

Testimony Before the Assembly Standing Committee on Mental Health and Developmental Disabilities by Dr. Al Pfadt on October 20<sup>th</sup>, 2015

Barriers to Implementing the OPWDD Transformation Agreement Successfully

My name is Dr. Al Pfadt. I am a mental health professional with nearly 40 years of experience in the developmental disabilities community here in NY State.

During that time I have served as the Clinical Administrator of a facility-wide toilet training program at Willowbrook Developmental Center, mandated by Stipulation 23 of the Willowbrook Consent Decree. That program successfully taught self-initiation skills to 90% of the more than 100 people with severe and profound levels of mental retardation who had been considered to be untrainable.

While still working at Willowbrook, I was the clinical coordinator for the first 2 state-operated group homes to be opened on Staten Island for people who were passed over by voluntary agencies as part of the closure process.

Later I served as a Research Scientist at the George Jervis Clinic in the NY State Institute for Basic Research in Developmental Disabilities for 20 years. In addition to working with a transdisciplinary team of medical specialists to evaluate and make treatment recommendations for individuals throughout NY State who had significant mental health needs, I also was the Clinical Administrator of the Willowbrook Futures Project. This project was developed in conjunction with Dr. Beth Mount and an array of stakeholders throughout NY State to use person-centered planning and clinical problem-solving to secure community placements for the last of the named plaintiffs in the Willowbrook Consent Decree. These plaintiffs were still languishing in state institutions long after Willowbrook had been officially closed. We were successful in helping 18 of the 19 people we worked with move into more inclusive community settings.

The last 10 years of my career were spent as the Director of Clinical Services and later as the Chief Ethics and Corporate Compliance Officer for the award-winning agency Independence Residences Inc. In 2004, I helped develop a comprehensive system of crisis services beginning with a \$25,000 Family Support grant in Brooklyn that turned into a program with an operational budget of more than 1 million dollars. The program also delivers services in Queens, the Bronx, and Long Island as well.

Additionally, I helped create the “Changing Places Initiative” which has enabled over 20 individuals in IRI’s residential programs to move from restrictive group homes to more inclusive settings in the community, thereby enabling people from institutions, costly out of state residential school programs, and in some cases psychiatric hospital beds to enjoy the benefits of living in the community without the necessity of purchasing and developing the 4 group homes that would have been required to accomplish this same objective.

I mention these experiences and accomplishments not “to toot my own horn”, but rather to call attention to the unique vantage points I have occupied during the past 40 years as our service system has transformed from one which was almost exclusively rooted in the network of infamous state institutions in the 1970s to one which now serves as a national example of how an effective infrastructure can be created within the community, providing an impressive array of supports and services enabling people with I/DD to lead lives of distinction in their local communities. In preparing for this testimony I re-read, then carefully read again, the Report and Recommendations issued 2 years ago by the Olmstead Cabinet. It is a remarkable document- the equivalent of a Bill Of Rights for people with disabilities, that is a tribute not only to the people on the panel who wrote the report, but to the coalition of parents, professionals, and other advocates who trace their lineage back to the heady days of the Willowbrook wars, who planned and conspired together about how to liberate people living under horrendous conditions in NY State institutions at that time. It is a tribute to the work of our current Governor, Andrew Cuomo, and others in his administration that the mission of his father, Mario Cuomo, to close all state institutions by 2000 is now back on track- with the stated objective of reducing our institutional census to 150 people by the end of 2018

These accomplishments were made by stakeholders from diverse backgrounds, who sometimes had deep and strongly felt differences about how things should be done, working together collaboratively to make sure that shared, valued outcomes were accomplished. This seems to be much more rare in the current political climate, where I perceive a greater level of distrust and fewer opportunities to work together collaboratively on projects that reflect common interests.

I will focus on issues related to affordable housing because that has been my predominant concern since I “retired” 3 years ago. The White Paper on “Self-directed Affordable Housing with a Path to Homeownership” that is included in this testimony was developed 3 years ago to refocus attention from use of agency owned and operated group homes in certified but segregated settings as the preferred solution to the housing needs of all people towards a truly more open-ended, person-centered planning process which begins by considering the life-style preferences and service needs of each person for whom housing is being developed as the basis for creating a solution that is sustainable and replicable- not in the sense of being the cookie approach typically employed when an RFS is sent out requesting agencies to submit proposals to develop and operate group homes for a pre-selected group of individuals who have sometimes been pre-packaged into assigned groups, but rather in a way that allows for a unique configuration of the basic elements which must be present to sustain any effective living arrangement so that it works for all of the participants involved.

**SELF-DIRECTED AFFORDABLE HOUSING WITH A PATHWAY TO OWNERSHIP-**  
White paper presented by Al Pfadt PhD ,Disabilities Advocate LLC,

There are several moving parts that must be aligned properly to create opportunities for self-directed, affordable housing by people with developmental disabilities. Each configuration of these basic elements must take into consideration

the unique preferences and needs of the person[s] who will be living in the house, as well as most appropriate cultural milieu for supporting his/her desired lifestyle. However, the over-all purpose is the same in each case- to maximize opportunities for each person to determine where to live, what types of meaningful work activities to engage in during the day, and who to socialize with in community settings that support choice and inclusion .The elements described below represent a menu of options from which those elements are selected that best accomplish these objectives. They are listed in no particular order, since this is not a linear process. Many modifications of the starting plan will be necessary in order for all the parts to work together harmoniously, and it will be necessary to fine-tune the final arrangement continuously throughout the individual's life span.

**The Individual[s] Living in the House:** Who will live in the housing unit is the most natural place to start. In some cases the housing arrangement may be designed to support only one person. However, even in cases where more than one person will be living together, it is necessary to consider each individual's unique circumstances, separately as well as together as a group. It is important to remember that it is not the person who must be "ready to live independently". Rather, it is the responsibility of everyone involved in the endeavor to be ready to identify and resolve the need for selecting the right combination of supports and services that is required to promote self-direction while protecting each person's health and safety. The choice of who will live in the housing unit must take into consideration not only each person's personal preferences but also the realities of selecting, developing, and maintaining the household. Some people may have direct access to the financial resources required to live in a single-family home. In those cases, the focus is on determining the supports and services required to help that person achieve his/her personal outcomes. In most cases, however, it will be necessary for individuals to pool their resources collectively in order to be able to afford the costs of acquiring and maintaining the living arrangement that works best for each of them. In order to promote the maximum amount of self-direction possible for each person under these circumstances, certain compromises will have to be made in an egalitarian manner.

**Identifying and Selecting the Real Estate:** Obviously, these decisions must be congruent with the preferences as well as the support and service needs of each person who will be living in the housing unit. However, in some cases, a house may become available and must be secured in a timely manner before its eventual inhabitants have been identified. This might seem to contradict the previous statement that decisions should be made in a person-centered manner, but in the course of looking for housing opportunities for one purpose, an opportunity might be available that is "too good to pass up". In this case, it might be necessary to select people whose preferences and service needs are the best match with the characteristics of the house or its location. Even then, however, it is important not to "fit square pegs into round holes". There is often some type of environmental modification that can be made to accommodate the needs of a person who truly wants to live in that house. Convenient access to public transportation is an important consideration, not only to promote community inclusion but also to ensure that the person can travel to and from work as independently as possible.

**Financial Backers:** Each living arrangement must be supported a funding source[s] which provides the capital required to purchase, renovate if necessary, and maintain the housing unit. Typically, funding for residential supports comes through mechanisms controlled by the federal [CMS] and state[ OPWDD] sources, although in some cases private financing might be arranged as well. A number of resources are available upon request that provide guidelines for securing low interest loans and other funds that can be used to buy and renovate the home or pay rent for the apartment, if that is the chosen living arrangement.

**Agencies Providing Supports and Services:** One of the defining characteristics of this approach is that it separates the control over the “bricks and mortar” that constitute the living arrangement from the provision of the “supports and services” required to operate it. Currently, agencies are funded directly for providing the entire package of residential and day supports each person requires. However, this is not financially sustainable and has not resulted in people experiencing the quality of life intended. Agency directed IRA’s typically cost upwards of \$80,000 per person, per year, just for the provision of residential supports. Individuals transitioning to the community from state-operated institutions or out-of-state residential schools, have template budgets of \$170,000 to \$190,000 per year awarded to agencies as an incentive for them to service this population of people with perceived, complex service needs. Under the proposed Medicaid reform guidelines, this “fee for service” model will be replaced by one where “Money Follows the Person”, promoting a greater degree of self-direction. The individual and his/her circle of support will be empowered to select agencies that can provide the specific supports and services each person wants and needs. In addition to providing supports and services, agencies also provide referrals by identifying individuals who have expressed an interest in self-directing their budgets and are an invaluable source of information about them.

**Governmental/Regulatory Agencies/Other Stakeholders:** Implementation of whatever affordable housing option is selected must take place within a highly regulated environment that establishes rules and regulations governing the provision of residential supports and services for people with developmental disabilities. It is important to involve these parties as stakeholders to the greatest extent possible in order to avoid subsequent conflicts.

**Linkages with Employment Opportunities :** In developing an intentional community that will support the individuals who are living in the housing arrangements that have been created, it is desirable to provide linkages with opportunities for meaningful employment. Some communities are developed in a setting selected for that purpose [such as farming.]. In urban settings, it might be possible to find a mixed-use building, which includes a storefront that could be used to operate a business such as a café or bakery, which employed some people living in the housing units.

## **Barriers Encountered in Moving from Systems-based to Person-centered Solutions to NY State's Housing Crisis**

First, let's consider some dimensions of the current housing crisis. In September 2014, OPWDD submitted an Implementation Strategy to CMS as part of its overall Transformation Agenda that would accomplish certain very specific objectives detailed in its ICF Transition Plan. As of August 1<sup>st</sup>, 2013 that was selected as the start date for making projections over the next 5 years through October 1<sup>st</sup>, 2018, there were a total of 37,228 people living in certified housing options in NY State. Of that total, 28,912 [over 77%] were living in Supervised or Supported IRSSs, with the remainder living in state-operated institutions [994], state-operated ICF group homes in the community [659] or in ICFs operated by voluntary agencies [5,669]. This meant that a total number of 1,988 transitions would be necessary to meet the outcomes that were established.

By the end of 2015, it was projected that the institutional census would be less than 500 and that nearly the same number [504] of individuals would continue to reside in state-operated ICFs. Furthermore, it was projected that the number of people living in ICFs operated by voluntary agencies would be reduced to 4,337. To accommodate these changes, the report projected that there would be an increase of 1,256 people living in "IRA-based housing" and that 732 opportunities would be created for people to live in what was described as "non-traditional residential housing and person-controlled housing". The total number of new opportunities created in this manner, was 1,988. However, moving numbers from one column in an Excel spreadsheet to another is not the same thing as planning with all stakeholders about how to accomplish such monumental changes, particularly when adequate funds have not been set aside to accomplish these objectives and systemic obstacles that stand in the way of such a massive increase in the number of person-directed housing units in non-certified settings have neither been thoroughly explored or resolved. From the sidelines, it looked like numbers were just pulled out of a hat to satisfy an auditing requirement without fully considering the operational ramifications of making changes in this order of magnitude- qualitatively as well as quantitatively.

It is also worth noting that for these newly proposed residential opportunities to be used to accomplish the objectives of the ICF Implementation Plan, none of them could be made available as new residential opportunities to meet the demands of the growing number of aging parents who kept their adult children at home with them as long as possible. They did so with the explicit understanding that when they decided that a group home placement was necessary, an appropriate one would be made available. It became increasingly clear to parents, during a number of confrontational public hearings and policy forums that the only opportunities available for their children to move into a group home would be through a backfill opportunity created by the death or movement of a current resident and that this would be offered on a "take it or leave it basis" only when the family's status had deteriorated to the point where they qualified to be placed on the "Priority One" list

that OPWDD was compiling. The previous “Waiting List” has been disbanded and replaced with a “Registry List” that was supposed to be the result of enrollment in a “Front Door Process” that was cumbersome and constantly changing. After much saber rattling and threats of a law suit, OPWDD finally capitulated to the demands to constitute a new “Waiting List” but the damage to its credibility had already been done and even as this testimony is being given there are changes to the due date because of flaws in the registering process.

What then can be done to address this housing crisis?

It seems that we must begin with the recognition that OPWDD does not need to develop any more agency-owned and operated group homes that exist solely to support people with developmental disabilities. This is a heretical thought to many people with vested interests in the current service system. However it is entirely consistent with the overall objectives of the Olmstead Implementation Plan. The problem we face within the I/DD community must be redefined as lack of access to the generic types of affordable housing available to others with low incomes and similar service needs.

This leads to an even more radical proposal- rather than trying to solve the housing needs for people with disabilities within which silo in our service system where they are sometimes arbitrarily assigned- OPWDD, OMH, OASAS, etc., we must finally come to the realization that adequate housing is a health issue and reorganize our system of care accordingly. A kidney stone is a kidney stone, regardless of whether the person has a developmental disability or a psychiatric impairment. Likewise, bipolar disorder is a significant mental health issue regardless of whether the person has a concurrent developmental disability. Instead of intra-agency competition for scarce resources, we must foster a climate where agencies are rewarded for collaboration. The Medicaid Redesign Team has taken a step in that direction by allowing agencies to reinvest savings accomplished in one sector into another. Through that mechanism, hundreds of millions of dollars have been captured to create affordable housing initiatives that benefit all New Yorkers.

In the past, OPWDD provided virtually all of the funds to create housing opportunities through a symbiotic relationship with voluntary service providers, unions, and other political entities that is described in great detail by a former senior policy analyst, Paul Castellani, in his book “From Snake Pits to Cash Cows: Politics and Public Institutions in New York”, published in 2005 by the State University of New York Press. In this book he reports that by 2000, voluntary agencies owned or leased over 3,500 properties and that a “conservative estimate” on the combined worth of the 4,654 state and privately owned properties was 582 million dollars. He states, “OMRDD [now OPWDD] and the private sector adopted the rhetoric of supported living, but the reality was that they owned beds that needed to be filled and refilled in order to generate the reimbursement needed to pay off the bonds and mortgages”[p. 262].

It is emerging as a clear consensus within the I/DD community that ownership of property should be kept separate from the provision of supports and services. There is an inherent conflict of interest when agencies are allowed to own the property where the people they support live. This was stated quite clearly by every presenter at a housing conference sponsored by NYSACRA this past April- one going so far as to state that 'agencies should never have been allowed to enter into the real estate business and must be prevented from doing so in the future'. It is not necessary to take such an extreme position to appreciate that encouraging real estate investors and developers to collaborate with service providers creates opportunities to leverage resources within each sector.

Arbitrary regulatory guidelines and funding restrictions serve as a disincentive for progressive agencies that want to think outside of the box to create cost effective and innovative service models. These manifest themselves in a number of ways. For example the rent stipends are very low to begin with for people who want to rent apartments under their own names in the NYC vicinity. This is compounded by the additional restriction that if two people (say, with a rent allocation of \$1,000 apiece in their approved budgets) decide that they want to rent an apartment together, they cannot combine their resources like any other citizen would do in similar circumstances. Rather, their rent allocation will be reduced and they will be priced out of the market. However, if an agency rents that same apartment and operates it as a certified setting, it will be given more than \$2,500 per month to cover the operating costs.

To the same point, I am familiar with one group of families on Staten Island who wanted to purchase a multiple family house where their children who knew each other for a long time could live together in a non-certified setting. They then proposed to transfer the property to a service agency who was working with them on this project, which would receive funding for the services it provided through self-directed budgets developed for each child according to existing regulatory guidelines. After 7 years of intense effort, and even with the families working together with the agency to reduce the level of paid staffing by working as volunteers, the only way that the plan was finally completed was to certify and operate the home as a Supervised IRA.

Unless there is some way for all stakeholders to have their actions match their rhetoric, it will not be possible for all parties to work together to make the wonderful dreams and good intentions expressed in the Olmstead Implementation Plan become a reality.