

Sue Bastien
262 Weatherside Road
Cheshire, CT 06410

Hi, I'm Sue Bastien from Cheshire. I am a member of Our Families Can't Wait! testifying in support of Senate Bill 918.

Knowing there would be a wait for services, my son Patrick went on the DDS Wait List for residential placement while still in school so that he would move to the top of the list by the time he was an adult. How naïve I was!

Patrick is 33 years old and still lives with me, waiting for funding to live in a medical group home in the community.

Patrick is quadriplegic. He is also intellectually disabled, epileptic and blind. He has a G-tube to drainage, a J-tube for his formula and medications, and a central IV port-a-cath for emergencies.

HE REQUIRES 24 HOUR ROUND-THE-CLOCK NURSING, because his trach must be suctioned, and monitored for blockage, and through which he gets at least 7 breathing treatments a day. Yet he only has a nurse 40 hours a week. I have to care for him the other 128 hours a week, including 64 hours straight every weekend. His care generally ends at 4 am daily.

I adore my son, but I'm a Senior Citizen turning 65, with my own medical issues. While he's been on the wait list, I've had sciatica and disc problems requiring back surgery, a stroke, hypertension, two torn menisci in my knee, and laser surgery on my leg for vascular insufficiency. Now that I have the beginning of macular degeneration I asked if THAT moves Patrick up the list. No, not until I go blind, I was told!

Welcome to our world and the DDS Wait List, where there are never enough funds

to go around, where your place in line is only an illusion, and where it matters not when you got in line on the List, nor for how long you've been waiting. Because the truth is, NO ONE moves up on the Wait List! The DDS Wait List is not a list or a line with persons moving steadily to the top in orderly succession. Rather, it is a massive pool.....a pool of persons with disabilities and their caregivers, struggling to keep afloat, struggling to keep their heads above water, until it is their turn to be mercifully plucked out. And when does this occur? When the caregiver drowns!

That's right, when I die or become incapacitated, THEN Patrick will be fished out and rushed to a placement...God only knows where...with no planning whatsoever for his complex needs.

Patrick needs an ENTITLEMENT to the DDS services he qualifies for. He needs your support for Senate Bill 918. Thank you.