



Across the Lifespan

A national perspective

Across the United States family caregivers are the primary source of support for both children and adults with intellectual and other developmental disabilities, including autism. In 2013, about 40 million family caregivers provided unpaid care valued at about \$470 billion to adults who needed help with daily activities such as bathing, dressing, meal preparation, and transportation, more than total Medicaid spending that year.(1) According to *Caregiving in the US 2015*, about 3.7 million family caregivers provided care to a child under age 18 because of a medical, behavioral, or other condition or disability. Estimates show that 25% of these caregivers are over age 60 and caring for their loved ones with I/DD in the home.

What about Massachusetts?

According to the Massachusetts Department of Developmental Services 18,000 individuals are living with family caregivers. More than 9,000 of these family members are adults; 3,100 of the adults are age 40 and older and they live with a caregiver over the age of 60 years. Many of these families do not receive enough financial support to meet the needs of their loved one in their home without significant hardship. They need our increased support.

When a family is caring for an individual with autism or another intellectual or developmental disability, it often means 24/7 oversight of one's child or adult family member. If there are significant intellectual and physical impairments or serious behavioral needs, that care may mean more trained help in behavior support to keep the individual and family members safe or it may include overnight support. We estimate that 450 million as the monetary value of caregiving for this group.

What do caregivers do?

Family caregivers help loved ones with eating, bathing, dressing, and behavior management. Behavior management can include de-escalation strategies, interventions for aggressive and self-injurious behavior, supports around safety and appropriate behavior in the community and more. Caregivers also provide transportation, and help managing finances, preform medical/nursing tasks, coordination of care and out of pocket payments for services such as therapies, respite, home modifications, transportation or nursing. The assistance family caregivers provide saves taxpayer dollars, helps to delay or prevent their loved ones from needing more costly residential care, and helps prevent unnecessary hospital readmissions.

What challenges do family caregivers face?

Family caregivers take on physical, emotional, and financial challenges. They commonly experience emotional strain and mental health problems, especially depression, and have poorer physical health than noncaregivers. (6) Studies have indicated that raising a child diagnosed with autism mirrors symptoms of post-traumatic stress disorder.

Family Caregivers struggle to meet the needs of their loved ones, with tremendous investments of their family resources. They are the most important advocates for the needs of their loved ones. In this 24/7 and life-long role this work comes at a substantial personal cost. Many of these family caregivers are not adequately assisted. Navigating, locating, and coordinating fragmented services is too often bewildering, complex, and very time consuming.

These caregivers are the foundation of long term care for our most vulnerable. As a result, they can experience a diminished quality of life and restricted job choices, which creates stress, financial and otherwise. Businesses experience decreased productivity from caregivers and this costs in the tens of millions of dollars annually. The amount is even higher when loss of family income is included. More than 3,100 of the individuals supported by these caregivers are over the age of 40 years, which means that the caregiver is most likely an older parent. We estimate that these family caregivers' increased health concerns cost an additional \$5.3 Million on an annual basis, placing more pressure on health insurers including Medicaid and Medicare

Why is a strategy to support family caregivers important?

Helping families to be strong and resilient pays off for our community and businesses with long-term cost savings.

Providing effective Family Support services can be 75% – 80% less expensive than out of home placement. Families in Massachusetts represent 60% of the individuals served by DDS yet family support funding is only 3.5% of the DDS budget. Supporting families in their commitment to care for their loved ones at home will result in direct savings in long term support costs while slowing the growth of current spending. It will also alleviate burdens on indirect costs, such as increased healthcare costs and lost worker productivity.

Please help us in the “Supporting Families” Campaign.

We have asked the administration for a multi-year commitment in the tens of millions for DDS Family & Respite Supports, the DESE-DDS program and the Children’s Autism Waiver program to help 5,700 families with the highest needs. In addition several other services such as Turning 22 and Adult Autism need our consistent advocacy so that funding can be provided and maintained. These services are an essential component in supporting caregivers. We hope that you can support the investment in these programs which will support families in the Commonwealth.

