



SUPPORTINGFAMILIES.ORG

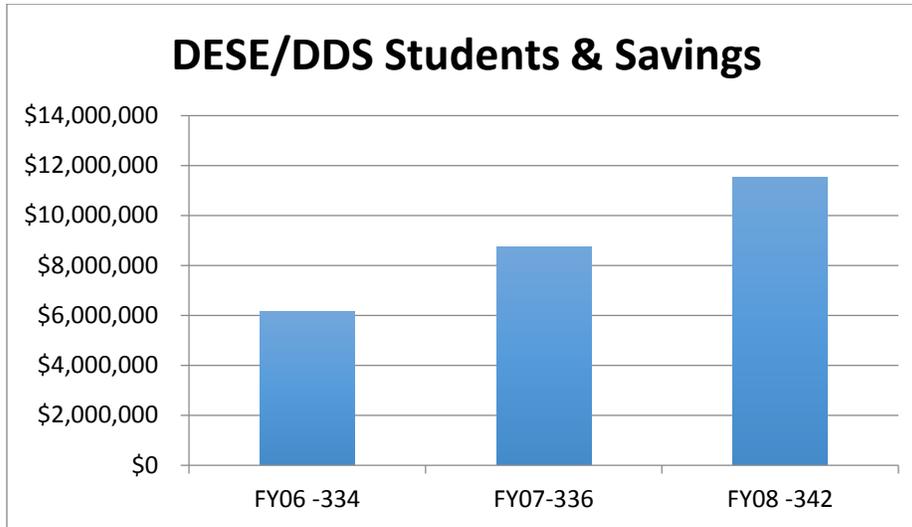
Summary statement: Across the nation, thousands of families who are supporting loved ones with intellectual and developmental disabilities are in crisis. They do not receive enough financial support to meet the needs of their loved one in their home without significant hardship. They need our increased support.

This crisis affects many of the eighteen thousand families in Massachusetts who support their loved ones at home. They are struggling to meet the needs of their loved ones, with tremendous investments of their family resources. They help their family member with daily needs and assist them in self-care; for some this is a 24/7 routine and a life-long role. This work comes at a substantial personal cost. Many of these family caregivers are not adequately assisted. 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.

- Family caregivers support over 18,000 individuals on the Department of Developmental Services (DDS) caseload; more than 9,000 are adults.
- 3,100 of the adults are age 40 and older; they live with a caregiver over the age of 60 years
- \$450 Million is a conservative estimate of the value of family caregiving for this group

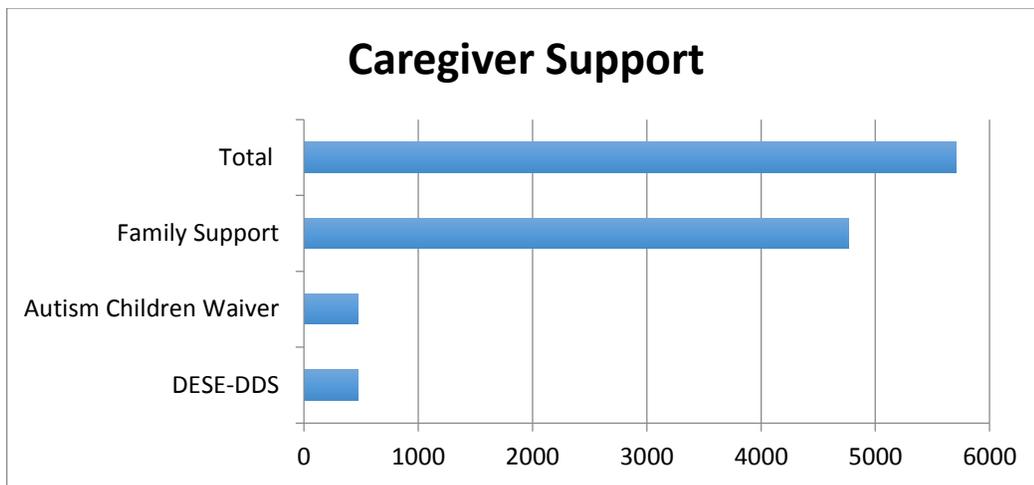
Helping families to be strong and resilient pays off for our community and businesses with long-term cost savings. The DESE-DDS (Department of Elementary and Secondary Education) program (started in 1997) provides a clear example of significant savings when caregivers are adequately supported. The

goal of the program is to prevent the separation of children from their families through placement in residential schools. The most recent DDS annual reports cover fiscal years 2006, 2007 and 2008. The chart below notes the number of students served by fiscal year, and the bars show the savings for each of those years. Note that the savings only cover the state DESE budget portion of savings, not local town or city savings. The retention rate cited in the reports is 96%.



Supporting families in their commitment to care for their loved ones at home and in their own community is an investment that pays off for families, our communities and businesses. It 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. Our proposal asks that the Commonwealth make a significant investment in families over a 4-year period. The monies will help 5,700 families with the highest needs.

- 18,000 families with caregivers on DDS caseload, over half are unserved or underserved
- *5,700 families estimated to be served with Initiative*
- Initiative will serve (as shown in chart)
 - 4,767 families needing Family Support – with 75% of new funding
 - 470 families needing Autism Children’s waiver supports
 - 470 families needing DESE –DDS supports



The chart above reflects the goal of the campaign –to reach 5700 of the families in most need of support. To adequately support and avoid higher out of home care costs, our goal estimates an average of \$15,000 per family per year (pfpy) for Family Support allocations and \$25,000 pfpy for the two other programs. Family support would receive 75% of new funding since it can be used for adults and children while the other two would share 25% in our proposal. If 20% of those with a high level of need had to move to residential services over a four year period, the estimated residential cost to the state would approach \$200 Million.

Caregiver Support 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 overnight support. Examples of caregiver support include: crisis or behavioral intervention, sick and emergency care, assisting with activities of daily living, such as bathing, toileting and dressing, and/or instrumental activities of daily living, such as meal preparation, feeding, transportation, managing medications, and money management.

“Supporting Families” is a collaboration of The Arc of Massachusetts, Association of Developmental Disabilities Providers, Massachusetts Families Organizing for Change, Advocates for Autism of Massachusetts, Autism Speaks, Massachusetts Down Syndrome Congress and Massachusetts Developmental Disabilities Council. For more information, go to SupportingFamilies.org.

FAMILY STORIES



RILEY'S FAMILY

I am a single parent to 3 children ages 9, 10 and 11. My oldest son, Riley, is severely autistic, my middle son Aidan has some anxiety and my youngest, Charlotte has a global developmental delay. I can only work part time out of the house which is really one day a week at a retail job because I have been with the company for years and they are compassionate to my situation.

A day in our life starts off with me, mom, sleeping on the couch to ensure that Riley does not set the house on fire by cooking in the oven, or trying to escape and turning my car on. He is very smart and figured out the locks on the doors. He usually wakes up around 4 AM

and almost always has had an accident. When he is up at this hour, he is often in an agitated state and will cry and thrash and bite. He will turn on the TV and other devices to help calm down. I encourage him to take deep breaths. He will lay on the now ripped, stained and sagging couch with me. When Aidan gets up he must stay in his room because if he comes out in the morning near Riley he becomes very upset and will attack him.

I often wonder what life would be like if Riley were not autistic and I can't think about it for too long. I have met some of my most favorite people in the world because of my son. The individuals that have shown him love, compassion and given their friendship to us have been amazing but I have gone to bed crying and so do my children. My daughter Charlotte has a "safe spot" in the home because in the last month Riley has escalated so much and is now going after her. Currently, I am trying to get Riley placed in a residential home because we can't live like this anymore. I can't begin to tell you how much I love my children. Riley is my baby and if this happens, I pray that he is safe and doesn't think that I don't love him. I wish I could do more for him and get help to keep my family together.



ISAIAH'S FAMILY

Isaiah arrived in the world 10 weeks premature and weighed 3 lbs. He took one good cry, then stopped breathing from respiratory distress and was rushed out of the room by the NICU team. I learned a few hours later that Isaiah did have Trisomy 21 but we also learned he had an intestinal disease called Hirschsprung's.

Isaiah had 20 hospital admissions during this first year of life and 16 during his second year. Family support funds came in handy to buy him a bed and to pay for his glasses, since Masshealth wouldn't cover the style he needed. We also used it as he was older to cover horseback riding lessons which I would never have been able to afford. Horses were huge for him since he had many stomach surgeries and the lessons helped to strengthen his trunk and core muscles.

Isaiah has come along way in the past 19 years. He is now a post graduate of Somerville High School. He takes one class per semester at Bunker Hill Community College. He works as a bagger at a local Stop and Shop working 20-25 hours a week. He is involved in Special Olympics with basketball and track.

Isaiah has been a strong self advocate since a young age. We have been part of medical student training program called Operation House Call since he was young. He was asked to join as a co-teacher and loves that! He now goes to Tufts Medical School and BU Medical School and talks to future doctors. I would never have believed any of this was possible back when we were in the NICU. It blows my mind how far my little guy has come and the wonderful young man he has turned into. I am excited for his future, which we hope includes a living situation with a roommate, support for the employment that he loves and many great friends who keep his social life full.



NEIL'S FAMILY

Last year, my family needed to pull together and persevere through some very difficult days. Having an aggressive, non-verbal, 13 year old son with complex medical conditions and another son, 10 years old, also with autism - meant figuring out how to balance the intensive needs of both boys and still find time for my 16 year old daughter, while working to support my family.

The challenges increased with a spike in my older son's behaviors that put him and my family at risk. His school's systems recommendation was to place him in a residential setting. My son's behaviors were so interruptive and dangerous that his team at his specialized school for children and adults with autism felt he was not able to learn.

My family was in crisis. We needed expert medical intervention. We counted on his Department of Education Secondary Education (DESE) and Department of Developmental Services (DDS) funding to use for behavioral supports and we relied on the resilience and strength of family and friends. The struggles were overwhelming but little by little we saw positive changes – my brave and beautiful son got back to solid footing. He is beginning to learn at school and he is able to spend time in his community. These small triumphs allowed us to keep our family together. Today, we still have immense challenges that can rattle us but we are together and lucky for that every day.