Until July 2018 my son Karl did not have residential funding and we were supporting him in the community. I am happy to report that Karl now has residential funding for community supports from DDS. Karl lives an integrated life in the community of New Haven thanks to DDS funding and the support from all the wonderful people at Marrakech, Chapel Haven and Bethesda Lutheran Church. (See picture of Karl dancing at his New Haven Church on the bottom of this testimony)

Karl has a rich life in New Haven but not without much supervision by my husband and myself. Karl has three agencies, cab rides and weekend rec programs that we need to coordinate. We pay for his assistive technology, rent, utilities, and recreational programs. As we age this will get harder to do. We are now retired teachers and have limited funds to continue to support him.

How many of you have had to care for your aging parent? Terri Gerratana, former chair of the Public Health Committee (committee of cognizance over the DDS) told Families First a year ago that until she dealt with the care for her mother, she never really understood what our families go through.

ID families who don’t have their loved ones placed outside of the family home have yet to experience some of the pitfalls of independent living. Sometimes staff can’t make their shift in the last minute and no replacement can be found. Doctors’ visits cannot always be made when our community support staff is on duty. We are always the ones that are there to fill in for Karl. It is difficult for us to do this now, but when we are older or gone from this earth, we will need a better option for Karl.
Karl wants to live in the wonderful residential community of Chapel Haven in New Haven. Chapel Haven has been one of the best options for independent living available in CT since 1972. Chapel Haven’s new state of the art facility has tiered living arrangements not unlike many retirement communities. Chapel Haven has designed a world-class model, which could be Karl’s forever home. Chapel Haven realizes that individuals may want to live independently in the community, but they require more oversight and structure.

Unfortunately, the CMS (CT Medicaid Services) settings rules prevent Karl from receiving funding for this living arrangement. The ruling is all about density restrictions for the amount of adults with disabilities living together. Karl loves his peers with disabilities. These adults live in Chapel Haven and have full access to jobs, volunteer opportunities and recreation at Chapel Haven and in the Westville CT community. If Karl lived at Chapel Haven, he could continue all his current activities but live more safely and without his family having to coordinate multiple agencies.

There is a national advocacy group called Together For Choice. This national group is receiving pro bono help from Eric Holder’s former law firm to help find a solution to federal Medicaid rulings that prevent people like Karl from living in the community of his choice. When Karl has his annual meetings with DDS, the plan we create as a team is called an IP or Individual Plan. It is time to take the “I” for Individual more seriously. DDS needs to give options for families and individuals who choose a campus-tiered setting like Chapel Haven, a farm community or cluster living, as well as living in a community apartment. Community living is wonderful but must be tailored to each disabled individual’s unique needs. I leave you with a medical analogy to the plight of disabled adults. If there was a very good medicine on the market, what doctor would say, “I think I will give that medicine to all my patients because it is a good drug”. What the doctor should order is a drug that will
help each individual patient in the exact dosage that they need. I ask that Karl be given the community living arrangement in the exact "dose" that is just right for him. Please appropriate the necessary amount of funding for DDS so people like Karl can live safely, productively and happily in the state of CT in the setting they choose.