

I am a person who has believed in keeping a focus on an individual person with disabilities since my son was a young child. I remember when home and community based services began and agencies were struggling with wrapping their heads around a support beyond living in a residence and going to day treatment. I have seen some of these agencies excel at moving to community based services. Now, those good agencies struggle with the value of the shrinking, eroding unit of community based, individualized services. Will provider agencies be supported or will they continue to be beaten down? They are needed. Please support them and recognize their importance, and at the same time, keep open and honest communication with families and people with disabilities.

In spirit, supporting a person with intellectual and physical disabilities with their needs on an individual basis makes sense. When a person with disabilities who is alone and has no one and no means of supporting themselves physically and financially, they are usually living at poverty level and dependent on others. Life above the imposed poverty level is not likely in the present or in their future. That is reality and will not change. At one time or another, all of us face a health or aging challenge and it is terrifying to lose independence. Most people have time to prepare and save for their future needs. An individual with disabilities is not afforded that opportunity. I understand what natural supports are and they are important, but cannot replace needed services. Would you expect parents who work having to depend on child care for two and three year old children being a natural support? It isn't sustainable.

In the newest systems transformation plans will the unit of service and self-directed budget erode or will the value and integrity be maintained? Regarding an individual's budget, will the line items defining services be so limiting that they restrict choice? Will budgets be eaten away with inflation and costs of living? Please ensure it is written into the transformation plan the commitment that self-directed budgets are sustained and not allowed to erode and be cut. Please ensure by the structure of the transformation plan, that through the coming years, the PRA amounts and budgets and specific budgeted lines will be sustained and not be cut because policy makers, who are not dependent on services, decide that people with disabilities don't need transportation, quality of life, quality clothing or a decent place to live.

We can push employment, but think about and look at what a job coach is paid. What's the message? The message appears to be we don't really value this work. The same holds true for all direct support staffing. Are they afforded the pay and benefits to support their family and plan for their own future?

NYS can use all the right words but the investment needs to move beyond words. In the past few years, the focus feels to families like it has moved from sincere care of people with disabilities to care of dollars. Responsible fiscal prudence is

crucial, but more and more dollars are being directed towards health care entities and administrative management. Health care is not the same as supporting people with disabilities; it is medical care. NYS is moving away from many of the local disability service provider agencies who know, care and understand the challenges faced by individuals with development and intellectual disabilities and their families. It is hard to believe that managed care entities are going to make a priority of serving individuals with the most complex needs

It is my hope that NYS government will, sincerely, remain committed to the needs and care of their most at risk citizens. That is why OPWDD was originally established as a separate entity – to safeguard and ensure that care and support happens. Please include a written commitment in the transformation plan that OPWDD does continue.

For families of individuals with disabilities, the detachment and focus on health care and health care entities is a deep concern and creates fear of the future.

Janice Fitzgerald  
[janicefitzgerald@roadrunner.com](mailto:janicefitzgerald@roadrunner.com)