

September 29, 2015

Transformation Panel Public Forum

Comments: Bradley Pivar – 44 Country Lane – Voorheesville, NY 12186 518-221-4308

Thank you for the opportunity to speak. My name is Brad Pivar and I'm a parent. I'd like to speak about choices.

My son Scott is 31 years old and lives at home. I'm here to speak for him because he can't. He's non-verbal. He needs 24/7/365 supervision. He will never be able to live in a supported apartment. He will never be competitively employed. The Transformation agenda has many admirable goals. It has taken far too long for self-advocacy and self-direction to become a meaningful part of the solution. It is long overdue that the developmentally disabled become accepted in the workplace and the community. But I have participated for over 20 years in workshops and committees that have promoted 'Person Centered Planning' as the Holy Grail of a service model for OPWDD and as with most things in life, one size does not fit all. Yes, this Transformation has many admirable, even lofty, goals. But not for my son.

It's about choices. We choose one thing over the other. Either-or. I'm going to eat a sandwich or a pizza. Not both. In this case NYS is going to promote individualized services – not develop more of the traditional services. This is the choice of the Transformation Agenda – but this is a false choice. We can and we must do both.

There is a desperate need for more residential development. You know the numbers – 1000's of Priority 1 placements needed. 10's of 1000's of individuals living at home with aging parents. (my wife and I included) The promise of NY Cares seems almost quaint in its naiveté. Almost.

There is a desperate need for more day programs – better day programs. Programs that develops skills. Programs that provides meaningful activities- even if it doesn't lead to employment.

There is a desperate need to raise the wages of direct care workers. Agencies cannot find staff. Self-direction offers the possibility of broadening the worker pool to include friends and neighbors, but rest assured, wages will determine whether or not an individual plan will work.

NYS is choosing to move to a managed care model for OPWDD services. At best, managed care has a mixed record of success in our health care system much less it's limited experience in delivering services to the developmentally disabled. The theory of managed care may offer a huge upside in providing preventative care or in managing chronic conditions, but the reality of managed care is that it has often been used a way to limit services

And, of course, it's all about money. We're told we must choose because we can't afford to do everything for everyone. Still, many of the choices we make leave us scratching our heads. NY chose to spend 10's of millions to keep late night TV in NY. Estimates of pork in the last NYS budget were as high as \$3Billion. Choices.

Choosing one group of individuals over another is a bad choice – a false choice. We can and we must do better.

Thank you.

