

Sat, Oct 10, 2015 at 10:32 PM

To: Neil.A.Mitchell@opwdd.ny.gov
Cc: nycfair@gmail.com

Dear Neil,

I'm sorry it has taken me so long to write, however the services available Downstate to our families is a total nightmare. There is no person centered planning going on with MSCs having forty cases to care for!! For parents willing to take on Self-direction, we take on the care of our children concerning their interests, behavior and then have billing roadblocks left and right. Are these plans only for the adults who get paid minimum wage and go to community colleges? Besides, parents are also required to layout money for memberships, transportation, fees and now we were told if classes are not inclusive they will not be paid for through the plans. That means if our children are not "normal" enough for society we as parents need to live forever and pay for all their learning!! When we have programs like PAL (police athletic league) willing to provide funding with county and private donations, classes that help our children learn social interaction through some sport activity, it's not inclusive enough. It's provided and held in a public facility. That's being included and accepted by society. That's not segregating our children from society!!! Downstate needs to utilize the Queens Fienstein property to be a center base for families to come to and have reps from agencies available to service the needs by checking computer bases for what programs are appropriate for the level of each individual's functioning. All the large agencies have repeatedly over billed Medicaid for years for services we have not gotten. Have them foot the bill for this new structure. Why do you think a panel mainly lawyers has a clue what is best for our special needs population?? Do they want to come down and provide respite for our autistic or epileptic children?? In some of the largest counties in the city there is no emergency respite site available. Our lives and jobs are full of stress just trying to get through each day down here and we have the most of the state's population of special needs adults and children. Shouldn't we have a voice in this Democratic country?? Please give us a voice since most of us keep our children for over thirty years at home with very uninvolved family members. It's not like upstate where people care about their neighbors and have a much different sense of community!! And we are not committing Medicaid fraud when we ask for simple support for this monumental task we have throughout our lives!!!! Please respond.

SINCERELY,

Judy Gleason

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