

# **Maine Developmental Disabilities**

October 15, 2019

Senator Gratwick, Representative Hymanson and distinguished members of the Health and Human Services Committee:

Please accept this **Program Evaluation Report** pursuant to the Government Evaluation Act, Title 3, MRS Chapter 35. Feel free to contact the Maine Developmental Disabilities Council with any questions or if you need additional information about any of the required reporting areas.

# §956. Program evaluation report: Each report must include the following information in a concise but complete manner:

1. Enabling or authorizing law or other relevant mandate, including any federal mandates

Title 34-B: BEHAVIORAL AND DEVELOPMENTAL SERVICES

Chapter 17: DEVELOPMENTAL DISABILITIES §17001 Maine Developmental Disabilities Council and

42 U.S. Code CHAPTER 144—DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS

SUBCHAPTER I—PROGRAMS FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES (§§ 15001 – 15083)

- 2. Description of each program administered by the agency or independent agency, including the following for each program:
- a) Established priorities, including the goals & objectives in meeting each priority

Five-Year State Plan GOALS & OBJECTIVES 2017-2021

GOAL#1

MDDC will engage in advocacy, capacity building, and systems change activities that support individuals with developmental disabilities, families, and communities to have increased choices, opportunities, and self-determination.

Objective 1.1:

MDDC will collaborate with DD Network Partners to increase the civic engagement of individuals with developmental disabilities and family members.

Objective 1.2:

MDDC will support diverse Maine communities to increase capacity to be fully inclusive of individuals with developmental disabilities.

## Objective 1.3:

MDDC will support the statewide self-advocacy organization to increase its effectiveness as an independent not-for-profit.

# Objective 1.4:

MDDC will partner with individuals with developmental disabilities, families, and communities to broaden the reach and increase the effectiveness of advocacy.

### GOAL#2

MDDC will engage in advocacy, capacity building, and systems change activities that support individuals with developmental disabilities and families to have greater access to their communities.

## Objective 2.1:

MDDC will improve integration of services and supports for individuals with developmental disabilities and families.

## Objective 2.2:

MDDC will support efforts to improve quality of services and supports for individuals with developmental disabilities and families.

## Objective 2.3:

MDDC will support efforts to expand access to all aspects of community life for individuals with developmental disabilities and families.

## Objective 2.4:

MDDC will increase access to information and services for underserved persons and families with developmental disabilities.

b) Performance measures or other benchmarks used by the agency to measure its progress in achieving the goals & objectives;

DD Councils are required to utilized standardized performance measures, as listed below, to track their progress in achieving goals and objectives.

## INDIVIDUAL/FAMILY ADVOCACY ANNUAL PERFORMANCE MEASURES

## IA 1: Output Measures1

IA 1.1	The number of people with developmental disabilities who participated in Council
	supported activities designed to increase their knowledge of how to take part in
	decisions that affect their lives, the lives of others, and/or systems
IA 1.2	The number of family members who participated in Council supported in activities
	designed to increase their knowledge of how to take part in decisions that affect the
	family, the lives of others, and/or systems

## IA 2: Outcome Measures<sup>2</sup>

IA 2.1	After participation in Council supported activities, the percent of people with
L	developmental disabilities who report increasing their self-advocacy
IA 2.2	After participation in Council supported activities, the percent of family members who
L	report increasing their advocacy

#### IA 2: Sub-outcome measures:

IA2	Individual Advocacy Sub-outcome Reasures
W221	The percent of people who are you better able to say what they want/say what is important to them
IA 2.2.2	The percent of people who had been participating in any advocacy group before involvement in Council supported activities?
IA 2.2.3	The percent of people who joined an advocacy group as a result of participation in Council supported activities
IA 2.2.A	The percent of people who are participating now in a group advocacy effort
IA 2.25	The percent of people who report that the Council supported activities helped to increase participation in the group advocacy effort or the advocacy group
IA 2.2.6	The percent of people who are on policy boards, advisory boards, governing
M 22.7	bodies as a result of experience with the Council  The percent of people who are serving in a leadership position within or for
	agencies and organizations
JA 2.2.8	
IA 2.29	The percent of people who are paid for their role
JA 7.210	The percent of people satisfied with a project activity
IA 2.2.11	The percent of people who indicate their life is better because of a project activity

## SYSTEMS CHANGE ANNUAL PERFORMANCE MEASURES

### SC 1: Output Measure

The number of Council efforts to transform fragmented approaches into a coordinated and effective system that assures 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, and integration and inclusion in all facets of community life

SC 1.1	Policy endior Pro	ocedure change			
SC 1.1.2		licies and/or pro	dure changes <i>cr</i> e cedures changes	ated to improve existi	ng policies

## SC Sub-output measures

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SC12 Statute and/or regulation changes	
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The number of statute and/or regulation changes to improve statutes and/or	
regulations	

SC 1.3 Promising and/or hest reactions	
SO 156. The number of new promising practices created	
The number of promising practices improved	
The number of promising practices supported	A114 1014
The number of new best practices created The number of best practices improved	Ajj.
The number of best practices supported	

SC (14 Collaboration) is successful to the second s	A 20 Z 20
The number of Council systems change activities with organizations actively involved	į

SC.2.1	The number Council efforts to transform fragmented approaches into a coordinated and effective system that assures 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, and integration and inclusion in all facels of community life that were adopted (sub-measures 2.1.2; 2.1.5; 2.1.8)
SC 2.2	
SC 2.3	The number Council efforts to transform fragmented approaches into a coordinated and effective system that assures 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, and integration and inclusion in all facets of community life that were implemented (sub-measures 2.1.3.: 2.1.6: 2.1.9).

#### Sub-outcome measures

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54. 2	Cutcome Measures (East This this thin East Canada and Canada Canada Canada Canada Canada Canada Canada Canada C
SC 211	The number of policy and/or procedure changes created as a result of systems
	CARRIES THE STATE OF THE STATE
SC 2.1.2	The number of policy and/or procedure changes adopted
SC 2.13	The number of policy and/or procedure changes adopted that were implemented
30 2 1 4	The number of statutes and/or regulations created as a result of system change
	activities
SC 2.15	The number of statute and/or regulation changes adopted
SC 216	The number of statute and/or regulation changes adopted that were
	implemented
SC 217	The number of promising and/or best practices created as a result of systems
	change activities
SC 218	The number of promising and/or best practices adopted
90.219	The number of promising and/or best practices adopted that were implemented

c) An assessment by the agency indicating the extent to which it has met the goals & objectives, using the performance measures. When an agency has not met its goals & objectives, the agency shall identify the reasons for not meeting them & the corrective measures the agency has taken to meet the goals & objectives;

The Program Performance Report is the required annual federal report that DD Councils submit to the Administration on Disability (AOD)/Office of Intellectual and Developmental Disabilities (OIDD). The PPR captures the DD Council's progress toward achieving the goals and objectives within the DD Council 5-year plan.

The purpose of the PPR is to document DD Council results and outcomes that occurred during the previous federal fiscal year for government reporting purposes. Reporting on activity-specific outcomes is intended to capture, on an annual basis, the results of initiatives funded by AOD/OIDD and administered by DD Councils including those initiatives conducted by grantees, DD Councils, members and policy and program staff.

Office of Intellectual and Developmental Disabilities staff monitor MDDC's reports and have mechanisms of addressing compliance issues. Maine has received feedback that it has a robust State Plan and strong annual reporting.

Copies of the most recent PPRs are available upon request.

3. Organizational structure, including a position count, a job classification & an organizational flow chart indicating lines of responsibility;

3.5 FTEs are employed in conducting activities related to the MDDC State Plan.

1FT (Exempt) Executive Director supervises all staff



1FT (Exempt) Associate Director and

1.5FTE (Nonexempt) Program Associates

4. Financial summary, including sources of funding by program & the amounts allocated or appropriated& expended over the past 10 years

upp	appropriated& expended over the past 10 years						
	Federal	State	Total		Federal	State	Total
	allocation	match	expended		allocation	match	expended
FFY19	506,300	160,155	*160,155	FFY14	452,431	0	452,431
FFY18	507,546	160,155	*466,092.38	FFY13	451,553	0	451,553
FFY17	499,452	160,155	659,607	FFY12	477,688	0	477,688
FFY16	487,511	158,975	646,486	FFY11	478,797	0	478,797
FFY15	472,622	84,000	556,622	FFY10	478,797	0	478,797

The Federal Allocation is to spent over three years. The FFY19 funds of 506,300 is budgeted to be expended in its entirety in the FFY20 budget. That said, the State match is expended in the fiscal year allotted by the State Legislature. A small portion of the FFY18 allocation will be liquidated in FFY20 as well.

5. Identification of those areas where an agency has coordinated its efforts with other state & federal agencies in achieving program objectives & other areas in which an agency could establish cooperative arrangements, including, but not limited to, cooperative arrangements to coordinate services & eliminate redundant requirements;

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 provide specific direction on the responsibilities of DD Councils. 25% of MDDC's membership consists of seats held by state agencies members. Three (3) members are from the Dept of Health and Human Services, including the Office of Aging and Disability Services, Office of Child and Family Services, and Children with Special Health Needs, State agency membership also includes

two members from the Dept of Education (Child Development Services and Office of Special Services and one from Dept of Labor, Vocational Rehabilitation Services. State agency membership is intended to promote collaboration on relevant initiatives related to developmental disability services.

DD Councils are specifically required to collaborate with its "sister agencies" that also receive funding through the DD Act, the Protection and Advocacy organization (Maine's Disability Rights Center) and the University Center for Excellence in Developmental Disabilities (Maine's Center for Community Inclusion and Disability Studies at the University of Maine, Orono). The Maine DD Council collaborates, formally and informally, though a variety of means (including contracts and memorandums of understanding, with state agencies and private sector providers to execute its State Plan activities.

DD Councils do not provide direct services and MDDC is not aware of any redundant requirements to which it is party.

6. Identification of the constituencies served by the agency or program, noting any changes or projected changes;

MDDC's constituency includes any Mainer who experiences a developmental disability and their family members, regardless of whether or not they receive certain types of services and supports.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines a developmental disability as 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 three 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, supports, or other assistance that are lifelong or extended duration and are individually planned and coordinated; includes infants and young children from birth to age nine who have substantial delay or specific congenital or acquired conditions, and may be considered to have a developmental disability without limitations in meeting three or more of the areas of major life activity with a high probability of resulting in DD later in life if services are not provided. Approximately 6 million Americans have developmental disabilities. There are approximately 26,000 Mainers with developmental disabilities.

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7. Identification of those areas where an agency has coordinated its efforts with other state federal agencies in achieving program objectives & other areas in which an agency could establish cooperative arrangements, including, but not limited to, cooperative arrangements to coordinate services & eliminate redundant requirements;	ents
The Developmental Disabilities Assistance and Bill of Rights Act of 2000 provide specific direction on the responsibilities of DD Councils. Utilizing alternative delivery systems would violate the federal guidance.	
8. Identification of emerging issues for the agency or program in the coming years;	
The Maine Developmental Disabilities Council addresses emerging issues through its plan. It initiated development of its 2022-2027 5 Year State Plan. Council members and staff assess progress on the current state plan, conduct a comprehensive review and analysis of services supports, and other assistance available to people with DD and their families, gather public i on needs, and develop the goals, objectives, and strategies for the plan. The Council may conduct activities and funds initiatives in "Areas of Emphasis" as defined within the Developmental Disabilities Assistance and Bill of Rights Act of 2000, PL 106-402, October 30, 2000. Areas of Emphasis include Quality Assurance, Education and Early Intervention, Child (Health, Employment, Housing, Transportation, Recreation, and Formal / Informal Communit Supports.	nput Care,
9. Any other information specifically requested by the committee of jurisdiction;	
Not applicable.	
10. A comparison of any related federal laws & regulations to the state laws governing the agency or program & the rules implemented by the agency or program;	
State law 34-B §17001 enables the Council to exist as a public instrumentality and specifical directs it to	ly
"perform its duties in compliance with the requirements of the Developmental Disabilities Assistance and Bill of Rights Act of 2000." As appropriate, state law does not provide any fur governance over the Council's activities and thus there are no rules implemented to Council governance.	

# 11. Agency policies for collecting, managing & using personal information over the Internet & nonelectronically,

MDDC does not routinely collect, manage, or use personally identifiable information for its State Plan activities. To address situations that may involve inadvertent access to such information, management of personal information utilized by functions such as membership, or other nonroutine situations, MDDC has developed the following policies/practices:

# o From MDDC's personnel policies:

# Confidentiality

Employees must not use or disclose any confidential information they obtain during employment with MDDC except as required by their jobs. This obligation remains even after an employee's employment relationship with MDDC ends. Confidential information is any personal, protected or proprietary information including, but in no way limited to, client lists, client files, personnel files, computer records, financial and marketing data, process descriptions, and research. Employees are expected to keep proprietary and confidential information that is maintained in the office secure from all other who do not have a legitimate reason to see or use such information. This may include but is not limited to locking offices, locking files, shredding unwanted documents, etc. in order to maintain physical security. MDDC employees are expected to utilize best practices in protecting sensitive information that is communicated electronically. MDDC employees are required to act in compliance with State and Federal laws with regard to confidentiality.

## o MDDC Online Privacy Policy

## Last updated October 9, 2019

At the Maine Developmental Disabilities Council, we are committed to protecting the privacy of those who visit our website. The policy outlined below explains what data we collect from website visitors and how we use that data. By using our website you consent to the practices outlined here.

### **Collected Information**

Non-personal information: Through our use of Google Analytics, MDDC collects non-personally identifiable information when you visit one of our webpages. Such information may include the name of the website from which you accessed our site, the browser and operating system you used while doing so, which pages you visited, and how long you spent on each page.

The Maine Developmental Disabilities Council collects this information in order to better understand our audience, and how that audience uses our website, in order to improve your experience.

Cookies: MDDC uses first-party cookies from Google Analytics on our site to collect non-personal information, in order to track the number of visitors and repeat visitors to our site, and understand which pages they viewed. You may use your browser's settings to opt out of cookies, but note that doing so may affect the functionality of our website. Personally identifiable information: The Maine Developmental Disabilities Council only collects personally identifiable information with the express permission of the user. We may do so through sign-ups to mailing lists or by responding to requests for information, and we never sell or otherwise share our mailing lists with third parties. We only collect

this information if you voluntarily give it to us. Visitors may always view our website anonymously.

**How We Use Collected Information** 

The non-personal information that we collect informs MDDC of how our website is being utilized, and how to better serve our partners and constituents.

When you share information about yourself, such as your name and email, we may put you on our mailing list. With your express permission, we may send you newsletters, information about upcoming events, and other emails we believe may be of interest to you. You have the right to opt out of these mailings at any time.

If you apply for membership to the Council through our online system, that information will be shared with the members of the Council for the purposes of vetting and discussing your application. Your information will never be sold or otherwise shared publicly. Links to Other Websites

Our website may contain links to pages on other websites. The Maine Developmental Disabilities Council is not responsible for the content of those sites or the information about visitors they may collect. Users should view the privacy policies of those sites in order to determine how they may use the information collected. The above policy solely applies to information collected on www.maineddc.org and the subpages contained therein.

**Updates and Contact** 

MDDC may occasionally update this policy in order to reflect changes to organization policies, user feedback, and state and federal laws. At that time, we will update the date listed at the top of this document.

o Finally, MDDC requires staff and me	mbers to sign a confidentiality agreement:
This is to certify that I,	, an employee of the Maine
Developmental Disabilities Council, underst	and that any information (written, verbal or
other form) obtained during the performan	ce of my duties must remain confidential.
This includes all information about member	s, clients, families, employees and other
associate organizations, as well as any othe	r information otherwise marked or known to
be confidential.	

I understand that any unauthorized release or carelessness in the handling of this confidential information is considered a breach of the duty to maintain confidentiality. I further understand that any breach of the duty to maintain confidentiality could be grounds for immediate dismissal and/or possible liability in any legal action arising from such breach.

(11) information on the agency's implementation of information technologies

MDDC is a quasi-state organization that utilizes the Maine State Office of Information Technology (OIT) to support its use of information technology. MDDC utilizes typical office technologies, including but not limited to telephone, network and storage, services, including but not limited to Office subscriptions, VOI telephone and internet, and products, including but not limited to computers and telephones. MDDC relies upon OIT for data management and security.

(11) & an evaluation of the agency's adherence to the fair information practice principles of notice, choice, access, integrity & enforcement;

MDDC addresses notice/choice by only collecting personally identifiable information only with the express permission of the user (opt-in).

MDDC addresses access, integrity, and security by not collecting or storing personally identifiable data as it conducts State Plan activities. MDDC utilizes managerial and technical controls to limit access to information, such as that regarding membership, to necessary personnel and by storing it on a secure server.

12. A list of reports, applications & other similar paperwork required to be filed with the agency by the public.

No reports, applications or other similar paperwork are required to be filed with the agency by the public.

12. a-e)

Not applicable.

12. f) A list of reports required by the Legislature to be prepared or submitted by the agency or independent agency.

Council report. The council, pursuant to its duties under subsection 4, shall provide information from the comprehensive review and analysis of services, supports and other assistance for persons with disabilities required by 42 United States Code, Chapter 144, Section 15024 (c) (3) to the Legislature by January 31st of each year.

Rachel Dyer, MBA
Associate Director
Maine Developmental Disabilities Council
-we believe communities are stronger when everyone is included

207-287-4221

Rachel.M.Dyer@Maine.gov