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I want to thank you Chairman Adolph and members of the Appropriation Committee for allowing us to share our information with you.

My name is Mary Saunders.

I am the mother of a three young men. My youngest son Troy is 24 years old and has CHARGE Syndrome with multi disabilities.

He is dual diagnosed with an intellectual disability and autism. Some of his other disabilities are his dual hearing impairment, limited speech & communication, difficulties swallowing, etc. He has endured over 36 surgeries with more to come.

He is a very caring, loving and compassionate young man. He has touched so many people's lives with his determination and sense of humor.

Life is not easy raising a child with a disability. We do our best to keep our children at home saving the state billions of dollars over their lifetime, yet when the families are in need of supports and services they languish on long waiting lists for home and community based services.

What do we know about the people with Intellectual Disabilities on the Waiting List?

There are currently 13, 531 people waiting as of July 31, 2016

4,616 Emergency Category

5,422 Critical Category

3,498 Planning Category

Where do they live??

85% of the people are living with and being cared for by their family and 7% are living on their own or with friends.

Break Down of ABOVE

11,451 individuals are living with and being cared for by their family

814 are living on their own

78 are living with friends

Of the 13,531 individuals who are waiting, only 2,487 are waiting for a 24/7 staffed group home.

HIGH SCHOOL GRADS

When our family members turn 21 and graduate from high school they lose all the services they were entitled to through special education and other programs. This is why we continue to push so hard for the High School Graduate Initiative that covers the 700 High School graduates who leave special education every year.

This is when they fall off the cliff and when the waiting really begins for families.

We have 683 individuals who are waiting that are 21 years' old

2,701 who are in the 18-20 age group and will soon be graduating with no services if we do not continue to fund the High School Students.

Our families are at the mercy of the general assembly every year and have to wait for the current budget year to be passed before they know if they will even receive services.

This year we pushed for a new High School initiative that would enroll our special ed students in their junior year of high school. This would allow them to transition out into the adult community without a delay in services after they graduate.

The estimated cost would be \$500,000 to pick up all 700 students for the first year.

As the system stands now it takes roughly 2-3 months to get enrolled into the waiver after the budget is passed and funding is made available.

ELDER CAREGIVERS

We have 2,487 Caregivers over 60---

There are 739 individuals in Emergency Need and 1,748 in critical need

We have caregivers who are 80 years old and older that have a family member that is on the waiting list.

More Numbers

718 of the individuals themselves on the waiting list are 60 years old or older

1,626 individuals who has had the of Death of Caregiver, their Caregiver is ill or the caregiver for other reasons cannot provide the care

409 individuals who are living in Intolerable Living Situation

Services most requested by people living with their families are individual supports like Habilitation, Transportation, Employment and Respite.

This Chart shows you the age groups of the individuals who are waiting.

PUNS as of July 31, 2016

By Region, County Joinder, Urgency of Needs and Age Group

Source: EDW HCSIS PUNS Monthly Report Fact

Age Group	Emergency	Critical	Planning	Grand Total
01: Age 17 or Below	497	1,188	1,392	3,077
02: Age 18 to 20	792	1,311	598	2,701
03: Age 21	520	129	34	683
04: Age 22 to 29	1,100	828	404	2,332
05: Age 30 to 39	576	640	418	1,634
06: Age 40 to 49	404	523	276	1,203
07: Age 50 to 59	449	513	221	1,183

08: Age 60 or Above	273	290	155	718
Grand Total	4,613	5,422	3,498	13,531

When I first started working with the waiting list campaign 10 years ago there was over 25,000 individuals waiting for services.

With the partnership we have built with you and the support of the General Assembly we have made a difference. We have reduced the waiting list by over 12,000. We need to continue to make this a priority.

I would like to thank you for your continued support and look forward to working with you to End The Wait for individuals with intellectual disabilities and autism.