

# IN THEIR OWN WORDS: THE NEED FOR FAMILY SUPPORT SERVICES

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# 1. Executive Summary

*“When someone has a special needs child their whole life changes.....It puts a strain on almost everything you do. ....I have been through hell and back in the last fifteen years so I may forget many details but it is clear that I feel that the support I received from the state was something to make or break me. It did make me. I would not have spent such quality time and enjoyment with my son. I would be broke and living God knows where. I would probably have had a nervous break down as well. ....I do have a great family and group of friends and co-workers who have been there for me through tough times but seriously, it was the State programs and funding that made the world of difference.*

*So hopefully, things will continue for special needs children and families because they deserve it. It is a bumpy rough road with many turns and road blocks. There are many setbacks and disappointments. So if the State can ease things for these families just a bit so they can live as best to their abilities, it is vital for the future of these children and community. ....No one in this situation chose this life. No one would ask for this help unless it was necessary.”*

- Across the state, more than 20,000 Massachusetts citizens are caring for a family member with an intellectual or developmental disability.
- While these families represent 60% of the individuals served by DDS, family support funding for caregivers is only 3.5% of the DDS budget.
- Family support is 75% to 80% less expensive than out-of-home placement (Section 4 of report). It is the service that can have the greatest impact on reducing more expensive residential demand.
- Families readily take on their role and require comparatively small amounts of support to help them continue. These modest funding amounts support the enormous unpaid contribution of caregivers and supplement the long term care service system in Massachusetts.
- Investing in family support provides immediate relief from the challenges of caregiving and paves the way for children and adults with disabilities to

continue to live with their families by building and maintaining a foundation of support to sustain their role as caregivers.

- Family Support helps avoid caregivers reaching the point where they feel helpless to continue and seek more expensive out of home options. Because of the lack of a predictable support system, many families view residential placement as their only alternative.
- Given the enormity of the national economic crisis in the past several years, funding for family support has experienced reductions.
- In the fall of 2011, DDS, in collaboration with eleven stakeholder organizations, initiated a comprehensive process and gathered input from over 1,300 families to inform the development of a future vision to support families caring for adults and children with intellectual and developmental disabilities.

The overarching themes voiced by families as essential to their caregiving are:

- the predictability and stability of knowing that resources will be there for them
- flexible options and ways of accessing services
- a range of supports and not a “one size fits all” approach
- recognition that families are the experts and should have choice and control over their supports

Families voiced that the following supports help their families:

- Respite Care
- Skills Training
- Flexible Funding
- Fostering Friendships, Socialization and Recreational Opportunities
- Access to Information, Assistance and Education
- Planning for the Future
- Community Education and Development
- DDS has created a strong foundation of family supports to build upon. Families expressed that they endorse the supports provided by DDS but more resources are needed to adequately support existing service recipients and to extend support to many more eligible families in need.
- Based on testimony from the forums and the results of an on-line survey, only 29% of respondents felt they received adequate family support from state agencies such as DDS.
- It is evident that more financial resources are needed. The Department asks that as the Commonwealth’s economy improves, additional funding is

provided to create a system of supports that makes available a nominal amount of resources to provide all families with some level of caregiving relief.

- DDS recognizes the need to strengthen its efforts to improve communication with families, create resources for future planning, enhance communication and collaboration with other agencies and examine other direct and indirect ways to support families.

*“I don’t feel like families are a priority for this state. There are more families to serve and less money.”*

- What is most remarkable about family support services is how these lower cost resources makes such a substantive difference in families’ lives and also significantly impacts the economics of the service system by stemming the flow of more expensive residential supports.
- Families need a comprehensive system of supports that they can rely on for help across the lifespan of their family member.
- The system must be transparent so that caregivers know what to expect during important milestones in their lives such as, when their family member becomes school age, or graduates at age 22, or when they themselves age and need to plan for a future for their son or daughter. The anxiety families currently endure every day and especially during these transitions could be ameliorated by a commitment to acknowledge and support their efforts and recognize that what they do is valued and makes sense economically for the state.
- DDS has invested in a well-developed system of residential supports that has been a major focus for the agency over the past two decades. It is time to shift the focus and make supporting caregivers the centerpiece of the agency’s development and advocacy efforts. The Department needs to be able to make a commitment to every caregiver who takes on this role that they will have supports available.
- Family support should be highly regarded as a service that is essential to families and not viewed as an ancillary or secondary support. It is as critical to the system of supports as any other service and is the most cost-effective service provided.

*“It is hard for people who don’t live this to understand how it can feel like you are driving on the edge of a cliff with no shoulder on the road. These small allocations, seeing that there is someone to reach out to who will welcome you and help you can feel like a moment of rest on a very long, very hard, although equally wonderful journey.”*

## 2. Overview

### Introduction

*“I am tired. We are all tired. We need to give ourselves all a pat on the back for what we do every day.”*

*“As you get older, you don’t know what tired is. I also take care of a granddaughter after school since my daughter is a single parent. It becomes more of a reality of how do I do this down the road, in the home. We don’t want to place him again.”*

The Department of Developmental Services (DDS) is at an important juncture. There are more and more children and adults with intellectual and developmental disabilities living with their families resulting in a greater demand for family support services. But, as a result of the economic downturn that began in 2008, funding for this service has decreased. This has created an even greater need to develop a direction for the future that demonstrates **the social and economic need for, and benefits of these services** and identifies solutions that are efficient and support families to take on and continue their role as caregivers.

**Twenty-six forums were held** across the state to **gain input from over 600 caregivers** about what they need to support their family member at home and in their community. The quotes included here are the ideas and feelings expressed by these caregivers **in their own words**. This input, and the **information received from 747 caregivers through an online survey**, form the basis of this report describing the need to make adequate family supports available to caregivers and the cost benefit of these supports to the Commonwealth. It is intended as a “preface” to more comprehensive strategies that need to be developed to create a sustainable future for family support services in the Commonwealth.

*“Even just a little amount of help would be phenomenal. To go out to a movie with my husband. To have that respite.”*

**Families are the largest group of service providers** for individuals with disabilities in the Commonwealth. If family caregivers were no longer available, the economic cost to the state for long-term services and supports would increase astronomically. Thousands of **individuals with disabilities** in Massachusetts are able to live at home with their families because family members undertake caregiving willingly. However, this caregiving can come at a substantial emotional, social and economic cost to the whole family.

*“We do the same job as a residential program if not more. . . . My wife and I have only been away from our son 2 nights in our 20 years of marriage. Divorce rates are high for parents of special needs individuals. We are continually running on empty. We don’t need a support group. We can never attend anything for our other children together. Taking care of our son is more than a full time job. “*

*The biggest challenge is the amount of time and effort. Our whole life is very different from other families. It’s a 24/7 job. It’s like running a company. Making the family function at home is a business.”*

In the fall of 2011, there were approximately 20,400 individuals living with their families who are eligible for DDS services. Their age ranges are:

- Number of children 8,500
- Number of young adults age 18 to 21 2,900
- Number of adults over 22 9,000

*“In the health care world, everything is focused on prophylactic care. The same applies for our kids. What will happen when my child is in the hospital? It will cost the state thousands and thousands of dollars. It could be prevented if these supports were available.”*

The contribution of family caregivers is an invaluable asset to the Commonwealth that should be acknowledged, supported and encouraged by making available assistance that promotes caregiving in the home by easing the stresses of day to day care. Investing in this support and promoting the contribution of caregivers **help to preserve one of the Commonwealth’s most valuable resources.**

*“Families are holding on by their fingernails.” “Things are getting worse- not getting better”. “We don’t expect things to be handed to us.”*

*“Trying to prevent residential placement for my severely autistic child. We want him home but he is getting unmanageable.”*

### **Process for Gathering Input**

In recognition of the importance of these supports, in July 2002 Chapter 171 of the Acts of 2002” An Act Providing Support to Individuals with Disabilities and Their Families” was enacted. This legislation specifies that all named state agencies, with substantial consultation from families and individuals with disabilities, need to prepare and submit an annual individual and family support plan. Consistent with this legislation, this fall DDS sought broad input from families, individuals, advocacy groups, staff and providers to gather insight and reflect their collective wisdom. This feedback provides a clear vision for the future of Family Support. The forums provided caregivers an opportunity to discuss what their needs are and to give input into what assistance is necessary for them to support an individual with disabilities in their home. These forums included some separate meetings with particular ethnic and cultural groups. Each region also met with self-advocates who live with their families to gain their perspective. A standard set of questions was used to prompt the discussions. The comments and ideas that emerged from these conversations were recorded and organized for use in this report.

With the assistance of the Shriver Center, a written on-line survey was also developed to gather input from families. The survey included 68 questions and allowed caregivers to record any comments or ideas they had. **Over 700 caregivers** who provide care to adults and children with disabilities living with them completed this survey.

We asked families what helps, what doesn’t help and what would a truly supportive system of supports look like, not just what DDS might provide but from all aspects of their lives. **A series of themes** surfaced from the forums and surveys that demonstrate a common set of

needs that challenge the ability of caregivers to support their loved one at home. This report presents **what we learned from caregivers**. It reflects their voices from the forums and through the on-line survey. It is based on what they expressed their families need and **their vision for a healthy, safe and satisfying life for their entire family**. It attempts to demonstrate the demands on caregivers and their families and the need for a system that genuinely supports families to be strong and healthy and that influences how they live and their ongoing ability to act as caregivers for their family member.

*“Fortunately things seem to be getting back on track – but the funding really helped with that, and more than gave me a little peace of mind when I was spending most of my time worrying – and that was truly a gift for me.”*

## WHAT IS FAMILY SUPPORT

*“I hope to see Family Supports elevated to an equal priority with Residential and Day and Employment Supports. It is so frustrating that each time budgets are trimmed, family support is the first thing to go!”*

*“In a perfect world, we would restore family services again, and also have some provisions for crisis mode. We should have benefits available to us like respite, funding for equipment, crisis respite when there is a death in a family, help with locks, beds, diapers, all of those things that helped normalize a little part of our lives. We would have someone to go with us to functions. We need to have our basic needs met, but we also need the flexibility when there are crises. Also, it’s amazing what you can get when you ask for something. Don’t be afraid to go into the community and ask for help.”*

*“We have no help, nobody to depend on when he isn’t in school.” “We’re not looking for a hand out but a hand up.”*

Family support is a variety of service options and assistance to families of individuals with disabilities that provides them with **“whatever it takes”** for them to live as much like other families as possible and enables them to stay together as a family and be welcomed, contributing members of their communities. **It is intended to help relieve the stress of caregiving** by focusing on the needs of the family and recognizing that what benefits the whole family benefits the person with a disability. These supports address needs or gaps where there are no other resources available and complement or supplement other sources such as private insurance, educational programs or Medicaid. By providing this assistance and needed support to caregivers, **the Commonwealth is making an investment** into a cost-effective future for individuals with disabilities by reducing reliance on more expensive out-of-home living options.

Family Support services need to be **responsive to different needs at different times in life**. Because they **help the entire family**, they must be viewed broadly. This view extends beyond what DDS can provide to other state agencies, social service agencies, generic providers, and informal and natural supports. **What is needed is a broad range of supports that are family responsive, flexible, culturally competent and emphasize integration into communities**. Family Supports are low-cost services that make extraordinary differences in people’s lives and offer the needed support to take on and continue the role of caregiver.

Family Support strives to achieve the goal of helping families stay together through:

- Developing families' natural capacity to meet the needs of family members;
- Offering additional supports such as staff resources, goods and services and financial assistance; and
- Enhancing the capacity of communities to value and support people with disabilities and their families.

This **holistic approach** to providing supports is based on individuality and flexibility. Family Support empowers families to make choices about what helps them most in their role as caregivers. Individuals with disabilities and their families are recognized as primary decision makers about their lives and the supports they need. Family Support includes respite care, individual skill building, recreation, social activities, peer support, service navigation, family networking, information and referral, and other services and supports that help relieve the stress of caregiving for the family and assist the individual with disabilities to live successfully with their family.

### **Evolution of the Service System**

Services for individuals with an intellectual disability have evolved from a system based primarily on residential supports in large institutions to a system that embraces the concept of living in the community. The initial emergence of community based supports focused on residential homes in the community as an alternative to institutional care. In 1989, for the first time spending for community services exceeded spending for institutional services nationally.<sup>1</sup> Massachusetts is in step with this national trend towards decline in institutional spending and a commitment of the majority of its resources to community services. DDS has built a 24-hour community residential capacity for almost 8,000 individuals. There are a number of other 24-hour residential options of support available through alternative program models. The Department believes that this part of the system has been stabilized and is sufficient to respond to the ongoing need of individuals who require this type of support. Each year, approximately 240 vacancies occur in this system and become available to address out-of-home placement when it is necessary. There is also a system of employment and day supports available to adults in out-of-home residential services and those living with their families.

Today, even though the majority of long-term care for individuals with disabilities is provided in family homes, **only a fraction of overall community spending is directed toward providing family support.**<sup>2</sup> DDS data shows that:

Total number of individuals in residential options or living independently	14,000	
Total number of individuals living at home with a caregiver	20,400	60%
Total number of individuals receiving DDS services	<u>34,000</u>	

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<sup>1</sup> Braddock pg. 13

<sup>2</sup> Braddock pg 43

Children and adults with an intellectual or developmental disability living with their families in Massachusetts represent 60% of the total population served by DDS. However, as indicated above, only a small portion (3.5%) of community spending is directed toward providing support to their caregivers.

More and more individuals with disabilities are continuing to live with their families. Their caregivers are looking for typical experiences for them and want to have an active role in supporting them. In each of the forums, caregivers identified Family Support services as critical to their ability to support their family member at home and to improve the entire family's quality of life. However, the results of the survey indicate that **only 29% of respondents felt they received adequate family support from state agencies such as DDS.**

### **The Current System of Family Supports**

DDS has been providing family support services since the mid-1990s. These supports are designed to supplement and build upon the capacities of families and are flexible and respectful of cultural, economic, social and spiritual differences. Currently, the appropriation for family support services is \$46 million. This figure represents an approximately 25% decrease in funding from the FY '09 level **which required the agency to reduce or eliminate services to many families.** Since DDS began providing these services, there's been minimal growth in funding and during periods of economic downturn, funding has decreased.

DDS has established an infrastructure for this service and an array of supports that includes both **programs** as well as **flexible funding** which allows families to directly purchase goods and services. Each Region has a Family Support Director who coordinates efforts across their region. Each Area Office of DDS has a contract with a **Family Support Center** whose role it is to conduct broad outreach to families and provide an array of supports such as information and referral, support groups, family trainings, parent networking and mentoring, service navigation, facilitation of social/recreational events, etc. The thirty-three centers are experts in generic resources and services in their areas and work to maximize natural supports. The Centers are expected to be integrated within their local communities and to establish strong local affiliations and partnerships with other state and grassroots community agencies in order to expand opportunities and services for individuals and families. They are the catalyst for educating their community so that individuals with disabilities can become integrated into the fabric of their city or town.

*"Forums and gatherings for families are most helpful to be able to network with other parents. You gain support from people who know what you are talking about and have been through it before themselves."*

There are also 10 **Cultural/Linguistic-Specific Family Support Centers** which respond to the unique needs of specific cultural and linguistic family groups in specific locations in the state. Because of language barriers, these families face extraordinary challenges accessing services. They often require skilled staff with strong experience and expertise to help them negotiate certain aspects of their families' lives.

A trend that must be noted is the increase in the numbers of children diagnosed with Autism or an Autism Spectrum Disorder (ASD). It is estimated that 1 in 110 children has an autism

spectrum disorder.<sup>3</sup> There are seven **Autism Support Centers** throughout the state that provide an array of information and referral services, resources and supports to children and young adults with an ASD. These Centers conduct broad outreach and provide service to families from diverse cultural, ethnic and linguistic communities in their geographic area and provide similar services to the Family Support Centers. DDS also manages a federal Autism Waiver Program for up to 157 young children with autism that provides direct in-home supports and services including one-to-one behavioral, social and communication based interventions.

DDS has several programs that provide more specialized assistance and support to eligible families that include the **Medically Complex Program** and **Intensive Flexible Family Supports (IFFS)**. DDS, in collaboration with the Department of Early and Secondary Education created the **DESE/DDS program**. This program provides supplemental supports to children living at home to prevent a more restrictive educational or out of home placement or to bring children in residential placements back to their family homes.

*“The DESE program has really worked. With that program support, we have been able to keep her safe, maintain some type of sanity. She is happy and functioning out in the community. None of this would have been possible without that support. Our program is self-directed which has been even better because we can control this.”*

There are a number of supports available through the DDS Adult Waiver programs that support adults living with their families. Participation in these waivers and access to these services is **dependent on the level of resources available to the Department**. The Community Living Waiver provides a model of more intensive in-home supports to assist caregivers and avoid the need for out of home placement.

While the Department has built an infrastructure to provide supports, **many families are receiving little or no family support due to the inadequacy of current resources**. The availability of sufficient resources for families in need would positively impact thousands of caregivers for children and adults with disabilities.

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<sup>3</sup> Center for Disease Control

## IMPACT OF CAREGIVING ON FAMILIES

*“He is very hyper - we have a lot of trouble with him at home. His behavior is very bad. I would like to have some support to keep fighting to keep him home. I am very worried about him. I am sick. If something happens to me some day I don't know what will happen. ....I really want everybody here to stand up to say a prayer for my son. I really don't want to move him out anywhere. We want to keep fighting to keep him home. I want everybody to keep fighting for those kids. “*

*“We live on one salary. We qualify for nothing. Because we do not qualify for any assistance, we go without much, even food.”*

### **Who Are the Caregivers**

The majority of caregivers for individuals living at home are mothers and fathers. They may be couples or single parents<sup>4</sup>. There are also a number of brothers, sisters and grandparents who have a family member living with them. Caregivers may be young families with other children who are typical or also have a disability. Some caregivers are also caring for elderly parents or another family member in their home. These are additional stressors that impact caregiving. Families living in poverty or with limited economic means face additional challenges and stresses. Survey data shows that:

- 25 % of respondents are single parents
- 12% of respondents have other children with a disability
- 61% of respondents are primarily responsible for the day to day care of other family members including young children or aging

*Maybe we can give a little bit of support just for the Moms.*

What is common about caregivers is their **commitment to care for their family member with disabilities in their home** and assume the challenges that come with this. Those who take on this unpaid role risk the stress, physical strain, competing demands and financial hardship of caregiving, and thus become vulnerable themselves. Family caregiving is now viewed as an important public health concern.<sup>5</sup> **Caregiving impacts the whole family emotionally, socially and economically.** Every day it affects siblings, relationships, employment, social networks and the dynamics of the family unit itself. Caregivers rated their own quality of life as follows:

- Excellent 12.1%
- Good 43.5%
- Fair 38.3%
- Poor 6.1%

*What's not working – I am exhausted. I am a single parent. I am getting older and I am tired and financially drained. I have to deal with my aging elderly parent. I am a cancer survivor. I am really tired.*

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<sup>4</sup> From survey

<sup>5</sup> AARP Public Policy Institute “valuing the Invaluable: 2011 Update: The Growing Contributions and Costs of Family Caregiving” page 4

Many families talk about the joy their family member with a disability brings to their family and how their family is enriched. An Easter Seals study reports that family cohesiveness is one of the areas most positively impacted by having an adult child with a disability.<sup>6</sup>

*"I have met so many wonderful advocates and families that have become friends. My son has taught me many valuable lessons. He is also a stabilizing influence on our family, bringing us closer together."*

However, what is different about providing care to an adult or child with a disability is that **most individuals will require a lifetime of support**. In many cases, the individual also requires constant supervision and cannot be left alone at home. This means that unlike typical adults or children of certain ages, a caregiver can't just leave the home to go to the market. In some cases, the individual may always need to be in sight. This is one of the realities of the caregiving demands on families.

*"My son's disability has affected every aspect of our lives. Now that he is a young adult, we realize that he will never be able to live alone independently, so all our family's decisions (financial, emotional, career, and residential) are influenced by that knowledge."*

*"She lights candles and crosses busy streets without looking. I fear for both of our safety."*

Among those families caring for someone with a disability is an **increasing number of caregivers who are aging**. There are many caregivers over age 65 who have been providing care for their family member with disabilities their entire lifetime. This increase parallels the increased lifespan everyone enjoys due to improvements in healthcare. The age of older adults with disabilities living with their families continues to increase as does the age of their family caregiver.<sup>7</sup> As caregivers age, their ability to continue in their role is sometimes compromised by their own health issues and the long-term affects of caregiving. A study about the health of aging caregivers indicated that by early old age (mid-60's), parents of individuals with intellectual and developmental disabilities have poorer health and mental health than parents of non-disabled children.<sup>8</sup> These caregivers feel increased stress about their current ability to continue and the future of their son or daughter.

*I hate to be selfish, but what about me? There is nothing to look forward to.....*

*"I am at a wall and I don't know what to do."*

Family caregivers who have **both typical and disabled children must balance** the competing demands of their children. A number of comments were made at the family forums about these challenges and how they impact the siblings of the disabled child.

*If I asked my other children what they would like best, it would be to have two parents do something together with them when half their brain is not focused on the other child. There is always one parent where half their brain is focused on the child with a disability."*

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<sup>6</sup> Easter Seals

<sup>7</sup> AARP pg. 10

<sup>8</sup> Seltzer, Floyd, Song, "Midlife and Aging Parents of Adults with Intellectual and Developmental Disabilities: Impacts of Lifelong Parenting, American Association on Intellectual and Developmental Disabilities, Vol. 116, No. 6, November 2011

*“People in the general public don’t know what it’s like for kids. It’s embarrassing for her. We can’t have kids over. We don’t do family events any more - it’s too hard. There needs to be some kind of supports for the other children. We need to have more Sibshop opportunities.”*

*“My other children don’t always want to do things based on autism. Something relatively fun that can get them away from the stress. Something in the community, not two hours away. A discount here, they can go to classes there. Don’t know if it is even possible. I sometimes feel shell-shocked – what’s going to happen next – etc – they pick up on it. They get stressed and it becomes a way of life of everyone.”*

*“What helped my family: All of my children could attend the Saturday morning group at (provider name).”*

### **Economic Impact on Families**

The demands of caregiving also have a financial impact on families, **especially on the employment ability of the caregiver**. Many parents have had to reduce their employment hours or quit their jobs entirely to care for a family member at home. Data from the survey show that 62% of caregivers have limited their job choices to meet the demands of caregiving. Caregivers have given up jobs, changed jobs for better hours, accepted lower paying jobs for better flexibility and benefits and refused job transfers or promotions.

*“It’s hard to do much of anything when I have to take care of my kids. I should get a job but I need the flexibility otherwise my kids are helpless without supervision. He also wanders and gets lost. It is absolutely scary and crazy!”*

Another financial impact comes with the amount of **extraordinary out-of-pocket expenses** caregivers must incur in caring for a disabled family member. These are costs above and beyond typical expenses. Almost **one-third of respondents** indicate that they **spend between \$2,000 and \$10,000** per year on these items. In addition, over 41% of respondents spend between \$50 and \$2,000 a year out of pocket on disability related items for their family member. The types of expenses are insurance co pays and costs, respite or child care, transportation, specialized educational materials, personal care needs such as diapers and Depends, communication devices, repairs of damages to the home and home or vehicle modifications. A study by the University of Minnesota<sup>9</sup> found that the **additional costs incurred by families** caring for an adult were \$6,300 per year in out-of-pocket expenses. A University of North Carolina study found that overall, families across all income levels who are raising disabled children are significantly more challenged to meet their expenses. Most public and private health insurances do not cover all expenses that caregivers encounter and they are therefore assumed by the family. The study noted that despite potential individual and family hardships, most individuals with disabilities wish to remain at home, a desire shared by their families. The availability of external supports has shown to increase families’ willingness and ability to keep their children at home.

Caregivers expressed that this combination of the emotional, physical and financial demands of caregiving can negatively impact their entire family and that a range of assistance is critical for them to be able to continue in their role.

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<sup>9</sup> Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota Volume 17, Number 1, February 2006

*I have paid up to \$130 in a week for my daughter for transportation – as little as \$30 and as much as \$132, so that can be her entire Social Security check.”*

*” I have an autistic 8 year old boy. I have been with (provider name) and they have been helping me, but they can only be there certain times but not all. I am a single mom with twins. My child has needed blood transfusions at the hospital. I need more funds for medical expenses.”*

*“My son has an older brother and sister. She would like to connect with other families. My son is registered with DDS. We don't have MassHealth and everything is expensive; need docs who take insurance.”*

*“My daughter is 18. She likes her movies and her music..... She is nonverbal. She makes her needs known by pointing..... Financially it is difficult. She destroys movies – I have had to buy Mary Poppins at least 15 times.”*

### 3. WHAT IS ESSENTIAL AND MOST HELPFUL TO FAMILIES?

*“Years ago, these individuals were warehoused in facilities with no life and no stimulation. Since then, parents have stepped up to keep kids at home and give them a chance at a normal life. Many supports WERE put in place to keep these kids out of institutions. UNFORTUNATELY, since we do such a good job, our supports become the target of budget cuts. We need help and we need POSITIVE long term options when we are not able to provide the care for our kids. NO MORE CUTS.*

Based on the forums and the results of the survey, there is a great deal of **coherence around the major types of services families state are most essential** to their ability to provide support to their family member at home. These include:

- Respite Care
- Skills Training
- Flexible Funding
- Fostering Friendships, Socialization and Recreational Opportunities
- Access to Information, Assistance and Education
- Planning for the Future
- Community Education and Development

Overarching themes that emerged from this process are that families need:

- the predictability and stability of knowing that resources will be there for them
- flexible options and ways of accessing services
- a range of supports and not a “one size fits all” approach
- families are the experts and should have choice and control over their supports

When these supports are available and based in these values, families readily take on the role of caregiver. Their expectations change about what their future will be and they are given hope and the security of knowing that support will be available for them.

#### RESPITE CARE

*“Respite funding is the most important thing to our family. It allows us to pay for childcare so my husband and I can go out for a few hours. That strengthens our marriage and reduces stress.”*

*“When we had respite, it was great to be able to depend on that time, even if it was just 2 hours a week. That was cut some time ago and now as a single parent of a child who has multiple special needs; this is what I need most”.*

Respite care **provides caregivers a physical and emotional break from the day to day demands and stress of caregiving.** It can be provided by neighbors, family members or trained staff depending on the needs of the individual. It can be provided in the family

home, in the home of the respite provider, or in a facility setting specifically designed for that purpose for either planned visits or for emergencies. It can be for a few hours in a day, overnight or for several days. Respite care was voiced resoundingly at every family forum as **the number one support needed by caregivers** to support a family member in their home.

*“As much as respite is needed for a break, I can’t tell you how many appointments I have had to cancel with my own diabetic doctor because I can’t find a sitter. Without the help, a lot of things take a back seat. It’s not just for a break to get a drink of water.”*

*“Support from neighbors, friends and extended family diminishes as the individual grows up. People are afraid to provide care for some individuals because they are not sure how to respond to a seizure or other medical issue. People also are unsure of how to care for a 6 foot tall teenager who is nonverbal though they did provide care to the same individual when he was younger.”*

*“Four hours of respite just means some cleaning and cooking. What has made a difference is overnight. Not just coverage.”*

Many individuals with disabilities require supervision 24/7 and cannot be left alone in their home. Respite allows caregivers to work, participate in trainings or support groups and attend to the day to day needs of the family and household. Respite must be flexible to meet these needs and available at all times and especially for caregiver relief, after school or day program hours, vacations and in case of emergencies. Providing relief from caregiving is an essential support.

*“It is a challenge to attend trainings or groups if respite is not offered as part of it.”*

As stated previously, many caregivers are unable to work because of the demands of caregiving. **By providing respite, caregivers are able to become employed** or maintain jobs that assist in maintaining the quality of life for their whole family. Resources for after day programs or after school programs were cited by caregivers as an important need to make things work for their family.

*“After day program care is an issue. Day programs are 6 hours long but my work day is 8 hours.”*

Related to the need for adequate respite care is the issue of **finding qualified staff** to provide this support. Difficulty finding qualified staff was voiced at every forum in relation to respite care and other supports such as skills training, recreation and socialization. Caregivers at every forum expressed difficulty in finding staff due to the following reasons:

- The capacity of providers to make available sufficient staff
- Staff salaries are insufficient to attract qualified people
- Difficulty finding staff for nights or weekend coverage
- The hiring bureaucracy and process imposed associated with meeting federal requirements

*“I used to recruit teachers from his school. Now it is harder to find people. No one else helped me find good respite people. I advertised on my own. I would lose people for respite. My lifeline are respite workers not famous behaviorists*

*who cost a lot of money (Provider name) has done a good job finding qualified people. Need to expand and start a clearing house for staff.*

*"I see fantastic people working very hard with limited resources.*

An important consideration for many families is **finding staff with specific expertise** and training to work with individuals who have specialized needs such as autism or intensive medical needs or behavioral challenges. These families face an added challenge. Caregivers cannot use "regular" sources to provide this service rather, they must find people with special skills to ensure the safety of their family member.

*"My son was placed. Respite workers could not continue to work as my son was too difficult. He was difficult and staff were not trained in physical management I have health issues and couldn't keep him at home. I'm not sure what will happen and the future is scary. Staff don't get paid enough. Need to have higher incentive to work with individuals with behaviors."*

*"Finding qualified respite workers can be difficult. For example, my child attends a summer camp but I need to find a worker to go with him. The school does not have people to suggest. The camps that provide staffing are too expensive to consider."*

*"Home health aides are very limited in the area I live in. The agency does not recruit in this area so I only have 1 worker. If that worker is out, there is no one to cover."*

## SKILLS TRAINING

Caregivers identified their desire to have their family member with a disability become more self-sufficient in daily living skills not only as a means of easing their role but also as part of their vision for their family member to **live more independently and fully at home and in their community**. Individuals need access to an assortment of resources to support skills training development in a variety of life areas such as learning to use transportation, money management, using the telephone, etc.

*A worker provides skill building with meal preparation and laundry. This is life skills training for my son.*

*"I need actual people to come into the home. I need help to get my son out of the basement. The mentor talks about the strengths and weaknesses of the family. I don't need that. I need someone more than 2 hours a week"*

By having in-home skills training available, individuals are more able to generalize what they learn in school or day programs to other environments. For individuals with behavioral issues, it is critical that techniques to address these issues are implemented consistently in all situations to be effective. Parents of children with autism expressed their need for behavioral supports in the home to help them support their child's development and provide carry over of behavioral programs from their school program. This requires the resources to find qualified staff who are trained in these techniques.

*"My son is 10, on the autism spectrum. I can never get someone to actually work with my child. There is a disconnect. What would work – a person who could come and work with my child - take him out into the community – another set of hands."*

A frequent theme heard from families of teenage children and adults was the **need for job skills training** and coaching so that an individual with disabilities has the ability to get a job and have something meaningful and productive to do during the day. Many adults with disabilities require some intensive training initially to gain job skills and then are able to maintain their employment with less frequent support. In the forums held with self-advocates, the need for employment and job supports was stated as their primary concern.

## FLEXIBLE FUNDING

*"I have an 18 year old daughter with complex medical issues and autism. She is also a cancer survivor. (Provider name) has helped us with the intensive family support program. They helped with school issues. School has been such a blessing to the family. My daughter is now transitioning into adult life and the flexible funding has been an amazing help to us. It has helped us to meet priorities that wouldn't have been met without them reimbursing us for things that are needed for my daughter. I just wanted to say thank you to (Provider). Couldn't have done it without the support we received."*

A unique feature of the Department's family support program is the availability of flexible funding that provides resources to caregivers so they can efficiently purchase allowable goods or services that are most responsive to their family's needs. These **intermittent purchases are made from a menu of allowable options**. Flexible funding offers a way to be responsive so families can identify what's most helpful to them as caregivers. It promotes flexibility, choice, respect and the recognition of the expertise of families regarding their strengths, competencies, capacities and needs and what will help them best provide for their family member with a disability. It provides some instrumental and tangible assistance and is highly valued by families. It gives them a sense of hope that they have support in their efforts.

*"Flexible funding allowed us to purchase what we need and hire neighbors and people who know my daughter to provide intermittent supports."*

This funding is provided through stipends or payment by a provider on behalf of a family. The most frequent use of flexible funding is for respite care in the family home by people who know the individual well and can support them in their home. Other flexible funding purchases address things such as recreational and social integration activities, short-term emergencies, extraordinary out-of-pocket copayments, adaptive supplies, specialized nutrition and clothing and skill building. This funding **is not intended to supplant assistance** available to families through private insurance or other state or federal sources. DDS has an established process for administering flexible funding through its funded family support programs. Given the currently availability of funding, the allocation to families who receive this support is between \$500 up to a maximum of \$3,000 annually. Typically, the average allocation is \$750 to \$1,500 annually. Again, most families do not receive this funding due to the level of available resources.

In Massachusetts and across the nation, service systems have advanced and now allow individuals and families more control over their service resources. The Center for Medicare and Medicaid Services (CMS) requires states to offer participant-directed models of support

in their Home and Community-Based Waiver programs. The ability to direct one's own services is recognized not only for individuals with disabilities but has also surfaced in the elder care system. Flexible funding is at the core of the participant directed model.

*The amount of diapers that Mass Health is providing is not enough. My son is very friendly and would like to spend time with other kids. I would like to have some flexible funds and a person for respite."*

The value of flexible funding was overwhelmingly voiced by caregivers at every forum. Having access to some level of flexible funding is essential to their caregiving and their ability to secure needed goods and services for their family member.

## FOSTERING FRIENDSHIPS, SOCIALIZATION AND RECREATIONAL OPPORTUNITIES

*"Teach him the skills he needs to be successful in life; work that is fulfilling and plentiful so he can feel good about himself and his accomplishments; reasonably priced activities that he can afford. Fulfill the needs of a whole person so he is welcomed and embraced by the community for the wonderful person he is.*

*"My son just wants a friend. He would say, would you help me find one friend?"*

*"My son is more socially challenged and for somebody to be with him and talk with him about what small talk is, leaving a tip in a restaurant, exercise,....."*

Many individuals with disabilities live largely in a world made up of their family, the people who provide their services and others in their programs. Individuals with disabilities are often isolated from their communities and have less frequent chances to engage in social activities and be part of their communities. **Caregivers want their sons and daughters to have the opportunity for a social life, friends and fulfillment that is available to all of us.**

*"A happy, safe and fulfilling life" "A world that is meaningful and has friends"*

*".....has been invaluable in allowing our son to have a personal connection outside of his family circle with well trained, compassionate and understanding providers. This service has allowed him to enjoy peer experiences in his home and community."*

People with disabilities need opportunities to take part in activities where they can meet their typical peers. They may need assistance with participating in these activities or someone to facilitate their involvement and interpret them to others in positive ways. Without this, people with and without disabilities might never get a chance to really get to know each other.

Individuals also need continuity of their relationships as an important source of security, comfort and self-worth.<sup>10</sup>

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<sup>10</sup> "Lutfiyya, "Personal Relationships Between People With and Without Disabilities, Center on Human Policy

Although many organizations welcome individuals with disabilities to take part in their activities, these individuals often require additional support to meaningfully participate. Family support funding can be used to provide this additional support making available resources for additional trained staff to help the individual take advantage of these activities.

*The YMCA is willing to do supportive things but they have to be through (Provider Name). There is a gap. The Y is willing but they don't have the funding to work with these kids. It's like we have it sort of, but without the funding we don't have it. How do parents get around that? ‘*

*My son used to attend Saturday morning recreational program and misses them. He needs 1:1 support for bowling and outside activity. He no longer gets this service.”*

There are some families who identified the need for **specialized social and recreational activities** so that individuals have the opportunity to interact with their peers with disabilities who have similar needs. This was particularly noted by families of children with autism who appreciate both family and individual events where they can share their experiences.

Transportation was identified as a major need in **the ability to access social and recreational activities** in the community. It also impacts an individual's ability to get to their job. A variety of flexible transportation modes are needed to ensure that individuals have ready access to services. Flexible funding can address many of these issues by providing caregivers and individuals the ability to directly purchase transportation from taxi services, public transportation and creative options such as coming together through car pools.

Peer support allows a typical or disabled peer to assist their peer with disabilities in social and recreational activities. Families identified that peer support was **especially important for teenagers and adults** to interact with individuals in similar age groups. For example, there are resources currently available in the community such as Best Buddies which partner typical peers who are high school or college age with an individual with disabilities. More models like this need to be available everywhere so that individuals of all ages are able to benefit from their shared experiences.

Social and recreational activities provide opportunities to build friendships develop social skills and create a healthy lifestyle. They are intrinsic to an individual's ability to have a satisfying life and happiness.

*“Someone to talk to my son. Make him feel like he is part of the community. Go out in the world with him. That way when he is presented with social situations he will be able to function. It's not so much funding as finding these people. I was on Sitter City to find someone to sit with my son. I can't bring myself to do it. I don't go anywhere, I cancel. Just a helping hand if I do have to go somewhere. He grasps so much more from other people than from Mom.”*

*“The flexible funding stipend is a financial help for recreation and some respite care. The amount is not excessive (\$500/year) but it is helpful to enable our child to participate in gymnastics and allow my husband and me to go out once every few months.”*

## ACCESS TO INFORMATION, ASSISTANCE AND EDUCATION

*“Even when you have a lot of information, making a decision is difficult. I attend forums and trainings but I’m scared to make a decision because I want to make sure it is what’s best for my child.”*

Families identified the importance of having **easy access to timely and current information and resources**. This includes information about understanding their child’s disability, such as effective interventions, strategies and services as well as public benefits, community and generic resources. Families indicated the need for different types of information at different life stages, especially at key transition points such as the movement from early intervention to public education services or from school to adult services. Having a knowledgeable person with expertise in disability information, benefit programs and generic community supports strengthens their ability to support their family member. Many families described not knowing what questions to even ask or where to begin.

In making information available, the system needs to be responsive to the needs of families from different cultural and linguistic communities. There is also a need to better use technology to expand ways to provide information.

*“I would like to see an increase in the use of technology. I don’t have time to keep track of which agency offers what on which day. I want all that information in one place. Webinars or online videos of trainings would be helpful so I could view the ones I couldn’t get to in person.”*

*“I had a difficult time finding a vendor for my son’s feeding tube and formula. The insurance company gave me a list but it took a lot of research to find one that offered the correct ones and some made you buy all of the items through them.”*

*“It is very difficult to find a primary care physician who is familiar with disabilities who also takes MassHealth. Our pediatrician had no suggestions. Another parent said that she interviewed doctors before choosing one for her son with many medical issues.”*

Families cited the importance of having a staff person help them **navigate the service system**. They are looking for individualized information, guidance and support to address their needs, connect them to potential resources and assist with problem-solving. Help in understanding what state services and/or federal assistance they may be eligible for and how to access them, as well as assistance in negotiating Social Security, MassHealth and private insurance is critical. Parents of children are looking for assistance to advocate for effective educational programs.

*“Not knowing if I have all the information I need is an issue. I didn’t know that both of us being guardians would limit our access to services (AFC) and had to go back and undo one of the guardians in order to be eligible for the service.”*

Families stressed the benefits of education and training on a variety of topics related to **supporting their family member throughout the lifespan**. Access to childcare or respite, and in some cases transportation especially for older parents, are frequently essential to make it possible for families to attend trainings. This is another area where use of technology can be helpful in expanding access to training.

Parent support networking and mentoring are important ways families benefit from learning from the experiences of other families “who have been on similar journeys and had similar experiences.” Families are looking for ways to build and foster these connections. Opportunities for leadership development were described as “life-changing”. These experiences, such as the Family Leadership Series funded by DDS, enable families to become more knowledgeable and empowered both in supporting their family member as well as advocating for broader changes in local communities and at the state level.

The creation of the Family Support and Autism Support Center established a source of information and referral for families. The centers offer support groups and training for the entire family. They assist families in finding the necessary resources they need to support their family member. They are a good foundation on which to build a more robust support for families.

Families voiced concern about bureaucracy and paperwork that is time-consuming and sometimes redundant. More interagency coordination is needed around challenges in accessing benefits. Although some of this is due to federal requirements for reimbursement, other processes need to be examined to determine if they can be streamlined. In some cases, providing an explanation why the process is the way it is would help families to at least better understand.

*Some standardization would be helpful in developing relationships with different agencies. Roles and responsibilities, clarifying services and the costs associated with those services. When you want to make a change, trying to get it to happen. Everything takes so long - why is that?*

*We lost flexible funding. Even if we did get funding, we would not be able to use it due to DDS rules. Better summer camps are in NH. DDS will not allow out of state programs,*

## PLANNING FOR THE FUTURE

*“There is the fear of: what will happen if I pass away first? I hope we go together.”*

*“My son is 21 and is going to be leaving high school. He wants to work when he leaves school but he will need a job coach. Not a huge amount of support, but he needs support. He wants to move into an apartment with a roommate.*

*“...the worry keeps me up at night. What will happen to him, what will happen to my other child's life when she is left alone to look after him when we are gone? The constant fear and worry is debilitating.”*

Families want a **long-term plan for their family member with a disability**. They are worried about what the future holds when they are no longer able to provide supports. They want to know what will happen when their young adult graduates from school. The repeated refrain heard at the forums was “Where will he live when I’m gone?” and “What will happen when school ends?” This issue is an enormous source of stress and anxiety for many caregivers.

In response to a survey question about their concerns for their family member’s future, over **80%** of caregivers noted that they are most concerned about:

- “What will happen to the person I support if I cannot care for them”
- “Making sure that the person I care for will be surrounded by people who love him or her”
- “Making sure the person I care for will have a place to live and enough money to survive”

Other concerns expressed were worries about the individual’s safety, making sure the person has friends and not burdening other family members.

*“Who will care for him when we die? Who will protect him? Who will know how to communicate with him? He does not talk and has limited vision. He is fed with a J-tube. We are not afraid of death because every day is a piece of hell. You have to fight for everything. Why do we have to fight the state for nursing hours? Every day is a battle. Why do I have to fight to keep my son healthy?”*

Families are interested in **ensuring that their family member is safe, happy and has a meaningful life** including the work, social and spiritual aspects of their life. Some families have already begun this planning through establishing trusts and making arrangements for their property. They want to plan for the future but need assistance in understanding what options are available to them and creating a vision for what their family member’s entire life will be when they are no longer the primary caregiver. This includes living options such as family partnerships, supported living, group homes and other out-of-home options. Caregivers expressed that they do not have information about the types of options available and what the possibilities are. Many families are interested in alternatives to group homes and ways they can participate in, and support their family member once they leave their home.

*“We plan to move out of the home when our son is ready to live alone. We purchased the house next door for another family member to live in so someone is close by.*

*“I want my son living in an apartment with help. I want him to do everything we can do.”*

*A daily job with a job coach. He is learning job skills right now at school through (Program Name). Meals on wheels, hotel, hospital, landscaping. Maybe a job with a landscaper with a job coach. As long as we can do it, our son will live with us. Home is home.*

*I want my daughter to be happy in the future. I have heard a lot of talk about productivity – I would like that too, but please let her be happy. I don’t want anyone to look at my daughter and assume we know what that happiness is for her. We need to watch and listen to her and try to figure out what SHE wants.”*

DDS needs to formalize how staff reach out and engage families in this discussion about their expectations and make available the resources and referrals needed for families to create a vision and plan for the future.

*“I have been involved with (Provider name) since 1994. My grandson is now 28 years old. I appreciate (Provider name) for everything they have done. My grandson has Down syndrome. We want him to be as independent as possible but we are always watching. I am co-guardian. I do have 7 children of my own. We are a close knit family. If tomorrow brings a different picture, I know I do have support in the family. However my grandson wants to be as independent as he can. His idea is maybe a shared living apartment. This sounds pretty good to him when he visits a*

*friend who lives this way. When you bring up the subject about a group home he gets scared - he thinks he will be leaving the family. This is something you have to work through with them. At this point I am interested maybe in shared living and what I can do to keep him as independent as possible. It's up to all of us as a community group to be participating on a family council that may be available and to have faith in your child and in yourself."*

*"My son is turning 22. He has higher functioning autism. He likes to read, use the computer, horror movies, going to the library. We try to make sure that he is self determining what his activities are. He likes to have his one beer on Friday night. I think he would like to live in an apartment. Am I ready for this? Absolutely not. But we will have to look at this, because he is an adult and that's what he wants."*

*"Estate planning is an issue. Forums on estate planning have been helpful but still have many questions about whether I'm doing the right thing. Individualized futures planning may help."*

### **Transition to Adult Services**

*"I need help during transition from school to "what's next". "What's next" is more than what services are available. It focuses on what the vision is for my son's future. Families with high functioning individuals as well as individuals with more needs need help with this."*

In Massachusetts, children are entitled to an education through the Chapter 766 mandate up to age 22. Caregivers are then faced with the question of **"What's next?"**

*"You go from services to no service so quickly. It is shocking and yet not shocking that there is no entitlement."*

*"Please continue to advocate for our family members who have had many years of special education but have very limited options for a productive life once they graduate from school."*

In the mid 1980's, the Legislature enacted Chapter 688 which makes available resources for individuals aging out of the educational system. This was in recognition of the investment in these young adults made through Chapter 766 and the need to build on the skills and training received through their school years by providing continuity in services to move towards employment and more independence. However, because Chapter 688 is not an entitlement, services are limited to the amount of resources appropriated each year. For the last several years, the Department's Turning 22 appropriation has not been sufficient to support all individuals who wish to work or to attend the most appropriate day program. Because of this, the period leading up to graduation is stressful and anxiety provoking for parents and students.

*How do I make all that stuff happen? That would be what I would want for him. I know he needs more support. I want the same opportunities for him that his sister has had. It all comes down to funding – making sure that the social recreational piece is there so the kids don't spend too much time on their own."*

Parents expressed confusion about this period in their son or daughter's life and the need for better coordination between school systems and human service agencies. They need better understanding of the Chapter 688 process, what is available from the human service system or other resources and help with planning for this period of transition to adult life. Many families talked about wanting their family member to have a job, be involved in meaningful activities and relationships in their community and to have a fulfilling life. They want help in developing this vision and finding the resources to actualize it.

*"My biggest concern is the medical piece. To continue what my child has been having at school into his adulthood. If he had a number of hours that followed him after school (when he turns 22). I have nightmares about this every day because I am not sure if it will. My son is 19 and profoundly disabled and severely medically fragile."*

## COMMUNITY EDUCATION AND DEVELOPMENT

*"Making sure the community understands our needs. They don't. We didn't either before we had a child with a disability. They are not helping because they don't understand and they don't know. Community education is crucial. ....Our communities are fuller and better because we are in them."*

*"We want a place to go which is accepting and we don't have to apologize for who we are."*

*"It is hard for other adults to understand what it's like having an adult child in the home with a disability."*

At several forums, caregivers told stories of their **disappointment and frustration with the community at large**. There still remains much apprehension and insensitivity on the part of the public about the needs of families and individuals with disabilities. Families experience this constantly in their local interactions. Much of this is due to a lack of knowledge or experience with individuals with disabilities or stereotypes.

The community can be an **enormous untapped resource of assistance** for families. If people understood the needs of families and had a way to reach out to them, important things could happen. There is an enormous need for public education and building bridges and connections that can benefit everyone.

*"We need the public to understand what families go through and what Family Support is. We already know what's needed. We need to educate the community so that when Joe down the street sees the van picking someone up, he understands why that's happening and that it's essential and saves the state dollars."*

Although many caregivers voiced their disappointments with experiences in their communities, there were also inspiring stories of people coming together through churches, civic groups and neighbors who learned about each other's needs and reached out. People developed friendships and offered their assistance to caregivers and individuals once they understood.

*"I gave a little presentation to my church about our family and my daughter. People said they had no idea about my life and what my family does. The outreach and support offered to me after that was amazing. We've gotten stuck and not been involved in our communities to share our stories and needs."*

Others talked about the help they had received from organizations like the ELKS, Chambers of Commerce, etc. with building ramps for their home or purchasing a wheelchair van. This happened after a presentation was made to the organization about what families struggle with and what they need. Again, once people understand, they respond enthusiastically and want to help.

*"We just don't have time to get out into the community. What would work - a marketing tool? People don't know about us. We are the silent majority. Funding is limited - we have to deal with that. We need a message to get out there to tell people what we need. Grandparents, high school swim groups, other people - we can reach out to those people"*

This sharing can multiply exponentially and have dramatic effects on communities. What is needed is **a catalyst to reach out and build these bridges**. Provider agencies do some of this outreach now. A more organized effort could be done through the Family Support Centers with the addition of a community organizer who works at a grass roots level to provide this education and let the needs be known. Much is done in school systems about acceptance, diversity and bullying but there is not an organized parallel in the community at large.

*"I know that my daughters love music and live theatre. I think she would say, can I please go to more theatre without people scowling at me because I make noise and I don't move my body right?"*

*"We want to do things as a family where we are accepted.*

*"When we go to a restaurant, they seat us in the back."*

*"He has the same rights as anyone else."*

## 4. COMPARATIVE COST OF SERVICES

*“Find a way to increase and sustain family support in the short run or the alternative costs will be multiple times larger in the future when we family caregivers burn out, age, become infirmed or disabled and ultimately die. Our lives are obliterated but if you could help us do right by helping us keep our disabled child at home until adulthood (if we can), it would go a long way.”*

What is most remarkable about family support services is how a lower cost, modest amount of resources make such a substantive difference in families’ lives and also significantly impact the economics of the service system by stemming the flow of more expensive residential supports. Simply stated, **family support pays off over time**. It is the service that can have the greatest impact on reducing the demand and need for more expensive residential care.

There is a great diversity of need for supports among caregivers and children and adults with disabilities. The amount of assistance each individual needs differs based the interaction between the needs of the individual and the capacity of the caregiver. The ability of each caregiver to provide support is related to issues such as their health, support system and other stressors in their life. As a system of supports is developed, it must be responsive to these varied needs. Some families will do well with a basic amount of support while others will need more moderate or intensive levels of support. Given this, ranges of resources must be made available to answer to each individual family’s needs.

It should be noted that the costs presented here are averages so that actual costs can be below and above these levels. Based on the agency’s experience, the estimate for the basic levels of support to adults and children is not representative of the current resources available to most families but are used here to provide an accurate estimate for comparative purposes.

### **Cost-Effectiveness of Family Support**

The following estimates are presented to illustrate the significant cost variance of providing a family with the supports needed in their home versus the cost of out-of-home care. Only costs related to **where people live** are presented. There are also **additional services costs associated with all children and adults**. Most children living at home participates in an **educational program** through their local school system. Most adults in residential programs or living at home with their families receive **day or employment supports and transportation**. Where things differ is the contrast of costs associated with living with a caregiver versus living out of home. Given the contribution of caregivers, family support is a much more economical way to support individuals.

### **Adults Costs**

There are numerous studies about the cost of a lifetime of out of home care. For adults with an intellectual disability in Massachusetts, the average cost of living in a **group home is**

**estimated at \$85,465 annually.**<sup>11</sup> Over a lifetime, the out-of-home cost of care can exceed \$4 million.

There are many adults with disabilities **who meet the agency criteria** for out of home residential placement **who live at home** with their family now because they opted for less expensive family and in-home supports. A number of family partnerships have emerged over the last decade where although the demands of caregiving were difficult, families felt that with certain supports they could and wanted to continue as a caregiver in their home. Creative packages of services were assembled that now allow these families to live together in a supportive environment with staff working intermittently in their home. The average cost of this model of support **is estimated at \$20,000 to \$25,000 annually or approximately 75% lower than the adult residential cost.**

The need for this model of support was requested by many participants at the family forums as a way they could continue in their role of caregiver. The Department's experience with this model has proven to be a successful and preferred alternative to out-of-home care.

<b><u>Adult Group Residence Cost:</u></b>	<b>\$ 85,465/ average per person per year</b>
<b><u>Adult Family Partnerships</u></b>	<b>\$ 22,500/average per person per year</b>

### **Children**

For children with disabilities in Massachusetts, the average cost of an out-of-home residential school placement **is estimated at \$126,000<sup>12</sup> annually.** Once these young adults age out of the educational system, they become part of the Chapter 688 process and request an adult out-of-home placement from DDS.

The Department's Autism Waiver Program provides an array of supports to young children with autism. This program provides up to \$25,000 for supports that augments the child's educational program during a critical period in their development. There are also a number of children at risk of out-of-home placement due to the intensity of their support needs who, through a more comprehensive package of supports, are able to live at home with their family. Through the Department's DESE/DDS program, supports are provided in the home that enable the individual to remain with their family and their local school district. An average cost range for participants in this program **is estimated at \$15,000 to \$25,000 annually or approximately 80 % lower than a residential school.**

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<sup>11</sup> Represents adult residential vs. in-home supports only; day services are not represented in either of these estimates; DDS residential cost estimates derived from DDS contracting data.

<sup>12</sup> Total average residential school cost is \$126,000. This cost represents services 24/7 and includes the daytime educational component. To determine an equitable residential only cost for comparison to in-home supports, the cost below is adjusted by the value of the daytime educational program component (\$30,000) to yield \$96,000 as the out-of-home residential cost.

<b><u>Residential School:</u></b>	<b>\$96,000/per child per year</b>
(\$126,000 total 24/hour cost <u>minus</u> \$30,000 day/education component    =    \$96,000 value of residential only)	

<b><u>DESE/DDS Program</u></b>	<b>\$20,000/average per child per year</b>
<b>(family and in-home supports)</b>	

Most families of children and adults require less intensive supports at home that are **a fraction of the cost of out-of-home placement**. The average cost for these family supports **is projected at \$1,000 to \$5,000 annually**. Again, there is variance in caregiver and individual needs that require resources above these levels. Also, over time needs will change and may require additional resources. However this range is sufficient for many families requiring support to allow the individual to continue to live at home and prevent or defer the need for more intensive or out-of-home supports.

There is a great deal of evidence in Massachusetts and nationally that a complement of family supports for caregivers to assist them in keeping their family member at home is **significantly less expensive than out-of-home placement**. For both children and adults, a range of resources must be available to meet the differing need levels of individuals and families. For children with autism or intensive medical or behavioral needs, more concentrated in-home supports are needed. For other children and families, lower levels of resources are needed for adequate respite, recreation and flexible funding to sufficiently provide families with the help they need to live without enormous stress and anxiety. There is a similar need for a range of resource levels for caregivers of adults with disabilities to enable them to continue their role.

These small amounts of resources support the enormous unpaid contribution of caregivers and fills big gaps in the long term care service system in Massachusetts. Without the work done by caregivers, the economics of the service system would be drastically affected. An AARP study examined the contributions of caregivers to an adult with limitations in daily activities. The value of their unpaid caregiving nationally was estimated at \$450 billion in 2009.<sup>13</sup> Estimates of the value of family caregiving are conservative because they do not quantify the physical, emotional and financial costs of care. Investing sufficient resources to lessen the strain on the daily lives of caregivers yields a positive return on investment and helps to contain service costs.

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<sup>13</sup> AARP pg.1

## 5. NEXT STEPS

The voices of families included in this report present the most powerful argument for the need for a comprehensive system of supports to families who provide care to a child or adult at home. There are 20,400 children and adults living at home with their families, many of whom receive little or no family support resources. The Department sought and received extensive input from families about what they need and the results of the forums and survey yielded no surprises. What we heard was consistent and clear; **families want to provide support to their family member in their home** but require a commitment of help that is predictable and stable. These supports ease the stress of caregiving and benefit the whole family. They need an array of supports that they can depend on across their lifespan. This is a good option for families and for the Commonwealth.

Massachusetts, like many other states across the country, is at an important juncture in developing a sustainable system of supports for families caring for children and adults at home. There is **a great deal of evidence that providing proactive, ongoing and early supports** to families makes it more possible for them to effectively care for their family member at home and helps avoid more costly out of home placements. The Department has many examples that are proof of this. Providing families the resources and supports they need makes it possible for the entire family to have a better life.

What is needed is the development of a system of support that uses a multifaceted approach and:

- Builds on the capacities of families;
- Is complemented by an array of state-funded resources that meet their caregiving needs; and
- Develops community generic resources, including formal and informal supports and reaches out and educates communities.

To be better positioned to respond to the growing need for family support, investments need to be made to create more balance in the system by making available an equitable proportion of resources for the families of the 20,400 individuals living at home. Currently, only 3.5% of the agency's funding is available for family support while family caregivers represent 60% of the individuals receiving supports. This will require a multi-year effort that examines how to expand, create and leverage existing and additional resources.

While the Department has developed a foundation of family supports that are well aligned with the needs of families, **what's needed is an adequate level of resources** to provide and sustain services to more families in need. Given the demands on the Department over the last several years, the focus of development efforts have been on other areas of the service system. A large part of this development has come with new resources as well as the leveraging of existing resources. It is important to maintain those levels of effort and not compromise the integrity of those supports.

Family support has lost ground over this period and in fact, funding is at a lower level than it was prior to 2008. The downturn of the economy has had a negative effect on human service systems across the country. Finding ways to meet the growing demand for services has never been more challenging.

Helping families continue their contribution of caregiving **makes great economic sense**. It is an efficient and cost-effective solution to providing supports. It benefits both the economy and families. Families are eager to take on and continue in this role and, as demonstrated here, **the costs are significantly less** than the alternative of out-of-home placement. These supports should now be the focus of the agency's development efforts. It is evident that more financial resources are needed. The Department asks that as the Commonwealth's economy improves, additional funding is provided to create a system of supports that makes available a nominal amount of resources to provide all families with some level of caregiving relief.

This report is a "call to action" to help families struggling with the demands of caregiving. Information gathered from caregivers will guide the development of a robust and responsive system of supports. This system must include direct supports to families in addition to information and training for families to help them in making decisions, planning and negotiating the system. There must be an expansive community development and education effort to foster opportunities for families to have positive experiences in their interactions with their communities. The information and ideas gathered through the forums and surveys will be the driving force for future activities.

Towards this goal, **DDS will concurrently work to strengthen, enhance and leverage its existing resources**. Other areas of focus will include:

- Expanding access to information, resources and supports for families and improving communication methods through the use of technology and multi-media approaches;
- Pursuing approaches to developing a sufficient cadre of qualified staff to support individuals and families and mechanisms for identifying staff such as an on-line directory;
- Improving communication about the Chapter 688 process and transition planning for individuals leaving school and entering the adult system;
- Expanding social opportunities in the community and creating resources that assist individuals in developing friendships;
- Developing an effective and comprehensive approach to community education and development, to explore partnerships and leverage other resources that benefit individuals and families;
- Improving interagency collaboration to facilitate access to the service system;
- Distributing and creating resources for families regarding planning for their family member's future,
- Creating a sustained and more predictable array of supports and services will necessitate a commitment from all levels. The partners in this effort are families, the Commonwealth and communities and the resources they each provide to reach the

common goal of helping families continue as caregivers in their home as long as possible.

*"I am so appreciative for the supports that are in place for my daughter. She has friends, a work place, our home to stay in and recreational opportunities. It is very upsetting to see that we have to continually worry about the money for these programs to continue. Their disabilities will always be with them. I wish we could rely on supports to be there for them and their families instead of always being put up for debate. Older parents worry that we will not be here to fight for them when they most need us. I hope the government could walk in our shoes to see that we do not have a choice. I hope they always continue to help the disabled without the debates."*