Dear Senator Osten, Representative Walker and members of the Appropriations Committee,

My name is Kathy Tremblay and I'm with Our Families Can’t Wait. I live in Putnam and my son Joe is 15 and has severe autism and profound ID. He will never be able to function on his own, he will require 24-7 care for the rest of his life.

I am worried about his future when I am no longer able to care for him. Where will he go? I can’t get respite out of home because I was told he had too many needs. Since my son's needs are so great, doesn't it make sense that I should get priority respite over someone who can do things on their own? I was promised by Storrs respite center that he’d get a slot 3x per year and I got my hopes up that I could finally spend time with my older 4 kids or 2 Grandkids who I hardly spend time with. Sadly, I was told in January that out of home respite is not an entitlement program and told he will not be getting what was promised. How is getting a break from a child who requires 24/7 care 3 x per year an ENTITLEMENT!? After much back and forth I was finally told that I could apply for “some” respite funds. That being said, it’s not fair that I have to spend money out of my own pocket to stay in a hotel to get respite paid for a caregiver to come into my home to care for my son. If I am home, my son will follow me around and therefore it’s not TRUE respite. I’m not getting a real break and not getting much time to recharge. My son does not have a case worker, he was denied Medicaid due to our income (we aren’t rich people!). We have expenses most parents do not have like: buying adult diapers, wipes, liners, bed pads, specialized clothing, harnesses, and much, much more.

I am up by 5 am EVERY DAY OF THE WEEK. I am filling holes in walls created by my son, building walls to separate rooms for my son’s safety out of my own pocket, and had to put up a fence in my yard to keep him from escaping - how entitled is that? Talk about expensive! My husband and I filed bankruptcy because we can’t make ends meet. We don’t qualify for anything for our severely disabled son, It’s SAD! I urge you to look into PAID PARENT CAREGIVER like many other states have. My son was on the Katie Beckett Waiver waiting list but got kicked off—I was told he is not disabled enough. Most of us can’t work a regular job due to our disabled child’s issues. If I lived just 10 minutes away in the state of Rhode Island, my son would automatically get on the Katie Beckett waiver which would help defer the cost of supplies he needs, there is NO waiting list in RI, he’d get Medicaid regardless of parent income, they have many, many programs for their disabled population, which includes respite care and in home help! Connecticut should model what Rhode Island and other states offer with no wait. Why should my location of only 10 minutes away disallow my son benefits?! This is unfair to my child and my family.

Connecticut needs to open more specialized local group homes for more frequent respite! Offering families a safe long weekend 3-4 times a year for their loved one would be acceptable, allowing us a break. In exchange, it would actually SAVE the state of CT a LOT of money in the long run. Caregiver burnout is real. If we get breaks to look forward to, we can pay better attention to our health, our marriages, our other family members and make us happier & BETTER caregivers for more years to come. Currently, the pay for homecare respite providers is low, increase the pay, create incentives for someone to want to do this difficult job, the turnaround is horrible. There's such a big issue of keeping providers! We need regular breaks we need help, we need a safe place for our kids to go to every now and then! DO SOMETHING! Respite centers need to have enough staff to be able to take for someone like my son Joe with severe needs. It is not fair for him to be denied respite
because he’s “too much work” ISN’T THAT WHY WE NEED RESPITE!?! Imagine what we have to go through every single day and night.

Currently, the future looks bleak. I thought I had a few breaks a year to look forward to, and that is no longer true. This may not seem like a big deal, but imagine my life day in and day out. I can't just pick up and go like the average person. I can't even go out just to grab a gallon of milk. It takes planning, who will watch Joe? Should I attempt to take him with me? What happens if I take him and he decides to pull my hair on the way or grab the shift in the car again? Will I avoid another accident? Will he have a meltdown once we get in the store? I can't leave him alone, ever. If I have to pay someone to watch him it costs me minimum $17/hour. What if he starts grabbing things off the shelf and throwing them? What about the stares from people that I have to dodge all the time? What if I get sick? What if I need emergency surgery? What if I'm out with him and I get into an accident, will he wander off? Who will look out for him? This is MY NORMAL EXISTENCE, what is yours like? My son is completely non-verbal and has no form of communication. My son functions on an infant level. He's 15 and does not know his own name, he can't point, he can't tell you what he wants in any way.

If I had an "ideal" picture of our future with Joe. I would like to be able to know that once he's aged out of school, that there will be a program ready for him during the day as an adult that's appropriate. I would like to know there is residential placement with enough highly trained skilled staff if it's needed, with no wait list. I would like to know that there is a safe place where I can bring him if he needs respite for a weekend. In home help would also be great.

My husband and I have so much worry on our shoulders, much more than the average parent ever could imagine. We worry and wonder how long we can be able to keep him in our home, if one of us passes away how will the other work and take care of him? What about if we get sick or develop health problems of our own? Who will look after our son? I have heard there are waiting lists over 20 years long for residential care- this is UNACCEPTABLE! No one should have to be kept up at night worried sick where their adult severely disabled child will live. As my son gets older and bigger, I don't know what behavioral issues will arise. I worry about him getting abused, which is a sad reality for someone like my son who could never defend himself. My son deserves a place where he can be comfortable and cared for and treated with dignity and respect for a disability that is no fault of his own or my own. I would love for my son to be able to stay in our home for as long as possible, but with caregiver burnout I don't see that happening. With the high caregiver turnaround rate, it's becoming increasingly difficult. We may have to move out of CT just to get help. Is this what the State of CT wants? Or do they actually want to help!?

Kathy Tremblay
Devoted mother of Joseph, age 15