

# MAINE STATE LEGISLATURE

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# **Maine Developmental Disabilities Council**

## **Annual Report to the 126<sup>th</sup> Legislature State of Maine, 2<sup>nd</sup> session**

**Pursuant to 34B: 17001; January 1-December 31, 2013**

**submitted**

**January 31, 2014**



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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## **The Maine Developmental Disabilities Council**

### *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.

The Council is comprised of 25 volunteer members, 60% of whom are people with disabilities or their representative family members. Membership also includes representation from state agencies responsible for developmental disability services, from nonprofit organizations, and from each "sister agency" also created by the Developmental Disabilities Act, the Disability Rights Center and the Center for Community Inclusion and Disability Studies.

### *What We Do*

The Maine Developmental Disabilities Council is required to engage in advocacy, capacity building, and systemic change activities addressing areas of focus that include: quality assurance, education, early intervention, childcare, health, employment, housing, transportation, recreation, and other services available or offered to people in a community which affect their quality of life. Through the development of a five-year plan, The Council narrows the focus and designs projects that best suit the current needs of the community. The Council is committed to collaboration with other concerned agencies and self-advocates and works to strengthen the disability community through technical assistance, grant allocation, and the development of joint projects. The Council is actively involved in public policy work through provision of information and education to legislators and other interested community leaders, through engagement on boards and committees, and through advocacy on behalf of people with developmental disabilities.

## Defining Developmental Disability

The US Dept. 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 serious 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 or bathing.
- **4.5% of Mainers have an Independent Living Disability**  
Approximately 83,700 Mainers (*ages 18 or older*) have difficulty doing errands alone such as visiting a doctor's office or shopping 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

## FACTORS IMPACTING THE FUTURE OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

### AGING CAREGIVERS

The aging of Maine's population stands to pose serious challenges to 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.<sup>2</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>3</sup>

### EMPLOYMENT AND POVERTY

According to U.S. Census Bureau statistics<sup>4</sup>, the economic status of persons with disabilities in Maine is significantly worse than that of persons without disabilities:

- **EMPLOYMENT**

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 (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.

- **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).**

### SYSTEMIC ISSUES

#### General Needs

##### *Dental Care*

Limited or lack of access to preventative and restorative dental care is a barrier to the health of people with developmental disabilities. Lack of access to dental care is even more significant for those who do not have access to waiver-level services.

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<sup>2</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>3</sup> Braddock, et al. (2011) The State of the States in Developmental Disabilities Second Printing, Revised, The University of Colorado

<sup>4</sup> U.S. Census Bureau, 2011 American Community Survey 1-Year Estimates <http://www.census.gov> accessed January 30, 2014

### *Transportation*

Most individuals with developmental disabilities (DD) do not drive. In a state that is largely rural with little public transit infrastructure, this severely limits the ability to travel. Individuals with DD rely on a patchwork of service providers, family and friends, public transit, taxis, and volunteer drivers. In response to recurrent budget cuts, agencies providing developmental services have, in some cases, limited travel by such means as traveling in groups, restricting mileage, or requiring approval for non-essential trips. Individuals with DD report especial difficulty obtaining transportation to social and recreational opportunities, particularly individual activities. 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. Individuals 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. Transportation costs can also have an effect on the availability of in-home services as providers have difficulty finding qualified workers who are willing to travel to distant locations. Even those placed in nursing facilities are unable to access transportation to maintain social networks of support or to work and it may be difficult for them to access transportation to utilize (medical) providers of choice.

### *Employment Supports*

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.

### **Children's Services**

Children's services are largely designed to provide entitlement to proactive intervention based upon the child's level of function.

The Council has received input about gaps in access to services. In certain areas of the state providers have difficulty recruiting and retaining staff to provide services, leading to situations in which children receive a lower level of service than is indicated or appropriate. For example, a child who requires three 30-minute sessions per week receives treatment one day per week for 60 minutes, or goes without treatment for two weeks because the provider is ill and there is no replacement available.

The Council has also received input about 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."*

## Special Education

Over the past ten years (from the 2002-2003 school year to the 2012-2013 school year), there has been a 12% decrease in the number of students in special education programs in the public schools. However, there has been a 193% increase in the number of students served in the Autism category during the same time period.

Concern has been raised regarding the cost of special education services having increased at the same time that the numbers of students receiving these services has decreased. This may be explained to a great extent by the relative change in numbers in various special education categories, given that students with some types of disabilities may require more supports and services as part of their educational programs.

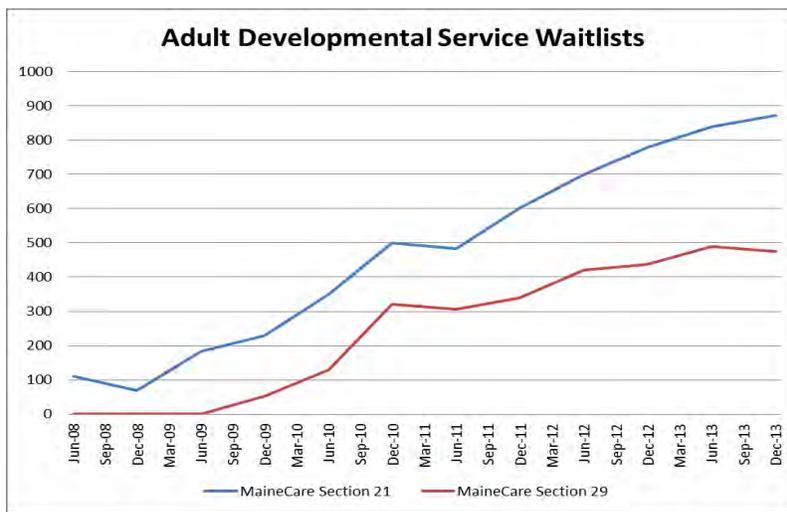
## Adult Services

### *Eligibility rather than Entitlement*

Upon reaching adulthood (between 18 and 21, depending upon enrollment in school), the availability of individual and family supports changes. 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). The State of Maine is one of a minority of states to also require an IQ score of less than 70 for disabilities other than an Autism Spectrum Disorder (for which Maine requires a functional score of greater than two standard deviations from the mean). Provision of services to those individuals with developmental disabilities who qualify under another part of the service system creates significant confusion and emphasis on alternative diagnoses which may lead to less than effective/efficient care.

### *Availability of Services*

There is significant concern about limited access to Developmental Services. Families talk about the looming "cliff" that their children face with growing waiting lists for Adult Developmental Services waiver programs.



## MDDC PROJECTS AND INITIATIVES

2013

### ❖ ADVOCACY AND EDUCATION FOR PUBLIC POLICYMAKERS

In accordance with its responsibilities under the federal DD Act, the 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. The Council 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

Disability Advocacy Day is an ongoing activity organized by the Maine Developmental Disabilities Council in concert with Speaking Up For Us (SUFU), Maine's self-advocacy organization (which is comprised of persons with developmental disabilities who often refer to themselves "self-advocates.") This program provides an opportunity for self-advocates, family members, and other interested parties to become more familiar with the legislative process and to take a more active role in communicating their concerns to their elected officials in the Legislature. The Council 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 400 self-advocates, parents and provider agency staff have participated in this program.

### ❖ SUPPORTING SELF ADVOCACY

Through an ongoing contract and collaboration with Speaking Up for Us, the Council provides support for local groups and statewide events that offer training, networking and social activities, and encourage greater community involvement and inclusion. Presentations and trainings provided by representatives of this group in schools and other community settings also help to foster increased appreciation for the rights of persons with developmental disabilities and their contributions to their local communities.

### ❖ AUTISM SPECTRUM DISORDERS STATE IMPLEMENTATION GRANT

The Council completed a 3-year grant contracted through DHHS, awarded by the federal Health Resources and Services Administration using funds from the Combating Autism Act Initiative. Third year grant activities included:

#### Medical Home Pilot

##### *Greater Bangor*

The Council contracted with a pediatrician's office to pilot an enhanced medical home model. The pediatrician's office hired a nurse who came to the job with experience with the multiple systems of care. Using nationally normed evaluation forms they provided services to children and youth coordinated multi-system treatment plans while provided and oversaw medical care. The pediatrician's office reported that they successfully enrolled and enriched the lives of 32 patients and their families. They stated that the reason this pilot was of interest to them is that the current system of treatment for children with developmental disabilities is both confusing and unwieldy.

The pilot has contributed to multiple policy changes including the development and posting of a social story and incorporating visual schedules into appointments to increase the likelihood of a successful, stress free exam.

#### Diagnostician and Early Childhood Professional Planning

##### *Greater Bangor, Greater Portland*

The Council funded quality improvement efforts between Developmental Pediatricians and Early Childhood Professionals in two distinct areas of the State. The project's goal was to find methods to consolidate planning for the medical and educational models. The projects have completed and analyses of evaluation results are currently being compiled.

#### Building Capacity of Primary Care Physicians

##### *Statewide*

The Council provided a train-the-trainer presentation to six developmental pediatricians throughout the state on a curriculum to improve primary care physician's comfort in providing medical care to individuals with Autism Spectrum Disorders (ASD) and other developmental disabilities. These developmental pediatrician then provided training and technical assistance to 94 other primary care physicians in order to improve health care for children and youth with developmental disabilities. In addition, the Council provided several physicians with intensive training in providing medical care for individuals with ASD.

#### Medical Home Parent Training

##### *Statewide*

The Council contracted with two local parent organizations to develop and present a curriculum on medical homes for families of children with ASD about advocating for better healthcare. An internet webinar module was completed, face-to-face trainings were conducted, a new webpage was developed, and over 119 families were trained.

#### Act Early Campaign

##### *Statewide*

The Council collaborated with the national Center for Disease Control 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." The Council has reached out to the general public through libraries, YMCA facilities and Children's Discovery Museums across the state to distribute information.

#### Autism Screening

##### *Statewide*

A DVD and accompanying curriculum was developed to train early childhood professionals and physicians on administering and scoring autism specific screening tools. All IDEA Part C and Part B section 619 professionals in Maine have received the training and adopted the recommendation of screening for developmental disability and autism for all referrals into their program. Similarly, many head start programs and public health nurses in Maine have received the trainings and adopted the new practice. In addition, the Council sponsored multiple physician grand rounds presentations regarding incorporation of screening tools into offices and partnered with MaineCare in their effort to provide technical assistance to practices adopting new screening protocols.

## ❖ ADDRESSING HEALTH DISPARITIES

### *Statewide*

The Council supported the development and provision of outreach and education activities to healthcare providers in support of efforts to provide accessible and effective care through the development and dissemination of a white paper outlining the health disparities experienced by persons with developmental disabilities and primary health care practices that address disparities. Over 120 health care providers were reached through this effort.

## ❖ QUALITY MENTAL HEALTH SERVICES FOR PERSONS WITH INTELLECTUAL DISABILITIES

The Council funded two pilot projects addressing access to mental health services by people with developmental disabilities.

### Increasing Clinical Capacity

#### *Greater Portland, Midcoast & Bangor areas*

A developmental services provider with the capacity to provide quality mental health services is increasing its clinical capacity and mentoring two other organizations to develop and sustain the ability to provide mental health care to persons with intellectual/developmental disabilities.

### Behavioral Health Home

#### *Greater Portland*

A developmental services provider is demonstrating how the model of the behavioral health home can be adapted for, utilized with and benefit adults with developmental disabilities and co-occurring behavioral health disorders.

## ❖ ADDRESSING DEMENTIA AMONG PERSONS WITH DEVELOPMENTAL DISABILITIES

The Council 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

## ❖ EMPLOYMENT

The Council funded two pilot projects addressing employment of persons with developmental disabilities.

### Transition from High School to Employment

#### *Midcoast*

A demonstration project in which youth preparing to finish high school, in collaboration with their families, support staff, education staff, and Vocational Rehabilitation, are provided targeted support for planning and accessing meaningful work experience with the goal of increasing the number of youth with developmental disabilities who transition directly from high school into employment.

### Employment of Persons with Significant and Complex Support Needs

#### *Greater Millinocket*

A demonstration project 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