

# 2015 - 2017 BIENNIAL REPORT

Advocacy • Capacity Building • Systemic Change

Maine Developmental Disabilities Council  
225 Western Avenue, Suite 4  
Augusta, Maine 04330  
[www.MaineDDC.org](http://www.MaineDDC.org)  
1-800-244-3990  
207-287-4213



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## A MESSAGE FROM THE EXECUTIVE DIRECTOR

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As I reflect on the past two years at the Maine Developmental Disabilities Council, all I can say is “Wow!”

In 2015, we celebrated the 25th anniversary of the Americans with Disabilities Act. This seminal law created equal protection for Americans with disabilities and “set the stage” for MDDC’s role in protecting and improving the quality of today’s system of community based services. While the fiscal and regulatory environments can be challenging, I am grateful for Maine’s longstanding commitment to persons with developmental disabilities.

It has been my privilege to work with our committed Council members and engaged communities as we identified concerns and priorities while developing our 2017-2021 State Plan. This plan reflects our commitment to creating and supporting opportunities for Mainers with developmental disabilities to share their gifts.

I am especially proud of MDDC’s 2015/2016 work supporting the development of self advocacy, efforts to improve healthcare for children and adults with developmental disabilities, and employment for youth with disabilities. We are indebted to our partners in state agencies, at the university, nonprofits, and most of all to the persons with developmental disabilities and family members who make this work possible.

I invite you to visit our office, our website ([www.MaineDDC.org](http://www.MaineDDC.org)), or our Facebook page to learn more about our work and how you can get involved!

*Nancy Cronin*

## MISSION

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***“Maine Developmental Disabilities Council  
is committed to creating a Maine in which all people  
are valued and respected because we believe  
communities are stronger when everyone is included. “***

## MDDC MEMBERS

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|                    |   |
|--------------------|---|
| Teresa Barrows     | DHHS, Office of Child & Family Services             |
| Jan Breton         | DOE, Office of Special Services                     |
| Alan Cobo-Lewis    | Center for Community Inclusion & Disability Studies |
| Staci Converse     | Disability Rights Maine                             |
| Deb Davis          | Family Member                                       |
| Kate Quinn Finlay  | Family Member                                       |
| Roy Fowler         | DOE, Child Development Services                     |
| Kate Hersom        | Family Member                                       |
| Susan Jarmuz-Smith | Family Member                                       |
| Shannon Johnson    | Family Member                                       |
| Avery Olmstead     | Self Advocate                                       |
| Kile Pelletier     | Self Advocate                                       |
| Christian Powers   | Self Advocate                                       |
| Denise Ranger      | Family Member                                       |
| Marc Roix          | Self Advocate                                       |
| Jeffrey Shapiro    | DHHS, Office of Aging & Disability Services         |
| Monique Stairs     | Speaking Up For Us                                  |
| Emilee Taplin-Lacy | Family Member                                       |
| Sarah Trites       | Self Advocate                                       |
| Elinor Weissman    | DOL, Vocational Rehabilitation                      |
| Monica Wood        | Self Advocate                                       |
| Jean Youde         | Family Member                                       |

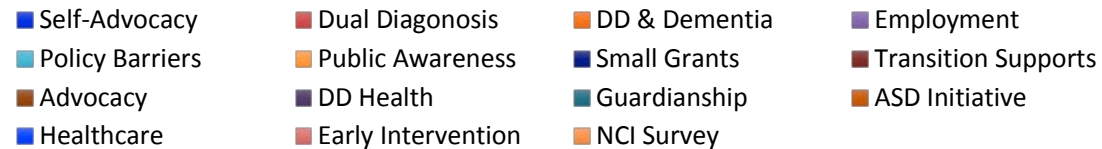
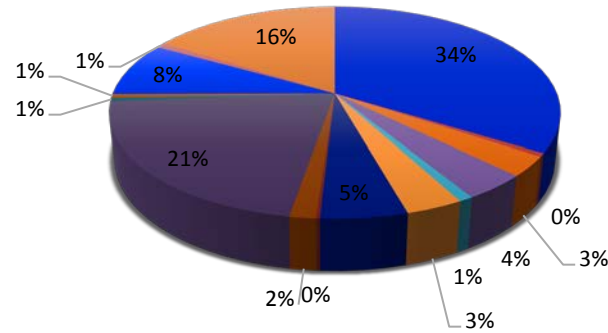
## MDDC STAFF

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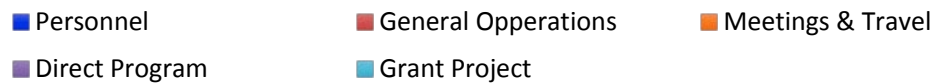
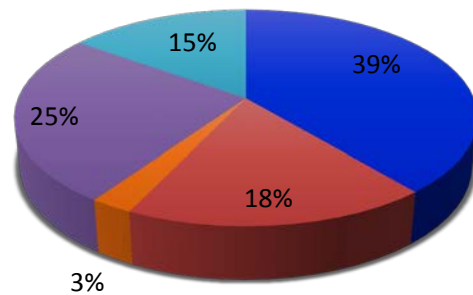
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|--|--|
| Nancy Cronin, <i>Executive Director</i>              | Rachel Dyer, <i>Associate Director</i>   |
| Erin Howes, <i>Office Manager</i>                    | Angela Burgess, <i>Program Associate</i> |
| Donald Johnson, <i>DD Health Project Coordinator</i> |  |

## FY15-FY16 MDDC EXPENDITURES

### PROGRAM & PROJECT EXPENSE DISTRIBUTION



### EXPENSE BY CATEGORY



## WHAT WE DO

MDDC promotes efforts to ensure that all individuals with developmental disabilities and their families are able to live and fully participate in their communities of choice. In partnership with people with disabilities, parents, advocates, and policy makers, MDDC works to increase 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.

### PROJECTS AND INITIATIVES 2015 / 2016

- 🌐 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
- 🌐 Developmental Disabilities Health Project
- 🌐 Dementia Services and Supports
- 🌐 Employment
- 🌐 Inclusion Awards
- 🌐 National Core Indicators
- 🌐 Quality Mental Health Services for Persons with Intellectual Disabilities
- 🌐 Raising Expectations
- 🌐 Small Grants Program
- 🌐 Supported Decision Making
- 🌐 Supporting Self Advocacy

## MDDC 5 YEAR STATE PLAN GOALS ~ 2017-2021

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### 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.**

#### **MDDC will:**

- Collaborate with partners to increase the civic engagement of individuals with developmental disabilities and family member.
- Support diverse Maine communities to increase capacity to be fully inclusive of individuals with developmental disabilities.
- Support the statewide self-advocacy organization to increase its effectiveness as an independent not-for-profit.
- 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. MDDC will:**

- Improve integration of services and supports for individuals with developmental disabilities and families.
- Support efforts to improve quality of services and supports for individuals with developmental disabilities and families.
- Support efforts to expand access to all aspects of community life for individuals with developmental disabilities and families.
- Increase access to information and services for underserved persons and families with developmental disabilities.

## “Disabilities”

by Brandon Whitney, Gorham High School  
2016 Inclusion Awards - Honorable Mention

### *Disabilities*

A word that leaves little to the imagination  
You see wheelchairs and crutches  
prosthetics and braces  
You see a man with down syndrome  
and a woman with autism  
But do you know what you don't see?  
Equality.

### *Equality*

A word that does not coincide with disabilities  
This word has been built for those who are whole  
those who are not affected by disabilities  
You see stairs and escalators proudly displayed  
while ramps and elevators are tucked aside out of the way  
And do you want to know why we put them off to the side?  
Embarrassment.

### *Embarrassment*

A word that is used to describe a society embarrassed by those who are not whole  
A society that won't look a human with disabilities in the eyes  
or give them the same basic courtesy as those around them  
So we create a false image that we are better because we are whole  
and we look down on those who are not  
And do you want to know the feeling that projects?  
Shame.

### *Shame*

A word that describes how the disabled are suppose to feel  
They are supposed to feel shamed that they are not like us  
and that they must rely on us to live out their lives  
And we as a society help breed the feeling of shame  
by publicly showcasing their disabilities  
But do you want to know who those who are disabled really are?  
Normal.



## INCLUSION AWARDS

In 2016, MDDC sponsored a writing contest for high school juniors and seniors that challenged students to develop essays in response to the questions “How has the Americans with Disabilities Act (ADA) not yet been fully realized for people with developmental disabilities? If the ADA was fully implemented, how might the world look differently for people with developmental disabilities?” This was a large scale effort to increase awareness and engaged students, educators, policymakers, and families. Over 80 entries were received. The winners were recognized at an awards ceremony in the Hall of Flags at Maine’s State House. Additionally, MDDC published a book of the top 14 contest entries entitled “Visions of Inclusion”. Copies of this book are available by contacting MDDC’s office.



## HIGHLIGHTS OF PROGRAMS AND ACTIVITIES ~ 2015 / 2016

### DEVELOPMENTAL DISABILITIES HEALTH PROJECTS

Healthcare for adults with developmental disabilities has been added to the existing State Improvement of Medicaid System (SIMS) project. DHHS contracted with MDDC to develop and deliver a curriculum targeting information regarding how behaviors change in response to pain, how to interact with the healthcare system, and understanding the multitude of systems and strategies for effective medical care coordination; to embed information regarding health and individuals with developmental disabilities to medical professionals into the existing learning collaborative; and to develop evaluation plans for each of the tasks.

In 2015-2016, over 1000 healthcare providers (physicians, physician extenders, nurses, and medical practice managers), developmental disabilities case managers and administrators, direct support professionals, guardians, family members, and support staff received the training “Improving Care and Communication for People with Intellectual and Developmental Disabilities”, focusing on pain-related behavioral changes. As a result of the training, 76% of respondents changed their communication style, 22% made changes to plans of care, 25% initiated pain assessments, and 23% have made other changes such as the way they treat behaviors, speak to individuals, and look for signs and symptoms of pain.

The Care Coordination for Children with Developmental Disabilities project’s goal is to evaluate the effectiveness of intensive coordination of services for children with developmental delays. In 2015-2016, 295 children had direct positive outcomes as a result of the enhanced care coordination project. 85% of these children were six years of age and younger. Most of the children benefited from advocacy that helped them access an adequate level of effective, appropriate services. In addition, the program reviewed over 600 developmental screenings, allowing physicians to provide a more comprehensive annual well-child check. This work is currently being evaluated for clinical and cost effectiveness to determine paths for sustainability.

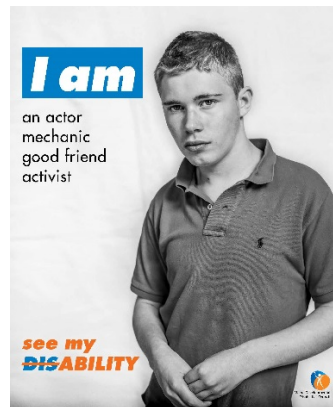
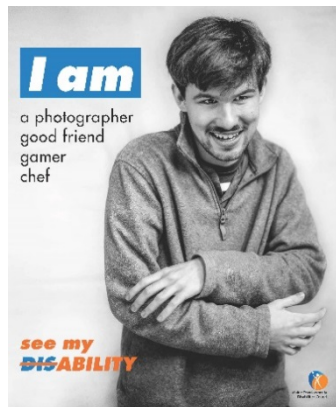
## SUPPORTING SELF ADVOCACY

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Through an ongoing contract and collaboration with Maine's statewide self advocacy organization, Speaking Up for Us (SUFU), MDDC provides resources and technical assistance to support individuals with developmental disabilities to have real, self-determined lives in the community.

In 2015-2016, over 450 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

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Participation in integrated community employment is strongly correlated with positive outcomes for people with disabilities: being a homeowner, having strong social supports, being engaged in community life, and utilizing fewer paid supports. Paid work experience is a strong predictor of adult employment, yet few youth with disabilities have summer jobs.

In 2015 - 2016, MDDC supported the Summer Work for ME Project, designed to provide youth with developmental disabilities with a range of work experiences to increase their understanding of work. Eleven greater Bangor area high school students receiving disability services participated in a six-week program in which they tried out three (paid) job sites at Eastern Maine Community College.



## NATIONAL CORE INDICATORS

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Maine is one of 46 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.

In 2015 and again in 2016, 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:

[www.nationalcoreindicators.org](http://www.nationalcoreindicators.org)