NEW YORK STATE OF OPPORTUNITY.

Developmental Disabilities Planning Council

Reclaiming Innovation in Housing

Overcoming Institutionalized Models of Service in NY

AIM SERVICES, INC.
The power of potential

About this project

As part of its long-term planning and policy initiatives, the NY State Developmental Disabilities Planning Council (DDPC) has examined ways in which housing options for people with Intellectual and/or Developmental Disabilities (I/DD) could be increased. Recognizing that there are many factors that have impeded the expansion of housing options, DDPC resolved to fund a study of two quantifiable variables: funding and regulation.

This report sheds light on regulatory and funding practices that may impede the creation of more housing, and it makes recommendations for how to address those impediments.

The DDPC funded AIM Services, Inc. to lead the project. AIM contracted John Maltby, M.S. as the Primary Investigator, and AIM staff included Carrie Locke, Brittany Hoosier, Joshua Phelps, and Derek Taylor.

As a leading service provider of person-centered support for people with disabilities, AIM inspires those we serve to impart meaning in their own lives, on their own terms. In addition to the basic needs of health, safety, and security, we believe that everyone should have access to enhanced opportunities that allow for choice, dignity, respect, and independence, while also creating deeper connections within the community.

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Abbreviations and Acronyms

Abbreviation or Acronym	Explanation
ACL	Administration for Community Living
ADM	Administrative Directive Memoranda
AMAP	Approved Medication Administration Personnel
AMI	Area Median Income
APS	Adult Protective Services
CAS	Coordinated Assessment System
CCO	Care Coordination Organization
CCS	Congregate Care Supplement
CDB	Childhood Disability Benefit
CDPAS	Consumer Directed Personal Assistance Services
CMS	Centers for Medicare & Medicaid Services
CON	Certification of Need
CPPC	Confirmation to Proceed with Program Certification
CR	Community Residences
CTS	Community Transition Services
DARS	Division of Administration & Revenue Support
DASNY	Dormitory Authority of the State of New York
DDP-2	Developmental Disabilities Profile-2
DDPC	Developmental Disabilities Planning Council
DDRO	Developmental Disabilities Regional Offices
DOH	Department of Health
DQI	Division of Quality Improvement
DSP	Direct Support Professional
EID	Earned Income Disregard
e-mods	Environmental modifications
e-scores	Evacuation Scores
FBR	Federal Benefit Rate
FDC	Facilities Development Corporation
FI	Fiscal Intermediary
FMR	Fair Market Rent
FSS	Family Self Sufficiency
FUP	Family Unification Program
FYI	Foster Youth to Independence
HCBS	Home and Community Based Services
HCR	Homes and Community Renewal
HEAP	Home Energy Assistance Program
HFA	Housing Finance Agency

Abbreviation or Acronym	Explanation
HUD	Housing & Urban Development
I/DD	Intellectual and/or Developmental Disabilities
IDA	Individual Development Accounts
IDGS	Individual Directed Goods and Services
IRA	Individual Residential Alternative
ISH	Integrated Supportive Housing
ISPM	Individual Services Planning Model
ISS	Individual Supports and Services
LIC	Live-in Caregiver
LIHTC	Low Income Housing Tax Credits
LRE	Least Restrictive Environment
LTC	Long-Term Care
LTSS	Long-Term Supports and Services
LTV	Loan-to-Value
Muni	municipal bonds
NADSP	National Alliance for Direct Support Professionals
NCI	National Core Indicator
NPA	Nurse Practice Act
NYAII	New York Alliance for Inclusion and Innovation
NY CRR	New York Codes, Rules and Regulations
OPWDD	Office for People With Developmental Disabilities
OTDA	Office for Temporary Disability Assistance
OTPS	Other than Personal Services
PA	Personal Allowance
PILOT	Payment In Lieu Of Taxes
PIOC	Price Index of Operating Costs
PN	Paid Neighbor
PPA	Prior Property Approval
PRA	Personal Resource Account
RRR	Residential Replacement Reserve
SCPA	Surrogate's Court Procedure Act
SDM	Supported Decision-Making
SED	State Education Department
SNAP	Supplemental Nutrition Assistance Program
SNT	Special Needs Trust
SONYMA	State of New York Mortgage Agency
SSDI	Social Security Disability Benefit
SSI	Supplemental Security Income
STAR	School Tax Relief
USDA	U.S. Department of Agriculture

Executive Summary

Forty-six years ago, the Willowbrook Consent Decree changed the way New York provided support for people with Intellectual and/or Developmental Disabilities (I/DD) forever. Since then, the state has developed a group home system that seeks to serve people in ways that are more integrated into the larger community. People's lives have improved. However, as the system has grown through the years, it has acquired a body of regulation that inhibits change and denies the opportunity for people to create more housing options. This report examines areas where regulations and oversight have had the unintended effect of limiting opportunities.

To effect system-change and create progress for more housing options, we must understand where the impediments arose and how they can be untangled. Establishing the basis for directing policy and advocating for needed change is more effective when the structure of existing financial and regulatory constraints is understood.

This report examines how housing is developed, staffed, and managed, and the regulations and practices that evolved with certified housing over the last forty years. The funding and oversight are compared for certified housing, for independent housing, and for people receiving support through Self-Direction. A consistent bias emerges. This institutional bias in funding and regulation favors certified housing over independent housing. Institutional bias has been present since inception and appears to have increased in recent years.

Certified housing receives favorable funding from inception through direct and soft state support in borrowing and funding for early-stage planning and renovation. Certified property cost reimbursement is based on prevailing market values. Certified housing is exempt from local taxes and capital gains on property appreciation. Conversely, independent housing receives no initial subsidy or soft support to facilitate financing, the housing subsidy is a decade outdated, property is taxed at the same rate as any other homeowner, and the environmental modification process is cumbersome and limited in scope.

Services for people in congregate housing are funded at higher rates than services for people in independent housing who have similar levels of need. Administratively, it is easier for providers to report and bill for services for people living in certified housing than it is for people using Self-Direction to live in independent housing. There is a chronic shortage of people to fill the Direct Support Professional (DSP) positions in certified housing with many positions

going unfilled. By contrast, support for a person to stay in their family home is limited and family members may not be paid for support. As a person with I/DD gets older, the system steers them to certified housing rather than to a more person-centered and family-based option.

NY State faces a chronic housing shortage for people with I/DD, yet regulatory and financial bias impedes the creation of new housing and prevents provider agencies from repurposing their existing housing to make it more accessible and amenable. Decades of evidence shows that people fare better in smaller settings, yet regulation, funding, and custom mean that newly created certified housing is still based on the more costly and more segregated five- or six-bed congregate model.

There are no incentives for providers to make their housing options more person-centered, smaller in size, and more in line with best practices as currently understood. Instead, providers face disincentives and active discouragement.

The business model founded on filling beds, DSP shift work, and property ownership is faltering. This report includes recommendations that, at no cost or low cost, could unshackle the system and allow for cost savings, innovation, and more opportunity. The report concludes that the state should convene stakeholders to review all its regulations and administrative practices and revive its internal policy and practice review capabilities.

Changing regulations and financial incentives is only one aspect of the fundamental system-change that is needed to create more housing opportunities. As a system, all of the people involved—people with I/DD, families, advocates, providers, and the state—need to affirm and reaffirm commitment to principles of Person-Centeredness, Self Determination, and individualization. New York State has chosen to continue with a failing business model of "heads on beds" over Personal Development, Social Inclusion, and Relationships. Now is the time for New York State to truly be the "state of opportunity" and reclaim its position as a forerunner in innovative housing options.

Introduction

> "What would you say if... you could create very affordable housing and not have to spend a dime on bricks and mortar... the housing was unencumbered by government regulations, at the same time you could meet the special housing needs of seniors and persons with developmental disabilities…?"
>
> NYS OMRDD, "It's time for change," 1996

Twenty-five years ago, the Office for Mental Retardation and Developmental Disabilities (OMRDD)—now the Office for People With Developmental Disabilities (OPWDD)—recognized that, while it had vastly improved the lives of many people, the certified housing model that evolved from the Willowbrook era was no longer sufficient to meet the needs of people with Intellectual or Developmental Disabilities (I/DD). Since that time, the need for more housing opportunities has become ever more pressing, but the state's housing efforts have failed to evolve sufficiently or to keep pace. The purpose of this report is first to examine how administrative rules, regulations, and legacy practices may have impeded the necessary changes and then to recommend a course of action.

We know the following:

- People with I/DD are living longer, healthier lives.[1]
- They will need more options as they age and their needs evolve.
- People with I/DD who are entering and will enter the OPWDD system have a higher likelihood of having more complex needs than the population of people served by OPWDD today.
- People with I/DD and their families are more educated, thanks to advocacy and forty-five years of free and appropriate public education under Pub. L. No. 94-142, now known as the Individuals with Disabilities Education Act (IDEA).[2] Their expectations and experience demand more inclusion.
- There is a long-term, demographically driven labor shortage of people who are willing to perform shift work as Direct Support Professionals

(DSPs) at the pay levels currently available.[3] This shortage is only worsening as greater competition for similar support grows in other sectors (e.g., elder care).

- Enabling technology, such as voice/text, location, and safety focused apps, has grown in capabilities, range of uses, and accessibility in price.
- The law, including the Americans with Disabilities Act of 1990 (ADA), the Supreme Court's 1999 Olmstead decision interpreting the protections of the ADA related to people with I/DD, the Patient Protection and Affordable Care Act of 2010, and related regulations require more inclusion, choice, and autonomy.
- Research into best practices and data gathered from the experiences of people with I/DD are clear: smaller housing settings and choice of where and with whom to live lead to a higher quality of life. Unfortunately, the National Core Indicator (NCI) survey shows that only 52% of the people reporting in New York had a choice as to where they lived or with whom.[4]
- The number of people with I/DD who will need residential support across a broad spectrum of need far exceeds the number of people the state currently provides with any form of support, not just residential.[5]
- There is little likelihood of any significant increase in funding for OPWDD residential services—New York depends on Medicaid to provide services, and the state already receives several times more per capita Medicaid funding than any other state. This funding is unlikely to be increased.[6]

New York has not made sufficient progress in providing new housing options for numerous and complex reasons. These include the historical segregation and congregation of people who are different, family fears for the safety and health of their children, weighting of parental choice, and the narrative which only addresses parental fears for health and safety in the context of certified housing. A history of paternalism and eugenics minimizes the competence as well as the role and responsibility of the family. Race and ethnicity, language, economic inequality and privilege, stigma and its obverse of idealization all play a part. These cultural biases are not the focus of this work, but they are expressed in how we fund and regulate housing. Many of the stakeholders who provided feedback to the creation of this report noted how central these broader issues are to the fractures in our housing system, and they certainly beg for more research.

Pressure from organized labor, notably in the state-operated part of the system, tension between upstate and downstate, and the power of large nonprofit provider agencies have also stalled progress in housing.

Regulations are the main tool of the regulator; they are a blunt instrument, and over time they accumulate, eventually forming a constricting carapace that can crush initiative. Regulations never die—they may lapse into nonobservance, they may even be repealed, but their impact can live on. While not all of the regulations we reference herein are rigidly enforced, they continue to impact practices. Similarly, regulatory bodies are bound by rules that are not always observed, for example the requirement to produce a five-year plan and to actively promote Self-Direction. Providers do what they are paid to do and are bound by funding that prioritizes control and safety over outcomes and efficiencies.

Method

The team reviewed federal and state law and New York Codes, Rules and Regulations (NYCRR) governing residential housing as well as available Administrative Memoranda from the state. OPWDD residential staff and OPWDD's Office of Counsel also provided input.

The team reviewed the process through which a provider agency budgets for the creation of a certified house and how the rate for that housing is created. The exercise was conducted for a Supervised Individual Residential Alternative (IRA), a Supportive IRA and for a "non-certified" or "independent" home.

Examples for certified housing were reviewed by certified residential provider agencies from each of the state's five OPWDD Regions, and their comments and revisions were incorporated into the report.

The team created a preliminary report for distribution to the DDPC and a statewide group of stakeholders including people with I/DD, family members, provider agencies, Fiscal Intermediaries (FIs), Self-Direction brokers, and housing navigators. Feedback from the stakeholders was included in the second preliminary report. A statewide group of housing stakeholders was invited to comment on the second preliminary report. The final report was submitted to the DDPC and shared with the general public.

Background

Medicaid and the medical model versus the social model

In 1965, the Johnson administration amended the Social Security Act to introduce Medicaid. Medicaid required coverage of Long-Term Care (LTC) in institutions but not in the home. Home and Community Based Services (HCBS) were introduced in 1981 to support, but not require, the states to provide LTC in the community.

Medicaid embodies "the *medical model* of disability, which sees disability as a problem that exists in a person's body and requires medical treatment. The *social model* of disability, by contrast, distinguishes between impairment and disability, identifying the latter as a disadvantage that stems from a lack of fit between a body and its social environment."[7]

While OPWDD and its provider agencies seek to become more Person-Centered, the medical model of disability is braided throughout the Medicaid-funded services for people with I/DD. This model is embodied in the Mental Hygiene Law's definition of developmental disability, the intake process at the Developmental Disabilities Regional Offices, and "needs assessment" instruments such as the

Codes, Rules & Regulations (CRR)

New York's Department of State explains: "The NYCRR primarily contains state agency rules and regulations adopted under the State Administrative Procedure Act (SAPA)." Per SAPA, OPWDD develops rule proposals internally, with input from counsel's office and appropriate OPWDD staff, typically at the Deputy Commissioner level, and, in some cases, involving stakeholders. Rules may be developed in response to a new statute, or to a change in the field, for example the creation of Care Coordination Organizations (CCOs). The agency may also seek to revise, modify, or repeal a rule if the need arises. Once the rule is drafted, it is reviewed by the regulatory review unit and submitted for approval to the office of the secretary of state. New York State Mental Hygiene Law Title 14 Section XIV governs OPWDD. Relevant CRR codes in this report will refer to 14 XIV Parts as CRR followed by its number, for example CRR 629.1.

ADMs

"OPWDD issues Administrative Directive Memoranda (ADMs) and Informational Letters to provide guidance or information to assist regulated parties in complying with applicable statutes, rules or other legal requirements." ADMs list the year and the number of the ADM in that year, for example: ADM 2018-06 was issued in 2018 to clarify issues related to CCOs.

Developmental Disabilities Profile (2) (DDP-2), and the Coordinated Assessment System (CAS). Services are only provided on the basis that all support needs adhere to treatment or goal-based plans rather than simply providing the necessary support as and when needed.

The fundamental manifestation of the medical model is the binding of support services to residential services in the certified system. A person cannot change their services without leaving their home without risking the loss of services. Agencies are paid a single fee that ties housing costs and service costs into one rate, making personalization of services and housing very difficult.

The medical model leans on measures of acuity—how serious is the illness and what are the treatments? The federal oversight authority, the Centers for Medicare & Medicaid Services (CMS), requires a functional assessment as a more appropriate measure for someone who needs Long-Term Supports and Services (LTSS). For the last ten years, New York has been in the process of reviewing and attempting to introduce a more functionally based instrument, the CAS, administered by a non-provider vendor. However, the process is seen by many as lacking person centeredness and still firmly rooted in the medical model.

Housing is created and funded within an outdated medical model context that hinders innovation and excludes people who desperately need housing and other support. Understanding this context is fundamental for overcoming barriers while moving toward alternatives aligned with social model approaches.

Part 1. Money

Certified housing receives direct and indirect funding for acquisition and maintenance. If the housing is owned, it is exempt from local taxes, and, if rented, it is reimbursed at a market-based rate. By contrast, independent housing receives no support for acquisition or maintenance costs, pays local taxes, and the rental subsidy is currently set at between 16% and 40% of the area rents.

Certified housing is subsidized for vacancies, staff costs for administration, transportation, including vehicles, and home maintenance, and it requires limited verification of service provision daily. Independent housing does not receive these subsidies, and services are required to be reported on at 15-minute intervals.

1A. Property creation: the capital component

Funding certified housing

An operator of certified housing (the agency) is paid a rate by OPWDD on a monthly agencywide basis in the case of a Supportive IRA,[8] and on a daily per person rate in the case of a Supervised IRA. The rate includes property acquisition (or capital) costs, maintenance (or facilities) costs, and staffing (or operating) costs.

(a) Capital costs. In brief, the agency budgets for the property costs of the project using a set of guidelines created by NY State Department of Health (DOH) and OPWDD. These costs are submitted to OPWDD for approval. Once approved, the agency receives a Prior Property Approval (PPA) letter stating the rate at which they will be reimbursed for operating the facility. This acts as a soft guarantee enabling the agency to fund the purchase through a commercial mortgage.

The approved budget for creating the property, whether it be new construction or acquisition and modification, is based, within realistic thresholds, on the actual cost. The thresholds stem from OPWDD's Rate Setting of July 2014,[9] and subsequent adjustments and are now set by the DOH and OPWDD jointly. Rates vary around the state, and the distinct property rates are no longer publicly disclosed by OPWDD. Reportedly, the rates range between $90,000 and $190,000 per bed, depending on location.

Recommendation 1. Unbundle property and support costs, and provide transparency to identify property costs. This will help agencies to actively separate the provision of property from the provision of services while allowing for personalized support and individualized budgets.

To learn in more detail about how OPWDD collaborates with agencies to create residential housing, see Appendix A.

(b) Shared bedrooms. Costs are based on the number of beds, not the number of bedrooms. This incentivizes the agency to require people to share bedrooms, many times with little say in who they share with.[10] More importantly, a business model rooted in providing a certain number of beds becomes unstable when one or more of those beds are unoccupied for any length of time. The revenue is associated with the house and the occupant of the bed, not the person or their need. The fixed property costs are inflexible and staffing levels are difficult to adjust in a larger house than they might be in a smaller house. Agencies are limited in who they can offer certified residential supports to, based on a list maintained by OPWDD. To their credit, many agencies have made great efforts to reduce the number of shared bedrooms.

Recommendation 2. OPWDD should identify the number of unrelated people sharing bedrooms in certified housing and attempt to identify whether the people chose to share. Incentivize agencies financially to reduce the number of shared bedrooms where people do not wish to share by providing bridge financing and gradually phasing out extra-bed payments.

(c) Obtaining capital funding. If the PPA meets a commercial bank's business criteria, the agency can use this to obtain a loan from the bank at up to 100% of the loan-to-value ratio (LTV), or more if renovation costs are included. This is not a guarantee by the state, but it is a soft comfort letter. Over the years, lenders have become confident that the PPA ensures smooth repayment of their loans. No such support exists for provider agencies or others to facilitate growth in supply of independent housing.

(d) Costs for independent housing. Conversely, when creating a non-certified home there are no construction subsidies from OPWDD, nor is a supporting PPA provided. An individual, family, or other entity will have to come up with a down payment as they are unlikely to be able to borrow at 100%

LTV. They will also have to become an expert on benefits and housing issues.

Programs to help people to own their own home are available from other resources. For example, Individual Development Accounts (IDAs) available through community banks and foundations provide matched savings programs and can be used to save for a down payment. Low-cost mortgages are available to first-time home buyers through the State of New York Mortgage Agency (SONYMA) and the U.S. Department of Agriculture (USDA). The costs to create independent housing are *not* supported by OPWDD. See Appendix B for more information about how noncertified housing is created.

Recommendation 3. (i) OPWDD should create a PPA-type comfort letter for commercial banks based on a Personal Resource Accounts (PRA) and housing subsidies to assist the creation of more independent housing. (ii) An effort should be made by provider associations to provide technical assistance to commercial lenders seeking business from people with disabilities.

(e) Rented housing. If the property is rented, per **CRR 635-99.1** the rent must be no more than "the property would most probably command on the open market as indicated by rents being paid and asked for comparable properties in the same geographic area as of the date of the appraisal." The regional and subregional guidelines exceed HUD's Fair Market Rent levels. (To learn more about HUD's FMR, see Appendix E.) This specifically impacts leases longer than five years where the rate is based on the number of beds thus incentivizing room sharing.

Per **CRR 635-6.3** (leases), "The commissioner may waive the limitations on allowable costs … upon a showing that such limitations would jeopardize the opening or continued operation of the program." In other words, rents can be market-based, and if rents increase, they may be subsidized.

(f) Depreciation. If the property is owned by an agency, it can be reimbursed for its depreciation (**CRR 635-6.4**). When a nonprofit corporation sells property that has been depreciated, it does not pay tax on any gain from the depreciated value. By contrast, property developed by for-profit developers will be subject to taxes on appreciation. This is the result of federal tax policy, and it is noted here for its contribution to the bias toward creating certified housing.

(g) Bonding. Agencies that create certified housing may be able to obtain funding in the municipal bond market (Munis)—either directly through the Dormitory Authority of the State of New York (DASNY) or through consolidating their loans through certain provider associations which then issue through DASNY. Historically, because of their tax advantages to investors, the municipal bond market has been able to underwrite loans at a significantly lower rate to borrowers than would be available from a commercial mortgage. In the extraordinarily low-rate environment at the time of writing (June 2021), that advantage is perhaps less relevant. For comparison purposes, a 1% difference in interest rate cost for $100,000 over a tenor of 15 years is approximately $9,000 (depending on the overall level of rates). There is a downside; borrowing costs less, but loan terms are inflexible. Muni bond issuers must provide investors with credible evidence of their expected revenue flows. If a site was purchased based on its revenue as that of a twenty-bed group home, then that is what it is going to be for the life of the loan, unless the borrower can engineer a defeasance or alteration. Changing the terms of a bond is expensive and complex, and there is no incentive in the current systems to do so.

Muni or DASNY funding has a long timeframe and requires minimum bond sizes which are multiples of the cost of one house. Consequently, many providers obtain a commercial mortgage, accumulate several, and then go to the Muni market or DASNY to refinance the commercial mortgages. The providers get a benefit that is not typically taken away by OPWDD as the reimbursement amounts to the provider stay at the original commercial mortgage rates.

Recommendation 4. (i) OPWDD should examine the extent and tenor of bonding strictures on certified housing and whether such strictures impede the creation of more appropriate housing. (ii) Examine the feasibility of a program to assist non-certified housing creators to access the lower rates available through the municipal bond market.

(h) Repurposing property. Agencies creating certified facilities may apply for a state aid grant (**CRR 621**) for capital costs of construction or for a mortgage loan from the NY State Housing Finance Agency (HFA) or from the NY State Facilities Development Corporation (FDC) (funded by tax exempt bonds). The state aid grant is intended to be repaid through a FDC mortgage and is designed to be short term. At the commissioner's discretion, funds may be advanced to secure title to a property. HFA loans may be used for all

stages of acquisition and construction. OPWDD is paid a fee by the agency for initial financing and the long-term mortgage on both HFA and FDC loans. It is not clear whether this option has been followed by agencies in recent years, or indeed if capital funding is available; however, there is a lingering effect. Per **CRR 621.15,** for an agency to change the purpose of a facility financed using FDC/HFA funds, it must receive permission from the commissioner to do so. If the agency has an HFA mortgage, it must also get permission from the HFA. The goal of the regulation is to ensure that sufficient facilities remain available to provide services, and it acknowledges the local tax exemption that may have been contingent on the purpose of the property. However, as sometimes interpreted by regional OPWDD personnel, the regulation has been an impediment to agencies that seek to downsize facilities, make them more person centered, or provide more necessary services. These regulations create barriers even in cases where there was never any direct state capital investment. There is a persistent myth within both the provider and OPWDD community that, even if agencies own their property outright, they are not at liberty to dispose or repurpose it as they see fit. This myth has stalled initiatives that are sorely needed. Progressive provider agencies have been able to downsize many houses to eliminate shared bedrooms and relocate or reinvest. Much depends on the will and resources of the agency and the knowledge and experience of their Regional Office counterparts.

Recommendation 5. OPWDD and provider associations should provide technical assistance to agencies seeking to update and repurpose existing properties to increase accessibility and flexibility in housing.

Start-up allowance

Certified. A provider agency establishing a certified residence will receive a start-up allowance of between $5,500 and $5,800 per bed.

Independent housing. Per NY's 1915(c) waiver, a person transitioning from certified housing to independent housing is eligible for up to $5,000 in reimbursable expenses to assist in transition. They cannot claim these funds however until they have made the move, which means they need to have financial support from their family or seek help from other sources.

Per OPWDD's Self-Direction Guidance for Providers (April 2020), with an ISS transition stipend, a person moving into independent housing from non-certified

housing is eligible for up to $3,000 in reimbursable expenses plus a security deposit reimbursement to assist in transition.

The expenses are reimbursed after the person transitioning has spent the money, and OPWDD can take months to make the payment. For people with very low incomes, this requires them to use expensive credit or receive support from a provider agency, the Fiscal Intermediary (which may or may not provide funding), or another source to fund the necessary expenses.

Recommendation 6. OPWDD should collaborate with lending institutions to create a cash flow facility to permit people who do not have resources or savings to participate in the reimbursement-based start-up or Self-Direction funding mechanism. This could be provided to a person directly or to their Fiscal Intermediary.

Property renovation and environmental modification (e-mods)

Certified. If a property needs to be renovated and made more accessible to meet the needs of future residents, the agency will include those costs in its proposal. The allowable thresholds for these costs stem from OPWDD's Rate Setting of July 2014 noted above, and subsequent adjustments. The thresholds are market based.

Independent housing. Funding is available for people seeking independent housing who need modifications to make their home accessible. The application process for OPWDD support is not set out in an ADM or clarifying document and varies from one regional office to another. Requests for modifications costing less than $15,000 are handled locally. Per the 1915(c) waiver, needs higher than $15,000 must seek higher approval. Approvals may take months—during which time the person's housing opportunity may have disappeared, or they may have remained in certified housing at higher cost. The request for modification process requires that the person be already living in the home or at least financially responsible for it, which makes transition difficult for someone who needs their home to be accessible before they move. People moving from a certified house cannot request funds until they move, creating a Catch-22 situation.

OPWDD strongly suggests that the person seeking a modification provide three bids for the work including minority- or women-owned businesses. Landlords may want to do the work themselves and get reimbursed, which has resulted in landlords refusing to permit the work to be done. If the non-certified housing is owned by a provider agency, the property will not be eligible for OPWDD e-mod funding. In addition to OPWDD's process for e-mods, funding for accessibility

may be available through the USDA, or NY State Homes and Community Renewal (HCR).

Recommendation 7. Clarify processes and rules around environmental modifications; establish ways to streamline the process and avoid lengthy and expensive delays.

Paying the rent or mortgage

Certified. To cover the property cost in certified housing, the agency charges the residents rent. The residents use their Supplementary Security Income (SSI) and/or their Social Security Disability Benefit (SSDI),[11] and the Congregate Care Supplement (CCS), less their Personal Allowance.

In many cases, the agency acts as the Representative Payee for their tenants, receiving their SSI and SSDI directly. Some people will have their family member or advocate as Representative Payee, and that person is obligated to pay the rent to the Agency.

The Congregate Care Supplement

People who qualify for SSI or SSDI receive their benefit from two sources: the federal government which pays the Federal Benefit Rate (FBR) of SSI and all of SSDI, and the state which pays a state contribution to SSI. In 1974, following the implementation of SSI payments and recognizing that the needs of people with I/DD and other special populations required enhanced funding, New York State created the Congregate Care Supplement (see Appendix C). The CCS was paid to operators of certified housing—Intermediate Care Facilities or OPWDD's certified Family Care. With the advent of Medicaid Waiver in New York in 1992 and the creation of IRAs, the supplement was extended to both Supervised and Supportive IRAs.

When the CCS was created, there was an assumption that people who had an I/DD and who needed LTSS would only be supported in certified housing. The rates were set at inception of the supplement in the 1970s and are adjusted by a Cost-of-Living factor annually. The current CCS is published by the Office for Temporary Disability Assistance (OTDA). The supplement represents significant support for providers operating certified housing.[12]

A person living in certified housing receives a Personal Allowance (PA) in an amount set annually by OPWDD. In 2021, the PA in IRAs is $176 per month (regardless of geographic location). This amount is set aside from the resident's SSI/SSDI, with the remainder of their SSI/SSDI and the CCS being paid to the

agency to cover the person's room and board. In cases where the person's SSDI exceeds the room and board cost (such as when they receive Childhood Disability Benefit by virtue of their parent's retirement or death), any excess is the property of the individual, and the agency should work with them to optimize their benefit, for example, by creating a trust.

After taking out their PA, a person living in a certified IRA in 2021 has SSI/SSDI, including the CCS, sufficient to pay between $1,012, and $1,042 a month in rent, (depending on where they are in the state). Their food cost will be supported by Supplemental Nutrition Assistance Program (SNAP) which is also payable to the provider agency.

If the person with I/DD is living in a certified Family Care house, then the operator will receive a CCS supplement and a stipend for each person living in their home. By contrast, if a person stays with their own family, there is no enhanced state SSI contribution and no stipend.

Agencies are thus incentivized to provide housing to as many people as practical within the property. Every additional tenant—and every shared bedroom—provides additional revenue.

The CCS is state money, as is the OPWDD housing subsidy. While there may be inter-department issues, those are irrelevant to the people needing support. It is worth considering permitting people living in certified housing to take their CCS payment with them when they move into independent housing. This would adhere to the Money Follows the Person program and move toward making up the shortfall between the housing subsidy and prevailing rents for affordable housing. This might be a first step that could be extended to people living in the community whose level of need warranted placement in certified housing but who had chosen to live more independently.

Recommendation 8. Rethink and revise the CCS to be distributed more equitably based on a person's need rather than their residential setting, all other things being equal. It should be attached to the individual rather than to the certified housing. It should follow the individual into the community if they move to non-certified housing, bridging the gap between the current housing subsidy and the real world.

Independent housing. A person living in the community, alone or with others, will receive their SSI and/or SSDI with the state supplement set between $23 and

$87 per month (2021). They may receive a housing subsidy from OPWDD which will allow them to pay no more than a third of their income in rent or mortgage, with the voucher paying the balance. This voucher operates in a similar fashion to HUD's Section 8 vouchers. As with HUD, the amount of rent that the subsidy will pay is limited to the HUD FMR which is set at approximately the 40th percentile of the area's typical rents. When there is more than one bedroom, the subsidy is increased at a diminishing marginal rate such that the increase from for example three-bedroom to four-bedroom averages only $119.[13] The HUD FMR is adjusted annually. The OPWDD housing subsidy used to be adjusted annually to match the HUD FMR, but since 2012 that has not been the case. From 2012 to 2021, HUD FMRs have risen by an average of 26% statewide. The OPWDD housing subsidy is now inadequate, and most people receiving the subsidy have no savings or means of increasing their income to make up the shortfall. The subsidy is so out of alignment that, anecdotally, people who had relied on the housing subsidy to seek Least Restrictive Environments (LREs) are unable to maintain their homes safely and may be in danger of losing them.

The FMR model is based on occupancy by a "conventional" family, and it assumes that children will share bedrooms. This is not how small groups of unrelated adults live. This contrasts with the certified model where there is a flat fee for every person added.

To learn more about HUD's FMR and other ways that housing could be subsidized, see Appendix F.

Recommendation 9. (i) Realign OPWDD's housing subsidy with HUD FMR. (ii) Review the number of people who share their homes and whether the HUD format is appropriate for a nontraditional family setting.

Ownership: agency versus state ownership

In 2015, a large New York City based provider agency failed due to over-leveraging its property holdings and other financial mismanagement. Since that event, OPWDD includes a lien on any new PPAs or refinancing of existing property operated as a certified setting. To complete its ownership of any property, the agency must discharge the lien. Once the agency has the title, whether its mortgage is completed or not and as long as it is not subject to any other lien, it is the owner of the property and able to dispose of it as it sees fit.

By contrast, OPWDD—through its Integrated Supportive Housing (ISH) funding—has invested in creating set-asides for people with I/DD within affordable housing developments. This housing is set aside in perpetuity for people with I/DD, and if the property is demolished, if the covenants that make the property affordable expire, or if the owner chooses to sell the property, OPWDD continues to have a claim. In other words, ISH funding invested to support independent housing is indeed an investment for the state as it retains a claim forever, and it has created a significant amount of long-term affordable housing for people with I/DD. ISH funding is only used in conjunction with Low Income Housing Tax Credits (LIHTCs) for new construction. This has the effect of limiting opportunities where costs might be lower than those in a LIHTC-funded property.

Rents in LIHTC properties are not based on area rents but on percentages of Area Median Incomes (AMIs). Thus, if the AMI in an area increases, perhaps due to gentrification, rents will increase. There is a risk that rising rents in ISH or LIHTC properties might price out recipients of OPWDD's housing subsidy if that subsidy is not aligned to current reality. OPWDD recently included a rule for new ventures that any rent increases must receive prior OPWDD approval.

Those considerations notwithstanding, the true value of ISH is that it separates the provision of housing from the provision of services, putting more control and independence with the person rather than the organization.

Recommendation 10. Highlight the effectiveness of OPWDD's ISH funding in creating set-asides, separating ownership of property from the provision of services and the retention of taxpayer-funded property. Make ISH easier for developers to incorporate in their funding.

Treatment of property upon dissolution

When a corporation owns property, it typically will depreciate the property and improvements over a period of time, typically 27.5 years. If it sells the property, a for-profit corporation will pay taxes on any gain from the depreciated value to the sale price. A nonprofit that sells the property will not pay taxes on that gain.

An individual or group of individuals who owns property cannot depreciate the property and must pay taxes on any gains when the property is sold. An LLC as landlord may be able to depreciate the property and manage its tax risk, but it too will have to pay taxes on any capital gain that is not rolled over.

As the population of people with I/DD ages, and as the preference for more independence and smaller settings is expressed, progressive agencies are seeking to repurpose their properties. See Recommendation 5 that advises support for agencies seeking to repurpose properties.

1B. Property maintenance: the facility component

(a) Certified housing. The agency's rate may include allowances for food (in addition to the person's SNAP), repairs, maintenance, utilities, household supplies, property and casualty insurance, telephone, housekeeping and maintenance staff, and administration. The agency will receive a Residential Replacement Reserve (RRR), currently $600 per resident per year to support the maintenance of the fabric of the property. This is an unrealistically modest amount, but nonetheless it favors certified settings. It also comes from the same source of funds that pay for DSPs and represents a diversion of resources from people to buildings.

Conversely, the state is not permitted to provide funds to improve a person's property. OPWDD thus has a cautious interpretation of what constitutes maintenance. When independent homeowners are confronted with an unexpected expense, they can be in danger of losing their home.

(b) State room and board supplement. If the agency is not able to meet the cost of room and board for the residents from the residents' SSI, SSDI, CCS, and SNAP, it may be eligible to receive an additional supplement from OPWDD to cover room and board. Except for the Live-in Caregiver (LIC) position (explained below), Medicaid will not pay for room and board, so this supplement is funded solely with NY State funds. Agencies that are able to cover all of their costs from residents' income will not receive the supplements. In 2020, supplements for those whose costs are not met from residents' income amount to $62.47 million in Supervised IRAs, or $2,647 per resident, and $7.88 million in Supportive IRAs, or $3,631 per resident.[14]

(c) Independent housing. A person who has Self-Direction may have some portion of their utilities, telephone, or internet reimbursed from their PRA depending on how they choose to allocate their funds. Additionally, there is provision for household-related goods and services to be included for reimbursement, but the annual cap is set by OPWDD at $1,500 and requires approval from a Fiscal Intermediary. This may include appliances, lawn care, snow removal, or maintenance services. They may also receive SNAP.

A person living independently who is not in Self-Direction may have some of their utilities included in their rental supplement. While this modest funding is termed "maintenance," it may not be used for anything that could be narrowly construed as home improvement (e.g., fixing a roof, a driveway, or a boiler). This contrasts with the maintenance funding for certified homes which can be used for these purposes.

Recommendation 11. (i) OPWDD should work with lenders to ease the provision of home equity and home improvement loans to enable independent tenants to maintain their homes through low-cost loans or grants.
(ii) OPWDD should review room and board expenses for people living independently and provide flexibility similar to that provided to certified settings as and when appropriate for short-term support.

Local taxes exemption

Certified housing is exempt from local taxation, but independent housing is not. In the absence of statewide data, some heroic assumptions must be made to approximate the level of real estate taxes that are avoided by having property owned by nonprofit provider agency corporations. For an example, see Appendix E. The example concludes that the tax exemption is worth approximately $1,137 per resident each year.

Recommendation 12. OPWDD should collaborate with state and local agencies to clarify and codify Payment In Lieu Of Taxes (PILOT) and School Tax Relief (STAR) exemptions and reductions in local taxes to support the creation of independent housing.

The PRA for independent housing

As we have seen, the rate for certified housing is an amalgam of long-term construction amortization, funding of borrowing, facilities, and operating costs. For independent housing, there is virtually no construction assistance, limited modification funding, and limited maintenance funding available. When a person is using Self-Direction, the funding for independent support and operating costs comes from the person's Personal Resource Account (PRA). "Based on the OPWDD Approved Needs Assessment Tool, the PRA establishes cost parameters for individualized budgets based on need profiles and comparable costs associated with supporting similarly profiled people with developmental disabilities in other models of support."[15] This budget takes into account all sources of income, including public benefits such as SSI and SSDI,

housing subsidies such as Section 8 or OPWDD's housing subsidy, income from employment, and in some cases asset levels.

People who do not use Self-Direction funding will pay for their housing using their SSI, SSDI, income from employment, and housing subsidies such as HUD section 8 vouchers and OPWDD's housing subsidy. Some may be able to supplement their own resources with support from protected savings.

Anecdotally, many PRA users do not spend all of their budgets, mostly because they cannot find the DSP staff they need. They may risk having their PRA reduced as a result. People's needs fluctuate, and this puts them in jeopardy if their needs increase, or if they are able eventually to fill the DSP vacancies.

While we do not know the cost of independent in-home supports, we do know the parameters within which those costs are confined. The limits for PRAs are shown in Appendix D using Individual Services Planning Model (ISPM) scores and two axes of the DDP-2.

Recommendation 13. Incentivize PRA optimization by permitting users to rollover a portion of their excess into the following year and to use it with flexibility.

1C. Staffing: the operating component

(a) Certified housing. The agency's rate also includes an operating component, which is primarily made up of staffing costs. These mostly consist of wages for DSPs plus vacation pay, fringe benefits, salaries for general and administrative work, and for clinical and nursing services. Also included are program supports such as transportation, staff travel, staff development, lease or rental for vehicles, depreciation of a vehicle, and participant incidentals.

(b) Independent housing. Staff support for people living in the community typically comes from three sources:

1. *Community Habilitation.* Per OPWDD's website, "Community Habilitation is a Medicaid-funded program . . . to provide one-to-one training to people with intellectual/developmental disabilities to develop or enhance the skills needed to live more independently in their homes or in the community." Also known as CommHab, this can also be provided to more than one person at a time with the rate payable to the employer varying accordingly. The reimbursement

rate to the employer of record varies depending on the region of the state from $10.67 per 15-minute increment to serve one person to $22.76 to serve three people. Rates will also vary on whether the service is Direct Provider purchase, through an Agency with Choice program, provided directly by an agency, or through self-hire.

2. *Live-in Caregiver (LIC).* A service available to people using Self-Direction, the LIC lives full-time in the same home as the person they support with tenancy and tasks set by agreement. They may not be related by blood or marriage to the person they support. Their support can range from simply being present in case of an emergency to other aspects of shared living with the exclusion of Activities of Daily Living or medical tasks. The LIC's room and board are paid to the FI, and the maximum amounts are (apparently) based on a HUD 2012 FMR two-bedroom housing subsidy, with added utilities and a food allowance. Families report that they are required to contribute funds to meet the shortfall arising from the underpayment of rent subsidies. The LIC may also, separately, provide CommHab to the person they live with, and if they do, their earnings will be exempt from taxation.[16] LIC is a Medicaid-funded service, and it is the only Medicaid service that pays directly for a person's housing. The cost of rent will vary depending on the number of bedrooms and location of the property, and it is capped at the OPWDD housing subsidy limits. These limits, as previously noted, pay a diminishing marginal subsidy as the number of bedrooms increases. There is no data currently available on how many people are receiving LIC support, and agencies and FIs report being deterred by the complexity of the funding. This complexity includes the reimbursement challenge and rules whereby rent utility and food payments may not be made directly to the LIC, but they must be paid to a third party, potentially the person receiving services.

3. *Paid Neighbor.* A person who is unrelated to the person receiving support, who lives within thirty minutes of the person, and who can provide support in the case of need may become a Paid Neighbor (PN). The PN is paid a monthly stipend of up to $800, and if they are required to perform support services, they are paid at the CommHab rate**.** Within the stipend limit, there can be more than one Paid Neighbor. There is no data currently available on how many hours of

residential support are provided through PN services, and uptake varies by region. This service is more common than the LIC.

Recommendation 14. The state should actively promote PN and LIC support services as a way to alleviate the chronic DSP shortage and provide genuine community support.

(c) Specialized template populations funding.

OPWDD provides enhanced funding to agencies providing housing for people who are returning from out-of-state placements or leaving state institutions. This funding is scheduled to end 9/30/2021. The rates are displayed on OPWDD's website,[17] and they are individualized and situationally determined using three tiers of level of need. The level of need is based on the DDP-2 scoring, and the amount of support is determined regionally. The enhanced rate is only for a prescribed period, and it assumes that the person is in fact appropriately placed and able to reduce their need for support within that environment.

OPWDD's Developmental Disability Regional Offices (DDROs) refer people who might need additional support to agencies when vacancies arise in their certified housing. Anecdotally, agencies report that the needs of the people who are newly entering are different to the needs of other residents. The other residents may be much older, perhaps less in need of behavioral support, and the dynamics of the home might be fundamentally changed, and not necessarily for the better, if a new person moves in. Agencies are not compelled to take people they believe would not fit with their current housing, but the pressure to do so is widely reported.

Placing someone with severe behavioral need or substance abuse in a multi-bed certified IRA is unlikely to be the best solution for that person or for the other residents. This is done because the system has an available bed. The certified system is designed to operate at full capacity, with little room for loss of revenue when there is a vacancy. The provider has limited choice if it wishes to continue to provide services to the remaining residents other than to seek full occupancy, even if that means taking in a person from the emergency CRO list for whom the home may not be the right setting. A better option for a person with significant psychiatric support needs might be to provide them with housing that is unique to them near the facilities that they need, with the kind of wraparound support, including technology supports, that would provide them with the highest quality of life.

Acuity is critical to placements in certified settings as certified housing becomes more limited. Due to the factors cited in the introduction, vacancies are actually rising. Anecdotally, vacancies arise in houses mostly occupied by older residents; therefore, they do not appeal to younger people. Provider agencies describe pressure from their OPWDD DDRO to place a person returning from a residential school, from out-of-state placement, or from the closure of a developmental center. The person's needs may be at odds with those of the other residents, or indeed with any congregate residential housing. Agencies also describe a shift in residential candidates proposed by the regional offices to people with more significant behavioral health support needs, rather than needs arising solely from a developmental disability. If an agency believes it is in the best interest of current residents and the quality of the life in the home, it has the option to refuse to accept a person they deem inappropriate for their setting. The people who are being referred with higher needs are not being supported with the extra funds needed to meet these needs. As a result, there are homes with vacancies that are unlikely to be filled by the people being proposed by OPWDD. Agencies are clearly disincentivized to encourage people with lower needs to move to a Least Restrictive Environment (LRE) as this will result in additional pressure to take people with higher needs for the same revenue. This issue is further complicated by the chronic shortage of people willing to work as DSPs. An agency may indeed be paid more for a person with higher needs, but if they are unable to hire the necessary staff, they will not be able to provide the support.

Recommendation 15. While it is fiscally tempting to fill voluntary operated vacancies with residents from state-operated facilities and reduce the number of out-of-state or residential school residents by assigning them to the resultant vacancies in state facilities, it is not person-centered or long-term fiscally responsible to do so. OPWDD should partner with providers to find the most effective placements, including non-congregate housing for people returning from out-of-state placements or leaving residential schools.

(d) Vacant beds. Under certain conditions, the Agency can be paid for continuing to keep a bed open even if the resident is absent (**CRR 641-1.6**).

Occupancy factor. An adjustment to Rate based upon vacancy experience which will be the lower of 5% of the agency's Rate or actual experience.

- *Retainer days* – days during which a resident is on medical leave, perhaps in the hospital. The agency is paid for the bed, with an annual cap of 14 days per person pooled agencywide.
- *Therapeutic days* – days when a resident is on vacation or visiting family. The agency is paid for the bed, with an annual cap on the total number of days that such a payment can be made.
- *Vacant bed days* – days when a resident has left the residence or died. The agency will be paid at 75% of their rate for up to three months.

The rationale for continuing to pay for an empty bed is that the agency's costs, both static (e.g., the property cost and operating or staffing), are inelastic. One person less in a six- or eight-bed group home does not immediately reduce staffing costs.

This rationale arises from a business model that is based on filling beds and budgeting property rather than providing individualized services.

The state currently spends about $300 million annually of state and federal Medicaid funds to compensate agencies for days in which the bed is vacant. This amounts to $10,076 per resident annually.[18] There is no such funding available for a person living in the community if they are away from their home for medical or other reasons.

Any reduction or re-incentivizing of these funds will need to be done with caution. Many agencies operate on very small margins in a very difficult environment. They will need time to plan and adapt to any new approach to housing, but if we want to shift away from a dying model, we need to take action.

Recommendation 16. Propping up a failing "beds-based" system is a losing proposition for the long term and represents a significant drain on scarce funds. As an alternative, OPWDD should encourage and incentivize providers to consider repurposing or adapting their facilities (see Recommendation 5).

Part 2. Regulation and Practice

2A. Administrative incentives for certified housing

Assessment

Just as Medicaid embodies the medical model, NY State's Mental Hygiene Law defines developmental disability in medical terms,[19] and this model frames OPWDD's eligibility criteria set out in **CRR 629.1**. Once a person is deemed eligible for OPWDD services using the Mental Hygiene Law criteria, the ongoing assessment instrument is the DDP-2 which was first used in New York in 1987. The instrument is deficit based, stressing what the person cannot do, as opposed to a Functional Assessment which would focus on what the person might need to help them to live as well as possible.[20] The instrument scores seven indices: Motor, Cognitive, Communication, Self-Care, Daily Living, Behavior Frequency, and Behavior Consequences. Adaptive, Maladaptive, and Health Factor scores are derived from the Index scores, and Individual Services Planning Model (ISPM) scores are derived from the Factor scores.

According to **CRR 671.99**, the ISPM provides: "The information derived from a person's DDP regarding his/her adaptive skills, health, and behavior needs that is utilized to estimate the amount of staff time needed to provide the specific level of staff support necessary to enable the person to live in a residential *situation of his/her choice*." ISPM scores range from 1 through 6; with 1 indicating low behavioral and support needs; 3 and 5 for people with progressively higher support needs and low behavioral needs; and 2, 4, and 6 being for people with progressively higher support and behavioral needs. The ISPM is currently the system's primary acuity measure.

It has been apparent for some time that ISPM scores of people in different residential housing do not necessarily correlate to the degree of supervision or support provided in their residence, particularly for people with lower ISPM scores.[21] In OPWDD's Region 1, close to half of people using Self-Direction and living independently have an ISPM score of 3—the typical score for a person living in a Supervised IRA.[22]

Consolidated budgets in certified housing

Historically, people living in certified housing had an individual budget within the certified housing. In the early 2000s, an administrative decision was made to "roll up" individual and single site rates into an agencywide rate. While this may have made it easier to administer from OPWDD's perspective, there were unintended consequences. By "rolling up" rates for certified housing, the state

created a disincentive to agencies to help people to move to less supervised housing. For example, if a person with moderate needs leaves an IRA and is replaced with a person with a high level of needs, the budget for operating the facility will often remain the same, even though the support need will increase.

Perhaps influenced by the "roll-up," many agencies "sweep" the individual SNAP payments because doing so reduces administrative costs. However, the practice separates the person from their nutrition decisions and prevents the acquisition of independent living skills.

Recommendation 17. OPWDD should align with CMS best practices and reinstate individualized budgets at all levels of services including certified residential. This would facilitate a more granular understanding of costs and service needs while facilitating movement within the system—including progression out of the system. Budgets should not only be individualized but also totally transportable and fungible.

2B. Administrative disincentives for independent housing

The 15-minute increment versus "heads on beds"

Most people living in a non-certified home will have their support staff services paid through CommHab, a Medicaid funding stream. Current compliance requires that services be recorded every 15 minutes (per **ADM 2015-01**). Payment is made to the provider based on the number of people served divided by the number of staff. Ratios may change throughout an evening. For example, a staff may begin with a one-to-one ratio, but as other residents come home, or other staff arrive, the ratio will change. Each ratio pays differently. In a home with three or four residents and one or two staff, that ratio may change throughout the evening. It is not uncommon for a single day's support to necessitate twenty or more different records of time spent. This can be further complicated when one staff shift ends and another begins, with no allowance for information exchange between them. It is highly doubtful that this level of record keeping provides any useful data, reduces fraud or misuse, or adds in any way to the residents' quality of life. However, this creates an extraordinary level of regulatory cost and audit expense that would be considered intolerable in the real world. By contrast, certified housing has only to record the number of people living in the residence each day, or "heads on beds" **(CRR 635-10.5** or **CRR 641-1).** There is no 15-minute increment requirement.

There is no data currently available on how many hours of CommHab are devoted to residential support, or how many millions of 15-minute increments are used annually, or whether any of this tabulation in any way improves the quality of a person's life. On the contrary, there is evidence that the complexity and failings of the reporting system affect retention of DSPs. Agency staff report that the compliance takes at least 20 to 30 minutes per DSP per day, or 1-2 hours a week, per DSP, per person served. The cost to the taxpayer in time spent on excessive compliance is in the many millions and surely exceeds any possible savings from misreporting.[23] The cost to the people receiving services and those providing them is not taken into consideration.[24]

Recommendation 18. Clarify whether the 15-minute increment is a CMS requirement or OPWDD's own initiative, then seek to eliminate it. Despite all the talk of supporting DSPs and parents, the fact that every worker receives an electronic tap on the shoulder every 15 minutes betrays the state's deep distrust of the people it supports and the means by which they are supported. Given that this only applies to people who are outside of the certified system, it is a clear institutional bias and directly counter to the principles of Olmstead.

While the funding for staffing is different between certified and non-certified housing, they are both rooted in the notion that DSP hours are the only tool with which to provide support. This limits flexibility in using other options, different allocations of managerial time, assistive and enabling technology, and informal supports like paid family members. A chronic demographically rooted labor shortage of DSPs has been building for decades, and it was exacerbated by the Covid-19 pandemic. A more qualified and compensated workforce of DSPs would likely be less subject to turnover, and—if combined with other supports—less shift based and labor intensive.

Recommendation 19. Building on work by the National Alliance for Direct Support Professionals (NADSP) and others, OPWDD should seek to create a career path and certification for DSPs.

Long-term effects of incentives that create more restrictive settings

There is an historical and regulatory basis to the fact that there are far more people in Supervised IRAs than there are in Supportive IRAs. In **CRR 686**, two stipulations stand out:

686.3 (5) *(i) A supervised community residence shall be issued an operating certificate for no more than 14 individuals….*

(ii) A supportive community residence shall be issued an operating certificate for no more than four individuals, and shall be certified on an address-specific basis.

In a system that incentivizes more people and more beds—including shared bedrooms—within a particular property, it is not surprising that agencies tend to open Supervised rather than Supportive IRAs.

686.8 states that **"***A person requiring long-term residential oversight and guidance in excess of an average* ***21 hours per week*** *is considered inappropriate for placement in a supportive community residence*." The rule is silent as to how many hours of "oversight and guidance" a person may receive in independent housing. It could be argued that the term "oversight and guidance" is an institutional construct and could perhaps be revised to more person-centered language. That said, the rule seems to require that a person needing more than 21 hours of oversight and guidance can only be supported in housing where there is round-the-clock support (i.e., 168 hours a week). Again,

Community Residences (CRs)

NY Began the "hostel" system in 1966, housing people who had left institutions with "house parents" who were eventually replaced by DSPs. Beginning in the early 1970s Community Residences (CRs) succeeded hostels. As costs rose and federal participation became available, most of these CRs were converted to ICFs, and, beginning in the 1990s, ICFs began to be converted to IRAs. There are still some 68 CRs in operation serving 234 people, and there are regulations that only apply to CRs and not to IRAs or ICFs. The "four or more" clause in the 1971 amendments that created ICFs may have sparked CRR 686.8 which in turn may have filtered down over the years to create the notion that the HCBS settings rules limit the number of occupants in a home—they do not.

this rule applies to CRs, and not to IRAs, but its history resonates in current practice.

The amount and nature of support a person needs will vary from one to another based on factors such as degree and nature of any cognitive impairment, mobility, degree and nature of natural support, whether time can be shared with roommates, communication skills, location, daytime occupation, medical conditions, and general health. The need for support will vary over time. Setting a limit as to the number of hours needed and using that number to determine where a person lives and how much public money is spent for their support is insupportable. These regulations may only be marginally enforced at the current time, but their long-term effects are clearly apparent.

The chart below, taken from *OPWDD's Housing Overview* presented to stakeholders in December 2020 shows that there are 13 times as many adults in Supervised IRAs as there are in Supportive IRAs. The cost per adult in Supervised IRAs is three times that of Supportive housing.

Housing Type	Children (0 to 21)	Adults (22 +)	Children (0 to 21)	Adults (22 +)
Developmental Center / Small Residential Unit	10	210	$2,404,558	$81,286,981
Family Care	167	1,454	$5,653,893	$44,540,684
Intermediate Care Facility	589	3,964	$98,844,782	$625,105,716
IRA Supervised	693	29,845	$74,174,029	$3,678,091,912
IRA Supportive	21	2,255	$551,761	$90,727,792
Specialty Hospital	26	33	$8,208,207	$11,298,141
Total (Unduplicated Count)	**1,447**	**37,064**	**$189,837,230**	**$4,531,051,226**

In the same report, OPWDD depicts Housing Type, need for Disability Support, and "Level of Functioning" (their term!).

Housing Type	(1) Low DS – Low B	(2) Low DS – High B	(3) Medium DS – Low B	(4) Medium DS – High B	(5) High DS – Low B	(6) High DS – High B
DC	11.6%	9.9%	23.8%	54.7%	0.0%	0.0%
ICF	0.20%	0.20%	16.8%	18.60%	40.70%	23.60%
IRA	10.20%	1.10%	39.7%	22.10%	16.40%	10.50%
CR	34.1%	2.2%	42.9%	17.6%	2.2%	1.1%
FC	3.9%	0.0%	41.0%	14.9%	19.7%	20.5%
ISS	75.7%	0.7%	21.4%	1.6%	0.4%	0.2%
Non Residential	29.1%	0.8%	44.1%	13.3%	8.6%	3.9%

Housing Type	Normal or Above	Mild ID/DD	Moderate ID/DD	Severe ID/DD	Profound ID/DD	Undetermined
DC	5.0%	83.9%	8.9%	0.0%	0.0%	2.2%
ICF	0.4%	9.5%	22.6%	24.0%	41.4%	2.0%
IRA	1.7%	39.2%	27.5%	14.3%	16.3%	1.0%
CR	2.2%	55.6%	30.9%	6.7%	2.8%	1.7%
FC	0.4%	32.6%	35.7%	19.4%	10.5%	1.4%
ISS	16.6%	75.0%	6.6%	0.1%	0.3%	1.3%
Non Residential	10.0%	43.2%	29.3%	8.1%	3.1%	6.3%

What emerges from these charts is that the level of need and disability does not correlate closely with the type or cost of housing. The reasons for this are many, including the shortcomings of the DDP-2, types of available housing, vacancy rates, advocacy, personal biases on the part of intake personnel, and geography. One important reason is that agencies are financially incentivized to create Supervised housing more than they are to create Supportive housing. It is also easier for them to operate a Supervised setting from a managerial standpoint since there is enough funding to justify a house manager.

Recommendation 20. OPWDD should collaborate with providers and provider associations, as well as family stakeholders, to better understand why people

with similar levels of need find themselves in housing with significantly different funding levels.

2C. Non-property-related impediments

Self-Direction favors people with independent resources

Much of the cost of services provided through Self-Direction is borne by individuals or their families. They perform much of the administrative role, including in some cases the human resources and training role as well. They then submit a bill to the Fiscal Intermediary, which submits its bill to OPWDD for repayment. People with disabilities who rely on SSI for their income are among the poorest in the country, likely to fall into the 12% of adults who are unable to pay an unexpected expense of $400.[25] This disadvantage is compounded by the lack of financial literacy among people receiving services and the providers that support them—compounding the financial challenges by perpetuating false information about employment, savings, and assets. There are Fiscal Intermediaries and providers who will help to cover this negative cash flow, but not all are able to do so. Self-Direction is easier for people where there are family or other resources to help them.

By contrast, given OPWDD's PPA process, commercial banks are more amenable to providing short-term credit for providers operating certified housing who need support for negative cash flows.

Lack of planning for sustainability of Self-Direction after families are gone

Families of people who self-direct fill many administrative and oversight roles that are essential for the functioning of the Self-Direction plan and the safety of the individual.

One option is for people who seek to use Self-Direction to partner with an experienced agency that helps to ensure that their staff are trained and that they arrive for scheduled shifts. This partnership can help them to comply with all the relevant regulation and support the person they love when they are no longer able to do so themselves.

Recommendation 21. (i)Establish pilot programs to develop ways to support people who self-direct to continue to live in their non-certified homes in their communities after families are gone. One option that has been used on a small scale is the "enhanced broker," a person who can assume many of the necessary tasks. This would not require a change in the waiver.

(ii) Increase options such as Agency with Choice to make Self-Direction more accessible. Agency with Choice reduces the administrative and compliance role of the person and their family members while allowing for professionally supported services. Guidelines for Agency with Choice have been provided by the U.S. Department of Health and Human Services.[26]

See also Recommendation 6.

History of buying into services

There has been a history of wealthy families donating (tax deductible) property or funds to provider agencies to create certified residences with the understanding that this donation will *quid pro quo* ensure that their adult son or daughter will have a lifetime of services in such a home. Given the disparity between the cost of creating a housing unit ranging between $150 thousand and $400 thousand in NY State, and the annual cost of services ranging between $125 thousand to $200 thousand, this is a poor trade-off for the state and an assertion of privilege with denial of services to those with the most need. At the end of the day the agency owns the asset. There is no rule that prohibits this practice.

By contrast, in the case of a person or family donating or funding a home for a person with I/DD whose services are funded through Self-Direction, there is no *quid pro quo* for services and no incentive to an agency to provide long term support. While the ability to secure housing clearly favors the privileged, it does not result in direct "buying in" to services.

Nonprofit agencies are obliged to raise funds for their very survival, and a reliable, appropriate source for these funds are the families they support with their services. Agencies need to steer carefully if those donations reach the point where they influence the agencies' mission and purpose.

Recommendation 22. While such practices sail close to the wind of the IRS's 501(c)(3) tax exemption status, OPWDD should make it clear that it is opposed to any quid pro quo whereby an agency acquires a property or donation in exchange for provision of taxpayer-funded services.

Disincentives for change

CRR 633.12 describes the objection to services process. Under **633.12** a person receiving 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. While there must always be a way to ensure that people receive the services they need and that their interests are protected, there should also be measures to ensure that those resources are appropriate for their need and that public funding is used fairly by creating incentives for individuals, families, and providers to enable people to move to more appropriate settings.

Guardianship

In 1969, The Surrogate's Court Procedure Act (SCPA) was amended to include article 17-A providing for the appointment of guardians for people with I/DD. The underlying assumption at the time was that I/DD was a permanent condition, and the person had no hope for improvement or autonomy. This results in "an immense loss of person liberty" and does not allow for partial decision-making authority for the person.[27] Unfortunately, 17-A has little room for nuance: if a person is subject to guardianship, they have no rights. While a parent may sincerely believe that a person should live in a certified setting, and the provider might encourage them to do so, the voice of the person needs to be heard and to carry some weight. A better solution is the emergence of Supported Decision-Making (SDM). SDM is a *process* by which a person with I/DD can be supported in making his or her own decisions. SDM draws on common experience of consulting or seeking assistance from others when making decisions or choices in our own lives. People living in certified settings need to have a more influential voice in decisions made about where they live, rather than having those decisions being made entirely for them.

Recommendation 23. The state should bolster a person's right to person-centered services while reforming 633.12 to support more equitable distribution of supports. The state should increase opportunities for SDM, specifically when planning for housing.

Lack of support for remaining in the family home

Many people with I/DD and their families want to stay in the family home for as long as possible, but families may struggle to maintain their own employment and take care of other family members while providing support for a person with a disability. Under the current HCBS Waiver, family members may only be paid to provide care under exceptional circumstances and at the Commissioner's discretion. As a result, a person with I/DD may move earlier than they wish into a certified or non-certified home where their support consists entirely of paid workers at much higher cost than the natural support they previously had, and they may be separated from the people who love them.

Recommendation 24. Increase options for people to stay in their family home. Helping people to stay in their family home can be done by paying a stipend to family members as in Family Care (except with their real family!) or through Consumer Directed Personal Assistance Services under the Department of Health waiver.

Increase paid support through more flexible use of respite funding which has proven effective at supporting families and reducing overall costs. Given the dire state of the DSP labor shortage, this would seem to be a smart and necessary approach.

Use Telehealth technology to facilitate connections to clinical staff and for overnight supports and alerts.

The Nurse Practice Act (NPA)

Under the state's Nurse Practice Act, medication administration is considered the role of a professional nurse, or certain exempted persons, including family members. In certified housing, a nurse may supervise trained DSPs who may administer medication. If a person is not living in their family home or a certified setting and is unable to administer the medication themselves, the only person who may administer medication is a professional nurse.[28] This clearly limits how many people with even modest medical needs can live and be supported in the community. The State Education Department (SED), which oversees the NPA, 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 $800 each. It is less clear as to how people who are self-directing their hiring can get the training funded, 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 25. OPWDD should seek to obtain the same exemption in the 1915(c) waiver that applies to people providing Consumer Directed Personal Assistance Services (CDPAS) under the 1915(k) waiver.

Telehealth and Telemedicine

"Telehealth (or Telemonitoring) is the use of telecommunications and information technology to provide access to health assessment, diagnosis, intervention, consultation, supervision, and information across distance…. For purposes of Medicaid, telemedicine seeks to improve a patient's health by permitting two-way, real time interactive communication between the patient, and the physician or practitioner at the distant site. This electronic communication means the use of interactive telecommunications equipment that includes, at a minimum, audio and video equipment."[29]

The Centers for Medicare & Medicaid Services (CMS) leave much of the regulation of Telehealth and Telemedicine to the states. During the Covid-19 pandemic, New York broadened the range of Telehealth services, including allowing it to be used for delivery of some Community Habilitation services. Prior to the pandemic, Telemedicine could only be delivered between certified sites or medical facilities. During the pandemic, Telehealth service expanded to include a broad range of "Distant sites" (the location of the clinician), expanded the list of professional "Telehealth providers," and expanded the list of "Originating sites" to include "the patient's residence located within the state of New York, or other location located within or outside the state of New York."[30] Disappointingly, in its guidance for providers of December 2020, CMS did not make the expansion of sites permanent.

The opportunities for Telemedicine did not change during the pandemic. Telemedicine is a long-proven way to reduce costs while increasing patient well-being. A patient needing a periodic check of their vital signs, for example, no longer needs to take time from their day, perhaps require DSP time, transportation, and waiting time at a clinic. Instead, a device based in their home can be used to transmit their vitals to a different location anywhere in the world, monitoring them daily if necessary. The cost savings in other sectors, in

particular the U.S. Department of Veterans Affairs, have been demonstrated to be substantial. There is no reason why, given any necessary training for the person, their family member, or DSP, that telemedicine could not be provided to people living in non-certified housing as the "Origination site." Given that members of the general public have access to telehealth from their own homes, this restriction might be considered a Civil Rights issue.

Recommendation 26. (i) The state should extend the Covid-19 relaxation of restrictions on Telehealth indefinitely—including for purposes such as Lifeplan meetings and some CommHab work meetings with CCOs and providers—and expand it to support people living in the family home.
(ii) The State should permit the use of Telemedicine with a person's home being the "Origination site."

Protection from abuse and neglect

One reason many parents perceive that certified housing is safer than a non-certified home is because it is more regulated. There is no data available in New York to help determine whether people with I/DD are safer in their own home or in a certified residence. While certain regulations (**CRR 633**) apply specifically to certified housing, other protective measures apply to anyone receiving services funded by OPWDD **(CRR 624, CRR 625**). People living in certified housing are more likely to be congregated and segregated, and they are more likely to share a room. Their day-to-day activities depend on the level of staffing and desires of the other housemates. All of these factors tend to reduce the quality of a person's life.

CR 633

633.15 governs the personal funds of people living in certified settings and their personal allowances. The amount to be set aside is set annually, currently $176 a month. The section is a 14-page regulation. The handbook for provider agencies is 107 pages long.

People living in the community using Self-Direction are more likely to have other people in their lives, including their Fiscal Intermediary, Self-Direction broker, Care Manager, and CommHab workers. There is more transparency and community connection. Living in the community also allows people to become an active member in their town or village and breaks down some of the walls

created by boxing people in certified settings. Exposure increases acceptance, sometimes creates friendships, and often affords more safety.

However, people living in the community can also be prime targets to be taken advantage of financially, emotionally, and physically by bad actors—sometimes including their own family members. Some families and individuals do not have the skills necessary to manage a complex system of reimbursement and resources and they can be exploited. When neglect is discovered, Adult Protective Services (APS), FIs, and OPWDD tend to point at one another to report, investigate, and address the problem. Anecdotally, once APS realizes the person receives services through the OPWDD system, they typically do not get involved. This is an area where thoughtful regulation could provide a positive impact.

Recommendation 27. (i) The state should convene a group of expert stakeholders, including Protective Services, law enforcement, and the Justice Center to begin with first principles: to consider what supports need to be in place to make sure a person can make informed choices and to examine how to create safeguards that will reassure families that people living in the community can be protected from abuse or neglect without the necessity and risk of congregation.
(ii) The State should sponsor Community Education to provide families with unbiased information regarding health and safety issues in certified and non-certified housing and related topics such as the role of the representative payee and basic financial education.

Quality and Regulation

In the world of I/DD, the word *quality* has different meanings depending on perspective. To a regulator, quality means adherence to regulation with health and safety paramount. The OPWDD Division of Quality Improvement's DQI Site Survey Protocol is based on federal and state laws, rules, and regulations and its measures refer to relevant rules. See Appendix G for more information. To the provider agency, defining quality includes making sure that their staff are well trained and supported, and that they measure up well to standards such as OPWDD's Compass designation or the Council on Quality and Leadership accreditation. Harder to measure is the perspective of the person receiving services, but the work of Beth Mount and John O'Brien, distinguished pioneers in creating person-centered perspective, provides helpful guidance. In collaboration with people with disabilities, they identified six measures of an individual's quality of life:

- People live in their own homes and if they live with anyone, it is by choice.
- People *belong* through relationships and memberships.
- They are *respected* because they play valued social roles.
- They *share ordinary spaces* with the rest of the citizenry.
- They make *meaningful contributions* to their communities.
- They have choices and control over meaningful decisions.[31]

Recommendation 28. The state should convene stakeholders, including people with disabilities and their families, to consider how the quality of life of a person being supported can become the most important element in any discussion of quality. Then, implement Quality of Life measures that take precedence over compliance.

Conclusion

There are many factors that have conspired to limit the development of more housing options for people with I/DD. Financial and regulatory impediments outlined herein are critical but are not the sole reason. Reforming all of the regulations and practices described will not fix the problem. Providing publicly funded support to tens of thousands of people requires a system. The systems have evolved over decades in the context of many factors: the tension between local and state, state and federal, state provider and nonprofit provider, generational perceptions of ability and disability, economic privilege and disadvantage, upstate and downstate, and many other cultural and social influences. The level of dissatisfaction with the current system and the level of unmet need, however, leave all stakeholders with no choice but to fundamentally rethink how to fairly provide the necessary support, with finite funding, to the people who need it. This support cannot be provided by the existing business model of certified congregate care.

We began by describing the medical model of Medicaid which runs through all of New York's services. Medicaid is beginning to recognize the importance of Social Determinants of Health, including the quality of stable accessible housing and safe neighborhoods. Former CMS administrator Seema Verma notes, "The evidence is clear; social determinants of health, such as access to stable housing or gainful employment may not be strictly medical, but they nevertheless have a profound impact on people's wellbeing." This is a call to all of us engaged in providing support to rethink how we do it.

A virtuous circle begins with research and advocacy, leading to development of policy, thence to legislation, then to rules and regulation, then to practice and the cycle begins again. For many years, New York State was at the forefront of innovative thinking and testing of new ways to provide support. However, in recent years, our circle has been broken. We have lost our spirit. The link between best practices, research, and policy is fragile, and we see the effects in the inability to effect change and a deterioration into institutional practices. OPWDD should revise its policy and practices internal think tank, encourage rather than discourage transparency in practices and sharing of data, and engage in active public education and transparent communication with stakeholders. This would enable everyone involved to think about first principles and what outcomes we want to achieve—and *then* design the systems.

Summary of Recommendations

FISCAL AND REPORTING

1. Unbundle property costs and support costs, and provide transparency to enable individual budgeting.
11. Ease the ability to cover property maintenance through loans and grants or, for Self-Direction, through OPWDD housing subsidy funding.
13. Permit a rollover in unused PRA funding.
14. Actively promote Paid Neighbor and Live-in Caregiver services.
16. Incentivize providers to repurpose existing unused beds and property.

PROPERTY FINANCING

3. Create comfort letters for Commercial Banks (like PPAs) for non-certified housing.
4. Examine bonding and other strictures on certified housing and other financing possibilities.
5. Provide technical assistance to agencies looking to repurpose housing.
6. Collaborate with lenders to create a cash flow facility for people in Self-Direction.
8. Rethink the CCS for SSI and allow it to follow the person.
9. Realign OPWDD housing subsidy with HUD FMR.

REGULATORY PROCESS

7. Streamline and clarify the processes and rules around e-mods.
10. Highlight long-term effectiveness of OPWDD ISH funding in creating set-asides.
18. Seek CMS approval to eliminate the 15-minute billing increment.
19. Create a certification and career path for DSPs.

23. Bolster a person's right to have person-centered supports and services.
25. Reform Nurse Practice Act and Medication Administration.
26. Permit Telemedicine between a person's home and medical personnel.
27. Establish safeguards for people living in non-certified settings.

WORKING WITH INDIVIDUALS, FAMILIES, AND PROVIDERS

15. Find the most effective housing for people returning from out-of-state placements or residential schools.
17. Create individualized budgets for all levels and types of services.
21. Expand the option for Agency with Choice.
22. Clarify OPWDD rule regarding family donation of property in exchange for services.
24. Increase options for a person to stay in his or her own home.
28. Convene experts to establish ways to develop quality measures that prioritize a person's values and outcomes over burdensome and unnecessary regulations.

DATA AND DEMOGRAPHICS

2. Release bed sharing numbers and other data about available services and need.
12. Determine the value of PILOTS and STAR amounts.
20. Examine and explain the data regarding people with similar needs living in different settings.

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Many thanks to the team at the DDPC headed by Vicky Hiffa, with Jackie Hayes and Drew Webster. They kept is focused on the needs of people with I/DD and making sure our recommendations would have a direct effect.

In particular, I wish to thank Ashley Greenman for her thoughtful and rigorous editing of this complex material and for bringing clarity to the final report.

John Maltby

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Appendix A. How certified residential housing is created

A brief guide

Let us consider a hypothetical agency that serves people with I/DD and that: (1) has demand for a group home from its existing clientele, and (2) seeks to create a certified residence for them.

Start-up and property costs: the capital component

This process is governed by **14-CRR-NY-XIV Part619** Certification of Facilities, **Part 620** Certification of Need, **Part 621** Financial Assistance for Capital Construction, **Part 635** Allowability of Capital Costs, **Part 641** Rate Setting for Non-State Providers, **Part 671** HCBS Waiver Community Residential Habilitation Services, and **Part 686** Operation of Community Residences.

The agency will collaborate with its DDRO to establish that the need it has identified is agreed upon and the course they wish to take is understood.

The agency will draft a budget to include the cost of acquiring and, if necessary, adapting or renovating the property. The budget will also project the operating income necessary to support the potential residents in the home. The DDRO will provide guidance on the level of costs that can be approved.

The agency must submit an application for Certification of Need (CON) to the DDRO to start the process. Once the CON is approved, the agency's application for a PPA will be reviewed. If approved, the agency will receive a PPA letter which is recognized by commercial lenders as an implicit guarantee from the state that operating revenues will be consistent and long term. This, in turn, enables the lender to lend at as much as 100% of LTV or more if renovation is required. Once the PPA is approved, OPWDD issues a form (Confirmation to Proceed with Program Certification (CPPC)/Division of Administration & Revenue Support (DARS)) which allows the agency to begin the certification process with the Division of Quality Improvement. The agency is required to go through the "Padavan process"—obtaining the approval from the local municipality, which shall not be unreasonably withheld, to establish the certified (tax-exempt) house (per NY Mental Hygiene Law 41.34, OPWDD site selection).

This process, including Padavan, generally takes six to nine months, during which the agency will not receive funding to cover the rent, mortgage, utilities, etc. If the property is purchased, the agency will recover the mortgage payments expensed during the certification; if the property is rented, the agency will not

recover the funds expensed on three months of rent during the certification process.

If the agency decides to rent the property, the rent will be subject to approval by the DDRO based on local rent levels (not HUD FMR).

Variables

1. **Is the residence to be Supervised, typically requiring round-the-clock staffing, or is it to be Supportive, with more flexible options for staffing?**
2. Is the agency going to own the property or lease the property?
3. **Where building/renting.** Depending on the location of the home, guidelines for the cost of acquisition, renovation, start-up, design fees, and, if applicable, rental will vary. The highest rates are for New York County (Manhattan) with rates for the NYC area similarly high; rates for Midstate, Upstate, and Western NY are lower.
4. **Interest rates.** The guidelines cap interest rates that may be paid for loans. In the current borrowing environment, this is not a significant factor.
5. **Start-up Allowance.** Will vary by location per OPWDD.
6. **Design Fees.** Maximum set by OPWDD based on renovation cost.
7. **Closing Costs.** OPWDD caps closing costs that can be reimbursed.
8. **Legal Costs.** Legal and accounting costs are capped by OPWDD.
9. **Pre-operational costs**. Utilities are capped by OPWDD.
10. **Soft costs.** Including**:** site surveys, builders' insurance, property & casualty insurance, bank site inspection, soil inspection, clerk of the works inspection—all subject to OPWDD guidelines.
11. **Depreciation.** Depending on when the provider acquired the property, they may or may not be recompensed for depreciation by OPWDD.
12. **Facility Cost Component.** Maintenance and allowable upkeep expenses
13. **Residential Reserve for Replacement**. Annual payment per capita for maintenance.
14. **Tax exemption (a)**. Property owned by the nonprofit is exempt from local taxes.
15. **Tax exemption (b).** As a nonprofit, any gain from selling the property, including depreciation, is nontaxable.
16. **Property Insurance.** Will vary based on area and value.
17. **Repairs.** Residential Reserve for Replacement set based on number of residents.
18. **Activities and program supplies.** Will vary depending on the needs and number of residents.

19. **Transportation costs.** Will vary depending on the number of residents and agency policy regarding the use of staff vehicles.
20. **Utilities.** Will vary depending on region and number of residents.
21. **The number of staff** and mix of DSPs, management, nursing, OT/PT, social worker, nutritionist, and other contracted staff as well as compensation for administration and director salaries will all vary depending on the level of need and location.
22. **E-score.** A factor derived from OPWDD analysis of Evacuation Scores to adjust staffing needs. E-scores are based on a person's prior evacuations and the amount of assistance they needed from staff. Not all IRAs require E-scores; only those certified as Life Safety Code.
23. **Acuity.** "Factor developed through a regression analysis utilizing components of Developmental Disabilities Profile (DDP) scores, average residential bed size, Willowbrook class indicators, and historical utilization data to predict direct care hours needed to serve individuals."[32] It should be noted that, since 2012, OPWDD as required by CMS has been in the process of implementing the CAS, a functionally based assessment instrument, to replace the 40-year-old DDP, which is a deficit focused instrument, subjectively administered and prone to bias. Basing acuity on previous institutionally based support levels would seem to be the embodiment of institutional bias.
24. **Higher Needs Funding.** "Complex level of Care" includes people grandfathered for Special Populations Funding (previously "template funding"). For people who are new to residential services, the agency must go through an application process for one of three tiers of higher needs funding. Which tier someone may qualify for is dependent on their DDP-2 scores; however, this does not guarantee that the higher needs funding will be approved. Higher Needs Funding is intended to be short term, especially the highest tier; the agency must outline how the need for the funding will be quickly diminished as part of the application.
25. **Training and Staff travel.** Within OPWDD allowances.
26. **Where.** Staffing costs are based on DOH regional direct care wages, fringe benefits, support costs.
27. **Where.** Administration. Regionally based insurance/administration costs
28. **Where (d) Regional Average program support component.** Staff travel, participant incidentals, staff development, vehicle and vehicle depreciation,

29. **Number of residents**. Not just the outright number of people but also shared rooms. Per New York Alliance for Inclusion and Innovation (NYAII) survey, 63% in certified housing share a room.
30. **Occupancy Factor.** Designed to reimburse agencies for continuing costs when a resident is not present for any reason (e.g., family visit).
31. **Retainer days.** Days during which an individual is on medical leave from the community residence (max 14 p.a.). As of 5/1/21, OPWDD is paying retainer days at 50% of the daily rate. Additionally, retainer days were converted from 14 per person per year to a pool; the agency receives 14 per certified spot per year; however, there is no longer a per person per year maximum usage.
32. **Therapeutic Leave.** Days during which an individual is away from the community residence and is not receiving services from residential habilitation staff, and the absence is for the purpose of visiting with family or friends, or a vacation. As of 5/1/21, OPWDD is paying therapeutic days at 50% of the daily rate.
33. **SNAP.** Each resident's SNAP payment which may be less than max (June 2021) of $234.
34. **Congregate Care Supplement.** State supplement to federal SSI which will be higher in certified housing.
35. **Higher needs.** Adjustments based on category of person served (e.g., returning from residential school, returning from forensic unit).
36. **Variable Social Security Income.** When the agency is not the Representative Payee it may not have access to the full amount of a person's SSI or SSDI sufficient to account for their rent and board.
37. **Room and Board supplement.** If the agency's income from the residents' SSI/SSDI/CCS/SNAP is insufficient to cover the costs of the residence, the state may pay a Room and Board Supplement.

Examples by Region of Acquisition & Renovation of a Certified setting. Thresholds per most recent OPWDD public information

Rate Setting for Non-State Providers IRA/CR Residential Habilitation and Day Habilitation Effective July 10 2014	Capacity/Bed/Residents	3		Manhattan	Bronx Kings Queens Richmond Nassau Westchester	Putnam Rockland Suffolk	Columbia Dutchess Orange Sullivan Ulster	Albany Greene Rensselaer Saratoga Schenectady Warren	All Other Counties
Purchasing property									
Capital; Thresholds for Residential Acquisition		Per Bed		$ 228,161	$ 159,182	$ 135,424	$ 117,605	$ 84,343	$ 77,622
Approved appraised cost Acquisition				$ 684,483	$ 477,546	$ 406,272	$ 352,815	$ 253,029	$ 232,866
Renovation Threshold per bed				$ 114,081	$ 79,591	$ 67,712	$ 58,803	$ 42,172	$ 38,811
			Septic						
			Fire Alarm						
			Generator						
Renovation		$49,000		$ 49,000	$ 34,186	$ 29,084	$ 25,257	$ 18,114	$ 16,670
Start up Allowance per bed				$ 5,800	$ 5,800	$ 5,800	$ 5,500	$ 5,500	$ 5,500
Start up cost		$ 5,800		$ 17,400	$ 17,400	$ 17,400	$ 5,500	$ 5,500	$ 5,500
Design fees		$ 3,000	17.50%	$ 11,575	$ 8,076	$ 6,870	$ 5,966	$ 4,279	$ 3,938
Loan Closing Costs (max 12%) Mortgage LTV		100.00 %LTV:							
Closing Costs			2.50%	$ 17,112	$ 11,939	$ 10,157	$ 8,820	$ 6,326	$ 5,822
Other (e.g. legal & accounting) Max $20k		$ 10,000		$ 10,000	$ 6,977	$ 5,935	$ 5,154	$ 3,697	$ 3,402
Pre-operational utilities (max $10k)		$ 1,500		$ 10,000	$ 6,977	$ 5,935	$ 5,154	$ 3,697	$ 3,402
Purchase options. Max 1Y premium $15k									
Short term interest max 1Y									
Soft Costs	**Max.**								
site survey	$ 500	$ 500		$ 500	$ 500	$ 500	$ 500	$ 500	$ 500
Builders insurance	$ 2,000	$ 1,200		$ 1,200	$ 1,200	$ 1,200	$ 1,200	$ 1,200	$ 1,200
Property Casualty Insurance	$ 2,000	$ 1,200		$ 1,200	$ 1,200	$ 1,200	$ 1,200	$ 1,200	$ 1,200
Bank Site Inspection				$ -	$ -	$ -	$ -	$ -	$ -
Performance Bond				$ -	$ -	$ -	$ -	$ -	$ -
Soil Inspection	$ 500	$ 300		$ 300	$ 300	$ 300	$ 300	$ 300	$ 300
Clerk of the Works	$ 500	$ 250		$ 250	$ 250	$ 250	$ 250	$ 250	$ 250
Security	$ 500	$ 500		$ 500	$ 500	$ 500	$ 500	$ 500	$ 500
Acquisition Cost				$ 803,520	$ 567,050	$ 485,604	$ 412,618	$ 298,591	$ 275,550

Examples of Operating costs by Region based on stakeholder input

IRA/CR Residential Habilitation and Day Habilitation Effective July 10 2014	Capacity/Bed/Residents	3		Manhattan	Kings Queens Richmond Nassau Westchester	Putnam Rockland Suffolk	Columbia Dutchess Orange Sullivan Ulster	Albany Greene Rensselaer Saratoga Schenectady Warren	All Other Counties
Operating Costs (Monthly)									
Mortgage	25. Year:	5.00%		$ 4,697	$ 3,315	$ 2,839	$ 2,412	$ 1,746	$ 1,611
	12. P.A. install:	300							
Depreciation property over 15Y	15. Years:			$ 4,464	$ 3,150	$ 2,698	$ 2,292	$ 1,659	$ 1,531
Depreciation Leased property									
Property Insurance (Annual)	$ 4,000			$ 333	$ 333	$ 333	$ 333	$ 333	$ 333
Repairs (Annual)	$ 8,000			$ 667	$ 667	$ 667	$ 667	$ 667	$ 667
Maintenance	$ 4,000			$ 4,000	$ 4,000	$ 4,000	$ 4,000	$ 4,000	$ 4,000
Utilities	$ 2,500			$ 2,500	$ 2,500	$ 2,500	$ 2,500	$ 2,500	$ 2,500
Depreciated equipment									
Residential Reserve for Replacement	$ 50	$ 1,800							
Property Cost				$ 16,661	$ 13,965	$ 13,037	$ 12,204	$ 10,904	$ 10,642
Not Inc. Depreciation				$ 12,197	$ 10,815	$ 10,339	$ 9,912	$ 9,246	$ 9,111
Operating Expenses									
(Taken from MCOP spreadsheet)				110%	70%	65%	60%	55%	50%
Variable Costs		Annual	Monthly						
Activities per resident	$ 150	$ 450	$ 38	$ 41	$ 26	$ 24	$ 23	$ 21	$ 19
Food per resident	$ 3,000	$ 9,000	$ 750	$ 825	$ 525	$ 488	$ 450	$ 413	$ 375
Program Supplies	$ 900	$ 2,700	$ 225	$ 248	$ 158	$ 146	$ 135	$ 124	$ 113
Transportation Other	$ 1,000	$ 3,000	$ 250	$ 275	$ 175	$ 163	$ 150	$ 138	$ 125
Vacancy Factor	10%		$ -	$ -	$ -	$ -	$ -	$ -	$ -
	subtotal	$ 15,150	$ 1,263	$ 1,389	$ 884	$ 821	$ 758	$ 694	$ 631
Fixed Costs				Monthly					
Contracted Services		$ 5,000	$ 417	$ 458	$ 292	$ 271	$ 250	$ 229	$ 208
Staff Travel		$ 2,500	$ 208	$ 229	$ 146	$ 135	$ 125	$ 115	$ 104
Staff Training		$ 800	$ 67	$ 73	$ 47	$ 43	$ 40	$ 37	$ 33
Office supplies		$ 1,200	$ 100	$ 110	$ 70	$ 65	$ 60	$ 55	$ 50
Vehicle Expense		$ 4,200	$ 350	$ 385	$ 245	$ 228	$ 210	$ 193	$ 175
Communications		$ 1,200	$ 100	$ 110	$ 70	$ 65	$ 60	$ 55	$ 50
Administrative Staff Support		$ 8,500	$ 708	$ 779	$ 496	$ 460	$ 425	$ 390	$ 354
Other									
		$ 53,700	$ 4,475	$ 4,923	$ 3,133	$ 2,909	$ 2,685	$ 2,461	$ 2,238

Examples of Staffing costs by region

	Rate Setting for Non-State Providers					Bronx			Albany		
	IRA/CR Residential Habilitation and					Kings		Columbia	Greene		
	Day Habilitation					Queens		Dutchess	Rensselaer		
	Effective July 10 2014	Capacity/Bed/Residents				Richmond	Putnam	Orange	Saratoga	All	
			3			Nassau	Rockland	Sullivan	Schenectady	Other	
					Manhattan	Westchester	Suffolk	Ulster	Warren	Counties	
Rate	**Staffing Costs**	Hrs/Week	Fringe %	Monthly							
$15.00	DSPs (1@168, 2@(5x16), 2@(12x2)	376	25%	$30,550	$ 33,605	$ 21,385	$ 19,858	$ 18,330	$ 16,803	$ 15,275	
$17.00	DSP Team Lead	20	25%	$1,842	$ 2,026	$ 1,289	$ 1,197	$ 1,105	$ 1,013	$ 921	
$17.50	DSP Union	0	32%	$0	$ -	$ -	$ -	$ -	$ -	$ -	
$30.00	RN	10	50%	$1,950	$ 2,145	$ 1,365	$ 1,268	$ 1,170	$ 1,073	$ 975	
$24.00	ABA/Social Worker	5	25%	$650	$ 715	$ 455	$ 423	$ 390	$ 358	$ 325	
$22.00	Medical Liaison/LPN	10	25%	$1,192	$ 1,311	$ 834	$ 775	$ 715	$ 655	$ 596	
$24.00	PT/OT	2	25%	$260	$ 286	$ 182	$ 169	$ 156	$ 143	$ 130	
$21.00	Nutritionist/Diet Tech	2	32%	$240	$ 264	$ 168	$ 156	$ 144	$ 132	$ 120	
	Other	0		$0	$ -	$ -	$ -	$ -	$ -	$ -	
	Contracted Staff	0		$0	$ -	$ -	$ -	$ -	$ -	$ -	
$27.00	Manager	20	30%	$3,042	$ 3,346	$ 2,129	$ 1,977	$ 1,825	$ 1,673	$ 1,521	
$30.00	Director	4	30%	$676	$ 744	$ 473	$ 439	$ 406	$ 372	$ 338	
	Other			$0	$ -	$ -	$ -	$ -	$ -	$ -	
				$40,402	$44,442	$28,281	$26,261	$24,241	$22,221	$20,201	
	TOTAL MONTHLY COSTS				$67,414	$46,263	$43,027	$39,888	$36,281	$33,711	

Appendix B. How non-certified housing is created

A brief guide

Non-certified housing is just housing, it is created in the same way that housing is created for all of us. Housing includes market rate developments, affordable housing development, and rental and mortgage subsidies that are available based on economic need of an individual or a region or municipality. At its simplest, all that is required is that a person find a home that they can afford to rent; at its most complex, it may require sophisticated ownership structures. In this brief, we will focus less on how new construction happens more than on how a person can afford a home.

This subject is complex, and this summary is only an overview. More information is available in NY Alliance's Housing Resource Guide.

New construction and renovation. Creating new housing requires input from a wide range of professionals and the larger the development, the more urban, the more complex it can become. Developers need input from environmental and ecological experts for zoning, sewage, water, and power; input from local government experts for approvals and grants at the municipal, county, and state level; input from bankers and dedicated housing funding organizations for short term construction funding and long-term borrowing; and input from lawyers from many specialties and insurers and so on.

New construction subsidies. Affordable housing generally means that a tenant will not have to spend more than 30% of their income on housing, to keep rents low, public support is provided to developers to reduce the amount of money they have to borrow. This subsidy reduces the interest cost they have to pay over the long term. In return for the public subsidy, they must agree to keep rents lower.

The most frequently used subsidies are LIHTCs. Broadly speaking there are two types of LIHTC, 9% credits, which in 2021 are limited to $2.8125 times the state population. NY State's population is 19.45 million ∴ $54.7 million, these credits are much sought after and bidding for the limited amount is competitive. The other type, 4% credits, may be combined with other borrowing and less competitive. The cap for 2021 is set at $110 ∴ $2.14 billion. Other tax credits include Historic preservation and NY City credits.

OPWDD, working in collaboration with NY State HCR, invests in affordable housing that is set aside for people with I/DD. Its ISH funding can pay for half of the cost of creating a housing unit. Since its inception in 2012, the funding has helped to create some 680 housing units which are permanently set aside for people with I/DD. Current funding is $15 million annually, potentially creating between 75 and 100 units. One key advantage of this funding is that OPWDD retains its stake essentially in perpetuity. If the property is sold, it retains the right to require that the units remain affordable and it retains its equity. If the property is demolished, it has a claim on the site. The rents for affordable housing are set on a formula based on the AMI such that tenants pay no more than 30% of their income on housing. Depending on the project, the development will include people with incomes as low as 30% of the AMI. Statewide SSI by itself only amounts to 20.6% of the Median Income. [33]

Variables

For people in Self-Direction their Residential support is limited to the budgeted Residential PRA. This is based on a scoring matrix that includes Direct Support Levels derived from DDP-2, Challenging Behavior levels and geographic location (per OPWDD previously quoted, "costs associated with supporting similarly profiled people.")

1. Is the person moving into a unit **set aside** for people of low income or with a disability? This may reduce rents to where a person whose only income is SSI can still afford housing.
2. Does the person receive a **rental subsidy** either in the form of a Section 8 voucher, USDA RD Section 521, or an OPWDD housing subsidy?
   a. HUD USDA and OPWDD housing subsidies vary by **County.**
   b. Does the housing subsidy include utilities and hazard insurance?
3. Does the person receive **CDB** by virtue of their parents' retirement or death thereby increasing their income?
4. Is the person using Self-Direction?
   a. If so, are they using Other than Personal Services **(OTPS)** to pay for internet, cellular, utilities, alarms, safety tech, pest control, remote monitoring, medication dispenser, induction stove-top, etc.?
   b. Are they using Individual Directed Goods and Services (**IDGS)** to pay for cleaning, minor maintenance, snow removal, lawn care, appliances, HEPA filters?

c. Is the person moving with Self-Direction and eligible for a **SD transition subsidy?**

5. Is the person living in public housing and is there consideration for Earned Income Disregard **(EID)** or Family Self Sufficiency **(FSS**) incentives?
6. Is the person exiting Foster Care and eligible for **Family Unification Program (FUP)** or **Foster Youth to Independence (FYI)?**
7. Is the person moving from a certified Setting and eligible for Community Transition Services **(CTS)?**
8. Does the person have assets or resources individually through **a 1st Person** Special Needs Trust **SNT** or **ABLE** account?
9. Does the person's family have assets that have been placed in a **third party SNT**?
10. Does the person or their **family** have **assets** that can be used to purchase or co-purchase property?
11. Does the person have a Qualified **IDA?**
12. Do they receive **SNAP** (if not they may be able to obtain food through OTPS?
13. Do they receive Home Energy Assistance **(HEAP**) funding?
14. Does the person receive **CommHab** alone or with others?
15. Does the person have a **LIC** (which may affect their housing subsidy)?
16. Does the person have a **PN?**

Appendix C. The Congregate Care Supplement

A person's Supplemental Security Income (SSI) consists of the Federal Benefit Rate (FBR) and a state contribution. If a person also receives Social Security Disability Insurance (SSDI), it will reduce the amount of SSI they receive. When the parent of a person with a disability begins to take their Social Security retirement benefit, the person with a disability may be eligible for Childhood Disability Benefit (CDB) (formerly Disabled Adult Child, or DAC). The amount will equal as much as half of the parent's amount while the parent is alive, and threequarters of the amount when the parent dies. Depending on the parent's contribution history, this may exceed the amount of the person's FBR, plus the state contribution, even if the state contribution is the CCS level.

This makes it difficult to calculate the total amount of the CCS. It is not simply the number of residents in Congregate Care multiplied by the CCS, which would be approximately $155 million. The population in Supervised housing skews older than the population in Self-Direction. It is probable that the parents of this older cohort are more likely to have retired or died than those in the younger cohort. As the Congregate Care population ages and the CDB element of room and board increases relative to the CCS portion, this may represent an opportunity for a more equitable distribution of the funds currently provided through the CCS between those in Congregate Care and those in independent housing.

2021 SSI and SSP Maximum Monthly Benefit Levels Chart (reflects the 1.3% federal COLA increase, effective January 1, 2021)

Fed L/A Code	State Supp Code	New York State Living Arrangement	Federal Benefit/ Individual	State Benefit/ Individual	Total Benefit/ Individual[1]	Federal Benefit/ Couple	State Benefit/ Couple	Total Benefit/ Couple[1]
A	A	Living Alone	$794	$87	$881	$1,191	$104	$1,295
A, C	B	Living with Others	$794	$23	$817	$1,191	$46	$1,237
B	F	Living in the Household of Another[2]	$529.34	$23	$552.34	$794	$46	$840
A	C	Congregate Care Level 1- *Family Care* NYC, Nassau, Rockland, Suffolk and Westchester Counties	$794	$266.48	$1,060.48	$1,191	$929.96	$2,120.96
A	C	Congregate Care Level 1-*Family Care* Rest of State	$794	$228.48	$1,022.48	$1,191	$853.96	$2,044.96
A	D	Congregate Care Level 2- *Residential Care* NYC, Nassau, Rockland, Suffolk and Westchester Counties	$794	$435	$1,229	$1,191	$1,267	$2,458
A	D	Congregate Care Level 2- *Residential Care* Rest of State	$794	$405	$1,199	$1,191	$1,207	$2,398
A	E	Congregate Care Level 3- *Enhanced Residential Care*	$794	$694	$1,488	$1,191	$1,785	$2,976
D	Z	Title XIX (Medicaid Certified) Institutions[3]	$30	$0[4]	$30	N/A	N/A	N/A
A	Z	See Next Page[5]	$794	$0	$794	$1,191	$0	$1,191

Revised October 30, 2020

Appendix D. Calculating the ISPM Score

Index Scores

- DDP-2. There are 7 index scores: Motor, Cognitive, Communication, Self-Care, Daily Living, Behavior Frequency, and Behavior Consequences.
- Each index score can range from 0 to 100. Higher scores indicate higher skills or fewer limitations.
- DDP-2 items used to create the index scores 20, 22–28.

Factor Scores

- There are 3 factor scores.: Adaptive, Maladaptive, and Health.
- Adaptive Scores range to 500, maladaptive to 200, and health to 31. Higher scores indicate more limitations.
- Adaptive and maladaptive factors are derived from the Index scores (maladaptive includes behavior frequency and behavior consequence; adaptive includes the other 5 index scores).
- DDP-2 items used to create the health scores 14–17.

ISPM Scores

- ISPM Scores range from 1 through 6. An ISPM of 1 describes people with low behavioral support and needs and low direct support needs; 2 describes high behavior, low direct support; 3 describes low behavior, medium direct support; 4 describes high behavior, medium direct support; 5 describes low behavior, high direct support; 6 describes high behavior, high direct support needs.
- ISPM scores are derived from the Factor Scores. Direct Support levels are a function of a person's Adaptive and Health Factors. Behavioral Support levels are a function of a person's Maladaptive Factor Score.

INDIVIDUAL AND COMMUNITY SUPPORTS PERSONAL RESOURCE ACCOUNT (PRA) ANNUAL ALLOCATION

These amounts represent the **OPWDD gross amount** of the total available PRA.

Bernard Fineson, Brooklyn, Metro, Staten Island DDSOs

2	3	4	5	6	7	8	9	10	11	12	13	14
LEVELS	**Behavior 1**			**Behavior 2**			**Behavior 3**			**Behavior 4**		
	Residential	Day	Total	Residential	Day	Total	Residential	Day	Total	Residential	Day	Total
Direct Care Support - 1	$ 69,185	$ 23,316	$ 92,501	$ 70,578	$ 24,230	$ 94,807	$ 71,801	$ 25,377	$ 97,178	$ 72,919	$ 25,805	$ 98,724
Direct Care Support - 2	$ 78,548	$ 24,612	$ 103,160	$ 79,494	$ 25,377	$ 104,871	$ 80,803	$ 26,727	$ 107,530	$ 81,998	$ 27,939	$ 109,937
Direct Care Support - 3	$ 89,948	$ 28,042	$ 117,990	$ 91,129	$ 28,677	$ 119,806	$ 91,919	$ 29,663	$ 121,582	$ 92,900	$ 30,921	$ 123,821
Direct Care Support - 4	$ 97,422	$ 31,000	$ 128,421	$ 99,209	$ 31,770	$ 130,979	$ 100,858	$ 32,757	$ 133,615	$ 102,084	$ 33,718	$ 135,802
Direct Care Support - 5	$ 107,863	$ 33,686	$ 141,549	$ 110,713	$ 34,559	$ 145,273	$ 112,112	$ 35,318	$ 147,431	$ 113,309	$ 36,439	$ 149,748
Direct Care Support - 6	$ 115,172	$ 36,857	$ 152,029	$ 117,594	$ 37,613	$ 155,207	$ 119,213	$ 38,377	$ 157,590	$ 120,994	$ 39,215	$ 160,209
Direct Care Support - 7	$ 122,788	$ 37,473	$ 160,261	$ 123,895	$ 38,115	$ 162,011	$ 124,923	$ 38,620	$ 163,544	$ 126,703	$ 39,884	$ 166,587
Direct Care Support - 8	$ 129,665	$ 39,915	$ 169,579	$ 131,473	$ 40,842	$ 172,314	$ 132,464	$ 41,981	$ 174,445	$ 133,722	$ 43,348	$ 177,070

Hudson Valley, Long Island DDSOs

LEVELS	**Behavior 1**			**Behavior 2**			**Behavior 3**			**Behavior 4**		
	Residential	Day	Total	Residential	Day	Total	Residential	Day	Total	Residential	Day	Total
Direct Care Support - 1	$ 63,329	$ 19,946	$ 83,275	$ 64,602	$ 20,650	$ 85,252	$ 65,719	$ 21,354	$ 87,074	$ 66,741	$ 22,058	$ 88,799
Direct Care Support - 2	$ 71,884	$ 22,762	$ 94,647	$ 72,749	$ 23,466	$ 96,216	$ 73,945	$ 24,170	$ 98,116	$ 75,037	$ 24,875	$ 99,912
Direct Care Support - 3	$ 82,301	$ 25,579	$ 107,880	$ 83,380	$ 26,283	$ 109,663	$ 84,102	$ 26,987	$ 111,089	$ 84,999	$ 27,691	$ 112,689
Direct Care Support - 4	$ 89,130	$ 28,395	$ 117,525	$ 90,763	$ 29,099	$ 119,862	$ 92,270	$ 29,803	$ 122,073	$ 93,390	$ 30,507	$ 123,897
Direct Care Support - 5	$ 98,671	$ 31,211	$ 129,882	$ 101,275	$ 31,915	$ 133,190	$ 102,553	$ 32,619	$ 135,172	$ 103,647	$ 33,323	$ 136,970
Direct Care Support - 6	$ 105,349	$ 34,027	$ 139,376	$ 107,563	$ 34,731	$ 142,294	$ 109,042	$ 35,435	$ 144,477	$ 110,669	$ 36,139	$ 146,808
Direct Care Support - 7	$ 112,308	$ 36,843	$ 149,151	$ 113,320	$ 37,547	$ 150,867	$ 114,259	$ 38,251	$ 152,511	$ 115,885	$ 38,955	$ 154,840
Direct Care Support - 8	$ 118,592	$ 39,659	$ 158,251	$ 120,244	$ 40,363	$ 160,607	$ 121,150	$ 41,067	$ 162,217	$ 122,299	$ 42,652	$ 164,951

Broome, Capital District, Central, Finger Lakes, Sunmount, Taconic, Western DDSOs

LEVELS	**Behavior 1**			**Behavior 2**			**Behavior 3**			**Behavior 4**		
	Residential	Day	Total	Residential	Day	Total	Residential	Day	Total	Residential	Day	Total
Direct Care Support - 1	$ 56,002	$ 17,251	$ 73,252	$ 57,124	$ 17,853	$ 74,977	$ 58,110	$ 18,455	$ 76,565	$ 59,011	$ 19,057	$ 78,068
Direct Care Support - 2	$ 63,546	$ 19,660	$ 83,206	$ 64,309	$ 20,262	$ 84,571	$ 65,364	$ 20,864	$ 86,228	$ 66,327	$ 21,466	$ 87,793
Direct Care Support - 3	$ 72,733	$ 22,069	$ 94,801	$ 73,684	$ 22,671	$ 96,355	$ 74,321	$ 23,273	$ 97,594	$ 75,112	$ 23,875	$ 98,987
Direct Care Support - 4	$ 78,755	$ 24,478	$ 103,233	$ 80,195	$ 25,080	$ 105,275	$ 81,524	$ 25,682	$ 107,206	$ 82,512	$ 26,284	$ 108,796
Direct Care Support - 5	$ 87,169	$ 26,887	$ 114,055	$ 89,466	$ 27,489	$ 116,954	$ 90,593	$ 28,091	$ 118,684	$ 91,557	$ 28,693	$ 120,250
Direct Care Support - 6	$ 93,058	$ 29,296	$ 122,354	$ 95,010	$ 29,898	$ 124,908	$ 96,314	$ 30,500	$ 126,814	$ 97,750	$ 31,102	$ 128,852
Direct Care Support - 7	$ 99,195	$ 31,705	$ 130,900	$ 100,087	$ 32,307	$ 132,394	$ 100,916	$ 32,909	$ 133,825	$ 102,350	$ 33,511	$ 135,861
Direct Care Support - 8	$ 104,737	$ 34,114	$ 138,850	$ 106,193	$ 34,716	$ 140,909	$ 106,992	$ 35,318	$ 142,310	$ 108,006	$ 36,674	$ 144,680

Note: These amounts include Clinic Services and any services billed on the Medicaid card except nursing services. These amounts include State Plan Services, such as Personal Care/Home Health Aide services, Medicaid Service Coordination and clinic services. Any Housing Stipends granted are Net of Countable Income, will be included in the PRA value, thereby reducing the amount available for services. Health Care Enhancements, Transportation and all administration, including Fiscal Management Services payments are

KEY:

ISPM LEVEL
1
2
3
4
5
6

Direct Su	Scoring Range	Challenging Behav	Scoring Range
1	0 to 17.61	1	0 to 3.99
2	17.62 to 23.53	2	4.00 to 25.66
3	23.54 to 29.30	3	25.67to 69.32
4	29.31 to 35.62	4	69.33 to 200.00
5	35.63 to 43.06		
6	43.07 to 52.84		
7	52.85 to 68.54		
8	68.55 to 136.00		

Direct Support Levels	Scoring Range	Challenging Behavior Levels	Scoring Range
Lookup	Lookup	Lookup	Lookup
0	1	0	1
17.62	2	4	2
23.54	3	25.67	3
29.31	4	69.33	4
35.63	5		
43.07	6		
52.85	7		
68.55	8		

Appendix E. Real Estate Taxes

Per the "State of the States in Developmental Disabilities,"[34] there are 38,829 certified beds in NY State. There are 3,087 people living in settings of 16+ persons. If we assume that the average is 16 people, and no more than 2 people per room, then there are 193 eight-bedroom homes. There are 18,520 people living in 7–15 bed settings—if we assume that on average there are 11 people in such a home, with no more than two to a room, then there are 1,684 six-bedroom houses. There are 17,222 people in settings with less than six people. If we assume that each person has a room plus staff, then there are 5,741 three- to four-bedroom homes. (OPWDD has information from each agency's Consolidated Fiscal Report regarding each property, but this is not readily transparent).

Per Zillow, the median price of a home in New York State is $328,677,[35] with extremes in different parts of the state. If we venture that larger homes cost more than smaller ones, and assign a premium for 16+ and 7–15 person settings of a modest 20%, then the portfolio can be valued as:

=(((193+1684)*328,677)*1.2)+(328677*5741) =$2.626 billion.

The statewide average tax property tax rate is 1.68% [36] ∴.

Annual property tax =$2.626 billion *1.68% = $44.13 million /38,829=$1,137 per resident annually.

Property taxes vary widely across the state, and people with disabilities may be able to obtain a STAR reduction in taxes in non-certified housing.

Clearly there are some heroic assumptions in this speculative exercise, but, in the absence of figures from the state, they are a conservative approximation.

It should be noted that this exemption for certified housing is "taxpayer neutral," that is, having one public entity (OPWDD, or the Social Security Administration, or other) not pay taxes to another public entity (e.g., local government), does not involve a net tax increase or reduction from the taxpayer's perspective.

Appendix F. HUD Fair Market Rent.

HUD's Section 8 Housing voucher is designed to help families achieve housing stability. The voucher pays the difference between 1/3rd of the tenant's income and the rent of the property. There are limits on the level of income to qualify, and HUD limits the amount of rent they will pay to its FMR. The HUD FMR is calculated by county, and in some cases by zip code. Per HUD, "*The FMR is the 40th percentile of gross rents for typical, non-substandard rental units occupied by recent movers in a local housing market.*"[37] The formula by which HUD calculates this number is detailed on their website. It is complex, but it is nonetheless transparent. It is important to note that the FMR is based on area rents, whereas the formula for calculating rents in housing created through LIHTC is based on area incomes.

To learn more about FMR see the HUD website.

https://www.huduser.gov/periodicals/USHMC/winter98/summary-2.html

Another option: Price Index of Operating Costs (PIOC). NY City's Rent Guidelines Board (RGB) is required to keep track of operating costs for rental apartments in the city as part of its role in creating rent guidelines that are fair to both landlords and tenants. "*The Price Index of Operating Costs (PIOC) measures changes in the cost of purchasing a specified set of goods and services (market basket) used in the operation and maintenance of rent stabilized apartment buildings in New York City. The PIOC consists of seven cost components: Taxes, Labor Costs, Fuel, Utilities, Maintenance, Administrative Costs and Insurance Costs. The specific goods and services (items) within each component were originally selected based on a study of 1969 expenditure patterns by owners of rent stabilized apartment buildings*." The Board has fifty years of detailed data which informs its decisions. With each year's guidelines neither the tenants nor the landlords are ever happy, so the RGB must be doing something right. The fact is that because of this work in NYC we know what housing costs, and a significant portion of the city's rental housing is covered by these rent guidelines. It would be equitable, responsible and timely for OPWDD's housing subsidy to be reflective of the RGB guidelines.

Appendix G. How regulation meets compliance and quality

DQI Site Review protocol — How Regulation relates to compliance.				
Section	**Item**	**Regulation**	**Regulation**	**Regulation**
1	**Heightened Scrutiny**			
1.1	The site is in a location other than on the grounds of a public institution	HCBS settings rule		
1.2	separate from a publicly or privately operated facility with inpatients	HCBS settings rule		
1.3	The site is not adjacent to a public institution	HCBS settings rule		
1.4	Did not convert from an ICF post 3/17/2014	HCBS settings rule		
1.5	Located apart from other certified facilities	HCBS settings rule		
1.6	Design appearance location not institutional, does not isolate from broader community	HCBS settings rule		
2	**Health & medication**			
2.1	Written plan re: life-threatening emergencies	633.10		
2.2	Staff know actions to take in the event of medical emergency	633.10		
2a.1	Registered nurse on site or available	633.10	633.17	ADM 2003-01
2a-2	DSP know how to contact the RN	633.8	633.17	633.4
2a-3 to 2a-9	Only DSP AMAP, LPN, RN, NP, PA, MD administer medication	633.17		
2a-10 to 2a-11	Site ensures individuals access professional healthcare per needs, choice	633.4	633.10	
3	**Personal Funds**			
3.1	PA is consistently available to individuals for routine expenditures and recreation	633.15		
3a-1	Cash on hand does not exceed congregate level 3 +$20	633.15		

3a-2	Personal funds are secured and safeguarded	633.15		
3a-3	there are ledger cards for accounting of individual's PA	633.15		
3a-4	the ledger clearly documents receipt of funds	633.15		
3a-5	ledger clearly documents disbursement including purpose	633.15		
3a-6	ledger accurately reflects individual's total fund amount	633.15		
3a-7	PA is not used for items or expenses for which the agency is responsible.	633.15		
3a-8	Receipts reconcile with ledger entries	633.15		
3a-9	Individuals reimbursed for any loss of money maintained at the site	633.15		
4	**Choice, Autonomy**			
4.1	Sufficient transportation is available and facilitated to support individualized choice	memo 10/13/15	441.301	ADM 2014-04 Person centeredness, rights
4.2	staff scheduling sufficient to support each individual's participation in individual/personal activity	memo 10/13/15		
4.3	Mechanism to assess individual satisfaction with service environment	memo 10/13/15	CFR 441.301 https://www.law.cornell.edu/cfr/text/42/441.301	
4.4	home has a mechanism to assess living arrangement choice	memo 10/13/15		
4.5	home has mechanisms to assess roommate choice and satisfaction	memo 10/13/15	441.43	
4.6	program takes timely action to address individual dissatisfaction with living/service environment	memo 10/13/15	441.301	
4.7	Mechanism to offer individuals keys to enter their home	memo 10/13/15	441.301	
4.8	Mechanism to offer keys to their bedrooms	memo 10/13/15	441.301	
4.9	home takes timely action to provide independent access to home/bedroom.	memo 10/13/15	441.301	
4.10	Individuals' schedules & routines personally determined rather than to staff schedule	memo 10/13/15	441.43	

4.11	Individuals are observed to engage in meaningful activity	633.4		
4.12	Individuals encouraged to participate in home routine (e.g., cooking, chores)	633.4		
4.13	Individuals encourage to have full access to broader community	memo 10/13/15	441.301	
4.14	Individuals' cultural religious lifestyle choices supported by staff	memo 10/13/15	441.301	
4.15	Individuals supported by staff to exercise control and choice	memo 10/13/15	441.301	
5	**Safeguards**			
5.1	Staff know individual's supervision needs	686.16	633.4	
5.2	Individuals receive meal/food in form and consistency re needs and OPWDD CPI specs	686.16	633.4	
5.3	Individuals receive support while eating in accordance with assessed and observed needs	686.16	633.4	
5.4	Individuals receive support for mobility in accordance with observed needs	686.16	633.4	
5.5	Individuals receive appropriate support and supervision based on other observed needs for support	686.16	633.4	
5.6	Adequate staff on duty to meet needs		633.4	
5.7	Facility has communication system and staff are aware contact on duty personnel/emergencies.	635.7		
6	**Rights & Protections**			
6.1	observed and reported interactions verbal/nonverbal are respectful	633.4		
6.2	site absent of rules/policies/procedures that limit rights, independence, choice, autonomy	memo 10/13/15		
6.3	individuals permitted to engage in any legal activities per their interests	memo 10/13/15		
6.4	individuals have full access to typical facilities	memo 10/13/15		
6.5	Individuals' health and other protected information is kept private/protected	memo 10/13/15	633.4	
6.6	people have privacy in their living quarters as appropriate	memo 10/13/15	633.4	

6.7	people have access to food any time	memo 10/13/15		
6.8	people can choose to eat meals when /where desired	memo 10/13/15		
6.9	Events that meet the definition of reportable incident have been reported	624.5		
6.10	Events defined in part 625 have been reported	625.4	625.5	
6.11	immediate care and treatment identified was provided to the individual	624.5		
6.12	Initial measures to protect individuals receiving services from harm were implemented immediately	624.5		
6.13	investigations of reportable incidents and notable occurrences are thorough and documented	624.5		
6.14	Measures identified to prevent future similar events were planned and implemented	624.5		
6.15	corrective actions reported to OPWDD and Justice Center were implemented	624.5		
6.16	Part 625 events and actions reported in IRMA regarding recommendations were implemented	625.3		
7	**Site & Safety**			
7.1	The residence appears "home-like" rather than institutional	memo 10/13/15	441.301	
7.2	Surveillance cameras are not present in the site	memo 10/13/15	441.301	
7.3	There is evidence that residents are allowed to have visitors of their choosing at any time	memo 10/13/15		
7.4	The site's physical characteristics support the independence comfort preference and needs of the individuals	686.3	633.4	
7.5	All ramps, doors, handrails, elevator controls, telephones and similar devises are operable/usable	635.7		
7.6	there are adequate supplies in the site to meet the needs of the individuals per the service	635.9		

7.7	Bathrooms provide personal privacy	635.7	633.4	
7.8	The site is clean	635.7		
7.9	The site is well maintained for safety and comfort of the individuals	635.7	633.4	
7.10	The facility operates in accordance with OPWDD smoking protection	633.2		
7.11	The temperature of the hot water is appropriate to the abilities of people served	635.7		
7.12	Facilities with private water source…test their water annually. Bacterial and chemical	635.7		
7.13	The site implements procedures to safeguard from drowning in recreational/therapeutic schools	635.7	633.4	
7.14	The facility has a land line telephone in working order	635.7		
7.15	Time out rooms constructed or significantly modified meet requirements of 633.16	633.16		
8	**Fire Safety**			
8.1	The site has an acceptable fire evacuation plan	686.16	635.7	ADM 2012-02 Fire Safety
8.2	All fire and evacuation drills must be documented			ADM 2012-02
8.3	The evacuation plan is practiced through drills with the frequency specified by OPWDD	686.16	635.7	ADM 2012-02
8.4	Evacuation drills are conducted in a manner to effectively train and assess participants	686.16	633.4	ADM 2012-02
8.5	Effectiveness of the fire evacuation plan is monitored by agency personnel per OPWDD requirements.			ADM 2012-02
8.6	Evaluation of drills results in identifying concerns and implementation of corrective action			ADM 2012-02
8.7	Staff can describe fire and safety and emergency evacuation procedures	633.4	633.8	

8.8	The certified site provides safe exiting to a public way	635.7		
8.9	There is fire alarm and detection equipment in the facility as required by regulation	635.7		ADM 97-01, ADM 99-01
8.10	Heat detectors are present in the residence as required by OPWDD			ADM 2012-02
8.11	Fire alarm and notification systems are operational and effective	633.4	635.7	686.16
8.12	Other fire protection equipment is operational	635.7	633.4	
8.13	fire alarm, smoke detection and sprinkler systems are inspected and maintained	635.7		
8.14	Maintenance and inspection of fire alarm and detection systems			ADM 2012-02
8.15	Maintenance and inspection of sprinkler systems			ADM 2012-02
8.16	At least 1 functional Class1-A-5BC, 2.5-pound extinguisher located accessibly on each floor	635.7		
8.17	Where individuals live in individual apts, but group of apts is supervised, mechanisms to ensure staff summoned	633.4	686.16	
8.18	A CO alarm is located on sleeping floors	633.4	635.7	
8.19	Facility free from observed fire safety hazards	635.7		
9	**Site Specific requirements**			
9.1	Site has a written Quality Assurance Plan that has been implemented	679.4	690.6	
9.2	Corrective actions identified per the QA plan activities are implemented	679.4	690.6	
10	**Specialized Risk Factors**			
	10a Risk Factor Skin Breakdown			
10a-1	There is a written plan to provide care for wounds and /or prevent worsening & further breakdown	633.4	680.7	690.5
		633.10	686.16	ADM 2003-01 Nursing
10a-2	Staff implement interventions related to care and monitoring prevention skin breakdown	633.4	633.1	686.16

10a-2		680.6	690.5	
	10b Risk factor discharge from hospital			
10b-1	Clear written instruction re care and monitoring (hospital discharge)	633.4	633.10	ADM 2003-01
10b-2	Instructions for documentation post hospital discharge	633.4	633.10	ADM 2003-01
10b-3	There is evidence that the staff implement require care and monitoring following discharge	633.4	680.6	
	10c. Risk Factor Current illness			
10c-1	RN or other medical professional informed re-signs/symptoms (ill person)	633.10	680.6	
10c-2	Clear written instruction for care and monitoring	633.10	633.4	ADM 2003-01
10c-3	Instruction as to what to document	633.10	633.4	ADM 2003-01
10c-4	Evidence that staff implement required care and monitoring	633.4	680.7	
	10d. Risk Factor Diabetes			
10d-1	Written instruction re monitoring diabetes	633.4	686.16	680.6
10d-1				ADM 2003-01
10d-2	written documentation re required care and monitoring	633.4	680.6	ADM 2003-01
10d-3	there is evidence staff implement required diabetic care and monitoring	633.4	686.16	680.6
	10e. Risk Factor Fluid Intake			
10e_1	amount of fluid to be consumed by the person is clearly indicated in a written plan	633.10	686.16	680.6
10e_2	Clear instruction how to implement fluid intake	633.4	680.6	ADM 2003-01
10e_3	documentation tracking person's fluid consumption	633.4	680.6	
10e_4	Written plan for fluid consumption is implemented correctly	633.4	686.16	680.6
	10f Risk Factor Oxygen use			
10f-1	Written instruction for oxygen use	633.4	680.6	ADM 2003-01
10f-2	Instruction includes what to document	633.4	680.6	ADM 2003-01

10f-3	necessary equipment for oxygen is available	633.4	633.10	
10f-4	documentation re ordered administration of oxygen	633.4	633.10	680.6
	10g Risk Factor Supervision			
10g_1	Sufficient staff on duty (enhanced supervision)	686.9	633.4	
10g_2	Required supervision/staffing ratios maintained per individualized plans	686.16	633.4	
	10h Risk Factor All Rights Limitations/Restrictions			
10h-1	Limit on rights due to behavior only as part of a written plan	633.16		
10h-2	The individual's Behavior support plan describes documentation	633.16		
10h-3	rights limitation only when informed consent from appropriate consent giver	633.16		
10h-4	only when approved by Human Rights Committee prior to implementation	633.16		
10h-5	Rights limits not part of a BS plan comply with HCBS re justification and documentation	636 1.4	HCBS	
10h-6	Other residents not affected by environmental protection due to person's needs	636 1.4	633.4	
	10i Risk Factor Behavior Supports			
10i_1	Behavior support provided per written plan	633.16		
10i_2	Behavior supports are reviewed for effectiveness by clinical staff	633.16		
10i_3	Behavior supports are revised as needed	633.16		
	10j Risk Factor Mechanical Restraints			
10j_1	Criteria for application, removal and duration of mechanical restraints in written behavior support plan	633.16		
10j_2	Restraints are applied only per the specific criteria described in the written plan	633.16		
10j_3	Restraints are removed per the criteria and duration described in the written plan	633.16		

10j_4	There is a current physician's order for the use of the Mechanical Restraining device	633.16		
10j_5	There is documentation that is a full record of the use of the MRD	633.16		
	10k Time Out			
10k_1	Time out is used only in accordance with the written BSP	633.16		
10k_2	The use of a time out room is reported electronically to OPWDD	633.16		
10k_3	Constant auditory and visual contact is maintained during time outs	633.16		
	Section 10l Physical Interventions			
10l_1	Physical interventions are used only in accordance with the written BSP	633.16		
10l_2	The use of restrictive physical interventions is reported electronically to OPWDD	633.16		

Endnotes

[1] People with I/DD are living longer than ever before. This is a testament to many factors, including the efforts of dedicated, caring, and skilled family physicians and caregivers. But there is more that could be done to enhance the well-being of people with I/DD as they grow older. Their average life span of 66 years remains considerably shorter than that of members of the general population. See https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6501708/ retrieved May 2020.
[2] Public Law 94-142, passed in 1975, guaranteed a free and appropriate education for all, including people with disabilities. In 1997, it was renamed the Individuals with Disabilities Education Act or IDEA.
[3] A report on DSP workforce Crisis by Regional Centers for Workforce Transformation: https://www.workforcetransformation.org/report-dsp-workforce-crisis/ retrieved May 2021.
[4] https://www.nationalcoreindicators.org/charts/?i=1&st=NY retrieved April 2021.
[5] OPWDD currently serves approximately 36,000 people in certified settings and provides rental subsidies to 6,000 more. A total of approximately 130,000 people receive services of all kinds from OPWDD. Conservative estimates of prevalence from the CDC, the National Arc, and others put the prevalence of I/DD that might need significant LTSS at 1.5%. In NY State this would equal some 225,000 adults.
[6] Per the *State of the States in Developmental Disabilities 2017,* NY receives 2.4 times the amount of federal funding per capita than CA and more than 4 times that of TX and FL. https://stateofthestates.org/create-idd-chart/state-profiles/ retrieved March 2021.
7. From Goering, S. "Rethinking Disability: the social model of disability and chronic disease" *Journal Musculoskeletal Medicine* (June 2015), pp 134-138.
[8] An IRA is a group home certified by the state and funded using Medicaid Waiver.
[9] "Rate Setting for Non-State Providers: IRA/CR Residential Habilitation and Day Habilitation, Effective Tuesday July 1 2014," OPWDD Emergency Regulations.
[10] Per the National Core Indicators question: "Did you choose the people who live with you? (if not living in the family home)," only 32% reported that they did. https://www.nationalcoreindicators.org/states/NY/ retrieved April 2021.
[11] SSDI may arise from the person's own work history or that of their retired or deceased parents.
[12] CCS for 2020 at https://opwdd.ny.gov/system/files/documents/2020/03/2020-maximum-monthly-benefit-amounts.pdf retrieved November 2020.
[13] Per OPWDD rates based on HUD 2012 FMR.
[14] Mental Hygiene Service rates OPWDD website https://www.health.ny.gov/health_care/medicaid/rates/mental_hygiene/ retrieved April 2021.
[15] From" Self-Direction Guidance for Providers," OPWDD April 2020.
[16] Per IRS code section 131 https://www.irs.gov/pub/irs-drop/n-14-07.pdf retrieved April 2021.
[17] https://regs.health.ny.gov/volume-2-title-10/1446320052/subpart-86-11-rate-setting-non-state-providers-intermediate-care retrieved February 2020.
[18] Amount of $300 million noted at the DDAC meeting of 4/12/21 by OPWDD Deputy Commissioner Enterprise Solutions. Population of 29,773 from OPWDD 2019-2020 Spending Results November 2020.
[19] NY State MHL 1.03 22 https://www.nysenate.gov/legislation/laws/MHY/1.03 retrieved January 2021.
[20] Full implementation of the Coordinated Assessment System (CAS) which is closer to a functional assessment and intended to replace the DDP-2, has been delayed for more than seven years.
[21] OPWDD Presentation to Provider Associations, December 2020.
[22] Region 1 Non-certified Housing Roundtable, May 2018.
[23] Two hours per person served, per week=c. $40 per hour CommHab rate x 2 hours a week x 52 weeks a year x 16,571 people served = $69 million in lost time annually.

[24] 16,571 people are in Self-Direction per OPWDD's December 2020 spending report. This number x 20 hours, x 4 quarters/250 sheets of paper per inch would create a column 4.35 miles high (this endnote is for conscientious readers only).
[25] Per Federal Reserve https://www.federalreserve.gov/publications/2019-economic-well-being-of-us-households-in-2018-dealing-with-unexpected-expenses.htm retrieved November 2020.
[26] See HHS "Understanding Medicaid Home and Community Services: a Primer" 2010 edition.
[27] I am indebted to Farrel & Fritz website: "Surrogate's Court Procedure Act Article 17-A and its Ever Changing Landscape" http://www.farrellfritz.com/surrogates-court-procedure-act-article-17-ever-changing-landscape/ retrieved June 2020.
[28] Article 139 of NY State Education law, see section 6908 http://www.op.nysed.gov/prof/nurse/article139.htm retrieved June 2021/
[29] https://www.medicaid.gov/medicaid/benefits/telemedicine/index.html retrieved February 2020.
[30] NY State "Telehealth delivery of services" Section 2999-CC
[31] From John O'Brien and Beth Mount, *Pathfinders: People with developmental disabilities & their allies building communities that work better for everybody*. Toronto, ON: Inclusion Press, 2015, pp. 95-96.
[32] Emergency Regulations: Rate Setting for Non-State providers 7/1/14, OPWDD.
[33] Priced Out: The housing crisis for people with disabilities: http://www.tacinc.org/knowledge-resources/priced-out-v2/#:~:text=PRICED%20OUT%3A%20The%202020%20Edition,disabilities%20across%20the%20United%20States.&text=Use%20the%20Priced%20Out%20Where,disabilities%20in%20your%20own%20community retrieved December 2020.
[34] Op.cit.
[35] Per Zillow https://www.businessinsider.com/average-home-prices-in-every-state-washington-dc-2019-6#10-new-york-321934-42 retrieved November 2020.
[36] Per SmartAsset. https://smartasset.com/taxes/new-york-property-tax-calculator retrieved November 2020.
[37] https://www.huduser.gov/periodicals/USHMC/winter98/summary-2.html#end3.