

New York State Association of Community Residential
Agencies & Westchester Institute for Human Development



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Report to the Housing Task Force

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December 2015

Housing for People with Intellectual and Developmental Disabilities in New York State

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About NYSACRA

Founded in 1977, The NY State Association for Community Residential Agencies (NYSACRA) affords not-for-profit service provider agencies with the opportunity to meet and share ideas and information. NYSACRA provides an important public voice representing the needs of its members at the federal, state, and local levels.

NYSACRA now represents more than 200 not-for-profit service provider agencies with a combined workforce of approximately 70,000 employees. The supports provided by these agencies and their staff are wide-ranging and include: supportive and supervised residential living alternatives, day habilitation, prevocational and vocational training, family care and respite services, clinical services, and educational and preventive education services.



About WIHD

Westchester Institute for Human Development (WIHD) addresses major social and health issues affecting people living with disabilities and vulnerable children by developing and delivering medical, clinical and support services to individuals, their families and caregivers. As a University Center for Excellence in Developmental Disabilities, WIHD creates better futures for these individuals through the creation and dissemination of innovative research, professional leadership education and best practices trainings. WIHD provides nearly 50 programs and services to families and professionals throughout Westchester County, the Lower Hudson Valley and beyond.

About the Task Force

The Housing Task Force is drawn from all of the regions of the state and beyond, and includes leading professionals in the fields of affordable housing development, banking, education and training, financial planning, municipal bonds, construction, town planning, housing, labor and estate law as well as state agencies and provider organizations. Their help in understanding the housing issues around the state, the creation of information networks and their input to the training curriculum has been invaluable. The members of the Task Force are:

- George Braddock. Creative Housing Solutions
- Nicholas Cappoletti. Executive Director Advocates Inc.
- Ray Cebula. Extension Faculty Yang-Tam Institute on Employment and Disability at Cornell University
- Tracy Conley. Vice President and Mortgage Officer the Community Preservation Corporation
- Ravi Dahiya. Associate Executive Director Operations and Quality Improvement, Independence Residences, Inc
- Norma Drummond. Westchester County Deputy Commissioner of Planning
- Henry Hamelin. Office for People with Developmental Disabilities Liaison
- Charles Hammerman. President, the Disability Opportunity Fund
- Brett Hebner. Assistant Director, Office of Temporary and Disability Assistance
- George Hezel. Clinical Professor Emeritus SUNY Buffalo Law School
- Robert Laux. President, Wild River Realty
- Sanford Loucks Baer. Area Specialist, Rural Development USDA
- Gregory LiCalzi. Executive VP Gates Capital Corporation
- Ron Little. Senior VP Finance and Agency Management, Heritage Christian Services.
- Robert Mascali Esq.
- Kevin Nickerson. National Disability Institute
- Adam Pekor Esq. Attorney, Sheppard Mullin
- Susan Platkin M.D. New York Self Determination Coalition
- Mike Riegel. Executive VP, COO Belmont Housing Resources for WNY
- Michael Skrebutenas. Senior VP Community Preservation Corporation Capital Region office.
- Leonard Skrill. Upstate Director of Development. NY State Homes & Community Renewal
- James Traylor. President, Upstate Special Needs Planning
- Hubert van Tol. Senior Director for Economic Development, PathStone
- Alexandra Wehr. VP Senior Corporate Relationship Manager, First Niagara Bank, N.A.

Executive Summary.

In 2015 NYSACRA received a grant from the Office for People With Developmental Disabilities (OPWDD) through the Balancing Incentive Program (BIP) which included funding to increase housing options for people with Intellectual and Developmental Disabilities (I/DD) in New York State. WIHD collaborated with NYSACRA on this portion of the grant. The NYSACRA-WIHD team created a statewide Housing Task Force which included a wide range of housing and related industry experts, representatives of state and local government, and provider agencies. The Task Force reviewed impediments to increasing housing options in the state and made recommendations to address those impediments. Concurrently NYSACRA and WIHD created the “Housing Navigator curriculum” designed to train I/DD professionals to assist agencies in understanding housing options and to guide people with I/DD and their families through the process of finding a home. The Task Force was a valuable resource in the creation of the curriculum.

This report to the Task Force sets out the major issues and impediments to more independent housing and recommends policies and practices that will increase options for people with I/DD.

The principle conclusions of the report are:

1. People with I/DD, their families, provider agencies and OPWDD need to create statewide and local housing collaborations that include the full range of stakeholders in affordable and supportive housing;
2. OPWDD and other stakeholders should create a Housing Resource Center to support people with I/DD and their families, as well as provider agencies and state agency stakeholders seeking to create and sustain housing;
3. OPWDD and other state agencies need to examine relevant laws and regulations in detail and understand how to ensure that where possible resultant policies and practices increase housing options rather than impede them;
4. Provider agencies and OPWDD should provide training to their boards, executives and staff that describes the changing housing options and how these changes will impact their future services; and
5. Provider agencies, advocacy groups, the Developmental Disabilities Councils, the University Centers for Excellence and other stakeholders should provide education for people with I/DD and their families to assist them in understanding and negotiating self-directed systems.

Introduction

This report summarizes the feedback that the NYSACRA – WIHD team received from the series of meetings held around the state from April through July of 2015, the meetings of the Housing Task Force and their written comments, and finally the input from the first cohort of students trained as “Housing Navigators” in the seven-week class that began in September 2015 and concluded in November 2015. While it is important to consider Housing and Service issues together, for the purposes of this report the focus is primarily on housing. At the end of each “issue” paragraph, there is a series of recommendations that members of the Task Force and others provided.

Regional Meetings

The NYSACRA –WIHD team, Carol Napierski MS, Senior Director of Administration at NYSACRA, and John Maltby MS, Director of the Community Support Network at WIHD, organized a series of meetings around the state as part of the Housing project pursuant to a grant received from OPWDD supported by funding from the Balancing Incentive Program (BIP) of the federal Department of Health and Human Services (HHS). The meetings began in Rochester and West Seneca on April 29th 2015 with subsequent sessions in Binghamton, Rome, Sunmount, Albany, Valhalla and New York City and concluded in Bethpage on July 29th 2015. There was at least one forum in each of the five Developmental Disability Regional Office (DDRO) regions of OPWDD. Attendees were mostly provider agency staff with a housing or self-direction background (60%), with staff from the OPWDD (16%), housing professionals from other than the I/DD provider business (11%), bankers (7%) and self-advocates and families (6%).

The meetings followed a common format: after introductions and a description of the project, participants would begin by discussing the unique considerations in their geographic area. As the series of meetings progressed this portion of the session would include descriptions of the unique considerations observed earlier in the series. Participants were encouraged to focus on the positive aspects of their region rather than simply the negatives. This discussion would be followed by drilling down into the impediments to the creation of more housing with a view to local considerations. The meetings would include discussion of the Housing Navigator role and the Navigator training curriculum in development, seeking the input of the participants to make the curriculum as relevant as possible.

Notes were taken by the NYSACRA-WIHD staff as well as the OPWDD staff. These notes were then circulated to the participants for comment, and once the comment period had concluded the final version of the notes was sent to all participants. This report is based on those notes and feedback.

Regional Considerations

Our state is richly diverse, and while mostly rural, it includes large cities and sprawling suburbs. Some characteristics that were thought to be regional were common statewide but others were local.

- “Priced out in 2014” lists New York as fifth in the country by most measures when ranking states by the percentage of Supplemental Security Income (SSI) necessary to obtain accommodation. OPWDD housing support funding is determined by the State Homes and Community Renewal (HCR) rental payment standards, which are based on the 40th percentile, adjusted standard quality gross rent, as set by the U.S. Department of Housing and Urban Development (HUD). These standards are universally seen as inadequate, in particular when applied to 3 or 4 people seeking to combine resources and live together in a house which meets their needs rather than an apartment.¹
- Homeownership rates range from as low as 19.4% in Bronx County where the median price of a family home is \$374,500 to 73% in Allegany County where the median price is \$69,600.²
- Statewide there is a scarcity of Section 8 housing vouchers.
- In some regions, providers of service to people with I/DD are actively helping people to develop options for non-certified housing, while other providers are not. The degree to which agencies are exploring non-OPWDD funding sources and non-certified housing varies between DDRO regions and among providers.
- Universities that support housing or disability studies have a significant positive regional effect in promoting community integration and adoption of creative housing solutions. A similar effect is observed where agencies have invested in Council on Quality and Leadership (CQL) training and are focused on Personal Outcome Measures (POMs).
- Adoption of self directed services varies widely across the state, but does not directly correlate to innovative housing practices. In areas where self direction is firmly rooted, there are sometimes staffing shortages and limited availability of training for brokers and Direct Support Professionals (DSPs).
- Family location, the age of the person with I/DD and their parents, and their experience with state systems all affect perceptions of congregate care and independent options.
- Depending on the region, low cost housing may only be available in areas considered unsafe or significantly under-resourced. Older housing stock is available but inaccessible to people with impaired mobility.

1 Priced out in 2014 <http://www.tacinc.org/media/52012/Priced%20Out%20in%202014.pdf>

2 US Census <http://quickfacts.census.gov/qfd/states/36000.html>

- In rural areas housing stock may be more available but there is limited access to transportation.
- In some regions, particularly Western NY, provider agencies have developed their own expertise in creating affordable housing. In others, there is little or no dialogue between housing developers and provider agencies or people with I/DD.
- Commercial banks have regional pockets of expertise, experience and commitment; lending officers have varying degrees of understanding of the housing options for people with I/DD.
- In parts of the state where “Home of Your Own” funding created home ownership for people with I/DD, agencies have begun to develop exit strategies for aging homeowners/ deteriorating properties.
- In Binghamton (Region 2), we heard that low cost housing was taken off the market by absentee landlords and rented to students for higher than typical rents. We heard this to varying degrees in other college towns and near military bases. In the Capital district, private colleges have purchased former large group homes for student housing. In Region 3 near Malta the growth of the semiconductor industry is also squeezing housing.
- In other areas there is accommodation available; for example 38.34% of properties in Schenectady are vacant. Vacant housing in cities creates both challenges and potential opportunities.³
- New York City is in a housing crisis; scarcity incentivizes landlords to seek shorter-term commitments, making it easier for rents to inflate. Securing housing may also require real estate broker property-finding services, adding to costs.
- Urban areas fare much better than rural areas for services – this is not new information but the contrast has become starker, in particular for issues such as transportation, provision of support and medical care.

3 Civic Dashboards Rental Vacancy rate http://www.cividdashboards.com/city/schenectady-ny-16000US3665508/rental_vacancy_rate retrieved September 2015

Impediments to increasing housing options for people with I/DD

According to the “State of the States in Developmental Disabilities” OPWDD provides residential support to approximately 67,000 people in NY State, 40,000 of whom live in some form of congregate setting. The population of people with I/DD in the state, including children, is some 310,000. ⁴ Per the Centers for Disease Control (CDC) ⁵ and the Arc ⁶ prevalence of I/DD sufficient to require lifetime support is conservatively 1.5% of the population. In New York state 1.5% of the adult population would represent approximately 230,000 people. ⁷ OPWDD’s budget states that it provides services of some kind to 126,000 people. Clearly our system is not reaching all of the people that may need support. Some are receiving support from other state agencies, but in terms of housing, the need will not be met through such means. Additionally, per “The State of the States” ⁸ there are some 50,000 people with I/DD living with caregivers who themselves are over 60 years of age. It is clear that as a state we need to significantly increase options for housing people with I/DD as a matter of public health and safety.

The focus of this project has been on the availability of “bricks and mortar,” but when it comes to increasing options for people with I/DD, housing and support services are inextricably entwined. The introduction of Individualized Budgets and Self-Directed ⁹ funding is the most significant change in the I/DD world in forty years, and its adoption and implementation is proving to be as tortuous as one would expect given such a fundamental shift.

OPWDD has successfully created housing using provider agencies and the “Prior Property Approval” (PPA) letter process for many years. Briefly, using the PPA model a provider agency submits a budget and plan to OPWDD to create a certified setting, and OPWDD upon approval provides a PPA letter to the agency. The agency can use this letter to borrow up to 100% (in some cases more if remodeling is required) of the “Loan To Value” (LTV) (i.e. the amount of the loan vs. the valuation of the property). Bankers understand that a PPA is not a guarantee, but they have also experienced a zero default rate on such loans, even when agencies were in financial trouble.

4 Per “The State of the States in Developmental Disabilities” Braddock et al. <http://www.stateofthestates.org/documents/NewYork.pdf> retrieved June 2015

5 CDC Website <http://www.cdc.gov/NCBDDD/cp/research.html> retrieved February 2015

6 Arc website <http://www.thearc.org/page.aspx?pid=2448> retrieved February 2015

7 Population estimate based on NY State DOH https://www.health.ny.gov/statistics/vital_statistics/2010/table01.htm retrieved October 2015

8 Op.cit

9 In its description of self directed services the Centers for Medicare and Medicaid Services (CMS) includes the term “Individualized Budget as being those funds for services that are in the control of the individual.” In this report we use the term as defined by CMS. <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html> retrieved November 2015

Bankers also understand that real estate is not the true heart of the collateral—the OPWDD commitment to providing ongoing support funding is the real critical credit element. While the PPA model has created housing for many people, it takes an enormous amount of time to process, is subject to long wait lists, can be very costly and unsustainable and is not reflective of individual choice. The lack of individualization also means that some individuals are now “placed” in more restrictive and expensive settings than their needs require. An OPWDD study in 2012¹⁰ that used Developmental Disabilities Profile (DDP) data—which have been acknowledged as not really reflecting the supports needed by people with the greatest challenges—estimated that as many as 10-15% of the people served in various levels of congregate care would fare equally well or better in less restrictive/expensive settings. The cost of this misalignment could be as much as \$40M annually - \$1B over 25 years.¹¹ However, because this model is familiar and adopting new methods can be difficult, providers have not sought alternative ways to create housing, and creators of housing have not been incentivized to address the needs of a wider range of people with I/DD.

There is considerable evidence that smaller residential settings are more desirable for people with I/DD, most recently set out in the National Council on Disability’s paper “Home and Community Based Services; Creating Systems for Success at Home, at Work and in the Community”.¹² In addition to these findings, considerable impetus to move towards smaller settings has come from the Centers for Medicare and Medicaid Services (CMS) through their requirements related to Self Direction embedded in the 1915 (c) Waiver, the Person Centeredness requirements set out by federal Health and Human Services as part of the Affordable Care Act of 2010¹³, and the Home and Community Based Services (HCBS) Settings guidelines issued by CMS in 2015.¹⁴

In October 2015 NY State Department of Health’s (DOH) 1915 (k) waiver was approved. The waiver reflects the Community First Choice option for states created under the federal Affordable Care Act of 2010. In the DOH waiver, which may provide services to people with I/DD, there is a requirement for a Functional Assessment using the Uniform Assessment System of New York (UAS-NY), which the pending Comprehensive Assessment System (CAS) currently being validated by OPWDD will be part of. There is increased provision for Assistive Technology, and Transition Funding to help people move from ICF settings into community settings.¹⁵ The next months will show how these innovations will be operationalized.

10 Information provided to the team by OPWDD analyst September 2015

11 If “conservatively” 10% of the 38,000 people in congregate care (per Braddock, “State of the States 2013”) could achieve \$10,000 annually in savings in a less restrictive setting.

12 http://www.ncd.gov/rawmedia_repository/HCBS%20Report_FINAL.pdf Retrieved July 2015

13 http://www.communitychoices.info/documents/2402a_Guidance_Person-Centered_Planning.pdf Retrieved August 2015

14 https://www.health.ny.gov/health_care/medicaid/redesign/hcbs_final_rule_transition_plan_presentation_1.22.15.htm

15 State Plan Amendment 13-0035per CMS letter of 10_23_15

Part of the task set by the grant was to identify impediments to increasing independent housing. The “Roadblocks” sub-group of the Task Force chaired by Nicholas Cappoletti, Executive Director, Advocates Inc., began with a raw list of issues and impediments based on feedback from the Task Force and the group’s own experience. During the course of the statewide meetings these issues were clarified and organized into two categories:

- I. Those directly related to creating more housing.
- II. Those related to providing support services to people seeking to live more independently.

The support service impediments were further categorized as:

- a. Legal,
- b. Regulatory,
- c. Financial,
- d. Social & Political, and
- e. Self-Direction implementation.

Recommendation 1. Create a Housing Resource Center or Centers.

Finding, creating and sustaining housing for people with I/DD are complex tasks that demand broad knowledge of housing, disability and health systems. Knowledge of federal, state and local funding sources, regulations and practices is essential. Learning the business of housing requires education and training. There is no current requirement or method to provide such expertise to agencies seeking to create options, to service coordinators trying to help people with I/DD, or to people with I/DD and their families. There are pockets of expertise around the state that could be coordinated as the foundation for a Housing Resource Center in the short-term, but OPWDD, provider agencies, the SUNY network, UCEDDs, trade groups and DD Councils should collaborate to develop a long-term model and practice.

CATEGORY I. Impediments to creating more housing

Repurposing of property.

There are two primary providers of certified housing in New York. The State through OPWDD owns and operates Development Centers, Intermediate Care Facilities (SOICFs) and Individualized Residential Alternatives (SOIRAs), and funds Family Care support (SOFC). The Voluntary agencies operate ICFs, IRAs, Community Residences (CRs) and Family Care (VOFC) Driven by their experience of best practices and the requirements of CMS and its HCBS settings rule, provider agencies are seeking or will likely be seeking in the future to get rid of large properties, repurpose medium size properties and increase the availability of smaller settings. Some of the properties involved are currently encumbered by bonds or mortgages with interest rates that are higher than the prevailing rates, so a refinancing would generate savings.

Provider agencies have expressed concern that in the event they were able to refinance or sell property, any funds generated (including those from refinancing) would have to be refunded to the state and would not benefit the agency or the people it serves. While proceeds from a closed site belong to the provider agency, lower property funding costs could potentially trigger a reduction in OPWDD property funding in the agency's operating rate, creating a loss for the agency. OPWDD implicitly expects funds from property sales to be reinvested and has leverage when considering any future PPA request. Some agencies, on the other hand, were not aware that they could re-finance or were under the impression that the work involved would be cumbersome.¹⁶

In May of 2002 then Deputy Commissioner of (then) OMRDD¹⁷, Alden B. Kaplan issued a memorandum on the subject of "Refinancing Savings Reinvestment" that discussed options for agencies that were refinancing property through bond issuance. Savings could be used to create NYS CARES¹⁸ opportunities, capital repairs to existing properties that would normally be funded through PPA, and family supports services. The memo did not mention non-certified settings or other residential options. While limited to the needs of the time and specific to bond issuance, the memo does set out some options.¹⁹

There is no stated plan at this time for the State to divest itself of property.

Recommendation 2.

- (i) While the state needs to reserve its discretion with regard to each agency's re-purposing intent, OPWDD and DOH should update the 2002 guidance and establish clear policies and incentives that agencies can follow to use savings achieved by refinancing or sale of property.
- (ii) Given the level of current interest rates refinancing makes economic sense even with prepayment penalties. Agencies need to engage consultants or a banker that will provide them with refinancing options. The providers' business offices must take the lead in this process in partnership with OPWDD the CEOs and agency boards of directors.
- (iii) If OPWDD would allow agencies to refinance for longer terms than the remaining term left on PPA's, agencies could leverage additional funds to do repairs, energy improvements, etc.

13

16 As a guide, a 30Y fixed \$1MM mortgage at 6% would be \$7,620.51; at 5% will cost \$6,993.22 monthly a savings over 360 months of \$225,824. (Source 1st Niagara online mortgage calculator)

17 OPWDD was formerly "The Office of Mental Retardation and Developmental Disabilities" (OMRDD), the name used from its creation in 1979 until 2010

18 NY State "Creating Alternatives in Residential Environments and Services"-NYS CARES launched in 1998 is the primary initiative creating certified settings.

19 OMRDD memo May 30 2002 Alden B Kaplan to DDSO directors, Associate Commissioner Broderick and provider agencies "Refinancing Savings Reinvestment"

Separate control of property from provision of services.

Congregate care combines services and housing. This means that if an individual with I/DD is satisfied with their services but dissatisfied with their housing or their house mates, their only recourse is to try and negotiate with the provider for a move to different housing, or vice versa if they are unhappy with their services. The system does not allow for much choice. As the State service system is increasingly based on self direction and community integration, it is imperative that we create systems where property ownership is disinterested and distinct from housing. There are circumstances in which agency ownership of property is the best option, but in such cases there must be alternative service options for an individual who wants to exercise more choices. The use of the individual budget is a critical way to improve quality and accountability. Current budgeting methods group individuals by site and do not apply individual budgeting to certified settings.

Recommendation 3.

OPWDD should institute individualized budgets in congregate settings, allowing individuals to have choice of setting and improved portability of services. Individualized portable budgets are a critical way to improve quality and accountability; people who are not satisfied with their housing and services can more easily switch providers.

“What happens when I’m gone?”

Some families believe that when an agency owns the home it will ensure that their loved one is safely looked after when they are no longer able to provide support themselves. They put their trust in an agency. The reality is that as with any other corporation the fortunes of agencies will wax and wane, and simply owning the individual’s home is no guarantee of continuity or quality of service—in fact, it may tend to the opposite. However, family concerns are genuine and deeply felt. In order to create more flexible housing options families must be given comfort that services will continue to be provided and that quality will be sustained.

Recommendation 4.

OPWDD and providers should collaborate to create a menu of services that will ensure continued quality support for people who do not have families, effective Circles of Support or advocates to speak for them or to monitor their programs. These services might include an ombudsman role, support for guardianship or other decision-making options, and access to legal services and resource planning.

Application of limits on housing support.

As noted above, housing support funding from OPWDD is capped at the rate set for NY State Housing and Community Renewal (HCR) by the federal department of Housing and Urban Development (HUD).²⁰ These rates are calculated at the 40th percentile adjusted standard quality gross rent, and increases are based on Consumer Price Index (CPI) inflation levels. CPI includes a housing component, but does not accurately reflect housing price inflation by itself. For example, as recently as July 2015, CPI rose .10% while shelter costs rose .40% in the same period.²¹ As long as housing costs rise faster than the rest of the CPI, the HCR rates will reflect this flaw. Rates are also based on the traditional nuclear family, with higher rates for properties with more bedrooms.

People trying to move from congregate settings where gross housing costs have been determined through the PPA process into a community where housing support is based on HCR guidelines are faced with a significant reduction in their housing support. By contrast, people combining under an agency group home model will receive acquisition and renovation monies of up to \$145k per person, and the budget PPA provides to the group home operator will cover the operator's mortgage costs rather than being based on the HCR guidelines. HCR rent supports range from a low of \$513 a month in Chautauqua County to a high of \$1395 per month in Nassau/Suffolk counties.

Recommendation 5.

- (i) OPWDD should develop a mechanism to allow people seeking to move from congregate to community settings to transfer their ongoing housing budget for a sufficient period to cover start-up costs.
- (ii) OPWDD should supplement HCR guidelines to reflect the difference between the needs of a group of people with I/DD who are exiting congregate care seeking to live together, and those of a typical family.

20 Rates available at the HUD Website http://www.huduser.gov/portal/datasets/fmr/fmr_il_history.html retrieved October 2015

21 Per "Market Watch" August 19th 2015 <http://www.marketwatch.com/story/us-housing-costs-continue-to-soar-cpi-shows-2015-08-19>

Commercial banking restrictions on consumer lending

Commercial bankers have a long history of lending to provider agencies to purchase property through the PPA process. Experience has shown them that even when agencies get into financial trouble, OPWDD will continue to support the people that live in an agency-owned home and in some cases even engineer the transfer of a facility to another agency. Default rates are effectively zero.

A bank will have different standards and practices for consumer lending versus those for corporate lending; therefore the compliance rules they have to abide by will be different. As we move to portable and individualized budgets, the funding for a person with I/DD's care is funneled through a Fiscal Intermediary (FI) directly to the individual. The level of residential funding may in theory be identical to the funding that was previously directed to the provider agency to serve the individual, i.e. per the Olmstead decision²². However, per banking regulation a lending institution may not lend to the individual at the same LTV as they would have lent to an agency. The contract between OPWDD and the individual is economically the same as that between OPWDD and the provider agency, but the bank may have limited or no experience with the individual or with lending directly to people whose primary support comes from federal and State benefit. The bank's consumer lending is, again, governed by different regulations to those which govern its corporate lending.

Recommendation 6.

- (i) OPWDD's funding commitment to an individual should be seen as economically equivalent to that individual's portion of a Prior Property Approval were they to be in a certified setting.
- (ii) It is difficult to provide subsidy dollars directly to an individual who receives benefits. Unless the individual is seeking home ownership on his/her own, it may be more feasible to encourage the private sector (nonprofit or for-profit) to own/rehabilitate/manage non-congregate housing for people with disabilities.
- (iii) OPWDD should develop a guide for commercial bankers regarding critical elements of the transition from congregate care to individual ownership and the nature of state support.

22 On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity. (Bazelon Law Center retrieved November 2015) <http://www.bazelon.org/Where-We-Stand/Community-Integration/Olmstead-Implementing-the-Integration-Mandate/The-Olmstead-Decision-.aspx>

Risks in individual home ownership

While it is difficult for someone with Extremely Low Income (ELI) (Lower than 30% of Area Median Income, AMI, per HUD) to obtain credit, there are programs to help first-time home buyers save for down payments and obtain preferential mortgage terms.²³ These include OPWDD's Home of Your Own program (HOYO). A person with I/DD can buy a home, by themselves or with others. However, funding for home repairs, maintenance and foreclosure prevention is not part of OPWDD's funding. Homeowners who wish to sell their property or their share of a property in order to move to a different setting are faced with significant liquidity challenges. Homeowners who sell their property may, in fact, have to forfeit all or part of the proceeds to Medicaid if they are over the age of 55.

Meanwhile, the benefits of tax deductibility of mortgage interest and local property taxes are skewed towards people with higher incomes. People with I/DD may have very low or extremely low incomes and neither of these home ownership incentives apply to them.

Part of OPWDD's mandate is to help people stay healthy and safe, which requires them to assure that people live in decent housing. OPWDD provides rental subsidies which effectively allow landlords to maintain property, and provides upkeep funds to certified settings. There is a case, therefore, for including a maintenance element in the housing subsidy.

Recommendation 7.

- (i) Part of the HOYO Process should include a "Useful Life" study of the property. This would project the costs of replacing major elements of the property over time. The owner can then create a projected maintenance budget and schedule which is built into the housing support budget.
- (ii) Provide training to individuals and their Circles of Support in how to manage their property
- (iii) With support from Community Development Financial Institutions (CDFIs) and energy companies, create an easily accessible database of affordable housing agencies and low-income based grant/loan programs. These programs allow grants for low-income housing upkeep/maintenance.

Highlight programs through New York State Energy Research and Development Authority (NYSERDA) that can provide individuals who qualify with repair and replacement money for new windows, refrigerators, AC units, furnaces etc.

23 See OPWDD's Home of Your Own program (HOYO) http://www.opwdd.ny.gov/opwdd_community_connections/housing_initiative/home_of_your_own_hoya

Limited developer experience with population.

Developers of Affordable Housing have experience working with people at a wide range of income levels, including ELI, and agencies that provide for Supportive Housing have experience providing for people of low incomes and for people with Mental Health or Substance abuse issues. Developers are becoming increasingly familiar with the advantages of working with people with I/DD, but there is still work to be done in educating many in the developer community regarding support from OPWDD and its provider community for supportive housing. In particular, there is a need to offer services to small upstate rural communities.

Limited provider experience with developers and incompatibility of rental rules with residential funding

Just as developers have limited experience with people with I/DD or the agencies that provide support to them, many provider agencies also have limited experience working with developers of mixed-use and affordable housing, or collaborating with Supportive Housing providers. Developers of affordable housing will typically rely on one provider agency to support people with I/DD in a building, and for that agency to execute a “master lease” with the property management. The management want to be assured that they can collect rent on a regular basis and comply with their funding sources so that they maintain a sufficient revenue stream to operate the building. However, in the event that one of the people being supported is no longer able to live in the building for any reason, the agency that is on the lease will be at risk for the rent regardless of whether the unit is occupied. It may take them some time to replace the tenant and they will be on the hook for the rent until they do. They will also need to take into account that per the HCBS Settings Final Rule, “for provider-owned or controlled HCBS settings (the) requirements include: the individual has a lease or other legally enforceable agreement providing similar protections:”²⁴

24 The HCBS final Settings rule per CMS January 2014. <http://www.medicare.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/hcbs-setting-fact-sheet.pdf> Retrieved November 2015

Recommendation 8.

- (i) In June 2015 CMS advised that it would reimburse housing related services for individuals with disabilities that included navigation of the housing system and sustaining people in housing²⁵. As part of the BIP grant NYSACRA & WIHD created the Housing Navigator Curriculum. The curriculum was taught to an initial 31 students from around the state in the fall of 2015. OPWDD should seek to include housing navigation services in its waiver.
- (ii) OPWDD should build on the informal links that have been developed with HCR and which it has fostered with the development community, matching providers with developers to create housing.
- (iii) Provider agencies should be provided resources to help in locating the developers of affordable housing who recognize the financial value of working with people with disabilities and those with low incomes.
- (iv) Provider agencies and OPWDD should establish a means of ensuring that building owners will have confidence that the provider master leaseholder will fulfill their financial obligations to the owner and ensure that their tenants comply with the requirements of the building, while preserving the rights of those tenants as required by OPWDD and by housing laws. In the event that a tenant may no longer stay in the building, both the landlord and the provider holding the master lease must have confidence that the vacancy will be of limited duration.
- (v) OPWDD should increase ties to the UCEDD and SUNY systems, in particular to institutions that provide training and education on housing issues.
- (vi) The Supported Housing Network of New York (SHNNY) has recommended that OPWDD providers and/or trade associations develop an internal capacity to create a “housing broker” role. This would fit with the training NYSACRA is providing to Housing Navigators per (i) above
- (vii) Create a Housing Resource Center that would work with the Housing Task Force to highlight housing needs. The Resource Center should create educational material and training opportunities for individuals with I/DD, families and providers that address their housing needs.

25 CMS Informational bulletin June 26 2015 “Coverage of Housing –Related Activities and Services for Individuals with Disabilities. <http://www.medicaid.gov/federal-policy-guidance/downloads/CIB-06-26-2015.pdf>

Scarce resources for renters to find housing, and room mates

In parts of the state, particularly in New York City, rental accommodation is scarce and connecting to landlords requires a considerable effort from the individual, their advocates, and/or a broker. Finding compatible roommates is also difficult.

Recommendation 9.

- (i) OPWDD should seek to modify the 1915 (c) Waiver to fund Housing Navigator services. The Housing Navigator training course developed by NYSACRA includes resources to locate available housing – HUD, HCR etc. — and identifies services which are available to help find suitable roommates/matches
- (ii) Different regions in the State are developing or accessing roommate connection programs, e.g. “The Driver’s Seat” in Region 1. In Region 4 people looking for a roommate work with their FI to reach out to other people on their list. These initiatives should be publicized and supported.

Aging housing stock needs refurbishing and is more expensive to maintain

Funding for renovation or maintenance is not always available from the same streams as funding for housing purchases. Older buildings are less energy-efficient, less amenable to technology, and frequently not accessible for a person with a disability.

Recommendation 10.

- (i) Agencies need to assess their property assets and may need to reconfigure their portfolios to focus on more efficient and appropriately sized homes. To the extent that OPWDD can act to facilitate such efforts, it should do so.
- (ii) Agencies should be provided with information, possibly as part of the Housing Navigator course, on how to access grant opportunities from the Federal Home Loan Bank, HOME funds etc., and from commercial and community based lenders.

Questionable assumption that bigger is better.

Provider agencies are planning for radical change in the service industry, change that may include collaboration and mergers. It is in their best interests to show financial strength. Property assets boost their balance sheets, although aging and large-sized housing assets may in fact serve to undermine their financial sustainability. OPWDD would like to see more consolidation in this regard. Larger balance sheets will be an advantage given the financial and managerial challenges that the Affordable Care Act and impending Managed Care transition pose. It is not clear, however, that size correlates with efficiency; in fact, institutional costs seem to invert economies of scale. Nor is size related

to quality. However because of the bias to large balance sheets agencies are reluctant to shed property, and this bias incentivizes the continuation of the Property Ownership-Provision of Services model. Developing metrics that show whether or not agencies are providing quality programs is critical. Value-based payment for services is a fundamental underpinning of managed care and New York's stated direction. The key will be to ensure that the value "indicators" actually work for the I/DD population.

Recommendation 11.

OPWDD should fund or develop residential quality metrics and standards and provide for a ratings system. When questions are subjective OPWDD should ensure quality results by having surveys administered by staff that do not have control over the day-to-day life of the individual being questioned.

Risks associated with Trust or ABLE ownership of property

A limited number of families have created Third Party Special Needs Trusts (SNTs) for their sons or daughters with I/DD, with the primary objective being that the trust eventually acquires a house for the person to live in. It is important that such trusts do not provide food or shelter, (which could compromise Supplemental Security Income (SSI) and imperil Medicaid eligibility). In addition, the trustees, often the parents, are required to act as fiduciaries, in the best interests of the trust. It is incumbent on a trustee to ensure that trust investments are not concentrated or as a whole illiquid – i.e. that the portion invested in a single property does not jeopardize the trust's viability or adherence to compliance standards. In order to be used to purchase a property a trust's assets must therefore be substantially greater than the cost of that property, such that the purchase does not overly concentrate the assets.

The federal Achieving Better Life Experience (ABLE) Act regulations are at this writing in the process of being formulated by the Internal Revenue Service. As currently drafted, they allow funds to be used to support housing needs, but would be subject to the same strictures as a trust with regard to their effect on SSI/Medicaid vis à vis provision of food and shelter. As currently drafted the NYS ABLE legislation would allow for the purchase or upkeep of a property. Once purchased this property would not have a Medicaid lien filed against it. To the extent that funds in the account remain under \$100k there will be no impact on SSI payment amounts.

Recommendation 12.

Provide information re: Trusts and Protected Savings. The NY State Developmental Disabilities Planning Council has published a guide to SNTs that was reviewed by NY State Estate Planning Attorneys. There is also information available from the Academy of Special Needs Planners and The Special Needs Alliance as well as the Elder Law Section of the NYS Bar association. These resources should be made available as widely as possible and referenced in OPWDD materials.

Risks in family or group ownership of property and Fair Market Rent (FMR) vs Medicaid claw back

Families or groups of families may come together to purchase property for the use of their adult sons and daughters with I/DD. In the past their proposal would be put to a provider agency, with the understanding that the families would ultimately donate the home to the agency which would in turn provide a placement in a certified setting for their adult son or daughter. Although this has sometimes been done, it is clearly unethical to permit an individual to receive a lifetime of services by buying in through the gift of a home, and they may compromise their eligibility for SSI-Medicaid if part of the “Deal” is providing shelter. Other concerns have included: 1) whether the individual in such a situation is, in effect, getting priority over others of similar or higher priority also in need of services; 2) what happens to the house if the individual cannot live there any longer due to changing needs; and 3) does the agency jeopardize its 501C-3 by accepting funds directed at an individual’s needs.

Self-Direction and individualized budgeting change that picture. In the era of self direction it is possible for families to purchase property, own it themselves, and have services provided by an agency—or, to manage the property themselves and through the FI hire a staff. The OPWDD has experience and guidelines to help them to arrive at a Fair Market Rent (FMR)-based subsidy to an individual who will then pay those funds to a landlord. OPWDD regulations do not prohibit reimbursement for rent to related parties for licensed sites. Rent payments are subject to a limitation that they must be the least of the contract rent, actual cost to the owner or fair market rent. For unlicensed sites, similar principles are applied.

Recommendation 13.

The state should encourage provider agencies and others to create housing ownership entities that have as their mission the provision of affordable, accessible housing to people with disabilities. Such entities can attract investors with social missions, e.g. Program Related Investors,²⁶ including families, to own equity in property as well as debt and to rent that property to people with I/DD. The investor does not need to act out of altruism; if the system is structured properly, they will have income and equity. There are experts within the state who can advise on the creation and funding of such entities. OPWDD should also disseminate examples of workable ownership structures.

²⁶ PRI Investments made by foundations to support charitable activities that involve the potential return of capital within an established time frame (Grant Space <http://grantspace.org/tools/knowledge-base/Grantmakers/pri/> retrieved November 2015)

Levels of local taxes

New York State has the highest property taxes in the nation; Nassau and Westchester counties alone represent numbers 1 & 2 respectively. The range of taxes as a percentage of property value is from below 1% in NY City to over 2.7% annually in northern and western counties where property values are lower.²⁷ The Padavan rule had the effect of limiting the concentration of tax-exempt property used to support people whose services fall under the Mental Hygiene law in any given municipality.²⁸ On the other hand, property that is not owned by a nonprofit, but that is owned by a for-profit or an individual, is subject to local taxes. School Taxes may be reduced for people with disabilities and senior citizens via School Tax Relief (STAR) exemptions, but only modestly. Anecdotally, agencies that have created housing that is owned by people with I/DD have been able to negotiate lower rates with municipalities, but this is not generalized.

The median value of owner-occupied housing in NY State is \$288,200; a 2% annual tax would therefore be \$5,764. As a (very rough) estimate: if the median home can house 3 people with I/DD, and they are required to pay local taxes, the total local tax bill for every 1,000 people housed independently would be \$1,921,000. In the overall picture this is not substantial, but it goes straight to the bottom line of budgets that “Follow the Person” from congregate care to community living. Some municipalities have allowed the “look through” to see the individuals living in the home, rather than applying the typical tax rates to the entity. This is on a case-by-case basis. No one likes to pay taxes, but paying taxes makes you part of your community.

Recommendation 14.

- (i) Encourage Non-Profits to create tax-exempt housing ownership structures.
- (ii) OPWDD should partner with state agencies to create a format for reduced local taxation, to be made available to housing ownership entities that are committed to providing accessible affordable housing in their communities, in particular if such a residence is replacing a formerly tax exempt property.

²⁷ See <http://reforminggovernment.ny.gov/reforminggovernment/propertytaxmap>

²⁸ 1978 N.Y. Laws ch. 468, § 2. The statute is named for State Senator Frank Padavan, then Chairman of the New York State Senate Mental Hygiene and Addiction Control Committee. The statute sets out a process for provider agencies to establish certified homes in municipalities in NY State. <http://ir.lawnet.fordham.edu/cgi/viewcontent.cgi?article=1255&context=ulj> retrieved November 2015.

Live-in staff and mixed building use

People with I/DD who are living in Affordable Housing may need support provided to them on a frequent or round the clock basis. This might require live-in staff or a 24/7 position. In some residential environments, other tenants might see these staff workers as a resource for them as well. If the staff is paid through Medicaid their duties would be as prescribed and they could not be a resource to others in the building – even if being so represented an opportunity for integration and collaboration. Traditional supportive housing often included security staff who served the entire building, and virtually all include an office for the support agency. The general experience is that having staff on hand or available for the individuals with disabilities is viewed by most other tenants as a positive, even when they are not a broader building resource. Some supportive housing is also workforce housing, and direct support professionals often meet income requirements.

Recommendation 15.

- (i) Inform developers and planners as to how the need for staff support can be transformed into an asset that an individual with I/DD brings to a developer of affordable or supportive housing.

Affordable /Supportive housing developers can then provide low cost housing to Direct Support Staff whose presence in the building adds to the building's integrity.

Negative cash flow in startup

Creating a Residential budget and perhaps finding other people to partner with takes time. In parts of the state, rental and ownership properties are so tight that the prospective renter or purchaser has to act swiftly. Some people have been caught in a Catch-22 – they will not get residential funding until they can provide a lease, and they cannot get a lease until they pay a deposit and several months rent. Some larger agencies may have the cash-flow to address these issues, but to depend on their ability to do so is not scalable or sustainable.

Recommendation 16.

Collaborate with Community Development Financial Institutions (CDFI) who can create bridge loan products to address the turnaround time it takes for Albany to come through with funding.

Lack of clarity regarding “Intentional Communities”

A May 2015 article in The Atlantic magazine²⁹ and later comment from the Association of University Centers on Disabilities (AUCD)³⁰ on the article highlighted the increasing discussion of “Intentional Communities”. These are conceived as clustered residential housing developments where most of the residents are people with I/DD. Funding for the property is private. Service provision is a mix of private and public funding.

On the one hand, in New York State we have a miserable institutional history. People with long experience in providing services have learned the hard way how planned communities can end up; their feeling is “Never Again.” We know that across many different situations institutional communities tend towards the insular and can become havens for abuse. CMS is aware of existing intentional communities and both require “Heightened Scrutiny” for such models and discourages the creation of new ones. At the same time, families are seeking ways to create housing, working with like-minded families, and unsure if their sons and daughters can live outside their family homes. The HCBS settings standards³¹ must be met in order for the state to receive federal Medicaid dollars. Referring to settings that have the effect of isolating individuals receiving HCBS funded services, CMS stated, “If states seek to include such settings in Medicaid HCBS programs, a determination will be made through heightened scrutiny, based on information presented by the state demonstrating that the setting is home and community-based and does not have the qualities of an institution.”

NYS policy is to invest where it can achieve the most leverage for scarce State dollars; the state may not have a view on the merits of planned or intentional communities, but the key to funding and sustainability is adherence to federal standards.

One option worth examining is the “KeyRing” model developed in England,³² that could be adapted for people with significant disabilities. KeyRing involves a small group of people who each obtain non-certified housing in a specific geographic region. They each use (the U.K. version of) self-direction, and their lives are their own. However, opportunities are purposefully created for them to get to know each other and form friendships if they wish.

29 Who decides Where Autistic Adults live? Lutz. A, Atlantic Magazine, May 6 2015 <http://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>

30 Community Living & Participation for People with I/DD http://aucd.org/template/news.cfm?news_id=11359&parent=16&parent_title=Home&url=/template/index.cfm?

31 January 2014 CMS published Settings Final Rule. <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/hcbs-setting-fact-sheet.pdf> Retrieved November 2015

32 See the KeyRing website at <http://www.keyring.org/what-is-keyring> Retrieved September 2015

Staff also develop relationships and agree to “cover” if someone does not show up. The KeyRing model has the advantages of preserving choice and individuality, offering potential for real relationships, and ensuring safety for people. It does not rest on the participation of “volunteers” or an extensive bureaucracy. The negatives of this system are the geographical separation of people in rural areas, and the difficulty of finding affordable housing in others.

The issues around Intentional Communities potentially create friction between the state, families and providers and there is a need for all to understand the issues, including the history and the potential opportunities.

Recommendation 17.

- (i) OPWDD should seek funding to support or identify a valid study of the Intentional Communities that already exist in NY State as well as elsewhere in the country, with a view to identifying best practices and quality outcomes for the people who live in such communities. Such a study might also review “Intentional Communities” for people who are aging or who have common interests. The goal would be to identify whether such communities are viable or desirable or can be economically justified and are acceptable under HCBS settings standards.
- (ii) Identify innovative and integrated approaches to community living such as the KeyRing model, including information from the Coalition for Community Choice.³³

³³ Coalition for Community Choice is a recently formed organization focused on different approaches to intentional communities around the country. <http://coalitionforcommunitychoice.org/>

CATEGORY II. *Impediments arising from support service issues*

Our focus has been on providing housing, but as noted previously accommodation and service provision issues are inextricably entwined. Throughout the series of fora participants raised issues related to self-direction funding and other barriers that are not strictly about housing but nonetheless have to be resolved if we are to create more opportunities. During the period in which we began the series of meetings around the state the Acting Commissioner of OPWDD convened her Transformation Panel, of which a sub group has focused on housing and services with a primary emphasis on how to address issues arising from the implementation of Self-Directed services, as well as methods of finding affordable housing

In our meetings around the State we found that the issues fell in to three broad categories:

1. Legal and Regulatory

The Nurse Practice Act.

Under the state's Nurse Practice Act the only person permitted to administer medication if an individual is not living in their family home or a certified setting and is unable to administer the medication themselves is a Registered Nurse (RN). This clearly limits how many people with even modest medical needs can live and be supported in the community. The State Education Department (SED) and OPWDD have floated a solution; rather than certify a site, the agency providing the service (e.g. Community Habilitation) would seek certification for the program, and train the staff in Approved Medication Administration Personnel (AMAP) procedures. AMAP training requires four workdays and a fee of approximately \$125 per trainee, (although some agencies provide training in-house). This solution will require that potentially many thousands of DSPs be trained at an (unfunded) cost of c. \$800 each. It is less clear as to how people who are self-directing their hiring can get the training funded or monitored, or to the acuity of the medication administration required. While this may have to suffice for the moment, it is not an adequate resolution.

Recommendation 18.

- (i) Advocates should increase the transparency around medication administration issues to encourage the involvement of family and providers. This issue is thorny, involving as it does professional standards and boundaries, but the cost of not arriving at a common sense solution is too high. The relevant model is the ability of self-hired staff working under Consumer Directed Personal Assistance Program (CDPAP) funding from the New York State Department of Health to perform “nursing” duties. These duties can include assistance with medication by the personal assistant, who is trained by a family member or another person who acts as the “consumer’s surrogate.” It is not clear why this is appropriate for people using CDPAP and not for people using OPWDD services.
- (i) OPWDD should identify how many DSPs will need to be trained in AMAP over how long a period and at what cost and for what reimbursement.
- (ii) There are examples of assistive technology for medication administration being used and monitored by a RN. The nurse can supervise ordering of meds, check if the meds have been taken, and can communicate with local staff if there are inconsistencies.³⁴ These and other options should be explored and made available.

IRS Section 131. “Difficulty of Care Payments”

Section 131 governs payment of tax-exempt stipends to caregivers. Previously the exemption could only apply to non-relatives, but in 2014 the IRS amended their rule in order to permit payment of tax-exempt stipends to immediate family members. This opens up a large potential labor force and the opportunity to reduce pressure on housing needs.

Recommendation 19.

OPWDD should amend its 1915 (c) Waiver to include the payment of “Difficulty of Care” stipends to adult direct family members, and to create a simple regulatory framework based on the reporting system required of SSI Representative Payees, i.e. honest reporting upon pain of perjury.

³⁴ See Touchstream solutions in Rochester NY. <http://www.touchstreamolutions.com>

NY-CRR 633-12.

New York Codes, Rules & Regulations Part 633.12 Objection to Services Process. Under 633.12 a person receiving Home and Community Based Services (HCBS) may object to any changes to those services, for example, being reassigned from one level of support to another or from one housing environment to another. This is complicated by the reality that some decisions are made by guardians or families that do not want any change, regardless of the individual's wishes or assessed need—or by agency representatives who prefer the status quo and its funding. This becomes critical in very high cost settings. Olmstead partially addresses this issue, by requiring that any shift to community based services “(take) into account the resources available to the public entity and the needs of others who are receiving disability services from the entity”. While this may typically be construed as only allowing community-based services if they are financially equitable, it can also be construed as requiring that funding not be extended unfairly to congregate settings when such a setting is unwarranted.

Recommendation 20.

OPWDD's Comprehensive Assessment Tool (CAS) ³⁵, coupled with a budget development protocol based on the CAS, is at the heart of the Transformation agenda. Given the tools to achieve Transformation OPWDD will then require the will to implement it. OPWDD should develop a consistent statewide message as to how services can be created appropriately and responsibly. OPWDD, in conjunction with providers and advocates, should create educational media to inform people with I/DD and their families as to how resources are allocated. This should include provisions for changes in an individual's needs, especially if those needs increase.

³⁵ The CAS is a needs assessment tool designed to highlight functional needs. It is hoped that it will replace the Developmental Disabilities Profile (DDP) currently in use which focuses on individual deficits. At this writing the tool is being validated.

Preferences for returning residential school students.

Students returning to their home districts from residential schools after graduating or “aging out” receive higher residential priority and funding than students whose families have provided support at home. In some parts of the state there is a perception that wealthier school districts have accommodated families by placing students in residential settings with the understanding that this is a gateway to residential services once the student “ages out.”

Recommendation 21.

While short-term funding considerations may favor congregate placement for returning students, long-term funding does not. Returning students should be required to go through the same processes and assigned the same priorities as those whose family members have supported them at home.

Sometimes there is no family, as for example with “aging out” residential foster youth and young adults. In such cases intensive, short-term cross-agency service coordination should be put in place prior to “aging out” to create a person-centered plan that will provide appropriate, rather than emergency or stop gap support.

OPWDD should also increase collaboration with the State Education Department and the Office of Children and Family Services (OCFS) to identify the issues that drive residential placement and study how such issues may be ameliorated so that students can be supported in their home school districts.

Institutional bias in oversight.

Congregate care provider agencies are required to provide a record of services that details how often a person was in residence, and to have a record of services delivered on a daily basis. In a non-certified setting where OPWDD’s Community Habilitation service is provided, the worker must record activity in 15-minute increments. If the number of people they are working with changes, or the staff ratio changes, they must record the change in 15 minute increments and the provider will be paid at a different rate for each ratio. This level of detail is not required by CMS, but creates an almost absurd level of paperwork that does not guarantee additional safety or oversight, and takes the attention of staff away from the individuals they are working with.

Recommendation 22.

Eliminate the 15-minute increment. Develop reporting systems that can be fulfilled with limited time requirement or skill required, where enforcement relies on penalties for perjury.

2. Financial

Congregate Care Supplements

An individual's SSI is supplemented by SSA (through the Office of Temporary and Disability Assistance (OTDA)) if they live in a Congregate Care facility. Rates vary between \$229 per month to \$694 per month depending on the Congregate Level (Family Care through Residential School) and the geographic area. The supplement ceases if the individual leaves the Congregate Care facility. As one of our forum participants, a senior agency executive, commented: "This is the single biggest reason why people will not be moved from congregate care into the community." The Congregate Care Supplement recognizes that people with disabilities may need additional funding support. The Supplement was created at a time when housing options were seen as necessarily institutional and certified, hence its application to the "Family Care" model which today is seen more similar to "shared living" than to a quasi-institutional structure.

The Supplement is based on the intensity of the individual's support needs, and should be available in both certified and uncertified settings; it should follow the individual (Olmstead).

Recommendation 23.

OTDA and OPWDD should review the application of the Congregate Care Supplement for applicability to the Self Direction model, the expansion of non certified housing, taking into account its fairness under Olmstead.

Fiscal Intermediary risk

A Fiscal Intermediary (FI) is the employer of record for any person hired by a Self-Directed individual (SDI) who is not purchasing their services from an agency. The FI is liable in the event that the Employee or the SDI is abusive or neglectful or breaks the law as it relates to their employment. The FI is required to perform a background check. It is not clear, however, that the FI has the authority to dismiss an employee without the consent of the SDI. It is very difficult for them to terminate the SDI from their services. This is a liability hornet's nest. It is not clear if the majority of FIs insure for this in the market or self-insure. Not surprisingly, providers are not rushing to take on this service.

Recommendation 24.

- (i) OPWDD provide the FI with the authority to require training and the ability to fire an employee for cause even if the SDI disagrees.
- (ii) OPWDD create a template contract between the FI and the SDI that addresses the risk etc.
- (iii) OPWDD clarify whether the FI can elect not to serve an individual, or to hire the individual's chosen support worker .

Institutionally biased rate setting

Agencies are paid approximately \$60 per hour to provide Medicaid Service Coordination (MSC) services (\$259 per case per month, max 40 cases per caseworker). They are paid \$40 per hour to provide Self Directed Support Brokerage services, where the work requires: flexibility, creative thinking, high-level communication skills, and the ability to create an individualized budget and modify it when necessary. The broker is also required to assist individuals/families in developing and maintaining a Circle of Support, interviewing prospective staff, developing initial community connections, monitoring self-direction expenditures, and conveying how to properly document services. This is demanding work, arguably requiring more training and skill than MSC work. Due to the lower reimbursement rate, uptake of the Self-Direction model has been understandably slow. There is no regional variation in reimbursement despite the enormous differences in labor rates round the state.

Recommendation 25

Tinkering with MSC services is sensitive—some families love the service and see their MSC as a genuine advocate, while some do not know who their MSC is. The service quality varies. Design of the Support Broker role did not envisage scale or accommodate the competencies required. As we go into Managed Care OPWDD should partner with stakeholders to redefine Care Coordination and the compensation distribution.

Staff recruitment for Self Directed individuals.

Individuals seeking Self Direction have experienced difficulty in recruiting and training staff. Some FIs are providing support but not uniformly.

Recommendation 26.

OPWDD organize FIs, or FIs organize themselves, to create a mechanism for families to identify and select staff people through a centralized registry. This would allow FIs to share a trained workforce and families to have backup for staff shortages.

3. Other impediments arising from Support Service issues

The Acting Commissioner's Transformation Panel has focused on issues related to self directed service funding and oversight. Given the enormous changes that arise from essentially inverting the payment structure, deeply embedded institutional culture, and longstanding funding streams, it is no surprise that the creation of new systems is complicated and frustrating. However, sixteen years after Olmstead and almost as long since the creation of Consolidated Supports and Services, the forerunner of self directed services, we have the opportunity to draw on the experience of pioneering families and agencies and make the system responsive and scalable. It is important to recognize that certification of the setting is a separate issue from individual choice and control or the de-emphasis on group homes as the preferred residential model. Certification of a particular home or apartment may still be a workable tool for ensuring appropriate support resources based on individual need. However, the growth of certified settings is likely to be limited, and of itself unable to fulfill the great need for housing.

This report has only touched on the issues arising from implementation of Individualized Budgets and Self-Direction, but the opportunity to scale up non-certified and non-congregate housing depends on the creation of a workable self direction system.

Conclusion.

Housing investments and expenditures account for approximately 18% of United States GDP³⁶, comparable to the investments and expenditures in Healthcare. Housing is a complex business affected by law, policy and regulation at every level of government; it is a business that is affected by macro economic issues but is, in the end, intensely local, especially in dealing with the kind of specialized housing that we seek to provide for people with I/DD.

The shift in funding from a historically institutionally based model to a consumer-directed model is revolutionary. Implementation is difficult, and yes, it will take years. However, the consumer-directed model is already turning the group home model on its head, and opening up many more opportunities to create housing for people with I/DD who cannot access the current system or who may need Long Term Supports and Services but for whom a traditional group home setting would be inappropriate. Obsolete regulatory practices should not be allowed to impede this process.

It is widely recognized that NY State is unlikely to provide any increase in overall funding for people with I/DD. The recommendations made by the Task Force, by the people who participated in the regional housing fora and by the Housing Navigator trainees reflect that reality. The recommendations are not focused on obtaining more money from the system, but rather working within the spirit of the Olmstead decision and CMS directives to increase self-direction. Two of the recommendations—identifying where people are receiving more services than their assessments indicate and defeasing high coupon bonds/re-financing high interest rate mortgages—would likely make more funding available.

Most of the recommendations fall in to two categories – simplifying & clarifying regulation and practices, and training individuals with I/DD, their families, and the provider agencies in housing issues. These are not cost-free, but they will provide leverage. NY State should also consider the creation of a Housing Resource Center open to all of the stakeholders providing LTSS to people with I/DD, to bring together the essential strands of knowledge required to create housing.

There is an overwhelming need to build collaboration with all of the participants in the housing industry. These include the legal, banking, design, construction and development professions. Providers of Telehealth and Telemedicine and other Assistive Technology, Affordable and Supportive Housing experts at all levels of government, for profit and not for profit agencies, and most importantly people with I/DD and their families who are currently at a loss to know what the future may bring. This is an opportunity for leadership—and compassion—that should not be missed.

36 Per National Association of Home Builders. <https://www.nahb.org/en/research/housing-economics/housings-economic-impact/housings-contribution-to-gross-domestic-product-gdp.aspx>

WHO WE ARE...

NYSACRA is a grassroots organization comprised of nearly 200 voluntary agencies serving people with developmental disabilities and their families. As the largest association of this kind in New York State, our membership is our strength. Together with our members, we've carried out our mission for over 30 years.

OUR VISION STATEMENT:

NYSACRA is a catalyst and leading advocate for public policies and practices that support and enhance member agencies that champion the rights, needs and desires of people with disabilities in New York State.

OUR MISSION STATEMENT:

NYSACRA represents the collective voice of its members in promoting public policy, public understanding and community action and is dedicated to the full participation of persons with disabilities in our communities of New York State.

*For more information
about NYSACRA or to
become a member*



www.nysacra.org



New York State Association of Community & Residential Agencies

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