Maine Developmental Disabilities Council

Annual Report

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This information has been compiled by Maine Developmental Disabilities Council, pursuant to its duties under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, to complete and update a comprehensive review and analysis of services, supports, and other assistance for individuals with developmental disabilities (as specified in 42 United States Code, Chapter 144, Section 15024(c)(3)).

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Council Members

Abbot Philson, Co-chair
Self-advocate

Kile Pelletier, Co-chair
Self-advocate

Stacy Smart, *Self-advocate*

Regina Bowie, *Self-advocate*

Jon McGovern, *Self-advocate*

Maryann Preble, *Self-advocate*

Stacy Atter, *Self-advocate*

Courtnay Schadtle, *Self-advocate*

Stephanie Vinson, *Parent*

Andrea Dole, *Parent*

Maggie Hoffman, *Parent*

Nicole Achey, *Parent*

Todd Marlowe, *Parent*

Tracey Webb, *Parent*

Monique Stairs
Speaking Up for Us

Maria Cameron
Nongovernmental agency

Stacey LaFlamme
Children with Special Healthcare Needs

Cheryl Hathaway
Office of Child and Family Services

Craig Patterson
Office of Aging and Disability Services

Staci Converse
Disability Rights Maine

Alan Cobo-Lewis
Center for Community Inclusion and Disability Studies

Leigh Lardieri
Department of Education

Shaun Nixon
Department of Labor

Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970. Maine's DD Council has been advocating for individuals with developmental disabilities for over 50 years. The DD Council is a federally funded, independent organization with members from across the state, including persons with disabilities, family members, and representatives of public and private agencies which provide services and/or funding for services for individuals with developmental disabilities. As required in federal law, we are involved in advocacy, capacity building and systemic change activities, with the goal that individuals with developmental and other disabilities of all ages are fully included, integrated, and involved in their communities and the decisions impacting their lives. Throughout FY24, as the Maine Developmental Disabilities Council (MDDC) executed its 2022-26 State Plan, we heard from members, stakeholders, and community members about their difficulties accessing high quality, person and family-centered services, noting gaps and long waits to access both community and education services. Concern from advocacy groups and providers regarding young children failing to access needed services increased. Adults report continued un and underemployment, even with historically low unemployment. This stress has been exacerbated by financial challenges related to inflation and by ongoing workforce challenges.

Throughout FY24 MDDC conducted and supported a variety of activities addressing quality assurance and self-determination, education and early intervention, employment, health, and community supports. MDDC utilized strategies including outreach, training technical assistance, supporting and educating communities, interagency collaboration and coordination, coordination with related councils, committees and programs, barrier elimination, systems design and redesign, coalition development and citizen participation, and informing policymakers to effect systemic change to improve the lives of Mainers with developmental disabilities and their families.

We thank our members and staff for their flexibility and commitment throughout 2024.

Nancy Cronin
Executive Director
207-480-1478
nancy.e.cronin@maine.gov
www.maineddc.org

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I. Maine Developmental Disabilities Council Overview

Who We Are

Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970 to "engage in advocacy, capacity building, and systemic change activities that are consistent with the purpose of the DD Act; and contribute to a coordinated, consumer and family-centered, consumer and family-directed, comprehensive system of community services, individualized supports and other forms of assistance that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive and be integrated and included in all facets of community life."

Maine Developmental Disabilities Council (MDDC) is a partnership of people with disabilities, their families, and agencies which identifies barriers to community inclusion, self-determination, and independence, and acts to effect positive change. The Council has a vision that all people are included, supported, and valued in communities that provide opportunities to participate and succeed as they choose. MDDC acts to affect positive change through advocacy, capacity building, training, demonstration projects, and support for other inclusive and collaborative systems change activities.

Mission

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.

Purpose

To **promote systems change** to ensure that all individuals with developmental and other disabilities are able to **live and fully participate** in their communities of choice. Working in partnership with people with disabilities, parents, advocates, and policy makers, MDDC works to **promote 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.

Enabling Federal Legislation

Under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, MDDC is required to ensure that 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, integration, and inclusion in all facets of family and community life.

Council Membership

Maine Developmental Disabilities Council’s specific priorities are shaped by its governing council. The Council consists of 27 members, 19 of whom are appointed by the Governor. 60% of MDDC’s membership is made up of people with developmental disabilities or their representative family members. The remaining 40% of MDDC’s membership is made up of representatives of State agencies administering federally-funded programs related to individuals with developmental disabilities, local non-governmental agencies/organizations that serve people with developmental disabilities, and MDDC’s “sister agencies”, so-called because they are also funded through the DD Act: Disability Rights Maine, Maine’s Protection and Advocacy agency for people with disabilities, and the Center for Community Inclusion and Disability Studies at the University of Maine, Maine's University Center for Excellence in Developmental Disabilities.

The breakdown of membership includes:

- 5 seats designated for individuals with developmental disabilities
- 5 seats designated for parents, guardians, or family members of individuals with developmental disabilities
- 6 seats designated for *either* individuals with developmental disabilities *or* parents, guardians, or family members of individuals with developmental disabilities
- 1 seat designated for a local non-governmental agency/organization that serves people with developmental disabilities
- 1 seat for the University Center for Excellence in Developmental Disabilities
- 1 seat for the Protection and Advocacy agency for people with disabilities
- 1 seat for a statewide self-advocacy organization
- 1 seat for each of the following State Agencies:
    - Department of Health and Human Services, Office of Aging and Disability Services
    - Department of Health and Human Services, Office of Child and Family Services
    - Department of Health and Human Services, Children with Special Health Needs
    - Department of Education, Special Services
    - Department of Education, Child Development Services
    - Department of Labor, Vocational Rehabilitation

Due to its diverse membership, the Council provides opportunities for disparate perspectives to come together to work toward systems that support individuals with developmental disabilities to be fully included in their communities.

<u>What We Do</u>

Maine Developmental Disabilities Council is required to engage in advocacy, capacity building, and systems change activities that address:

- ❖ Employment
- ❖ Health
- ❖ Child Care
- ❖ Recreation
- ❖ Housing
- ❖ Transportation
- ❖ Community Supports
- ❖ Quality Assurance/Self-Determination
- ❖ Education and Early Intervention

MDDC develops a five-year plan that best suits the needs of the community. Current strategies include:

- Promote and provide small grants for activities that expand the capacity of communities to provide opportunities for individuals with developmental disabilities to actively participate in community life
- Advocate for systems change that allow individuals with developmental disabilities to achieve full integration and to pursue meaningful and productive lives
- Increase public awareness and work to eliminate barriers that negatively impact independence, productivity, and inclusion of people with developmental disabilities
- Foster and support coalitions and other advocacy and community groups
- Support close working relationships among the various public and private service providers

<u>Five-Year State Plan</u> – *See Appendix A.*

II. Defining Developmental Disability

The US Department of Health and Human Services' Administration on Intellectual and Developmental Disabilities states that:

"A *developmental disability* is 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 3 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, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated

An individual from birth to age 9, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described above if the individual, without services and supports, has a high probability of meeting those criteria later in life." (Developmental Disabilities Assistance and Bill of Rights Act of 2000)

The federal definition is *functional*; that is, it is intended to describe the nature and scope of limitations without reference to medical diagnosis.

How Many People Have Developmental Disabilities?

The Administration on Intellectual and Developmental Disabilities estimates the population prevalence of developmental disabilities at 1.58%.

Approximately 21,000 Mainers of all ages have developmental disabilities.

The overall prevalence of disability among all people in the United States is 12.6%[1]; among people in Maine it is 16.3%[2] Approximately 217,000 Mainers report having a disability

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[1] https://www.disabilitystatistics.org/reports/acs.cfm?statistic=1

[2] https://www.disabilitystatistics.org/reports/acs.cfm?statistic=1

III. Concerns of Maine Families Affected by Developmental Disability

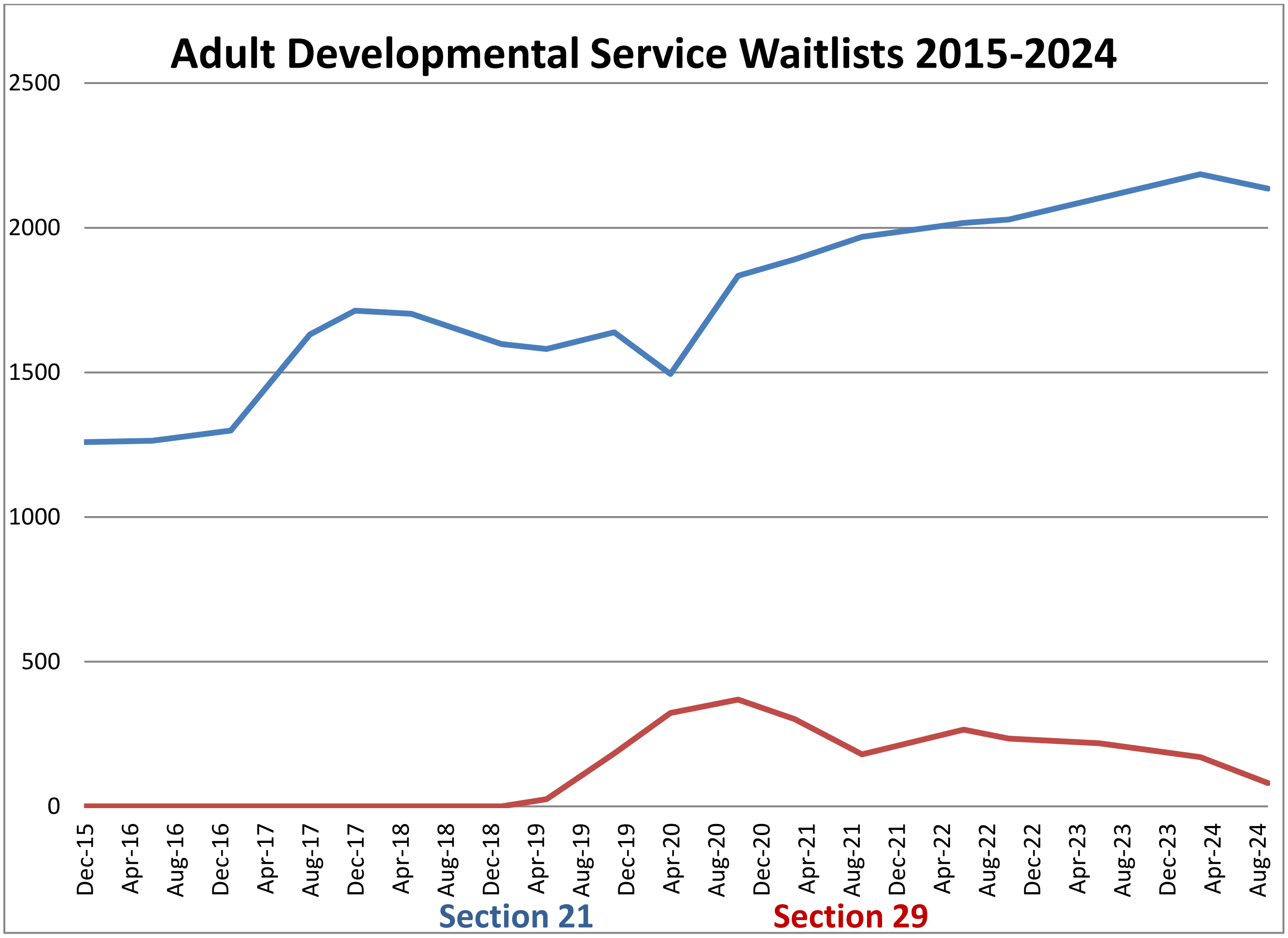
Access to Services and Supports

Maine Developmental Disabilities Council monitors available data about services and supports available to Mainers with developmental disabilities and gathers input about gaps in the system.

Adult Developmental Services

Upon reaching adulthood, the availability of individual and family supports changes from a model of entitlement to eligibility. To be eligible for Developmental Services, an individual must demonstrate substantial functional limitations in three (3) or more of the areas of major life activity (such as self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency).

MDDC has noted with appreciation the attention to the state's addressing the waitlists for waiver services. However, there continues to be a significant, growing, need for services. MDDC also notes the challenges encountered by eligible persons in actually accessing those services, particularly people with challenging behaviors. Waitlist data was provided by the Office of Aging and Disability Services and its predecessors.



Children's Services and Special Education

Children with developmental disabilities are entitled to a fairly robust array of services and supports. However, Maine families experience very significant challenges in accessing those services, especially the areas of:

Early intervention: Young children who are at risk of developmental disability need early intervention services. They are not receiving timely and effective services due to (de facto) waitlists, high rates of staff turnover, insufficient funding, lack of inter-department coordination and erosion of service delivery capacity due to systematic regulatory changes.

Obtaining community supports: At times, families do not receive needed services because qualified providers are not available. This is noteworthy in long waits for Section 28 services. One father spoke to MDDC of having to decide whether an unreliable support person was preferable to no support person and of changing holiday plans based upon the availability of support. Another spoke of having no choice but to pursue residential placement (due to the lack of availability of support). Another parent spoke of a child receiving speech therapy once every other week for a 90-minute session rather than the 20 minutes three times a week that the child needed.

Inadequate transition planning: One mother's comments reflect many other families' concerns. She said:

> *"…Transition is one thing, but if there is little of quality or even adequate to transition to, the point of transitioning is completely lost. My experience and observations are that a sufficient and qualified pool of support people doesn't exist, aren't paid or supported well enough, etc. Right now, my husband and I feel like the most realistic plan for our daughter's future is that we must never become ill and must never die OR we should clone ourselves. I know that seems absurd, but it is not said necessarily in jest. I'm sure many other families relate to those kinds of sentiments, nor is it new to you."*

Other Services

While the Office of Aging and Disability Services (OADS) provides developmental services to approximately 6000 individuals, there are thousands more Mainers who meet the federal criteria of having a developmental disability. Some receive appropriate services through another section of Maine Care such as Section 19, 20, or 50. Some have multiple diagnoses and receive services such as Section 65 or 96 which may create emphasis on alternative diagnoses, leading to less than effective/efficient care. Some do well with no services at all. Some are in the criminal justice system. MDDC hears from/of many Mainers with significant intellectual and developmental impairments and their family members who simply do not qualify for services. They struggle to obtain and retain housing, transportation, employment, and healthcare. These people are disproportionately poor and have been impacted by such issues as Maine's response to Medicaid expansion, affordable housing policy, and income-based supports such as SNAP, TANF, general assistance, and heating subsidies.

Other Issues

Maine Developmental Disabilities Council monitors other issues that significantly impact Maine families affected by developmental disabilities.

Poverty[3] **32.4% of working-age Mainers with disabilities live at or below the federal poverty level** (compared to **7.7% for people without disabilities)**.

Unemployment

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[3] https://www.disabilitystatistics.org/reports/acs.cfm?statistic=7

Historically, the unemployment rate[4] of people with disabilities is double that of the general unemployment rate. While numbers specific to people with developmental disabilities are not available, relevant data such as the National Core Indicators[5]suggest that the numbers for people with developmental disabilities are considerably worse, with only 30% of people employed.

For individuals with developmental disabilities who do not receive waiver-level services, access to ongoing employment supports is extremely limited. This significantly limits people's ability to work.

Aging Caregivers

The aging of Maine's population stands to pose serious challenges in meeting the support needs of persons with developmental disabilities. Families continue to be the primary providers of care. According to national statistics, an estimated 76% of individuals with developmental disabilities live at home. In 25% of these households, the family caregiver was age 60 or older and the average age of the family member with a disability was 38 years. There are an estimated 641,000 adults over age aged 60 who have developmental and related disabilities, a number that is projected to double by 2030. [6] **In Maine it is estimated that approximately 4,230 persons with developmental disabilities are living at home with caregivers over the age of 60**.[7]

Dental Care

Limited or lack of access to both preventative and restorative dental care is a barrier to the health of people with developmental disabilities who are not institutionalized. Lack of access is even more significant for those who do not have access to waiver-level services.

Transportation

Most people with developmental disabilities do not drive. In a state that is largely rural with little public transit infrastructure, this severely limits the ability to travel. People with developmental disabilities rely on a patchwork of service providers, family and friends, public transit, taxis, and volunteer drivers. Individuals with developmental disabilities report that obtaining transportation to social and recreational opportunities, particularly individual activities, is especially difficult. Community transportation (public/regional and volunteer) is limited geographically, making short trips complicated and limiting vocational and social opportunities, and is essentially non-existent in the evening or on weekends. People with physical disabilities have additional difficulties with transportation in that taxis and private vehicles of family, friends, and volunteer drivers may not be accessible, public transit has limited accessible seating, and in the winter, people may have difficulty negotiating icy conditions.

MDDC has noted with concern the access and safety challenges of persons with developmental disabilities utilizing Non-Emergency Medical Transportation.

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[4] www.maine.gov/labor/cwri/disabilities/index.html

[5] https://www.nationalcoreindicators.org/upload/core-indicators/ME_IPS_state_508.pdf

[6] Heller, Tamar Ph.D. (2011) Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Clearinghouse on Aging and Developmental Disabilities, Chicago, IL

[7] Braddock, et al. (2015) *The State of the States in Developmental Disabilities* Tenth Edition, The University of Colorado

IV. Maine Developmental Disabilities Council Projects and Initiatives 2024 Highlights

Supporting Self Advocacy

Speaking Up for Us (SUFU) is Maine's self-advocacy organization run by and for people with I/DD. Created in 1993 to help ensure that individuals living with I/DD in Maine are equal, thriving members of their communities. SUFU's mission is to create new opportunities for adults living with I/DD to discover their abilities, exercise freedom and contribute to their communities. Supporting self-advocacy has been MDDC's most important initiative for many years in terms of fiscal effort and organizational support. In FY24 MDDC provided funding and technical assistance for self-advocates to develop leadership and advocacy skills, to increase understanding of and participation in policymaking and expanding awareness of and membership in self- advocacy, including youth and underserved populations. Kile & Stephanie, self-advocates from Aroostook County, are affected by the "marriage penalty" & have been relentless in their endeavor to reform social security. They met with their Congressional delegation to share their experience & ask them to sign on to social security reform. Ultimately US Senator Susan Collins agreed to sign onto legislation regarding Social Security Reform.

Advocacy

In accordance with its responsibilities under the federal DD Act, Maine Developmental Disabilities Council has provided ongoing information and support to legislators and other public policymakers in the development and review of proposed legislation, rules, and other policies in the areas of civil rights, education, healthcare, employment, housing, and other matters of concern to individuals and families impacted by developmental disabilities. The virtual option for the legislative and rulemaking processes seems to have decreased travel related barriers, increasing diversity of stakeholders in policymaking. In 2024 MDDC supported an effort that improved the advocacy capacity of 50 parents of children with disabilities.

Addressing Sexual Abuse

In FY23 MDDC released "Support Survivors of Sexual Violence", a resource for health providers who respond to sexual assault of people with ID resulting in behavioral healthcare practices reporting increased capacity to address sexual abuse. https://www.maineddc.org/images/PDFs/COP_report_Final.pdf . In 2024 MDDC supported a project to train self-advocates to teach the Healthy Relationships and Sexual Health for All Abilities curriculum.

Early Intervention

The National Center for Disease Control's Act Early program aims to improve early identification of children with disabilities so children and families can get needed services and support to improve functional outcomes. MDDC's Executive Director is the "Learn the Signs, Act Early" Ambassador to Maine. This project distributes educational materials regarding developmental milestones to childcare workers and healthcare professionals so that young children with DD can be identified early and access appropriate services. MDDC consults with Help Me Grow, a system so that young children can be screened for disabilities and families can access what they need and now host the Early Intervention Huddle, a diverse systems change partnership that includes parents, family organizations, service providers, Head Start and childcare advocates.

Health

People with developmental disabilities experience a variety of health disparities including but not limited to being more likely to report being in poor health, having shorter average life expectancy than the general population, being less likely to receive preventative care, having higher rates of undiagnosed hearing and vision impairments, higher rates of/poorly managed chronic health conditions, and being prescribed higher rates of psychotropic medication. There are a variety of contributing factors, including societal/attitudinal barriers (stigma), barriers due to disability related conditions and/or functional limitations related to his/her disability, and other barriers. In FY24 MDDC completed Project CONNECT, a 2-year project aimed at bridging gaps in understanding, empowerment, and empathy that are endemic within I/DD healthcare. It created a Research Community of Praxis (consisting of individuals with lived experience with I/DD, family members of individuals with I/DD, researchers, policy makers, advocates, and medical professionals) and developed strategies to engage members are equal partners providing collective leadership to I/DD research related to clinical care delivery and access.

Post-Secondary Education

Despite many years of effort with the state colleges and universities, Maine has not had any residential postsecondary education options for youth with ID. Thus, MDDC was excited that its support for capacity building at a small liberal arts college resulted the first student with ID beginning their post-secondary education journey at the end of FY23 and continuing successfully through 2024.

Empower the Learner

In response to concerns about low expectations of and for people with I/DD, MDDC funded the development and testing of a multi-media self-advocacy tool designed to raise expectations for children's community and school environments, available here
https://www.mpf.org/download/empower-the-learner/

Reducing Restraint and Seclusion

Alongside other members of the DD Network, MDDC supported the Coalition Against Restraint & Seclusion (CARS), a workgroup consisting of family members, self-advocates, & other advocates that addresses systemic issues. CARS advocated for and obtained clarification that restraint is not a Medicaid billable service and advocated for rules that would provide protections to children in public schools.

Self-Direction

CMS says: "Self-directed Medicaid services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process." In 2024, self-directing individuals and families noted challenges in accessing high quality support brokerage, a key component of robust self-direction. MDDC provided small grants to a diverse cohort of eligible community members to train and enroll as independent support brokers, increasing the community's access to this service.

Appendix A –MDDC Five-Year State Plan ✦ 2022-2026 ✦ Goals and Objectives

GOAL # 1 People with developmental disabilities, families, and communities will have increased opportunities for choice, self-determination, and community membership.

- *Objective 1.1:* MDDC will promote the civil rights of individuals with developmental disabilities.
- *Objective 1.2:* Support Maine's self-advocacy organization and promote development of diverse leaders among people with developmental disabilities and families.

GOAL # 2 Improve systems of support for people with developmental disabilities and families.

- *Objective 2.1:* Decrease health and educational disparities experienced by people with developmental disabilities.
- *Objective 2.2:* Improve access, quality, and integration of services and supports for individuals with developmental disabilities and families.
- *Objective 2.3:* Support efforts to expand access to information and services for underserved individuals with developmental disabilities and families.