

Dawn V. Di Noto
15 Bettswood Road
Norwalk Ct 06851

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People with disabilities want the same things as anyone else. Like most people, they hope to live a long , healthy, productive, and happy life. When they look back they wantto know that they were respected and valued in their community for their unique characteristics (I would say talents) and contributions to their community throughvarious activities and organized involvement.

These are the words captured in the DDS vision written from the previous 5 year plan. In the past, DDS emphasized presence and participation in community life as a goal. Today, reviewing the 5 year plan, the emphasis is on the development of mutually beneficial relationships where people give as well as receive and in turn are valued as contributing citizens.

The initial focus of the plan begins this way, however, we need to talk about how to assist people with disabilities to live the “vision” DDS set out to begin with separate from the conversations about the inevitable constraints of political policies and budgetary crisis in our State.

There are ways we can still reach out to families and individuals with disabilities to support them even when the budget is not there to give what is acknowledged as appropriate for the list DDS set up for their “rights” to have supported.

On the website for DDS, there is a link to Hope House, a model that fosters meeting the needs of a wide range of individuals with a wide range of needs on a continuum that honors the more intense the needs the more intense the support.

They celebrate diversity in such a way that their web site is truly easy to review and clearly stating their commitment before even looking at the funding. When DDS refers to a paradigm shift at the end of this 5 year plan, I say this is where you need to start! In all cases, an individual can have emotional, physical, medical, and cognitive challenges, not limited to a category for a primary disability based on IQ. IQ is no longer a research based supported methodology and DDS must come to terms with this as it creates a significant discriminatory factor. Consider those families with individuals like my daughter Anisa who has multiple challenges and they co-exist in often unpredictable waves in her life. All of which are valid and all of which must be considered in her planning.

For individuals with Autism, sensory integration, neurological impairments, mental health challenges that debilitate them from an early onset in their life, we know these challenges are lifelong. We also know that there are many ways to support them to cope, improve and gain the ability to become the vibrant part of their community they want to be.

When DDS expanded the Autism waiver from young children to adults over age 21, set up a web site that specified the areas they need based on research (factual), and stated the rate staff caring for them can be paid by vendors they then decreased the amount for self-directed care. Nonetheless, the rate was telling us they know the level of skill and training must be there for these complex profile individuals or we have significant safety and mental health wellbeing issues to deal with.

When you then say even though you have lived your life for 18-21 with Autism and other co-existing challenges, you cannot have access to these types of supports because you tested below 70%. Only those high functioning intellectually individuals with Autism can access the needs that all people with Autism have. And you tell us that we have to have our individuals function under a waiver that is not acknowledging our needs, rather discounting our needs. DDS needs to follow DSMV.

Hope House emphasized the following that we must consider for all individuals with disabilities because no two people have the same needs.

- Help them live as ordinary a life as possible
- In the least restrictive environment
- Where the settings emphasize flexibility, therapeutic as needed
- And creative services designed specifically for that individual.

I hoped that the Self Direct model would provide me with the options to do this for Anisa. I am grateful for the budget I receive and willing to put my all into being creative and flexible, training a self-directed staff, and looking for community resources. It is my hope that this paradigm shift will include the following:

- Provide waiver options for self-directed care providers that include those listed for Autism and ID
- Provide continuity of rate compensation for staff in conjunction with the level of need of the individual not the specified primary disability
- Discontinue the archaic IQ criterion
- Provide budget options when increased budget cannot compensate for the missing pieces.

Missing Pieces

- A weekly fund for the individual to participate in recreational activities to foster socialization
- Include in the weekly budget for purchasing items that SSI funding is not able to support (nonfood) for daily living needs.
- Work with community to identify merchants who will give discounts to individuals self-directed the same as a group DDS accommodation, allow us to be part of the groups – share the schedules of where and when to go so we too can benefit.
- Develop a central place in the community (could be a vendor) where self-directed families can join “peers” and participate in enrichment activities-music therapies, art therapy, (see the model for CPW in NY).
- Invite self-direct individuals to participate in community events and outings.
- Improve communication to self-directed families for all the things those in group day programs know about.

In a self-directed setting we also work on shopping, managing money, cooking meals, getting dressed, and life skills. We are functioning as both the Individual Day Support and there is a need for the following:

- Evening time with consistent trained staff with rate of pay to be allowed beyond the limitation of less than 40 hours per week.
- Weekend support time with consistent trained staff with the rate of pay to be allowed beyond the current limitation for IND self-directed.
- Overnight care needs to be with trained consistent familiar staff at rate that would be for the Autism Waiver stated level due to complexity and intense work.
- In all instances there needs to be allowable flexibility for self-directed providers to hire level of staff with training for those times we determine our individual need for their safety and wellbeing. Where we can we then have the choice with our individual's contribution as appropriate to plan for less rate per hour staff when we can (home health aide, and other staff less training).
- Family respite time,

Hope House states based on research they validate that “of course, in fact, the majority of the people we support have dual diagnosis of intellectual disabilities and mental health challenges.”

The Self Directed care providers need to be able to have Positive Behavioral Therapists in the home setting where the individual lives, and in the community where they volunteer.

We need to be able to have ability to hire our own BCBA staff and have our own staff trained. We need a budget to support this at least initially upon hiring staff and as incident reports merit the need.

From joining a gym to taking a pottery class, to asking a volunteer setting peer to lunch, the self-directed care provider is providing the Least Restrictive for the individual and is increasing exposure and time in community to the best of the individual's ability.

If the budget is recommended to us by CFC model and they deduct the amount for DDS budget, we as self-directed providers need to have the ability to maintain the same consistent pay rate at the higher level because that is what is stated she needs for her intensity of care.

In closing, when reading the lengthy 5 year plan from DDS, many phrases are noted throughout that focus on the DDS function, organization, as an agency and not on the individuals with disabilities. I still do not know what the impact will be for my daughter, and I have not heard anything about what we can look forward to, only what we need to know we will no longer have.

- Let's know more about the federal dollars and the fact that this goes to the general fund
- Let's talk about stating over and over in the 5 year plan "Quality for individuals with ID", this implies we are not inclusive of other co-existing disabilities.
- Let's talk about the reduction in staff, services, decreased in rates and how this will impact the available budget concerns and where this money will then go?
- Let's talk about a priority list for those things we cannot fund and what needs to be funded first, next, then.
- Let's talk about options rather than resolve to the fact that DDS doesn't have this, or can't do that. If everything in place is pending available budget then we are not given any reassurance.

DDS please re-define your paradigm and describe to us the "overarching shifts" and consider the shift to all individuals with disabilities with a true People First not office /committee/project focus first. The excessive use of the word stakeholder should be made clearer as this is very broad.

Stakeholders are all people impacted; let's say individual receiving support and then acknowledge the primary care givers/guardians, separate from the DDS/DSS staff agencies. Then we can use the word "WE" to represent all of us working together. A huge part of this 5 year plan is shifting far too much to the families calling it stakeholders but really falling on us to bear the brunt especially in light of the recent news of the resignation of the commissioner.

On behalf of all families self-directing and all individuals with co-existing challenges impacting their lives in a very emotionally and physically painful way I thank you for your consideration, time and attention.

Dawn V. Di Noto

Referenced in letter:

www.hope-house.org/

www.cpw.org