

Paul Cassone's Testimony for Public Hearing – January 14, 2016

My name is Paul Cassone. I am the brother and legal guardian of a 66 year old person with developmental disabilities, Frank Cassone. I have worked as a direct support professional and administrator in the field of developmental disabilities since 1971. I am currently the Executive Director of the Guild for Exceptional Children in Brooklyn and worked for 28 years with Lifespire, where I participated with Mrs. Goodman on Community Board 11's Mental Health Committee.

New York State's Service System for People with Developmental Disabilities is Badly Broken

- Because developmental centers were kept open for too long and NY failed to develop appropriate programs for people sent out of state for services, families who have done the right thing for their sons and daughters with developmental disabilities and NYS for many years are being put into crisis regarding the long term needs of their children.
- People with developmental disabilities continue to be needlessly confined to hospitals and nursing homes because New York State has failed to develop community based residences for them.

Residential development has been virtually frozen for the past decade. Parents who have done their best to maintain their son or daughter at home, expecting that at some point in the future a residential opportunity would be available, are now considered a "Low Priority" and are being told that no group home opportunity will be available for the foreseeable future.

These families have "done the right thing" by their son or daughter and have done their best to provide a loving home environment. Unfortunately, no one lives forever. Many parents have lost a spouse, and then become too ill to continue to care for their son or daughter. In many cases, both the parent and the individual with a developmental disability suffer, as their existence becomes isolated, lonely and in some cases unhealthy due to poor living conditions.

- When a crisis, such as the passing of the only remaining family member occurs, the person with a developmental disability is placed in a dangerous situation. He or she can likely not live independently and most often is not even listed on the lease for an apartment. Given the lack of available community based residences, the individual is brought to a hospital. At the hospital, there is no staff adequately trained to provide necessary care. In some situations, these individuals are then confined to a psychiatric ward. Most often, if the individuals do not have severe behavioral challenges, the individual is transferred to a long term care rehabilitation facility, receiving congregate care from staff who have never received the necessary training to help the individual lead an independent and productive life. **Individuals in this situation often regress and withdraw, losing basic skills necessary for a productive life.**

- Individuals are often confined to hospitals for weeks, months and even years due to the lack of community based residential development - even though there was no real medical reason why they needed to be in a hospital.

Unnecessary Confinement to Hospitals and Nursing Homes is a “lose – lose” situation. Neither the individuals nor the taxpayers of NY are benefitting from situations like this.

Such confinement is also a flagrant violation of the Olmstead Act, which specifies that individuals (whether with a developmental disability or any other problem that requires custodial care) must be served in inclusive settings. NY is interpreting this as group home settings of 4 or less, yet due to current systems failures, these individuals are ending up in hospitals and nursing homes!

- **Families who have saved the state millions of dollars by keeping their children at home should have equal access – 50/50 – to new development.** For individuals living at home OPWDD offers only vacancies in existing residences, which sometimes works but is often not viable.

Not for profit agencies provide 80% of the services to people with developmental disabilities in NYS have been systematically de-stabilized over the past 8 years.

- This will affect the ability of the state to meet the needs of people with developmental disabilities for decades to come.
- NYS based not-for-profit agencies have been subjected to continual cuts and increased regulation. **Rates are actually the same or lower now than they were 6 years ago, while regulations and expectations increase almost daily!**
- Health Insurance and workers compensation costs, energy costs and regulatory requirements have increased dramatically over the past 6 years, simultaneous to reductions in rates!
- Long established agencies are serving a generation of senior citizens in their residences who require extra staffing in order to safely evacuate the residence.
- Hospitals and nursing homes require agencies to provide one to one staffing when individuals are hospitalized because they are unable to provide staff to supervise them and have not been trained in managing behaviors without using restrictive techniques like physical and pharmacological restraints. **During the hospitalization and nursing home stay the not for profit agency cannot bill for its services.**
- Due to regulatory changes that occurred in 2014, agencies cannot make rate appeals related to vacancies or increased labor costs and this is creating unsustainable losses for many agencies.

The above factors are creating unsustainable losses in the not-for-profit agencies that are the lifeblood of the NYS service system. NYS must re-evaluate ways to fund the not-for-profit agencies based upon the complexity and level of need of the individuals they care for and must reinstate the

ability to appeal rates when catastrophic losses occur due to hospitalizations and intensive staffing requirements.

Well established agencies like FEGS and Catholic Charities Brooklyn/Queens have already given up OPWDD services.

The de-stabilization of not for profit agencies is penny-wise/pound foolish on the part of NYS since the not for profits provide services at a fraction of the cost of the state operated entities.

It has been publicly stated by high level NYS officials that the endgame is the dissolution of many of the smaller not-for-profits, forcing them to merge or be “taken over” by larger entities. During this process, the well-being of thousands of people with developmental disabilities is being put at risk. The dissolution of the smaller not for profit agencies – which are often guided by a Board of Directors made up largely of the family members of the individuals being served by the agencies – is not consistent with OPWDD’s stated commitment to a “People First” approach. Those families’ wishes – that their son or daughter receive services from an agency known to them and which they can directly guide – are being ignored.

Movement to managed care has been a disaster thus far.

Developmental Disabilities Individualized Support and Care Organizations (DISCOs) – while supposed to be a means to manage the costs and growth of costs – will add layers of review and administrative fees which will most likely drive down the amounts of money available for actual services. CMS has not approved various OPWDD proposals and the roll-out is significantly behind schedule. No other state has converted as many people as quickly as proposed by NYS and no other state has combined the medical and long term care needs of the individuals in their waivers. This whole process is ill-conceived and likely to fail if not drastically re-thought.

NYS Has Failed to Articulate A Comprehensive Vision for How Services Will Evolve and Whether or Not Existing Residences and Day Programs will Continue to Exist.

What about the people who are currently in the system? What will happen to existing residences and day programs? There are no answers as to what will happen to the “base” of services, the existing residences and day services, other than NYS stated commitment to eliminating ICFs because they are “institutional”.

The “Front Door” Has Been A Disaster

All new services must be accessed through a continually changing system called the Front Door. Parents and individuals are told that they must enter the system through the “**Front Door**” and be assessed for the level of care and amount of services they can receive through OPWDD.

- This level of care is supposed to be measured by standardized assessment instruments which haven’t even been developed yet. **If and when these instruments are available, I strongly recommend that they be actuarially tested to verify real world costs.**

- Temporarily, OPWDD is using the DDP2, an old instrument that was never meant to be utilized to determine funding levels. The assessments are completed by people who don't even know the individuals to be assessed. The assessments will determine how much, how many, what type of services the person may receive and the dollar amount in the person's "budget" for services.
- **The "Front Door" is broken and is being called the "Slammed Door" by many parents and advocates. Attempts to get services lag months and months if not longer.**

There seems to be a disconnect between reality and the way services and supports are envisioned by OPWDD and NYS Government in General.

We are all told that there will be no more "bricks and mortar" residential development; that parents must keep their adult children with developmental disabilities at home as long as possible and that when services are absolutely necessary that they should be developed in a "creative" manner that does not call for 24 hour supervision.

- Those of us in the field and who are family members know that a very limited number of people with developmental disabilities can actually live safely without 24 hour supervision.
- If OPWDD is not paying for bricks and mortar, what will it pay for? If leases, who will hold the lease? Will the allowable lease amounts be reflective of fair market appraisals in the region? We are told CMS does not want agencies controlling properties, that it must be "money follows the person".
- **There are models described as imminent but seemingly never arriving, ever changing answers given, no actual protocols that have worked and no end in sight.**

Our direct care workforce is at risk. They work for very low salaries as it is and have only recently gotten any kind of raise. If the minimum wage is raised to \$15 or more, people with developmental disabilities and the agencies that serve them are in real trouble. There must be some legislation related to keeping direct support professional's salaries advancing as minimum wage advances.

All of the above are setting the civil rights/human rights movement for people with developmental disabilities back decades.

Recommendations To Stabilize the OPWDD Service System

1. Appoint an actual Commissioner (not another acting commissioner) to OPWDD. The Commissioner must have first-hand knowledge of actually running a service agency as well as knowledge about public policy, including knowledge of how OPWDD operated for many decades. Cuts to OPWDD over the past years have caused a damaging loss of institutional memory. Well thought out systems of the past have been replaced with new systems and policies that have not been well thought out and tested prior to implementation. This has resulted in a constantly changing set of procedures for even the simplest tasks, which has been confusing to families and providers and further stalled service delivery.

2. Mandate that the Commissioner meet on a quarterly basis with parents and agencies in each county to assess needs and progress towards meeting those needs.
3. Develop a strategy for how existing services will be utilized and issue a detailed “schematic” showing how existing models and newer alternative models will be utilized and funded going forward. **There needs to be an acknowledgement that the existing ICF and IRA residences and day services will continue to be needed for some people due to their age and/or level of need.** It is not uncommon for people with developmental disabilities to live well into their 60s, 70s, 80s and even 90s and beyond with the improved levels of care they have been given over the past decades.
4. Carefully review the historical performance of not for profit agencies and work with provider associations (IAC, NYSACRA, NYSARC, UCP NYS) to determine fair rates that are indexed to the cost of living, region and adjusted for the characteristics and needs of the individuals served.
5. Re-think the current policies that are destabilizing the not for profits and work instead to stabilize them so they can continue to provide quality care in NYS.
6. Determine how many people have been needlessly confined to hospitals and nursing homes and work with providers to develop appropriate community based settings for them, phasing up the new residential alternatives so that within a 2 year period there will be no individuals remaining confined to hospitals or nursing homes unless those settings are appropriate matches to their level of need.
7. Ensure that OPWDD works closely with providers in each county to assess which families are in imminent need of significant support and/or alternative living arrangements for the individual with developmental disabilities and assign a case worker to those families to ensure that community based alternate living arrangements are created prior to the trauma of the individual becoming homeless due to the death of the family member.
8. Follow a strategy – with new residential development – similar to NYS Cares and establish a target time frame by which everyone requiring an out of home residential living option will have one.
9. Develop legislation that will ensure that the starting salary for direct support professionals working with individuals with developmental disabilities will be significantly higher than minimum wage.
10. Include adequate funding in the 2016 – 2019 budgets to do all of the above.