilities** either received training or achieved greater independence as a result of SUFU's work. This was 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.

This year, SUFU also began supporting its members to take on community service projects that varied with the needs of communities and interests of members, from doing check ins and taking care of surf boards and wet suits at Special Surfer's Night to partnering with a motorcycle club to support Toys for Tots.

**Maine Developmental Disabilities Council**

**Five-Year State Plan ✦ 2011-2016 ✦ Goals and Objectives**

**GOAL # 1: Access to Quality Comprehensive Services and Supports**

**MDDC will support self-advocates, families, and stakeholders in advocacy, capacity building, and systems change activities that result in individuals with developmental disabilities being able to access services and supports that enable them to participate in community life as they choose.**

*Objective 1.1:*

Support three (3) initiatives to improve awareness of mental health disorders and promote access to mental health services for individuals with developmental disabilities.

*Objective 1.2:*

Engage with at least three (3) other partners to remove barriers to expanded implementation of the “medical home” model and promote coordinated and cross-disciplinary services for individuals with developmental disabilities.

*Objective 1.3:*

Engage in three (3) or more cross-disciplinary initiatives to remove barriers to early identification and access to timely and well-coordinated early intervention services for young children w/developmental delays and disabilities.

*Objective 1.4:*

Expand access to quality healthcare services for individuals with developmental disabilities and their families by engaging in at least four (4) initiatives that result in increased numbers of medical care providers who have received training and expanded their capacity to address healthcare needs of children and adults with developmental disabilities.

*Objective 1.5:*

Support at least three (3) cross-systems initiatives to increase access to appropriate and effective services and supports for adults with developmental disabilities and dementia-related conditions.

*Objective 1.6:*

Provide opportunities for at least 200 state-level policymakers in the executive and legislative branches to learn about the needs of un-served and under-served individuals with developmental disabilities and their families and about key components of quality services that support self-determination and community inclusion.

*Objective 1.7:*

Engage in at least five (5) activities that monitor policy and practice and/or funding to address access to and/or quality of education programs, community services, and natural supports for individuals with developmental disabilities and their families.

## **GOAL # 2: Self-Determination**

**MDDC will engage in advocacy, capacity building, and systems change activities so that Maine residents with developmental disabilities and their families will be able to exercise self-determination by exercising choice and control.**

### *Objective 2.1:*

Provide opportunities for at least 200 individuals with developmental disabilities, their families, and stakeholders to learn about civil rights and less restrictive guardianship options.

## **GOAL # 3: Self-Advocacy**

**MDDC will collaborate with the statewide self-advocacy organization and other stakeholders to increase the participation of self-advocates in policy making activities and in leadership roles.**

### *Objective 3.1:*

Provide comprehensive advocacy training in leadership, public policy development, and self-determination.

### *Objective 3.2:*

Provide opportunities for at least 400 individuals with developmental disabilities, their families, and supporters to be engaged in advocacy activities with state and federal policymakers regarding issues of interest to the developmental disabilities community.

### *Objective 3.3:*

Support development of opportunities for individuals with developmental disabilities to engage in leadership and policy making roles.

### *Objective 3.4:*

Support initiatives to increase the diversity and effectiveness of advocacy by and on behalf of Maine residents with developmental disabilities.

## **GOAL # 4: Opportunities for Inclusion as Valued Members of Communities**

**MDDC will engage in advocacy, capacity building, and systems change activities to promote individuals with developmental disabilities and their families having equal opportunities to be included as visible, active, and valued members of their communities.**

### *Objective 4.1:*

Expand opportunities for individuals with developmental disabilities to participate as integrated members of Maine's workforce.

### *Objective 4.2:*

Participate in initiatives that result in at least 3,000 members of the public having opportunities to expand their understanding of the value of community inclusion and accessibility for individuals with disabilities.

### *Objective 4.3:*

Engage in at least three (3) initiatives addressing recognition of contributions of individuals with developmental disabilities in valued roles in their communities and/or natural supports in inclusive community activities being available to individuals with developmental disabilities.