



## Massachusetts Developmental Disabilities Council 2019 Annual Report to the Citizens of Massachusetts

*Providing opportunities for people with developmental disabilities and their families to enhance independence, productivity, and inclusion.*

### Our Purpose

The Massachusetts Developmental Disabilities Council (MDDC) is an independent agency funded by the federal government to work with the Commonwealth of Massachusetts to better support people with developmental disabilities and their families.

### Our Beliefs

Individuals with developmental disabilities must have the opportunity to live full, productive and independent lives in the community. Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities.

### Member Spotlight

Raquel Quezada is a Council Member, parent and alumnus of the Allen C. Crocker Family Fellowship, co-sponsored by the Massachusetts Developmental Disabilities Network. Prior to moving to the United States in 2001, Raquel worked as a journalist for television and radio in the Dominican Republic. Raquel moved to Massachusetts in 2003, where she married and had a child born with Cerebral Palsy.

"I quickly learned that the struggles I faced raising a child with a disability were made even more difficult by language barriers and cultural differences," stated Raquel. Her efforts to obtain information and support were often met with hostility, but Raquel persevered to gain the knowledge needed to be sure her son has the opportunity to live in an inclusive community.

Using her experience as a journalist, Rachel initiated the radio show "Cambiando el Mundo de Personas Con Discapacidad" ("Changing the World of People with Disabilities"). The station broadcasts on WLLH, a commercial AM radio station in the Merrimack Valley region of Massachusetts, branded as La Mega 95.1. Rachel uses this medium as a platform to engage Latino families to expand their knowledge about laws, policies, processes and services related to children and adults with disabilities. Raquel believes her prior experiences serve as a constant reminder of her purpose and concern for people with disabilities and their families.



Raquel has elevated the work of the Council with the Latino community by live streaming the Council's annual Legislative Reception and Legislative Breakfast, as well as providing information about Council sponsored events and initiatives.

### Our Report to the Citizens

We are pleased to present our annual *Report to the Citizens of the Commonwealth*. This report is also available on the Council website [www.mass.gov/mddc](http://www.mass.gov/mddc). We encourage you to give us feedback. Please send all questions and comments to [craig.hall@state.ma.us](mailto:craig.hall@state.ma.us).

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### ***Chances are you know someone with a developmental disability***

Although the exact number is unknown, it is estimated that over 157,255 citizens in the Commonwealth of Massachusetts have a developmental disability.

### What We Do

- Work to improve the system of supports for individuals with developmental disabilities and their families by bringing advocates together with lawmakers to make sure people with developmental disabilities are included in public policy decisions.
- Foster partnerships with disability advocacy groups and support initiatives that help to build the self-confidence, interpersonal and leadership skills that people with developmental disabilities need to live independently and play active roles in their communities.
- Serve as an impartial educational resource, informing public policy at the local, state and federal levels, to better meet the needs of individuals with developmental disabilities and their families.

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# State Plan Implementation Progress Report: Year 3

Goal	By the Numbers (Our Measures)
<b>1. Advocacy and Leadership</b>	688 individuals with disabilities participated in Council sponsored programs, which included the Crocker Fellowship, Self Advocacy Leadership Series, Independence College, Youth Leadership Forum, Individualized Education Program and Special Education trainings grants. Impact: A 95% satisfaction rate was achieved through these Council Activities.
<b>2. Supporting Families</b>	354 family members family members participated in Council supported activities, which included the Supporting Families Coalition, Statewide Transition Conference, Council policy education, Fetal Alcohol Spectrum Disorder , MASS Health and Autism Insurance Trainings, and Family Support Training. Impact: 100% satisfaction rate was achieved through these Council Activities.
<b>3. Inclusive Communities</b>	263 individuals with disabilities and stakeholders were educated about Council supported activities, which included policy-maker housing education, Independence College Employment Training, the Massachusetts Partnership for Transition to Employment and the Employment Task Force. Impact: 100% satisfaction rate was achieved through these Council Activities.
<b>4. Exercising Rights</b>	271 individuals with disabilities, families and the public were education on Council initiatives, which included the Supported Decision-Making Legislative Group, Massachusetts RevUp, the Guardianship Working Group, and Legislative Advocacy Training. Impact: 97% satisfaction rate was achieved through these initiatives.

*Note: This chart was derived from the preliminary data collected for the 2019 Program Performance Report. The full report will be published in the spring of 2020 and located at [www.ddsuite.org/search/](http://www.ddsuite.org/search/). The five year State Plan is located at [www.mass.gov/mddc](http://www.mass.gov/mddc).*

## Supported Decision-Making

The Council brought to the forefront the need for viable alternatives to full guardianship for people with disabilities during 2019. One such alternative is known as Supported Decision-Making (SDM). SDM is when people with disabilities keep their rights and decision-making capacities. Instead of a guardian making all choices for them, people with disabilities have supporters who help them make their own choices in specific areas of life.

The Council worked extensively with self-advocates, ensuring they had a seat at the table and a voice in the discussion through accompanying self-advocates at meetings with policymakers throughout 2019, and assisting Council members in drafting testimony to the Joint Committee on Children, Families, and Persons with Disabilities. The Committee held a public hearing in June on HB 172: An act relating to authorizing SDM agreements for certain adults with disabilities.

Council Member Becky Fillmore (pictured) attended the hearing and echoed other self-advocates in admitting that she needs help making certain decisions, but not all decisions, and how SDM could help in these situations.



The Council also played a lead role in including self-advocates in policymaking decisions by participating in the SDM Legislative Task Force, which into the Massachusetts Advocates for SDM coalition (MASDM). The Council continues to assist the MASDM by tracking the legislation and assisting self-advocates in educating as many legislators as possible on the positive impact alternatives to full guardianship will have.

## Council's Guardianship Workgroup

The Council's Guardianship Working Group (GWG) brought together various stakeholders who worked extensively on creating an educational guide for individuals navigating the guardianship system in Massachusetts.

The Guardianship Challenges and Options guide contains resources for individuals who seek help with a guardian who may be limiting their access to family and friends, and might not be following through with their commitment to the person, or who may no longer be necessary as a guardian. The guide includes steps that can be taken, including references to important information ranging from forms for requesting an attorney to forms to file for termination of a guardianship.

The guide was published in June of 2019 by the Massachusetts Developmental Disabilities Network. More than 200 copies of the guide were distributed through stakeholder organizations who participate in the GWG, such as the Mental Health Legal Advisors Committee, Massachusetts Department of Developmental Services, Delta Projects, the Center for Public Representation, and the Disability Law Center.

### Guardianship Challenges and Options

**A guide for concerned persons when you think there may be a problem**



*"Unless someone like you cares a whole awful lot, nothing is going to get better. It's not."*

~Dr. Seuss

This information is not offered as legal advice and should not be used as a substitute for seeking professional legal advice.



Please visit our website, [www.mass.gov/mddc](http://www.mass.gov/mddc), for more information!



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# Revenue and Expenses

## Revenue

Source of Revenue	2019 Revenue (in \$)
Federal Funding	\$1,299,302.06
Commonwealth Non-Financial Match	\$202,742.02
Sub-Grantee Match	\$55,804.56
Developmental Disabilities Suite	\$137,244.71
<b>Total Revenue</b>	<b>\$1,695,093.35</b>

The **financial mission** of the Council is to maximize the use of our federal awards, while leveraging additional resources from the Commonwealth, our grantees and other collaborations and partnerships, to meet our five-year State Plan goals and objectives.

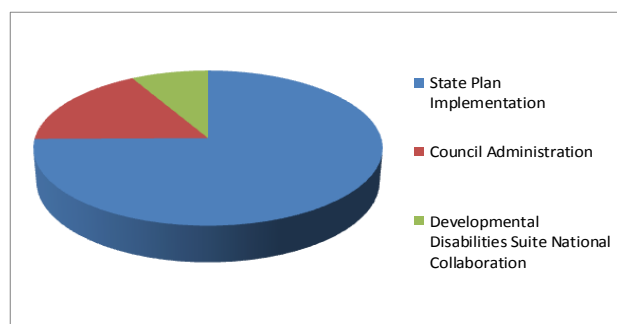
**Note:** The Council is funded through a federal formula grant and is authorized under Subtitle B of Public Law 106-402, the Developmental Disabilities Act of 2000, and through Governor's Executive Order #512.

### Independent Audit

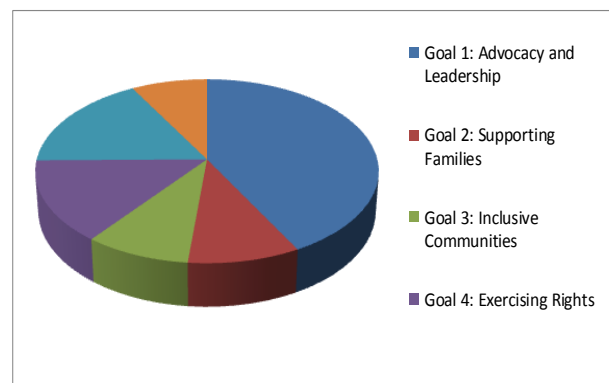
The Council participated in the independent audit, receiving a clean opinion. Complete financial information is available at [www.mass.gov/osc](http://www.mass.gov/osc).

## Expenses

By Functional Area	2019 Expense (in \$)
State Plan Implementation	\$1,268,447.28
Council Administration	\$289,401.36
Developmental Disabilities Suite	\$137,244.71
<b>Total Expenses</b>	<b>\$1,695,093.35</b>



By State Plan Area	2019 Expense (in \$)
Advocacy and Leadership	\$715,150.34
Supporting Families	\$159,147.68
Inclusive Communities	\$150,068.55
Exercising Rights	\$244,080.72
Council Administration	\$289,401.36
Developmental Disabilities Suite	\$137,244.71
<b>Total Expenses</b>	<b>\$1,695,093.35</b>



### A Model of Transparency

The Council's 2018 report received the Certificate of Excellence in Citizen-Centric Reporting from the Association of Government Accountants for advancing government accountability. The logo recognizes the importance of a citizen focused initiative for financial reporting.



### What We Do: Our Primary Program Areas

The Council has two primary program areas. The **functional area** divides the organization by our program and administrative activities.

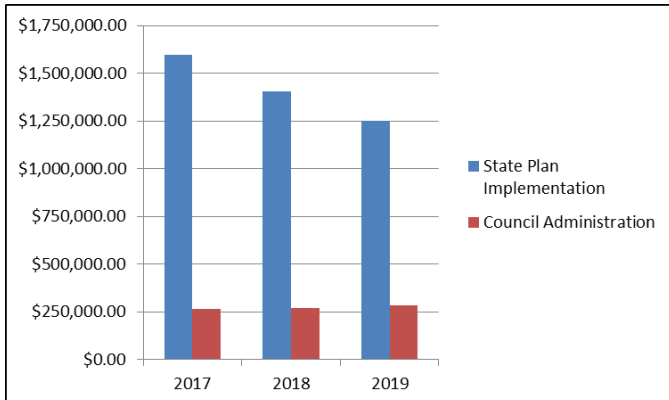
The **state plan areas** identify the program activities we undertake to successfully meet our five-year State Plan goals and objectives.



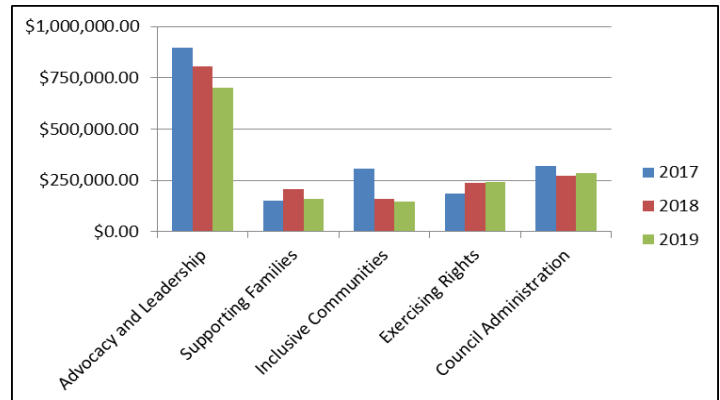


# Looking Forward: Challenges Ahead

The table below illustrates the decrease in funding available for State Plan Implementation over the first three years of the current State Plan. Despite diligent efforts to maintain lower administration costs, this trend will continue due to level funding.



The table below shows spending by Goal Area through the first three years of the current State Plan. Although spending has remained relatively consistent, performance evaluation has led to priority adjustments within the Goal Areas,

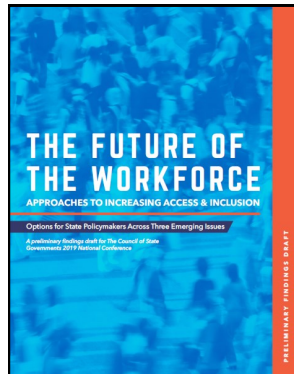


## Early Planning Stage for Next Five Year State Plan 2022-2026

The DD Act (P.L. 106-402) requires Councils to develop five-year State Plans based on data-driven strategic planning. In 2020 the Council will begin a comprehensive “looking forward” process to develop our next State Plan (2022-2026). Council members, staff, network partners and key stakeholders will evaluate our current work and initiatives, identify emerging issues, and develop a vision for the future, providing the framework for new goals and objectives. The challenge ahead is to strategically allocate funds in a manner that focuses on priority outcomes while maintaining the high level of success achieved over the past 20 years.

## Council “Leader” in Future of Work Efforts

In 2019 the Council participated on the **Stay at Work/Return to Work Leadership Team**, a continuing effort of the Council of State Governments, in collaboration with the U.S. Department of Labor’s Office of Disability Employment Policy’s State Exchange on Employment and Disability (SEED).



The latest report, **The Future of the Workforce: Approaches to Increasing Access and Inclusion**, will be published in 2020. This report will focus on advances in automation and technology, the rise of the gig economy and the changing nature of apprenticeships.

The reports are available through the Council’s website.



July 26, 2020 marks the 30th anniversary of the Americans with Disabilities Act. This landmark civil rights legislation has impacted millions of Americans with disabilities by prohibiting discrimination and guaranteeing that people with disabilities have the same opportunities as everyone else to participate in the mainstream of American life.

Logo Credit: ADA National Network ([adata.org](http://adata.org)).

## Maintaining High Customer Satisfaction

The Council conducts customer satisfaction surveys for all grants and projects funded or implemented by the Council. Survey results help determine the impact of our efforts on the lives of individuals with developmental disabilities and their families. The data is mandated by the U.S. Office on Intellectual and Developmental Disabilities and the results are reported in the Council’s annual Program Performance Report. Customer satisfaction in 2019 was 97.7%, based on responses from 475 individuals.



Please visit our website, [www.mass.gov/mddc](http://www.mass.gov/mddc), for more information!



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