



Massachusetts Developmental Disabilities Council 2021 Annual Report to the Citizens of Massachusetts

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

Abuse Registry Bill Signed into Law

The Council priority legislation to prevent abuse and neglect of people with developmental disabilities passed in the most recent legislative session. In February 2020, Governor Charlie Baker signed the Abuse Registry bill, also known as Nicky's Law. This success was a result of tremendous advocacy by partner organizations and the disability community, including Council members Hillary Dunn Stanisz and Kathleen Amaral, who shared their poignant testimonies as to the importance of the bill and its impact on the community.



Pictured: The Chan family, with Nicky (second from right), the namesake of the bill. Courtesy of The Arc of Mass.

Nicky's Law creates a registry run by the Disability Persons Protection Commission for caretakers funded through or working for programs licensed by the Massachusetts Department of Developmental Services who have substantiated abuse allegations. The goal of creating the registry is to prevent these individuals from job-hopping and continuing to abuse or neglect people. The registry includes a comprehensive formal appeal process and is accessible only to certain approved employers.

Advocating for Access to Higher Education

Council Self-Advocate Member, Kate Bartlett, a former student of Middlesex Community College, continues to support legislation about education for people with developmental disabilities in the Commonwealth. They gave powerful testimony to the Joint Committee on Higher Education on An Act creating higher education opportunities for students with intellectual disabilities, autism, and other developmental disabilities (SB 846/HB 1331). Kate emphasized that they would not be able to succeed in their job at a Boston staffing company without the skills they learned during college.



"I know I got further in college than most people with Down syndrome. I was qualified, had documentation about my disability and accommodation needs, and yet, I still ran into roadblocks. Unfortunately, there are still barriers to higher education for people with disabilities, even for people who have met the requirements to attend college," they said. "I credit my education, college included, as an important reason I am working, living independently and supporting myself financially." said Kate.

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. We encourage you to give us feedback. Please send all questions and comments to 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 161,688 citizens in the Commonwealth of Massachusetts have a developmental disability.



State Plan Implementation Progress Report: Year 5

Council Spotlight on Impact through Coalition Work

Guardianship Alternatives and Innovation Coalition - The Council has been instrumental in efforts to promote supported decision-making and alternatives to guardianship across the state. Activities over the last five years include educating legislators, strategically convening partner organizations and stakeholders to form a working group, and having members share public testimony in support of targeted legislation. The Council also provided grant funding to the Center for Public Representation to develop curriculum on guardianship alternatives for the Probate Court and to develop and pilot an innovative decision-making curriculum for transition aged youth. Most of all, the Council has established strong partnerships with stakeholders and influential organizations working to promote the practice of supported decision-making. Through this work Council has helped build a strong foundation for systemic changes that will give disabled people control over their lives and avoid unnecessary guardianship.

The Council serves as a member on the **Coalition for the Rights of Families with Disabilities**, which was formed in response to the Massachusetts Department of Children and Families' November 2020 settlement with U.S. Department of Justice and Health and Human Services. The settlement focused on improving services for parents and children with disabilities. The Coalition is an external stakeholder group that represents a cross-section of organizations and people who have extensive experience with both the Massachusetts child welfare system and expertise working with parents with disabilities involved with Department of Children and Families. The goal of the coalition is to provide information and community input during a critical implementation phase of the settlement agreement.

The Council's Self-Advocacy Partnership

State Plans must have an annual goal related to self-advocacy. The Council partnered with Massachusetts Advocates Standing Strong (MASS) in Fiscal Year 2021, providing \$48,000 in grant funding to create leadership, mentorship, training and collaboration opportunities for people with intellectual and developmental disabilities (I/DD).

MASS' accomplishments include training individuals with I/DD and increasing awareness about issues and policies impacting them, including supported decision making (SDM), self-advocacy, Individual Support Plans (ISPs), COVID-19 safety and vaccines, history of people with disabilities in large institutions, and legislation to ban aversive shock therapy in Massachusetts.

MASS' Rainbow Group provided support and training to strengthen the voices of underserved LGBTQ+ individuals with developmental disabilities.

Fourteen self-advocate trainers and 7 MASS staff and coordinators were certified as Leadership trainers for the Self-Advocacy Leadership Series.

MASS coordinators hosted weekly and monthly regional and statewide meetings. Approximately 550 people with I/DD participated in training and other grant-sponsored activities.

MASS' first ever online Zoom statewide conference attracted more than 600 individuals, resulting in more than half of the attendees connecting to MASS for the first time and continuing their participation in MASS programs after the conference ended.



DD Network and COVID Funding

Vaxabilities is a series of disability-friendly vaccination events across Massachusetts. These events had extra staff to provide skilled support to people with disabilities and/or sensory support needs. Most of these events offered COVID vaccinations for children.

This partnership is led by the Massachusetts Developmental Disabilities Network including the Eunice Kennedy Shriver Center at the UMass Chan Medical School, the Institute for Community Inclusion at UMass Boston, the Disability Law Center and the Developmental Disabilities Council. The partnership includes numerous other partners including state agencies, major clinical centers throughout the Commonwealth and other professional groups.



Customer Satisfaction Exceeds 97%

The Council solicits feedback about our program initiatives and our work with policymakers and the community on a continuous basis. Based on responses from 306 individual surveys, customer satisfaction in 2021 was 97.7%. Based on 1733 responses the average over the 2017 -2021 five-year state plan was 97.5%.



Please visit our website, www.mass.gov/mddc, for more information!



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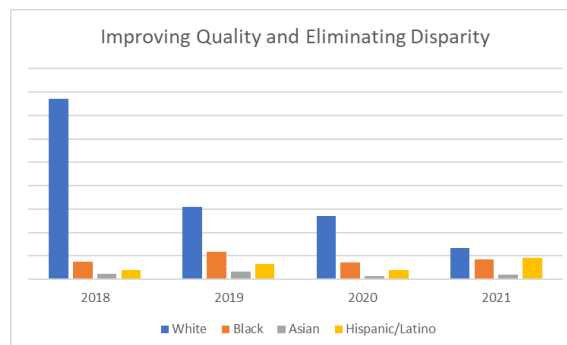
Special Five Year Report: Program Results of 2017-2021

State Councils on Developmental Disabilities (Councils) are self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems change that help these individuals gain more control over their lives.

Councils are required to submit a plan that includes 5-year goals, developed through data-driven strategic planning for advocacy, capacity building, and systemic change related to DD Act, Section 124, (C)(4)(A). Councils report annually on performance.

Targeted Disparity: Subpopulation and Area of Disparity

Based on findings of the comprehensive review and analysis the Council identified a subpopulation of the larger population of people with developmental disabilities who are vulnerable to disparities. One result of proactive strategies decreased the differences in advocacy skills among the Latino and African American students. Between 2018-2021, and illustrated in the table below, the percentage change for White decreased from 85% to 41%, Black an increase of 8% to 26%, Asian an increase of 2% to 6% and Hispanic/Latino an increase of 4% to 27%.



Goal 1: Advocacy and Leadership

People with developmental disabilities and family members will engage in self-advocacy, systems advocacy and leadership.

192 people reported increasing their self-advocacy and leadership efforts in 2021. Five-year total = 657

Goal 2: Supporting Families

Families will have access to the supports they need to ensure fulfilling lives for their family members with developmental disabilities in the community

149 individuals and family members participated in Council supported activities in 2021. Five-year total = 2301

Goal 3: Inclusive Communities

People with developmental disabilities will enjoy meaningful and inclusive lives in their communities.

52 people reported increasing their advocacy around community inclusion in 2021. Five-year total = 161

Goal 4: Exercising Rights

People with developmental disabilities will exercise their rights and be safer in their homes and communities.

45 individuals and family members participated in Council supported activities in 2021. Five-year total = 1098



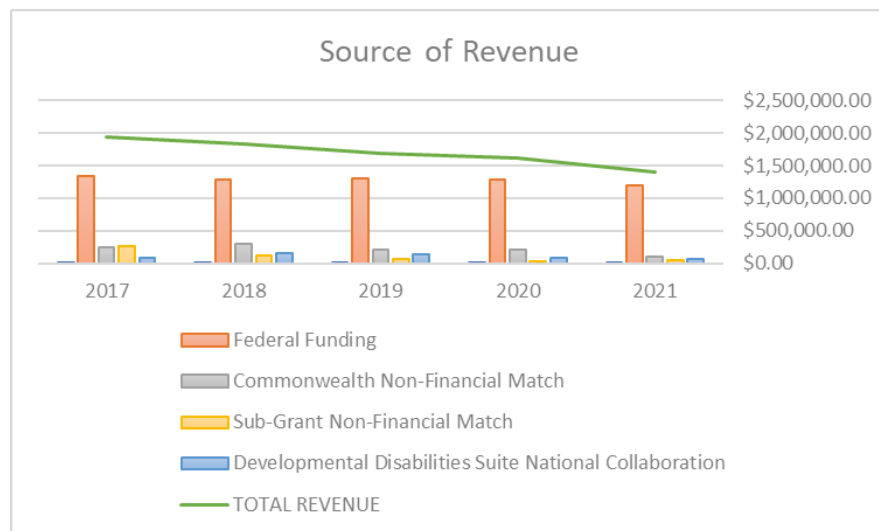
The preparations for our 2022-2026 Five-Year State Plan coincided with a once-in-a-century global pandemic. But that did not stop us. Through virtual forums held in English and Spanish, we gathered public input about future priorities. When there was a scarcity of personal protection equipment, we reached out to the media whose reporting resulted in significant donations. When vaccines became available, we hosted disability-friendly VaxAbilities clinics throughout the state. Finally, when it came to our continued efforts to advance disability-related legislation, we helped move a number of our endorsed and supported bills closer to the finish line.

—Gyasi Burks-Abbott, Council Public Policy Chairperson and pictured above.



Special Five Year Report: Spending Results of 2017-2021

State Councils on Developmental Disabilities (Councils) are funded through formula grants authorized under Subtitle B of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Under the Act, states shall establish and maintain a Council to undertake advocacy, capacity building, and systemic change activities as well as implement a State Plan.



The table “Sources of Revenue” illustrates a continued gradual decrease in federal funding. As federal funding decreases, and costs increase, the Council’s impact and influence is challenged.

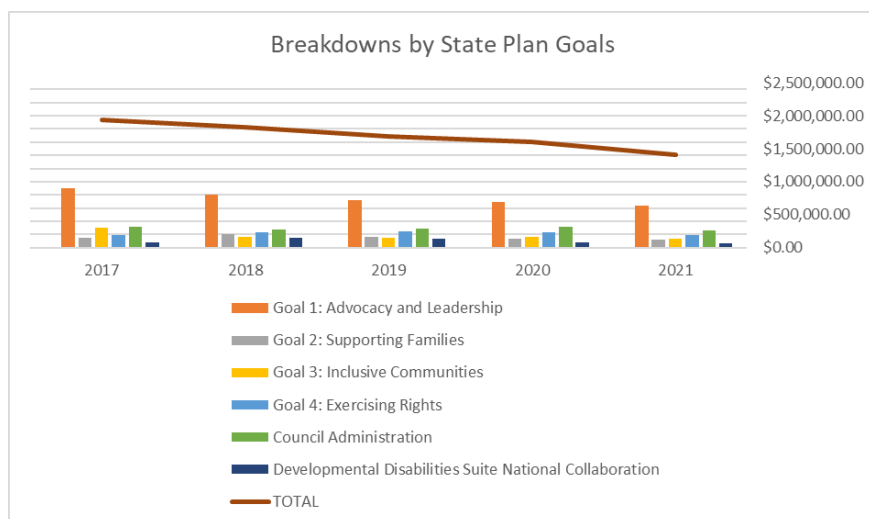
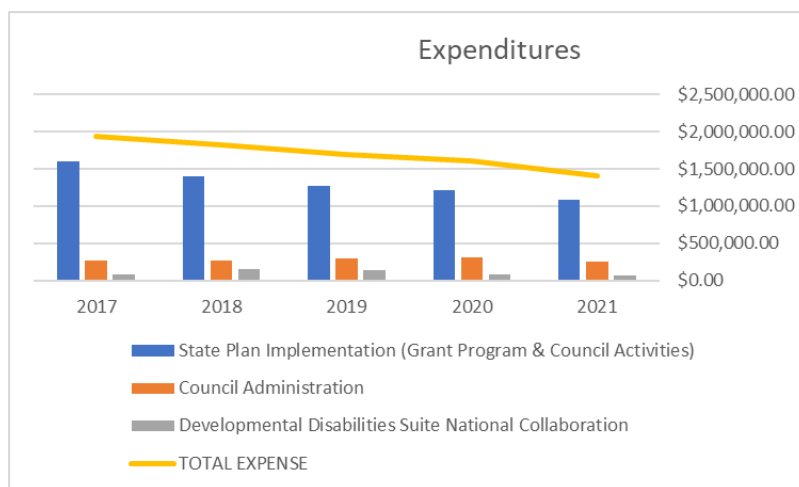
The table below “Expenditures” illustrates the decrease in spending in the State Plan Implementation, but also the challenge to decrease Council Administration.

The Council also recognizes the Developmental Disabilities Suite National Collaboration, which is a partnership of Councils nationwide, is affected by overall federal funding decreases.

39 Grants Awarded Between 2017-2021

The Council awarded 39 grants totaling more than \$514,063 with projects included self-advocacy, housing, education, youth leadership, special education, guardianship alternatives, and autism insurance. These projects addressed all four State Plan Goals.

FFY	Subgrants	Spending
2017	7	\$59,919.64
2018	8	\$194,844.15
2019	6	\$77,638.00
2020	7	\$113,314.36
2021	11	\$68,347.61



The table “Breakdowns by State Plan Goals” illustrates spending by Goal area in each year of the five-year State Plan. The average spending by year was approximately \$1,304,000.

The Goal of Advocacy and Leadership was the largest area of spending at approximately \$3,750,000 through the five years. This area included people with developmental disabilities who participated in Council supported activities.

The number of people increased from annually. In 2017, 1,491, 2018, 2,907, 2019 4,401, 2020 1,974 and 2021 1,832. The upward trend was disrupted by the COVID-19 Pandemic. However, analysis suggests that the projects adapted to the pandemic and are continuing to meet the goal.



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Revenue and Expenses

Revenue

Source of Revenue

	2019	2020	2021
Federal Funding	\$1,299,302.06	\$1,282,119.67	\$1,192,317.42
Commonwealth Non-Financial Match	\$202,742.02	\$210,391.04	\$103,546.51
Sub-Grant Non-Financial Match	\$55,804.56	\$34,972.56	\$45,358.49
Developmental Disabilities Suite National Collaboration	\$137,244.71	\$81,993.56	\$67,066.97
TOTAL REVENUE	\$1,695,093.35	\$1,609,476.83	\$1,408,289.39

Independent Audit

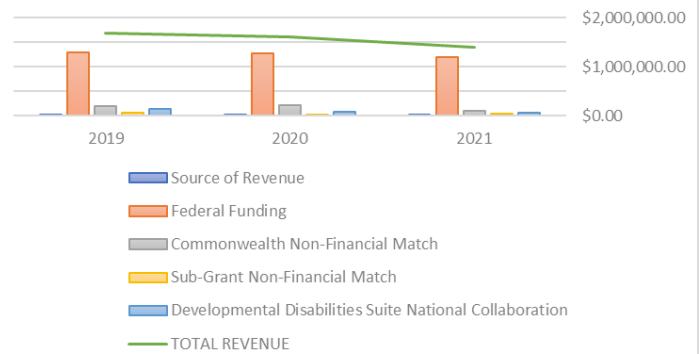
The Council participated in the independent audit, receiving a clean opinion. Complete financial information is available at www.mass.gov/osc.

A Model of Transparency



The Council's 2020 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.

Source of Revenue



Expenses

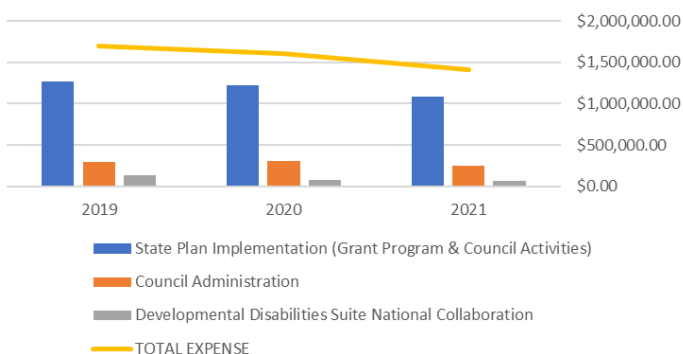
Expenditures

	2019	2020	2021
State Plan Implementation (Grant Program & Council Administration)	\$1,268,447.28	\$1,218,821.05	\$1,087,351.94
Council Administration	\$289,401.36	\$308,662.22	\$253,870.49
Developmental Disabilities Suite National Collaboration	\$137,244.71	\$81,993.56	\$67,066.97
TOTAL EXPENSE	\$1,695,093.35	\$1,609,476.83	\$1,408,289.39

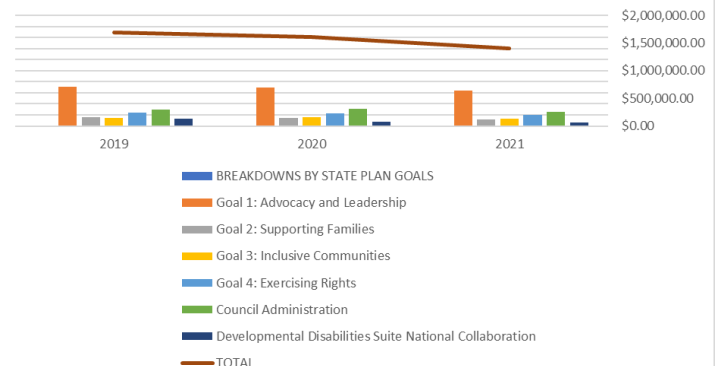
BREAKDOWNS BY STATE PLAN GOALS

	2019	2020	2021
Goal 1: Advocacy and Leadership	715150.34	\$696,281.01	\$636,010.92
Goal 2: Supporting Families	159147.68	\$138,635.88	\$123,040.70
Goal 3: Inclusive Communities	150068.55	\$157,776.52	\$133,854.44
Goal 4: Exercising Rights	244080.72	\$226,127.64	\$194,445.88
Council Administration	\$289,401.36	\$308,662.22	\$253,870.49
Developmental Disabilities Suite National Collaboration	\$137,244.71	\$81,993.56	\$67,066.97
TOTAL	\$1,695,093.36	\$1,609,476.83	\$1,408,289.39

Expenditures



Breakdowns by State Plan Goals



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Looking Forward: Continued Progress

Comprehensive Review and Analysis: The Next 5 Years

In preparation for the 2022 - 2026 five-year state plan, the Council conducted a thorough analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families. The 2020 census reported that there are 7,029,917 residents in Massachusetts. The Hispanic/Latino population increased to 12.6% in 2020, up from 9.6% in 2010. The Black/ African American (non-Hispanic) population increased slightly to 6.5%, and the Asian population increased from 5.3% in 2010 to 7.2% in 2020. The U.S. Census Bureau's American Community Survey 2015-2019 report states that 23.8% of Massachusetts residents speak a language other than English at home, 9.1% of households speak Spanish, 9.0% speak other Indo-European languages, 4.3% speak Asian and Pacific Island languages, and 1.4% speak other languages. 9.2% reported not speaking English well. Residents born in other countries comprise 16.8% of the population in Massachusetts: 37% from Latin America, 32.5% from Asia, 20.4% from Europe and 9.1% from Africa.

The Council's State Plan review and analysis process included input from public forums, surveys, Council members, stakeholder groups, and review of online data and reports. The following groups of people with disabilities and family members were among those identified as unserved or underserved: people of color; People with DD who don't have intellectual disabilities; People with IDD in the LGBTQIA+ community; People with DD who also have mental health conditions; People with IDD dually diagnosed with another disability; Black and brown male youth and young adults with disabilities; Young adults with autism and other IDs who age out of the special education system & their family caregivers; Aging individuals with developmental disabilities; Parents with disabilities; Families who speak a primary language other than English/ have limited English proficiency; Rural residents; Elder family caregivers: parents and grandparents who are primary caregivers; Recent immigrants; and Families whose children have complex medical needs and other disabilities requiring in-home specialized care and supports.

A significant barrier for full participation of underserved groups is due to the workforce crisis. This crisis is due in part to low wages paid to employees compared to workers with comparable skills in other sectors. It presents a severe shortage of qualified professionals working directly and long term with people with disabilities, including but not limited to direct support staff, personal care attendants, in-home skilled nurses, behavioral health therapists, early intervention specialists, paraprofessionals in schools, American Sign Language interpreters and clinicians. In addition, there is a dearth of qualified bicultural bilingual staff to work with individuals and families who are not native English language speakers.

The COVID-19 pandemic has exasperated many of the barriers which existed prior to the pandemic. The technology barrier became apparent for individuals and households that have limited access to internet services and devices. Factors include rural locations, lack of funds, and inability to engage with others online. On the other hand, many households with internet and devices had easier access to telehealth, therapies and other services and supports.

The goals under the new 5-year State Plan for the period 2022-2026 include:

Goal One - Self-Direction and Leadership: More people with developmental disabilities will lead and sustain self-directed lives. They will do this by developing leadership skills. This will also happen by educating their families.

Goal Two - Policy Change: More policies will support people with developmental disabilities to lead full lives in the community.

Goal Three - Community Inclusion, Choice, and Civic Engagement: More people with developmental disabilities will make their own choices about their lives. More people with developmental disabilities will live and work in the community. People with developmental disabilities and their families will get the education and resources to do these things.

Commitment to Diversity, Equity, and Inclusion

The pandemic has disproportionately devastated Black and brown communities, which further underscores the persistent racial inequities that continue to wreak havoc in our society. The Council is committed to ensuring diversity, equity, and inclusion and anti-racism becomes a foundational building block for all the work that we do for the disability community and the impact we have moving forward. Having a strong awareness and understanding of systemic racism will help the Council in identifying what our role, responsibility, and response will be to disrupt and dismantle these systems.

The Council is taking an intentional, strategic, and multi-pronged approach to this work with an emphasis on self-assessment, education, and relationship-building. In developing the Council's next five-year state plan, diversity, equity, and inclusion was incorporated systematically into every activity. Staff approached this by applying an equity lens throughout the strategic planning process and embedded into every goal and planning for how to achieve each goal through specific activities. The Council is also establishing a subcommittee of members tasked with driving Council activities on diversity, equity, and inclusion and to inform our values, policies, and priorities.

