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Report to the 126th Legislature State of Maine, 2013

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**Maine Developmental
Disabilities Council**

**Report to the 126th Legislature
State of Maine**

April 2, 2013

This information has been compiled by the 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 persons with disabilities (as specified in 42 United States Code, Chapter 144, Section 15024(c)(3)). The data analysis included in this report uses the most recently released data from the U.S. Census Bureau, along with information from other sources.

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The Maine Developmental Disabilities Council

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."

The 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.

The Council is comprised of 25 volunteer members, 60% of whom are people with disabilities or their representative family members. Membership also includes representation from state agencies responsible for developmental disability services, from nonprofit organizations, and from each "sister agency" also created by the Developmental Disabilities Act, the Disability Rights Center and the Center for Community Inclusion and Disability Studies.

What We Do

The Maine Developmental Disabilities Council is required to engage in advocacy, capacity building, and systemic change activities addressing areas of focus that include: quality assurance, education, early intervention, childcare, health, employment, housing, transportation, recreation, and other services available or offered to people in a community which affect their quality of life. Through the development of a five-year plan the MDDC narrows the focus and designs projects that best suit the current needs of the community. The MDDC is committed to collaboration with other concerned agencies and self-advocates and works to strengthen the disability community through technical assistance, grant allocation, and the development of joint projects. The MDDC is actively involved in public policy work through provision of information and education to legislators and other interested community leaders, through engagement on boards and committees, and through advocacy on behalf of people with developmental disabilities.

Defining Developmental Disability

The US Dept. 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 1.8%. Approximately **24,000** Mainers of all ages have developmental disabilities.

The prevalence rate of disability (any disability, by self report) among people across the life span in Maine is 15.5%, according to the **2010 American Community Survey** completed by the U.S. Census Bureau. Federal data documents a higher prevalence of disabilities among people living in Maine than in other parts of the country. **The national prevalence rate of disability among people in the United States ages 5 and older is 12.1%.**

According to the **2011 American Community Survey 1-Year Estimates, U.S. Census Bureau:**

- **15.5% of Mainers report having a disability**
Approximately 203,400 Mainers (*of all ages*) report having one or more disabilities.
- **2.1% of Mainers have a Visual Disability**
Approximately 27,250 Mainers (*of all ages*) are blind or have serious difficulty seeing even when wearing glasses.
- **4.8% of Mainers have a Hearing Disability**
Approximately 63,800 Mainers (*of all ages*) are deaf or have serious difficulty hearing.
- **7.8% of Mainers have an Ambulatory Disability**
Approximately 97,000 Mainers (*ages 5 or older*) have serious difficulty walking or climbing stairs.

- **7% of Mainers ages 5 and older have a Cognitive Disability**
Approximately 93,000 Mainers (*ages 5 or older*) have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition.
- **2.6% of Mainers have a Self-Care Disability**
Approximately 31,800 Mainers (*ages 5 or older*) have difficulty dressing or bathing.
- **6.3% of Mainers have an Independent Living Disability**
Approximately 83,700 Mainers (*ages 18 or older*) have difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition.

FACTORS IMPACTING THE FUTURE OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

AGING CAREGIVERS

The aging of Maine's population stands to pose serious challenges to 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 member with a disability was 38 years. Because adults with developmental disabilities are living longer, families have a longer period of caregiving responsibility.¹ **In Maine it is estimated that more than 3,500 persons with developmental disabilities are living at home with caregivers over the age of 60.**²

EMPLOYMENT AND POVERTY STATUS OF ADULTS WITH DISABILITIES

According to U.S. Census Bureau statistics³, the economic status of persons with disabilities in Maine is significantly worse than that of persons without disabilities:

- **EMPLOYMENT RATE = In 2011, 30.2% of working-age persons with disabilities were employed (compared to 70.1% percent of persons without disabilities). The Employment rate of persons with cognitive disabilities was 22.5%.**
- **PERCENTAGE WORKING FULLTIME = 18% of persons with disabilities age 21 to 64 years employed (compared to 56.3% of working-age people without disabilities who were working fulltime/full-year)**
- **Mean Annual Earnings of working-age people with any disability was \$23,200 in 2011. (That compares to \$35,300 for working-age people without disabilities. Mean Annual Earnings of persons with cognitive disabilities was \$15,400)**

¹ Tamar Heller, Ph.D., Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Clearinghouse on Aging and Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Road, Chicago, IL 60608-6904

² Braddock, et al. *The State of the States in Developmental Disabilities*. Second Printing, Revised, The University of Colorado, Department of Psychiatry, School of Medicine.

³ U.S. Census Bureau, 2011 American Community Survey 1-Year Estimates

POVERTY RATE = 31.8% of working age persons with disabilities live at or below the federal poverty level (compared to 14.2% for people without disabilities).

GAPS IN THE SERVICE SYSTEM

General Needs

Dental Care

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

Transportation

Most people with DD do not drive. In a state that is largely rural with little public transit infrastructure, this severely limits the ability to travel. People with DD rely on a patchwork of service providers, family and friends, public transit, taxis, and volunteer drivers. In response to recurrent budget cuts, agencies providing developmental services have, in some cases, limited travel by such means as traveling in groups, restricting mileage, or requiring approval for non essential trips. Individuals with DD report especial difficulty obtaining transportation to social and recreational opportunities, particularly individual activities. 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. Transportation costs can also have an effect on the availability of in-home services as providers have difficulty finding qualified workers who are willing to travel to distant locations. Even those placed in nursing facilities are unable to access transportation to maintain social networks of support or to work and it may be difficult for them to access transportation to utilize (medical) providers of choice.

Employment supports

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

Children's Services

Children's services are largely designed to provide entitlement to proactive intervention based upon the child's level of function.

The Council has received input about gaps in access to services. In certain areas of the state providers have difficulty recruiting and retaining staff to provide services, leading to situations in which children receive a lower level of service than is indicated. For example, a child who requires three 30 minute sessions per week receives treatment one day per week for 60 minutes, or goes without treatment for two weeks because the provider is ill and there is no replacement available.

The Council has also received input about 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."

Special Education

Over the past ten years (from the 2002-2003 school year to the 2012-2013 school year), there has been an 11% decrease in the number of students in special education programs in the public schools. However, there has been a dramatic increase in the number of students served in the Autism category during the same time period.

Concern has been raised regarding the cost of special education services having increased at the same time that the numbers of students receiving these services has decreased. This may be explained to a great extent by the relative change in numbers in various special education categories, given that students with some types of disabilities may require more supports and services as part of their educational programs. The 11% decrease in the total special education population includes the following changes in individual categories over the same period of time:⁴

Category	2001-02 school year census	2012-2013 school year census	Percentage change
Autism	846	2,989	324% Increase
Emotional Disability	3495	2353	33% Decrease
Intellectual Disability	985	686	30% Decrease
Multiple Disabilities	3,210	2,925	9% Decrease
Other Health Impaired	3,780	6,110	62% Increase
Specific Learning Disability	12761	9,193	39% Decrease
Speech and Language	9,744	6,848	30% Decrease

⁴ Data provided by the Maine Department of Education, January, 2012

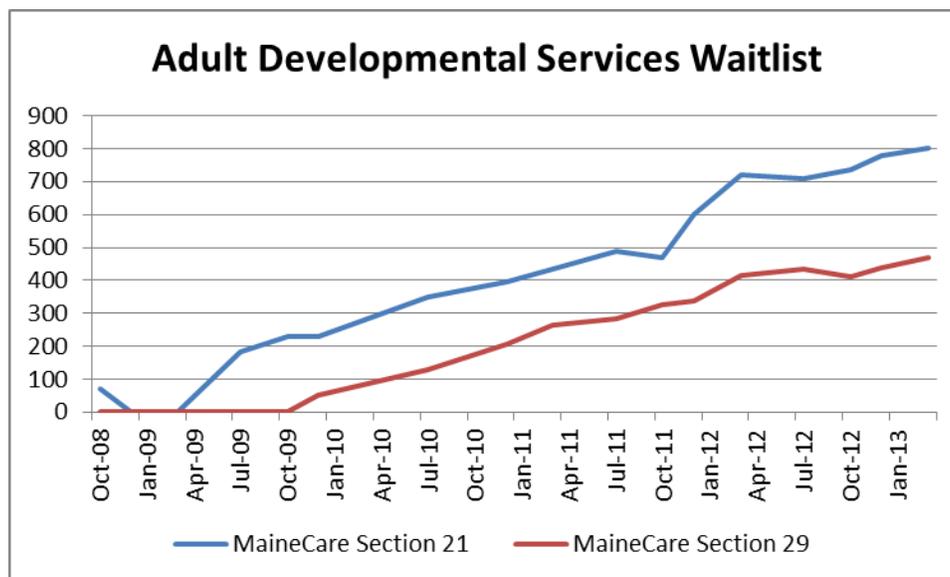
Adult Services

Eligibility rather than Entitlement

Upon reaching adulthood (between 18 and 21, depending upon enrollment in school) the availability of individual and family supports changes. To be eligible for Developmental Services an individual must demonstrate substantial functional limitations in 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). The state of Maine is one of a minority of states to also require an IQ score of less than 70 for disabilities other than an Autism Spectrum Disorder (for which Maine requires a functional score of greater than two standard deviations from the mean). Provision of services to those persons with developmental disabilities who qualify under another part of the service system creates significant confusion and emphasis on alternative diagnoses which may lead to less than effective/efficient care.

Availability of Services

There is significant concern about limited access to developmental services. Families talk about the looming “cliff” that their children face, with growing waiting lists for adult Developmental Services waiver programs.



Systems Recommendations

The following actions could help address disparities in access to services in order for people with developmental disabilities to live safely and productively in their communities, now and in the future:

Adopt, in statute and rule, a functional definition for developmental disabilities (as in the federal DD Act) with provisions that service expansion will be based upon available resources. Adopting the federal definition will enable the Department to identify unmet needs, understand scope of needed resources and advocate for provision of services.

Address the changing demographics of those receiving Developmental Services, including the needs of aging people with developmental disabilities. As the body of medical and clinical knowledge

changes and grows, the system will need to be prepared to better address specialized needs such as those of older adults and of persons with autism spectrum disorders.

Address the need for an equitable, comprehensive community based service system for all people with disabilities. For people with developmental disabilities who do not qualify for the current waivers, there is no single point of entry to the service system (if in fact they meet eligibility requirements for services) and if they are eligible there is a significant disparity in the availability of community supports.

MDDC PROJECTS AND INITIATIVES

2011-2013

❖ ADVOCACY AND EDUCATION FOR PUBLIC POLICYMAKERS

In accordance with its responsibilities under the federal DD Act, the 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 affecting persons with developmental disabilities and their families. The Council has provided information and participated in the revision of statutes and rules affecting civil rights, education, health care, employment, housing, and other matters of concern to self-advocates, parents and other family members.

❖ AUTISM SPECTRUM DISORDERS STATE IMPLEMENTATION GRANT

The Maine Department of Health and Human Services has contracted with the MDDC to manage a three-year grant award by the federal Health Resources and Services Administration, using funds from the Combating Autism Act Initiative. The grant is intended to improve health outcomes for individuals with Autism Spectrum Disorders (ASDs) by identifying ASDs early and providing effective, coordinate treatment and a long-term comprehensive medical home for each person with an ASD. Grant activities include development of a standardized screening process for young children utilizing existing resources, streamlining referral and access to early intervention services, and expanding training opportunities for primary care physicians and other medical personnel to expand their capacity to provide high quality medical homes for their patients with ASDs. Now in the third and final year of the grant, the Autism Implementation Grant has accomplished much towards the goal of prompt early identification, smooth entry into early intervention, and improving the health of individuals with ASDs in Maine.

❖ DISABILITY ADVOCACY DAY

Disability Advocacy Day is an ongoing activity organized by the Maine Developmental Disabilities Council in concert with Speaking Up For Us (SUFU), Maine's self-advocacy organization. This program provides an opportunity for self-advocates, family members, and other interested parties to become more familiar with the legislative process and to take a more active role in communicating their concerns to their elected officials in the Legislature. The MDDC provides advocacy training and makes arrangements for participants to meet with their senators and representatives personally at the State House and in their local communities. Individual participants in turn become mentors for others who wish to speak up for themselves about current issues affecting persons with disabilities, and organize ongoing connections with policymakers. Since 2007, more than 300 self-advocates, parents and provider agency staff have participated in this program.

❖ INTEGRATION OF CHILDREN WITH ASD IN PRIMARY MEDICAL CARE OFFICES

This project is designed to ensure that children with Autism Spectrum Disorders (ASDs) are able to access quality health care in their local communities. In 2009, the MDDC provided funding for the development and delivery of training and technical assistance for general practitioners regarding strategies they can adopt to improve routine care for children with ASDs. Pre-training survey results identified that medical practitioners were much less comfortable providing on-going care for children with ASDs than for other disorders. Specifically, only thirty percent of the physicians who attended the trainings rated themselves as comfortable or very comfortable providing ongoing care for children with ASDs. Over the next year, the developmental pediatricians will be providing training and technical assistance to ten more primary care medical practitioners.

❖ **PROMOTING ARTISTS WITH DISABILITIES**

The Council provides ongoing opportunities for persons with disabilities to display and market their artwork through collaboration with the STIR Collective and the Center for Community Inclusion at the University of Maine, Orono. The Council provides space in its Augusta office at no cost for artists to display their work, and promotes their endeavors through periodic events to showcase new artwork and artistic competitions.

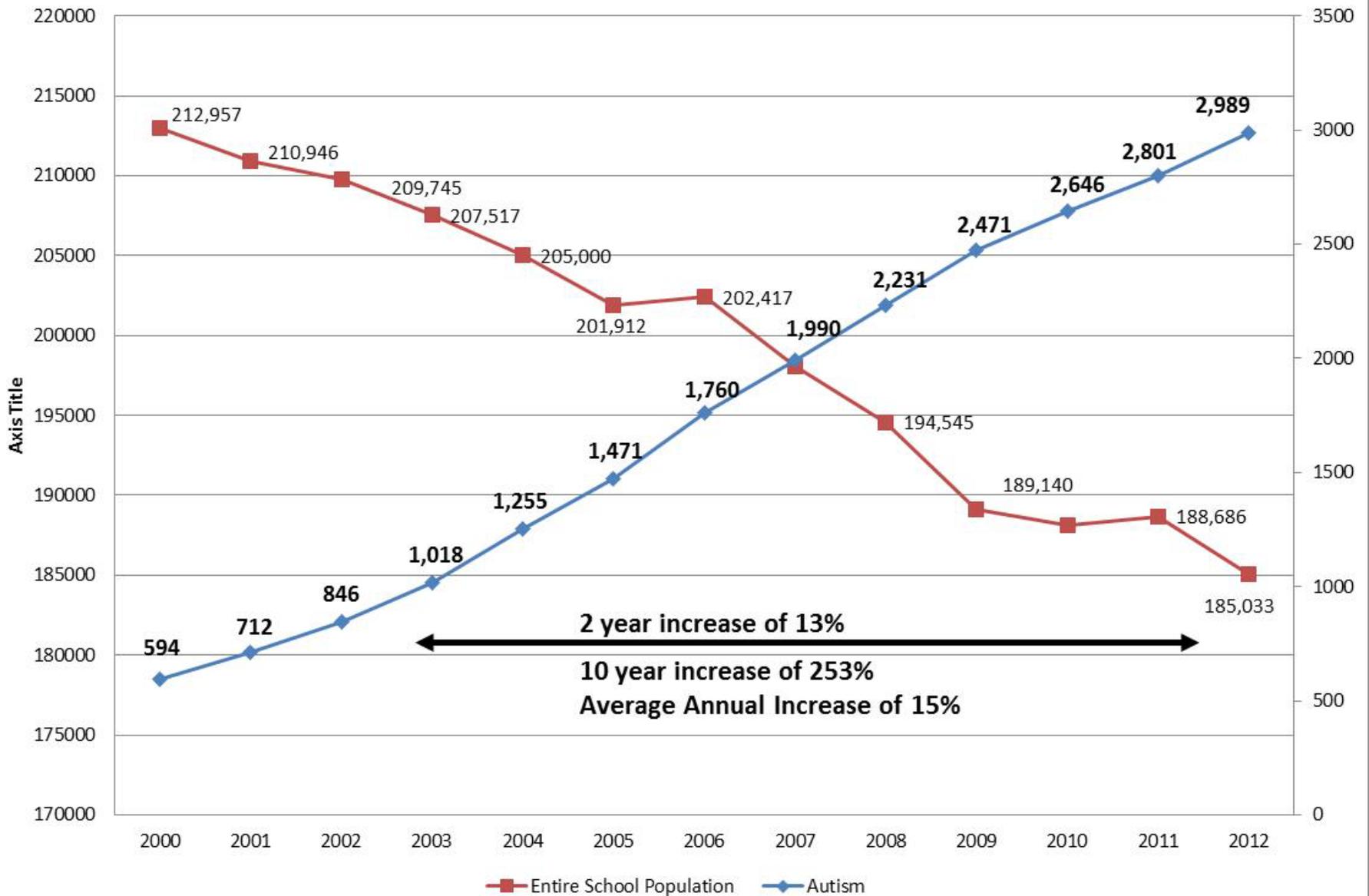
❖ **QUALITY MENTAL HEALTH SERVICES FOR PERSONS WITH COGNITIVE DISABILITIES**

The MDDC has provided funding and staff support for a project involving state and local agencies, self-advocates, family members, and advocates in assessing current services and determining and implementing changes to improve the quality of mental health services for adults with developmental disabilities. The Council has supported consultation by a national expert from the National Association for the Dually-Diagnosed and support for meetings of the interagency task force, as well as training opportunities for over 500 stakeholders, including professionals in the targeted service systems across the state.

❖ **STATEWIDE AND REGIONAL ORGANIZATIONS FOR SELF-ADVOCATES**

Through an ongoing contract and collaboration with Speaking Up for Us, a statewide self-advocates' organization for persons with developmental disabilities, the Council provides support for local groups and statewide events that offer training, networking and social activities, and encourage greater community involvement and inclusion. Presentations and trainings provided by representatives of this group in schools and other community settings also help to foster increased appreciation for the rights of persons with developmental disabilities and their contributions to their local communities.

Comparative trends in the # of children served in Maine public schools under the Special Ed category of Autism as compared to the total # of Students in Maine



20% Growth Between FY 2009 and FY 2012 in Number of Individuals with an ASD Whose Claims Were Paid Through MaineCare

