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Maine Developmental Disabilities Council

Annual Report

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This information has been compiled by the 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 persons 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."

The 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

The 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 State agencies administering federally-funded programs related to persons with developmental disabilities, local non-governmental agencies/organizations that serve people with developmental disabilities, and representatives of 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

The 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 integrations 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

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 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 12.2%.

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.

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

III. Concerns of Maine Families Affected by Developmental Disability

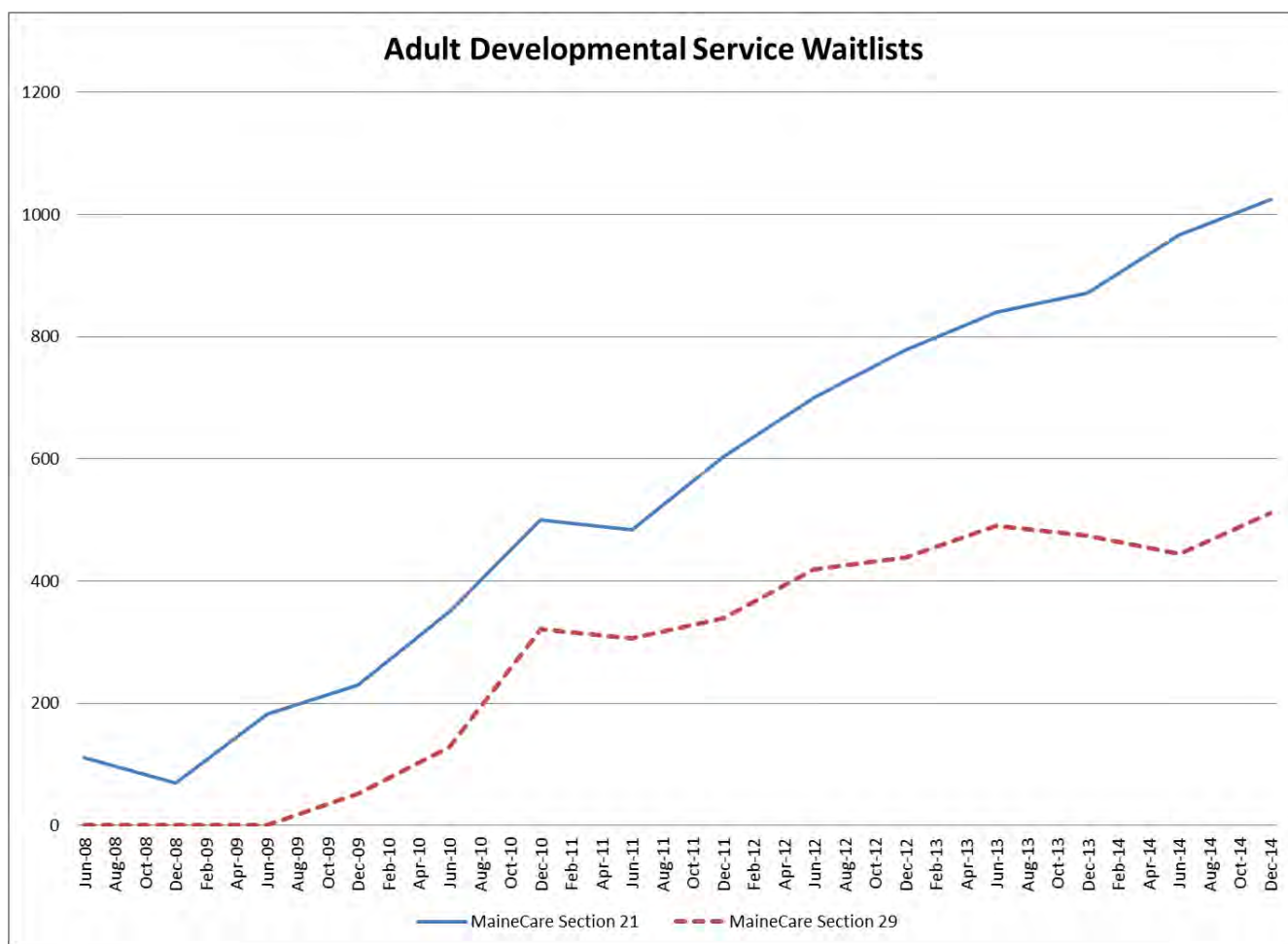
Access to Services and Supports

The 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 waiting list(s) for adult developmental services, especially those assessed to be at risk for health and safety (priority 1 of the Section 21 waiver). While the overall waitlist numbers have increased, a reversal of that trend is anticipated this year.



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 family's 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 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

The 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 statistics², 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 care giving responsibility.³ **In Maine it is estimated that approximately 4,350 persons with developmental disabilities are living at home with caregivers over the age of 60.**⁴

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.

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

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

⁴ 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 2014

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. This work yielded extensive data about the quality of health and healthcare for Maine citizens with ASD. (*Report available on MDDC's website at www.maineddc.org/resources-publications*)

This research revealed a number of possible positive trends in healthcare for individuals with ASD in Maine. These included the following:

- A much earlier median age of identification and diagnosis among the youngest cohort of children
- High ratings of overall health
- High ratings of overall healthcare
- Satisfaction with the Primary Care Providers (PCP)
- Satisfaction with the ability of the PCP to meet the patient and family's individual needs
- A relatively good understanding of ASD among PCPs
- High ratings of PCP responsiveness and communication
- Relatively little difficulty finding a PCP
- Access by most patients with ASD to regular healthcare, routine care, and screening.

The research points to a number of areas of concern, however. These include the following:

- Difficulty by a small number of respondents in finding a PCP who could meet their needs
- Poor communication among some medical providers
- Failure of medical practices to make requested accommodations, especially those related to difficulty in waiting rooms
- A very high rate of GI issues
- Frequent failure of PCPs to notice or act upon a possible relationship between GI and behavior issues
- Lack of communication with PCPs about using alternative therapies
- A lack of support and planning for families related to the transition to adult healthcare
- Difficulties that some patients had with completing routine care and screening procedures
- Inability of some individuals with ASD to communicate pain or illness in ways that are universally understood

Act Early Campaign

MDDC collaborated with the national Center for Disease Control's "Learn the Signs, Act Early" campaign to improve early identification of autism and other developmental disabilities and worked to promote the "Autism Case Training: A Developmental Behavioral Pediatrics Curriculum." MDDC has reached out to the general public through libraries, YMCA facilities, and Children's Discovery Museums across the state to distribute information.

Advocacy and Education for Public Policymakers

In accordance with its responsibilities under the federal DD Act, the 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 persons 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 persons 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 persons with disabilities and organize ongoing connections with policymakers. Since 2007, more than 450 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 is housed at a large general pediatric practice in central Maine. The project consists of the use of a care coordinator who works with families, usually by phone, to address care coordination needs. This project began enrolling children in June 2012 and will continue through FFY15. 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 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, reporting that families generally need care coordination at four critical times:

- *When a Developmental Screening is received by the practice* – the care coordinator reviews the screening and provides a brief analysis of the results with, when appropriate, potential needs for early intervention. Results thus far indicate that this practice is saving significant time for the physician as the care coordinator reviews the screening prior to the well child check.
- *Upon initial referral for evaluations by the Primary Care Physician because of concerns regarding developmental delays* – the care coordinator can help parents better understand the process of diagnosis and what they can expect at each step. This eases anxiety and provides the parents with information they will need in making informed decisions along the way. Parents experience an incredible amount of stress around the possibility of autism as a diagnosis and the delays they see in their child. Knowledge provided by the care coordinator is power and relieves anxiety.

- *After the diagnosis is received and guidance and support is needed in navigating the multi-layered systems* – Once the diagnosis is given, parents embark on a journey of working with multiple interventional services from multiple providers. They have many questions about services, IEP's, medical versus educational services, and how to access them all – and make it work with their schedule. The care coordinator regularly guides parents through this process.
- *During times of crisis* – Parents often experience periods of time when their child goes through a transition and they find themselves in crisis: the child is not sleeping and is keeping the whole family up at night, the child becomes aggressive, the school is telling parents that the current interventions are not working, or sensory issues increase. Parents have turned to the care coordinator to find out where to go next. Talking with them on the phone has often been sufficient to determine what is needed and prevent an office visit. The patient's need may be a new occupational therapy evaluation to determine sensory needs, an earlier appointment for medication management, or a referral to speech therapy to assist with supports in communication, among others.

Outcomes of this project include

- Over 300 screenings have been reviewed by the care coordinator
- Over 70 children have received care coordination including: expedited appointment at a diagnostic clinic for early identification, expedited access to evidence based, medically necessary services, prevention of Emergency Room visits by identifying complex medical issues early, provision of family support, and the elimination of duplicative services and enhancement in the quality of services by coordinating educational and medical plans

Preliminary evidence indicates that this low-cost service is effective in increasing quality of care and appears to actually be a cost saver when factoring saved physician time, prevention of higher cost emergency services and expedition of early intervention, a long-term cost saver. Four local news stations featured the story about this “One of a kind Autism program.”

Dementia Services and Supports

Persons 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 persons 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 persons 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 and looks forward to releasing that report in the coming weeks.

Employment

Research demonstrates, and is corroborated by experience, that participation in integrated community employment is strongly correlated with positive outcomes: being a homeowner or lease holder, having strong social supports, being engaged in other aspects of 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 persons with any type of disability. Despite this progress, **employment rates of persons with developmental disabilities continue to be very low** and systems of support have not systemically institutionalized this understanding.

In FFY14, MDDC funded two projects to test novel approaches to support individuals with developmental disabilities in obtaining and retaining competitive employment.

One project was aimed at addressing the barriers to obtaining permanent, community based employment for older students who are within one to two years of transitioning out of school (aging-out). Contractors engaged students, families and education staff to be involved in all aspects of career exploration and work placement. The Division of Vocational Rehabilitation's work exploration curriculum was employed with participants for determining characteristics of jobs desired by each individual. Family groups were convened to describe services available and to identify ways that families can be of support. After the exploration process, jobs were found and youth supported within those jobs.

The second project demonstrated the operationalization of Customized Employment in which Employment Specialists are provided with specialized training to enable them to increase the employment options and outcomes for persons with significant and complex support needs.

One individual's (de-identified) experience with the Customized Employment Project:

*When John was a young child he had an accident which resulted in a lifelong developmental disability. Regardless of his disability, John's family instilled in him a strong work ethic and never let his disability be an excuse for idleness. John had a limited but steady work history; however, he had been out of work for over two years. He wanted to be an important contributor to a small business that didn't involve "fast food" and knew he would find such a business with the assistance of the Customized Employment Project. The Customized Employment Coordinator arranged an informational interview and meeting with the owner/operator of Bangor Laundromat and Drycleaner. John was hired. A task list was negotiated, VR contributed 10 hours of job coaching plus funding for a non-rolling laundry cart, folding board, and pouch for quarters (all accommodations for Chris' limited use of one hand), and the employer purchased plastic gloves that Chris could easily maneuver on his hands and **refused any wage subsidies or other employer benefits**. John is doing well with natural supports from his colleagues and is pleased to be able to get to his job by taking the city bus.*

Results of Employment Projects include:

- Eight additional individuals became employed
- Three adults with developmental disabilities are employed and no longer need formal supports
- 28 persons with developmental disabilities engaged in the projects although they have not yet attained employment
- 137 people had the opportunity to learn about individualized employment for people with developmental disabilities

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. At the request of OADS, MDDC interviewed 400 adults with developmental who receive case management and at least one other service and consent to participate.

The interviews address individuals' experiences with the services that they receive and measure person-centered outcomes and 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 seemed happier and that many participants seemed to have limited awareness about the availability of choices in services and supports. The HSRI report is expected to be available in spring 2015.

Non-Traditional Advocacy

MDDC contracted with an organization to build a multi-layered, participatory and self-directed Virtual Community for individuals with Autism Spectrum Disorders (ASD) and their families. Based on the model of self-direction, the provider is working with individuals with ASD to develop, control, and maintain the website. The goal of this virtual community is to provide a setting for:

- Informal exchange and referral
- Peer connection
- Skills development and training
- Community advocacy
- Self-advocacy
- Social connectivity, networking, and entertainment

Quality Mental Health Services for Persons 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 2008, MDDC, in collaboration with the Department of Health and Human Services (DHHS), initiated a project to address the systemic challenges to assuring that quality mental health services are readily available to adults with intellectual and developmental disabilities. From May 2009 to September 2011, MDDC contracted with a nationally-recognized expert in the field of dual diagnosis who provided training to over 500 people throughout the state.

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.

Increasing Clinical Capacity: A developmental services provider with the capacity to provide quality mental health services was mentored to develop and sustain the ability to provide mental health care to persons with intellectual and developmental disabilities.

Behavioral Health Home: The primary focus in Maine's work promoting Health Homes has been on physical and mental health conditions, with little attention to developmental disabilities. This project explored how a Health Home model might best work for adults with developmental disabilities.

Outcomes of these projects included:

- Over 50 clinicians able to provide improved services in the area of dual diagnosis
- Nine clinicians able to provide improved supervision in the area of dual diagnosis
- Two participants with decreased use of Emergency Department services
- Nineteen adults with developmental disabilities able to receive mental health services

Raising Expectations

A public outreach campaign to raise the expectations of and for individuals with developmental disabilities, their families, and the general public. 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 to move into a group home and engage 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 has engaged with the civil rights teams at two area high schools. Initial focus group 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 have been hung in the schools. At the end of the school year, a follow-up focus group will be held with the students to determine whether the posters have effected a change in attitudes and perceptions.

Small Grants Program

The Small Grants Program provides funds to support individual or community activities and/or short-term research, demonstration, or other projects that help realize the goals and objectives of 5-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.

Supporting Self Advocacy

Through an ongoing contract and collaboration with the 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 FFY14 **over 250 individuals with developmental disabilities**, either received training or achieved greater independence as a result of SUFU's work. They accomplish this through a wide array of activities including, but not limited to:

- 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
- Educating individuals with developmental disabilities about less restrictive guardianship options
- Engaging in systems advocacy through leadership and policy making roles at the state level

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 persons 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 persons 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 with developmental delays and disabilities.

Objective 1.4:

Expand access to quality health care services for persons 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 health care 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 and directing their own services.

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 policymaking activities 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 initiative 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 persons 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 persons with disabilities.

Objective 4.3:

Engage in at least three (3) 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.