

2014

ANNUAL REPORT

ADVOCACY • CAPACITY BUILDING • SYSTEMIC CHANGE



**Maine Developmental
Disabilities Council**

Maine Developmental Disabilities Council
225 Western Avenue, Suite 4
Augusta, ME 04330
www.MaineDDC.org
Toll Free: 1-800-244-3990
Telephone: 207-287-4213
Fax: 207-287-8001



A MESSAGE FROM THE EXECUTIVE DIRECTOR

“Convince me that you have a seed there, and I am prepared to expect wonders”

Henry David Thoreau



The Maine Developmental Disability Council (MDDC) works with State Agencies to identify potential solutions to systemic problems and funds projects to test whether or not the solutions are effective. We are a unique agency in that it is our job to try out new ideas, evaluate their effectiveness, and apply the lessons learned for systemic improvements. What a wonderful opportunity to seed new ideas and watch them grow. This past year, staff has worked with State Agencies, individuals with disabilities and their families, and other members of Maine’s communities to ensure that all individuals with Developmental Disabilities have an opportunity to share their gift and obtain meaningful employment, early intervention services, effective education and community services, and adequate and appropriate healthcare. It is a privilege to work with the Council Members and staff at MDDC. Perhaps I sit here waiting for spring, but I have truly seen the work of MDDC blossom this year and I am hopeful that you will read this report and explore some of MDDC’s exciting initiatives.

~ Nancy Cronin, Executive Director

MAINE DEVELOPMENTAL DISABILITIES COUNCIL – WHO WE ARE

The Maine Developmental Disabilities Council is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self determination, and independence. The Council acts to effect positive change through advocacy, training, demonstration projects, and support for other inclusive and collaborative systemic change activities.

MDDC MEMBERS

Patrick Adams*	Family Member
Angie Bellefleur	DHHS, Office of Family Services
Jan Breton	DOE, Office of Special Services
Alan Cobo-Lewis	Family Member
Deb Davis *	Family Member
Shannon Johnson	Family Member
Kim Moody	Disability Rights Maine
James Norton *	Family Member
Avery Olmstead	Self Advocate
Christian Powers	Self Advocate
Denise Ranger*	Family Member
Marc Roix * (Chair)	Self Advocate
Susan Russell	Center for Community Inclusion & Disability Studies
Jeffrey Shapiro	DHHS, Office of Aging & Disability Services
Emilee Taplin-Lacy	Non Governmental Agency
Sarah Trites	Self Advocate
Toni G. Wall	DHHS, Children with Special Health Needs Program
Elinor Weissman	DOL, Vocational Rehabilitation
Monica Wood	Self Advocate

* MDDC Executive Committee members

MDDC STAFF

Nancy Cronin, *Executive Director*

Rachel Dyer, *Associate Director*

Erin Howes, *Office Manager*

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 a National level.

PROJECTS AND INITIATIVES IN 2014

-  Act Early Campaign
-  Advocacy and Education for Public Policymakers
-  Assessing Healthcare: The Experience of Individuals with ASD in Maine
-  Care Coordination for Children with Developmental Disabilities
-  Dementia Services and Supports
-  Employment
-  National Core Indicators
-  Non-Traditional Advocacy
-  Quality Mental Health Services for Persons with Intellectual Disabilities
-  Raising Expectations
-  Small Grants Program
-  Supporting Self Advocacy

MDDC 5 YEAR STATE PLAN GOALS

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.

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.

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.

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.



HIGHLIGHTS OF PROGRAMS, ACTIVITIES AND PARTNERSHIPS IN 2014

NATIONAL CORE INDICATORS

Maine is one of 43 states participating in the National Core Indicators (NCI) project, a voluntary effort to gather a standard set of performance and outcome measures that can be used to track performance over time, to compare results across states, and to establish national benchmarks for service delivery.

Between January and June of 2014, MDDC interviewed 400 adults with developmental disabilities who receive case management and at least one other service and who consented to participate.

The interviews addressed individuals' experiences with the services that they receive and measured person-centered outcomes and system-level indicators related to employment, choice, relationships, care management, inclusion, and health. For more information about the NCI project and for the most recent report visit: <http://www.nationalcoreindicators.org>

DISABILITY ADVOCACY DAY






Each legislative session, MDDC provides the opportunity for individuals with disabilities, their families and supporters to learn more about the Maine State Legislature and how to advocate through its Advocacy Day Program. Participants learn how the legislative process works, are given a tour of the State House, and, when possible, personally meet and speak with their elected officials. In 2014, 50 self-advocates, family members and provider agency staff participated in this program.



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 2014, over 250 individuals with developmental disabilities participated in SUFU 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
-  Educating individuals with developmental disabilities about less restrictive guardianship options
-  Engaging in systems advocacy through leadership and policy making roles at the state level

EMPLOYMENT

In 2014, 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). Students, families, teachers, and other supporters were engaged in all aspects of career exploration and work placement.

The Division of Vocational Rehabilitation's work exploration curriculum was utilized with participants to determine characteristics of jobs desired by each individual. Families were engaged to identify ways that they could help. After the exploration process, jobs were found and youth supported within these jobs.



The second project demonstrated the operations of Customized Employment in which Employment Specialist are provided with specialized training to enable them to increase the employment options and outcomes for persons with significant and complex support needs. Results of Employment Projects include:

- 👤 Eight individuals became employed
- 👤 Three adults with developmental disabilities who are employed no longer need formal supports
- 👤 28 persons with developmental disabilities participated in the projects and are on the path to employment
- 👤 137 people had the opportunity to learn about individualized employment for people with developmental disabilities

ACCESSING HEALTH CARE: THE EXPERIENCE OF INDIVIDUALS WITH ASD IN MAINE

In 2014, MDCC continued its work in assessing the experience of Maine adults and children with Autism Spectrum Disorders (ASD) in accessing healthcare. 107 structured in-person interviews were completed and a quantitative analysis on the data was completed.

This research revealed a number of positive trends in healthcare for individuals with ASD in Maine:

- 🕒 Early median age of identification and diagnosis
- 🕒 High ratings of overall health and healthcare
- 🕒 Satisfaction with the ability of Primary Care Providers (PCP) to meet patients' and families' individual needs
- 🕒 A relatively good understanding of ASD among PCPs
- 🕒 High ratings of PCP responsiveness and communication
- 🕒 Good access to routine healthcare and screening

The research also pointed to a number of areas of concern:

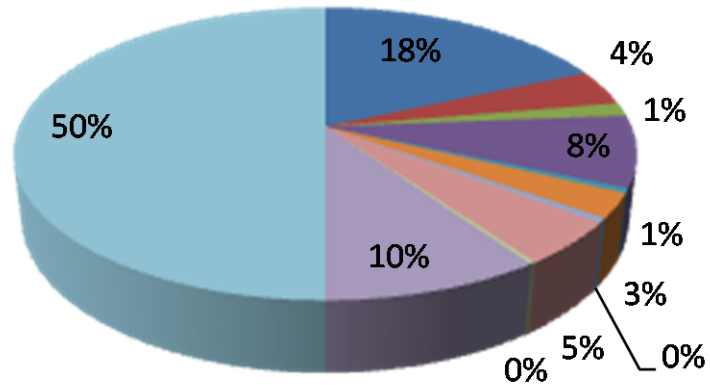
- 🕒 Difficulty by a small number of respondents in finding a PCP who could meet their needs
- 🕒 Poor communication among some medical providers
- 🕒 Failure of medical practices to make requested accommodations, especially those related to difficulty in waiting rooms
- 🕒 A very high rate of gastrointestinal (GI) issues
- 🕒 Frequent failure of PCPs to notice or act upon a possible relationship between GI and behavior issues
- 🕒 Limited patient communication about their use of alternative therapies
- 🕒 Lack of planning for transition to adult healthcare
- 🕒 Patient difficulties with completing routine care and screening procedures
- 🕒 Inability of some individuals with ASD to communicate pain or illness

The report is available at: <http://www.maineddc.org/resouces-publications/>

FY14 MDDC EXPENITURES

- Self-Advocacy
- Dual Diagonosis
- DD & Dementia
- Employment
- Policy Barriers
- Public Awareness
- Small Grants

PROGRAM & PROJ
EXPENSE DISTRIBUTION



- Personnel
- General Opporations
- Meetings & Travel
- Direct Program
- Grant Project
- Other

EXPENSE BY CATEGORY

