



## Massachusetts Developmental Disabilities Council 2020 Annual Report to the Citizens of Massachusetts

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

### Rethinking Guardianship

The continued work of the Council's Guardianship Working Group (GWG), a diverse group of stakeholders in the Massachusetts guardianship system, led to the development of a curriculum to train Probate and Family Court personnel on less-restrictive alternatives to plenary (full) guardianships. In 2020 the Council partnered with the [Center for Public Representation \(CPR\)](#) and provided a \$20,000 grant to collaborate with the GWG on curriculum development. CPR utilized the expertise of the members to solicit feedback on the curriculum, and to discuss which court personnel to target, how to best to conduct training and insight into how to ensure a positive response by the court.

The curriculum will be finalized early in 2021 and will include live and virtual presentations, short videos accompanied by a manual outlining the alternatives to guardianship, and a reference guide for judges to utilize while deliberating on guardianship proceedings.

### Innovative Response to the Pandemic

At the onset of the COVID-19 pandemic, with scarce resources the Commonwealth prioritized distribution of personal protective equipment (PPE) to hospitals, health care providers and other congregate care facilities. However, families of people with disabilities living at home, particularly the medically fragile, were also among the most vulnerable. A family member contracting COVID-19 in the home will put the member with a disability at significant risk.

Holly Simione is a Council Member and mother to Elizabeth, who was one of more than 800 medically fragile kids in Massachusetts with developmental disabilities. Holly and Daniel Shannon, Council Executive Director, worked with Ryan Kath at NBC10 Boston to spotlight the crisis



*Council member Holly Simione and her daughter Elizabeth.*

that families with complex medical health care needs were facing (watch: [PPE Shortage Threatens Safety of Medically Fragile Kids](#)).

Following this media coverage, the Council connected with a Harvard Business School project, dubbed the "PPEople First Procurement Team", securing over 3,600 KN95 masks in April, followed by an additional 5,280 N95 masks and 10,000 gloves (watch: [Harvard Students Secure PPE Donations for Medically Fragile Children](#)). The Council set up a life-line to distribute PPE to families with medically fragile children, as well as other individuals and families with developmental disabilities, in-home nurses, personal care attendants, home health workers, homeless shelters, community action councils, and veterans' organizations. Simione said simply that she was "blown away" by the Council's efforts and the outpouring of support since she shared her story. "It brought me to tears. Not just about what we are facing, but really the Council helping all the people in our state like my daughter."

### 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@mass.gov](mailto:craig.hall@mass.gov).

### Who We Are

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

### Our Belief

Disability is a natural part of the human experience, and people with developmental disabilities have the right to make their own choices, to live independently, and to fully participate in and contribute to their communities.

### What We Do

- Work to improve the system of supports for individuals with developmental disabilities and their families by bringing advocates together with policymakers to be sure people with developmental disabilities are included in policy decisions that impact their lives.
- 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 have active roles in their communities.
- Serve as an objective resource to inform public policy at the local, state and federal levels, to better meet the needs of individuals with developmental disabilities and their families.

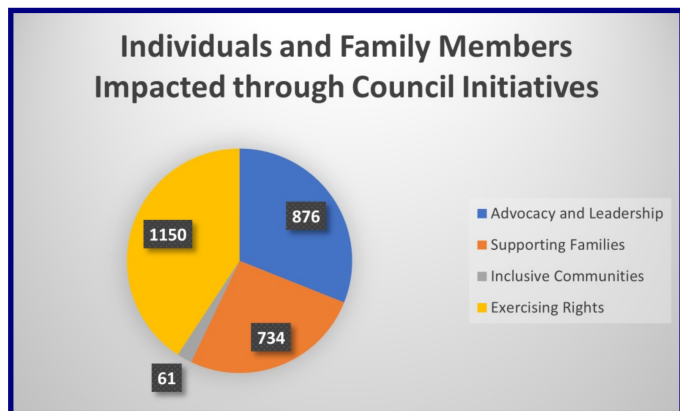
### ***Chances are you know someone with a developmental disability***

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



# State Plan Implementation Progress Report: Year 4

The pie chart below represents the direct impact of strategic initiatives through education, training, partnerships and collaborations across Goal areas.



## Targeted Disparity

The Council encountered significant barriers in our efforts to reach individuals with developmental disabilities and their families from the many diverse, non-English speaking communities in Massachusetts. The lack of effective trainings and translated materials was uncovered across all Council goals areas focusing on health care, education, and supporting families. To address these gaps, the Council partnered with and awarded grants to [Mass Advocates for Children \(MAC\)](#), [Autism Insurance Resource Center \(AIRC\)](#), and the [Federation for Children with Special Needs \(FCSN\)](#) to conduct trainings and develop resources in multiple languages. MAC conducted 9 in-person special education workshops in underserved Spanish-speaking communities, reaching 94 Latinx family members of children with developmental disabilities. MAC also held two virtual workshops with 35 Latinx parents. AIRC conducted trainings for underserved linguistically diverse family members to access autism health insurance and Medicaid for their family members with disabilities. The trainings provided information about accessing insurance benefits, treatment, and therapies for family members with Autism and other disabilities. The trainings were conducted in Spanish, Vietnamese, Cantonese, Mandarin, Somali, and Portuguese, reaching more than 100 families. FCSN provided training on special education to Haitian and Latinx parents of children with developmental disabilities. The trainings utilized a mix of in-person and virtual platforms, helping more than 50 families to improve their special education knowledge and skills.

## Council Co-Sponsors Legislative Event on Employment of People with Disabilities

In recognition of National Disability Employment Awareness Month, in October 2019 the Council sponsored a panel session at the State House to discuss barriers to meaningful employment of people with disabilities.

The event drew more than 50 state legislators, Council Members, and other citizens. The event was hosted by [Representative Josh Cutler \(D\)](#) and [Senator Patrick O'Connor \(R\)](#), highlighting the bipartisan efforts in Massachusetts to ensure that more people with disabilities gain meaningful employment.

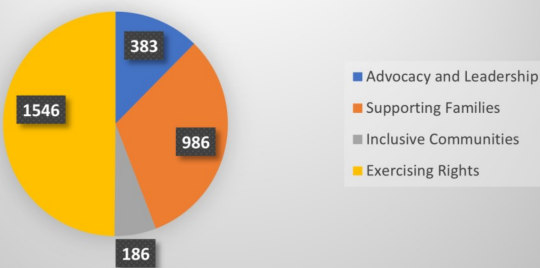
Participants (some pictured below) were also able to network and speak with key legislators about the barriers that exist for people with disabilities seeking employment. The event included a panel discussion, led by Kristin Britton, the Council's Director of Public Policy, with key stakeholders speaking about the successes and challenges of employment for people with disabilities in Massachusetts and the nation.



Panelists included Joe Bellil of [Easter Seals](#), Jim Cassetta of [Work, Inc.](#), both from disability services organizations; Kathy Petkauskos of [Work Without Limits](#), a network of employers, educational institutions, and employment service providers; Carl Richardson, Mass State House ADA Coordinator; and Rebecca (Becky) Fillmore, a Self-Advocate DD Council Member and intern for Senator O'Connor.

Panelists offered their expertise to highlight the barriers people with disabilities face in gaining employment and recommended solutions that policymakers can utilize in addressing those barriers.

## People Educated through Council Systems Change Initiatives



The pie chart above represents the Council's efforts promoting policies that facilitate and reinforce systemic change for people with developmental disabilities across Goal areas.



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	2020 Revenue (in \$)
Federal Funding	\$1,282,119.67
Commonwealth Non-Financial Match	\$210,391.04
Sub-Grantee Match	\$34,972.56
Developmental Disabilities Suite	\$81,993.56
<b>Total Revenue</b>	<b>\$1,609,476.83</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.

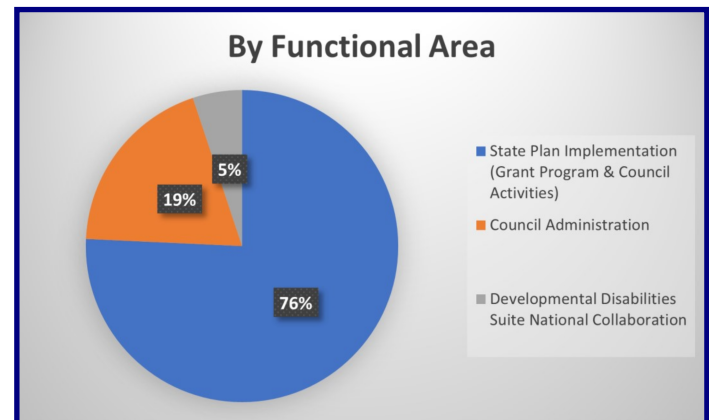
**Note:** The Council is funded through a federal formula grant and is authorized under Subtitle B of Public Law 106-402, the Developmental Disabilities Act of 2000, and through Governor's Executive Order #512.

### Independent Audit

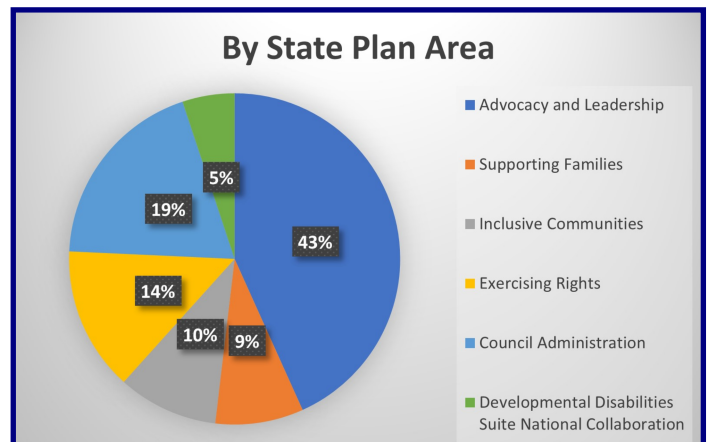
The Council participated in the independent audit, receiving a clean opinion. Complete financial information is available at [www.mass.gov/osc](http://www.mass.gov/osc).

## Expenses

By Functional Area	2020 Expense (in \$)
State Plan Implementation	\$1,218,821.04
Council Administration	\$308,662.22
Developmental Disabilities Suite	\$81,993.56
<b>Total Expenses</b>	<b>\$1,609,476.83</b>



By State Plan Area	2020 Expense (in \$)
Advocacy and Leadership	\$696,281.01
Supporting Families	\$138,635.88
Inclusive Communities	\$157,776.52
Exercising Rights	\$226,127.64
Council Administration	\$308,662.22
Developmental Disabilities Suite	\$81,993.56
<b>Total Expenses</b>	<b>\$1,609,476.83</b>



### A Model of Transparency

The Council's 2019 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 areas** portray 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.



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



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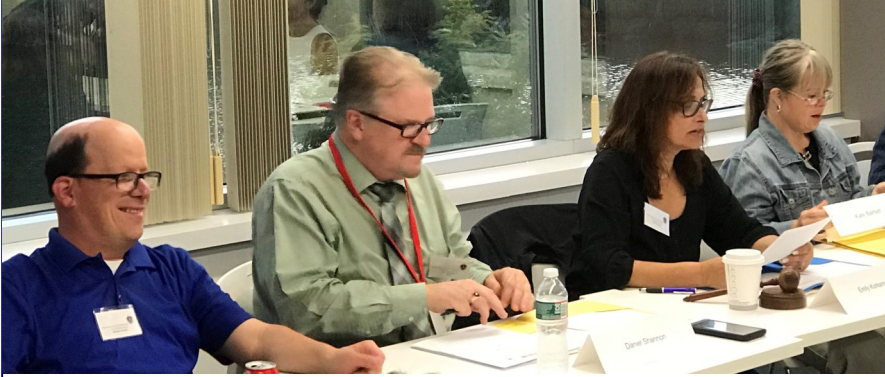


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# Looking Forward: Challenges Ahead

## New Five-Year State Plan Begins October 2021



Fall 2019 Council Meeting. Left to right: Matthew Bander, Vice Chairperson, Daniel Shannon, Executive Director, Emily Korkaris, Chairperson, and Kate Bartlett, Secretary.

In 2020 the Council began the process to develop our next five-year State Plan, which begins in October 2021. The Council State Plan Committee developed and widely distributed the first of two public input surveys in Spanish and English, seeking input from individuals with disabilities, family members, disability advocates and other stakeholders about the most critical issues facing people with developmental disabilities and their families in Massachusetts. More than 200 responses were received.

Three virtual public forums were held in the early fall, with over 100 people participating. One forum was held for Spanish speakers, facilitated by Council member Rachel Quezada. This Input was used by the State Plan Committee as the basis for considering Council priorities.

Work continues to complete a comprehensive review and analysis of services and supports for people with developmental disabilities and families. An analysis of the data and findings will be presented to the State Plan Committee early in 2021, and the committee will present recommendations for five-year goals and objectives to the full Council in June. The public will have a 45-day period to submit comments prior to the final State Plan submission to the federal Administration on Community Living in August 2021.

## Training Programs Adapt to COVID-19 Pandemic

All Council in-person trainings abruptly stopped in March 2020 due to the COVID-19 pandemic. The Council training team, including Tamara Huntley (pictured) immediately worked to modify all training curricula for use in virtual classrooms. The team leveraged Zoom and Google Classroom as new training platforms, piloting online versions of the Self Advocacy Leadership Series, Independent College Employment Series, and Legislative Advocacy.



119 students completed virtual training during 2020. Online training is more accessible and convenient for most students, and the number of students reached more than tripled. Feedback from students, teachers and parents has been overwhelmingly positive.

Transportation problems are removed through virtual training. The Council is looking to expand virtual training in the future, providing opportunities for more schools to participate, and to better reach more remote areas in Southeastern and Western Massachusetts.

## New Commission in Support of People with Disabilities

[Chapter 253 of the Acts of 2020](#) established a new Commission on the Status of Persons with Disabilities.

The Council will have a seat on the commission and will work with partner agencies and advocates "to advance the cause of all persons with disabilities in the commonwealth."

The commission will "study, review, advise and report" on a range of matters.

## Learn More About Our Online Trainings at [MASS.GOV/MDDC](https://www.mass.gov/mddc)

All Council training series are taught by people with disabilities.

[Self-Advocacy Leadership Series](#) is a 7 week online interactive series for adults with intellectual and developmental disabilities between the ages 18-22. The series focuses on soft skill development and the fundamentals of communication and leadership.

The [Employment Series](#) is a 5 week interactive training series held two days each week, designed for young adults with intellectual and developmental disabilities between the ages 18-22. The series assists students in achieving independence and reaching their goals for competitive and integrated employment.

[Legislative Advocacy Training](#) is a two-part series designed for people with intellectual and developmental disabilities focusing on the legislative process, communicating with legislators, and voting.

## Customer Satisfaction over 97%!

The Council solicits feedback about our program initiatives and our work with policymakers and the community on a continuous basis. Responses help us to measure the impact of our efforts on the lives of citizens with developmental disabilities and families, and provides input that helps shape our future efforts. Based on responses from 418 individual surveys customer satisfaction in 2020 was 97.8%. These results are also included in the Council's annual Program Performance Report.

