

The Housing Resource Guide

*Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities*

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In 2014, WIHD received additional funding through a Community grant awarded by Autism Speaks to augment the original work, and to lay the groundwork for a Housing Navigator curriculum that could train professionals to help people with ASD-I/DD find housing. The creation of this guide was supported, in part, through these generous grants.

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Introduction

New York (NY) State has a long history of caring for people with ASD/I-DD in congregate settings, beginning with the group home system that grew out of the Willowbrook lawsuit¹ and the deinstitutionalization related reforms of the 1970s. However, over the years the congregate care model has taken on some of the characteristics of the institutional settings it was designed to replace. While there are many excellent certified group homes in the state, the system that has developed is expensive, segregated and exclusionary, and is no longer economically or socially sustainable.² People with ASD/I-DD and their families are compelled to seek alternatives.

This Guide has been written to help people with ASD-I/DD understand the systems and options for housing. It is intended for the use of people with ASD-I/DD, their families and the people who provide their support including Direct Support Professionals and Provider and oversight agencies.

New York State is home to just under twenty million people.³ For the purposes of this project we estimate the number of people with ASD-I/DD in the state with significant support needs, that is, people who need some level of support all day every day, to be approximately 74,000. Approximately 400,000 additional adults and children need less comprehensive care, across a wide spectrum of need. NY State currently supports approximately 36,000 people with ASD/I-DD in congregate and community housing throughout the state, with an additional 12,000 people on state and county waiting lists for congregate care.⁴

¹ Following the expose of horrendous conditions in the state run Willowbrook School in 1972 families sued the state, in *NY State Association for Retarded Children vs. (Governor) Carey*, the state settled via the Willowbrook Consent Decree of 1975 paving the way for the group home system that grew up over the next 40 years. http://www.leagle.com/decision/19821716551FSupp1165_11530.xml/NEW%20YORK%20STATE%20ASS'N%20FOR%20RETARDED%20CHILDREN%20v.%20CAREY Retrieved May 2014.

² The Group Home system is described in section IV of the Resource Guide.

³ Per the US Census Bureau 2013 report pop. 19,651,127 2013 estimate <http://quickfacts.census.gov/qfd/states/36000.html>

⁴ "OPWDD ICF Transition Plan Implementation Strategy" September 2014. OPWDD.

In the 40 years since the Willowbrook Consent Decree, NY State has developed an extensive group home system.⁵ Funding for this system, primarily from Medicaid and Medicaid Waiver⁶ has been directed to state run facilities and non-profit provider agencies sometimes called “voluntary” agencies because they are controlled by volunteer boards. Voluntary agencies cannot be compelled to provide services, and have the right to select whom they serve. Group homes have been developed by agencies, sometimes with active family involvement, and sometimes independently. Funded by Medicaid, the emphasis has been on health and safety and compliance with a significant body of regulation to govern operations and funding. Financial and programmatic transparency has been limited. This era is coming to an end. Certified settings are seen as expensive,⁷ segregated, over regulated and increasingly out of line with best practices. Federal and state reforms are pointing the way to more self-determination, individualized plans and budgets, lighter regulation and more integrated settings. In the future, housing options will be more flexible, but the process of establishing a home will require more commitment by the person and their family and will demand more flexibility of the provider agencies. In 2012, across the United States more people with ASD-I/DD received Medicaid funded supports and services in their own homes than in congregate settings. New York state lags in introducing more community based options.⁸

The last forty years have also seen many changes in the world of people with ASD-I/DD. Autism was not included as a diagnosis in the Diagnostic and Statistical Manual(DSM) until DSM III was published in 1980. The definition has significantly broadened over time. The overall population of the United States has increased by 50%,⁹ since 1970 and is expected to increase by another

⁵ Braddock et al. The state of the states in Developmental Disabilities 2011 <http://www.stateofthestates.org/index.php/intellectualdevelopmental-disabilities/state-profiles> Retrieved February 2014

⁶ Medicaid Waivers allow states to use Medicaid funding to provide care in non institutional settings. NY Has a 1915(c) waiver, for more about waivers visit the Medicaid .gov website at [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915 \(c\)#waivers](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915%20(c)#waivers)

⁷ The Average annual per person expenditure for ICF/IID per daily participant in NY Was \$444,122 in 2012. (RISP report 2012, University of Minnesota 2012. P 77.)

⁸ As reported in the National Residential Information Systems Project (RISP) 2012. Univ. Minnesota 2014.

⁹ See :“CensusScope” http://www.censusscope.org/us/chart_popl.html retrieved November 2014

40% in the next forty years.¹⁰ It has also been almost 40 years since the passage of PL 94-142, the precursor of the Individuals with Disabilities Education Act (IDEA), and while the education system it created is not perfect, it has benefitted millions of people with disabilities and increased expectations of community integration at all stages of life. Residential settings have to address these realities-a much larger population, that will expect to be more included in the community against a background of static or reduced funding.

The Guide begins with an overview of housing options in the state and how those have been shaped. We then set out paths and options that may be available to an individual and their family. The Guide also lists the “system based” resources that will affect an individual’s housing options. These refer to governmental subsidies and incentives to home builders that will lead to the creation of more housing stock. The guide describes the housing options in the Office for People with Developmental Disabilities (OPWDD) certified system and other state systems. This edition of the Guide includes new sections on Affordable and Supportive Housing, Services and Supports and updated information about Self Directed Services. This edition has sought to provide a more statewide perspective, including the addition of a review of the Institutional Bias impediments that we have to address in order to move the housing agenda forward, and some suggestions as to how we might go about doing so. Finally, the guide describes how to begin to create a housing plan, and how to choose from the options available.

We are very grateful to the Organization for Autism Research for the initial funding that made this guide possible, and to Autism Speaks for the expansion of the guide. We are grateful to both organizations for their continuing commitment to the vital issues that affect people with ASD-I/DD.

¹⁰ US Population projections 2000 to 2050. <http://www.census.gov/population/projections/files/analytical-document09.pdf> retrieved November 2014

THE HOUSING RESOURCE GUIDE

I. First Steps: Eligibility and Entitlement

The path to housing starts with finding out what resources an individual might already have. We begin by determining the governmental services for which an individual may be eligible, and what they need to do to obtain those services. While still in high school a student is entitled to receive Transition Planning Services,¹¹ and these should include plans to become qualified wherever they are eligible for the adult services and opportunities listed below. Whereas children and young adults under the age of 21 are entitled to a Free and Appropriate Education, services for adults over the age of 18 are based on an individual being eligible. Eligibility criteria vary from one state-provider agency to another, and the fact that an individual is deemed eligible does not necessarily guarantee that services will be provided.

A. Supplemental Security Income (SSI) The first step in the application process is to apply for Supplemental Security Income (SSI). SSI pays benefits to adults and children with disabilities who have limited income and resources. The Social Security Administration (SSA) focuses on an individual's ability to be self-supporting, so to qualify for SSI they must demonstrate that they are unable to achieve "Substantial Gainful Activity" (SGA), (currently set at \$1,090 income per month for 2015),¹² by virtue of a disability, and that the disability is expected to last for one year or more. If the application is for a minor child, family income is taken into consideration. For individuals over the age of 18, their individual income is the only one considered. In order to qualify an individual may not have assets in excess of \$2,000. (see notes re "Special needs Trusts" in section II.)

Individuals should contact their local Social Security field office to apply. In most cases family physician reports will be sufficient to establish the disability need. In NY State a person receiving SSI automatically qualifies for Medicaid. An individual can apply for SSI by phone, or in person and may have assistance from a family member or other representative. For more information about how to apply please go to the Social Security website at <http://www.ssa.gov/ssi/text-apply-ussi.htm>.

SSI may be paid to the individual directly, or to an individual they designate as their **Representative Payee**, usually their parent or relative. The "Rep Payee" acts to ensure that the

¹¹ NYS Ed Law requires transition planning begin at the IEP Preceding 15th year. Federal IDEA requires at beginning of 16th year.

¹² To confirm the SGA visit SSA website. <http://www.socialsecurity.gov/oact/cola/sga.html>

Social Security payments are spent appropriately and that the funds are accounted for annually in the Representative Payee report provided to the SSA.

When an individual resides in Congregate Care, the Provider agency generally becomes the Representative Payee, (it is at the individual's option, agencies might pressure an individual to have them become rep payee) and receives an additional "Congregate Care Supplement" to the individual's SSI. The individual in turn receives a modest allowance for personal expenditures, administered from their SSI by the Provider agency. This will be further described in Section V.

B. Social Security Disability Income (SSDI) An individual may also qualify for Social Security Disability Income (SSDI). Social Security is an insurance program, so it requires that an individual should have worked for pay and made at least the minimum monthly contribution to the insurance fund over a specified time, that time being measured in "units" or quarters, the number of which will vary according to the person's age. A person may also be eligible if they have a parent who is retired or deceased and who paid into the fund. For more details, please check the Social Security webpage.¹³ SSDI payments are taken into account when calculating SSI. Once SSDI reaches a certain threshold it may reduce SSI to zero and affect continuance of Medicaid, so individuals and their service coordinators need to monitor the SSDI level. SSDI by itself does not qualify individuals for Medicaid, but once they have been receiving it for 24 months they will be eligible for Medicare. Medicare is the national health insurance program that provides access to health care for the elderly and for people with disabilities. While people with ASD-I/DD may be enrolled in Medicare it is a medical insurance policy and is not directly involved in housing.

- **First Steps**
 - A. Obtain SSI-
 - B. SSDI
 - C. Medicaid
 - D. ACCES-VR
 - E. OPWDD
 - F. MSC
 - G. Waiver
 - H. ISS
 - I. SDSO
 - J. DSS
 - K. County-based DSS
 - L. Income Assessment

C. Medicaid is a health insurance program for people with disabilities, as well as senior citizens and people with low incomes. It was created by the addition of Title XIX to the Social Security Act in 1965. Medicaid is a federal program administered by the states. Funding is at least 50% from federal sources, with the balance being paid by the state. In NY State the counties also contribute to the state payment. States have to administer Medicaid funded programs in adherence to guidelines agreed to with the federal Centers for Medicare and Medicaid Services (CMS). Medicaid is the primary foundation for funding for Long Term Supports & Services (LTSS).

¹³ <http://www.ssa.gov/dibplan/dqualify2.htm> retrieved February, 2014

D. Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR)

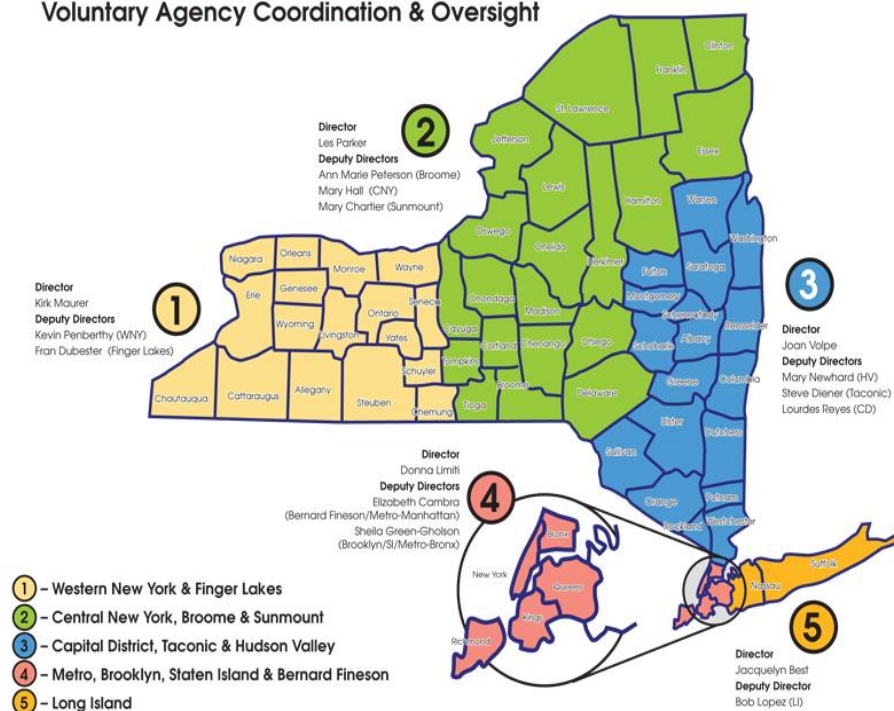
will help people with disabilities to obtain job training and development. The Office for People With Developmental Disabilities (OPWDD) is the principal agency serving people with ASD-I/DD in the state. OPWDD requires that people seeking employment support from OPWDD first seek support from ACCES-VR for most of its programs. If they are not deemed qualified to receive such support from ACCES-VR then they may be able obtain it from OPWDD. Employment is obviously related to housing, and this step is a necessary one on the path to receiving other support from OPWDD.¹⁴ ACCES-VR services can be applied for directly from the regional office, and the application process should begin when a student enters the last year of High School. The application should be included in the student's Transition Plan and school counselors should connect the student with the ACCES-VR process.

E. Office for People With Developmental Disabilities (OPWDD) OPWDD is responsible for coordinating services for New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, Autism Spectrum Disorders, and other neurological impairments. Individuals should apply to one of the 5 Developmental Disabilities Regional Offices (DDROs).¹⁵

5 Developmental Disabilities Regional Offices

Voluntary Agency Coordination & Oversight

Updated: 7/13



¹⁴ It is a sad fact that in order to obtain OPWDD services an individual must first be rejected by ACCES-VR. ACCES-VR emphasizes work and fitness for work, and OPWDD currently emphasizes needs for support.

¹⁵ From OPWDD's website http://www.opwdd.ny.gov/opwdd_contacts/ddro . retrieved June 2014

Once deemed eligible by OPWDD, the current route to obtain services is through the “**Front Door**” Process,¹⁶ which is handled directly by the DDRO. The Front Door process and all aspects of planning are governed by OPWDD’s “**Individualized Community Supports**” (ICS) philosophy which stresses self-direction and choice.¹⁷

1. **OPWDD, The Front Door.** The Front Door process includes an assessment of a person’s needs, which in turn is intended to guide the services that will be provided and the budget associated with those services. Since the 1980’s NY State has used an assessment instrument called the Residential **Developmental Disabilities Profile 2 (DDP2)**.¹⁸ The DDP2 generates a score across three domains; Adaptive, Behavioral and Health. These scores are used to generate a budget and **Personal Resource Account (PRA)** (see (G) below). The algorithm used to generate the PRA is not transparent. The DDP2 also generates an Individual Service Planning Model (ISPM) score on a scale of 1 to 6, with 6 being the highest level of need. This is used to help determine an individual’s level of need. The DDP2 instrument was revolutionary when introduced as a post institutional model in the 1980’s, but it is deficit based and implicitly incentivizes applicants to highlight their disabilities in order to achieve a high level of services and a generous budget. NY State is now introducing the **Coordinated Assessment System (CAS)**. This is a well-tested instrument¹⁹ that seeks to identify a person’s functional needs for support rather than to simply highlight their deficits. Functional need connects to the eventual development of a budget and PRA. The PRA is critical to developing a service plan, and is based on the principle that “**Money Follows the Person**” (MFP).
2. **Money Follows the Person.** The principle that funding for an individual’s services should be “attached” to the individual instead of the agency that provides services was enshrined in the Supreme Court’s Olmstead decision in 1999 in a suit brought under the Americans with Disabilities Act,(ADA). The court ruled that as long as health and safety were assured, an individual could require that services be delivered in a milieu of their own choosing, as long as the costs of the new setting did not exceed those of the institutional setting they had previously been in. Six years later under the Omnibus

¹⁶ Refer to OPWDD Front Door site. <http://www.opwdd.ny.gov/welcome-front-door/home> retrieved February 2014

¹⁷ For more re ICS see OPWDD’s Statewide Comprehensive Plan 2012-2016 http://www.clmhd.org/img/uploads/file/507_Final_1_4_12.pdf. Accessed May 2014

¹⁸ Medicaid requires that states implement a Preadmission Screening and Resident Review (PASRR). The move to CAS is required to maintain compliance. Medicaid’s 2014 report on PASRR described the existing processes as inadequate in much of the country.

¹⁹ The CAS is based on the “Inter RAI”. For more information see their website. <http://www.interrai.org/instruments.html> retrieved May 2014

Budget Reconciliation Act of 2005 President George W. Bush signed the principle in to law affirming that wherever possible money for services and supports should “Follow the Person.” This change in how services are controlled, funded and delivered is the most significant change in policy and practice since the deinstitutionalization of the 1970’s and while it is only slowly being implemented it has far reaching consequences for all stakeholders.

3. **Eligibility for OPWDD.** Eligibility is narrowly defined; an individual must test as having an I.Q. of 60 or lower, or if their I.Q. is higher than 60, must have significant adaptive needs. As OPWDD services have become more expensive, eligibility has become narrower. A significant population of people with ASD-I/DD who need LTSS risk being “shut-out” unless the State can adapt the ways in which services are delivered to be more flexible and individualized to support a spectrum of need.

F. Medicaid Service Coordinator. If a person is approved by OPWDD for its services at the Front Door, he or she should request a **Medicaid Service Coordinator (MSC)**. The MSC will help to ensure that the person is receiving the services for which they are qualified. The MSC also maintains the documents that ensure continuity of service, and creates the **Individual Support Plan (ISP)**. The MSC will assist people in obtaining the Medicaid Waiver, an essential component in securing a flexible budget for housing.

G. Medicaid Waiver. States may negotiate with CMS to be permitted to “waive” certain elements of the Social Security Act, to allow them more flexibility in delivering Medicaid funded services. These generally fall under the mantle of a “**Home and Community Based Services**” (HCBS)²⁰ Waiver. HCBS waivers allow for funding to be directed to the individual need rather than to an agency program, and their introduction in 1981 was intended to increase opportunities for individualized services. They were adopted in New York in 1992, but HCBS funding was soon absorbed in to system based funding rather than individually based funding. NY is currently negotiating a new waiver, the “People First” waiver,²¹ (more technically a 1915 (b) (c) waiver). Under the waiver CMS requires that Medicaid funded programs be more individualized; specifically:

1. Waivers should encourage **Self Direction**.
2. Waivers should include **Person Centered Planning**.
3. Every participant should have an **Individualized Service Plan (ISP)**.

²⁰ HCBS services were created in 1981 but were not taken up in NY until 1992.

²¹ OPWDD’s people first waiver description

http://www.opwdd.ny.gov/opwdd_services_supports/people_first_waiver/home Retrieved December 2013

4. Every participant should have an Individualized Budget, and a **Personal Resource Account (PRA)**.
5. The state must provide Information and Assistance in support of **Self Direction**.
6. The state must monitor for **Quality Assurance** and improvement.

The reforms that OPWDD is initiating coupled with the freedom that the “Waiver” creates, allow for a much more flexible path to housing.²²

H. Self-Direction and Circle of Support. Two critical concepts that are fundamental to individual choice and to which the federal and state funding agencies refer frequently are “Self Direction” and the “Circle of Support.” (OPWDD recently adopted the term “Planning Team” as part of the Self Directed Service Options (SDSO, see x below) process. While the Circle of Support is involved in planning it is also designed to be part of the individual’s life for years to come, to be adaptable to change and to advocate for the individual. We prefer to continue to use the term of art, “Circle of Support” in the context of housing.)

1. **Self-Direction.** The term “Self-Directed” is used by the CMS to mean that “participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports. The self-directed service delivery model is an alternative to traditionally delivered and managed services, such as an agency delivery model. Self-direction of services allows participants to have the responsibility for managing all aspects of service delivery in a person-centered planning process.”²³
2. **Circle of Support.** OPWDD defines a Circle of Support as “a dedicated group of individuals that assists in visualizing, expressing and accomplishing dreams of the focus person. While professional staff is not excluded, the Circle participants are selected by the individual from a wider group, focusing on family, friends, neighbors and other community members. The individual has a controlling voice in all decisions.”²⁴ The OPWDD definition emphasizes an individual’s dreams, but it is always important to keep an eye on realities and what is possible. If an individual is funded through Self Directed Service Options their MSC is required to be a member of the Circle of Support.

I. Individual Supports and Services (ISS). ISS funds are “state only” funds, derived directly from state taxation, and are independent of Medicaid funding. As such they can be used at the

²² NY State issued its “Road to Reform” publication in 2013, which describes the changes in its system and the move to much more individualized and less congregate housing. It is available at the OPWDD website http://www.opwdd.ny.gov/opwdd_about/commissioners_page/commissioners_message/Road_To_Reform . Retrieved January 2014

²³ CMS Website <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>. retrieved April 2014

²⁴ OPWDD website http://www3.opwdd.ny.gov/wp/wp_catalogp1033.jsp retrieved April 2014

state's discretion, allowing for more flexibility. In the past, ISS could be used to pay for a wide range of services, but currently it is only used as a means to provide housing rental subsidies which are based on guidelines from the NY State Department of Housing and Community Renewal (HCR) and which take into account the individual's income. ISS funding can be included in an individual's plan along with their SDSO day funding, but if an individual is using SDSO for their residential plan ISS may not be used.

J. Self- Directed Support Services with Budget and Employer Authority /Self-Directed Service Options (SDSO) formerly known as Consolidated Supports & Services (CSS) is an option for people who already have Medicaid Waiver and who seek to have more Self - Direction of their budgets.

For SDSO individuals must apply through the Front Door, where the DDRO will assess whether they would be best served by the Self Directed model. If approved for SDSO the DDRO will provide them with a list of brokers, (formerly termed "Start-Up" brokers). The broker will help them and their Circle of Support to create a Person Centered Plan and budget for the services they need, including residential support. Under SDSO the MSC must be a member of the Circle of Support, and cannot simultaneously function as a broker and an MSC. Best practice suggests that the MSC should not work for the primary provider agency, or for the Fiscal Intermediary. Once the budget has been approved by the DDRO and by the Division of Budget in Albany, the broker will either continue to work with the individual or alternatively forward the brokerage role to another broker, (formerly termed the "Support Broker") who will work with the individual to implement and sustain the plan. Under SDSO individuals may choose to obtain services from a provider agency, or, subject to certain restrictions and requirements, hire someone they select themselves. This is known as self-hire. Services that are not directly purchased from an agency are paid for through an OPWDD approved **Fiscal Intermediary (FI)** (formerly known as Financial Management Service agency or FMS) which acts as the employer of record for any self-hires. SDSO was created in 2009 but is only now being scaled up and there are frequent operational changes as the system adapts. These changes can be frustrating to all involved, but the principle behind SDSO - Money Follows the Person - is essential to realizing housing independence, and SDSO, sometimes coupled with ISS, is the current mechanism within OPWDD services that is built around that principle.

K. County based Departments of Social Services (DSS) The Department of Social Services (DSS) is under The New York State Office of Children and Family Services (OCFS). The DSS within New York State's Medicaid program covers personal care services, also known as home attendant services, for those that qualify for these services. This is a type of unskilled, custodial care provided in the home to people with physical or mental impairments that interfere with their ability to independently perform activities of daily living. They can provide funding for

personal aides and other support and medication management through **Consumer Directed Personal Assistance Program (CDPAP)**. These funds cannot be used to purchase housing services but they expand the options for residential supports. Application is made through the DSS using a 1050 form. Eligibility is based on the level of need, and applicants must have Medicaid.²⁵

L. Income Assessment. People with a disability who have limited access to gainful employment will probably have low incomes. “Low Income” is defined at various levels by the federal government but the base Federal Poverty level published by the US Health and Human Services administration for 2014 is \$11,670 for a one person household. SSI payments vary depending on individual circumstances but the current individual payment in NY State is \$808 per month, or \$9,696 per annum. People who rely on SSI qualify for most federal and state programs that are based on low income. These include:

1. **Supplemental Nutrition Assistance Program (SNAP).** Formerly known as Food Stamps and funded through the US Department of Agriculture, the program is administered through the local DSS. Eligibility and extent of SNAP and HEAP (below) are both based on the household income, not just the individual’s. The person’s MSC should help to coordinate this application.
2. **Home Energy Assistance Program (HEAP).** This program is funded through the US Department of Health and Human Services to assist with home heating needs for people with low incomes.²⁶ If an individual receives SSI or SNAP, they will also be eligible for HEAP. The application process usually starts around Thanksgiving each year. The MSC should coordinate this application.
3. **ConEd CONCERN.** The "Concern" program covers billing options, third party notification, and other services. Con Ed also has a "**Low Income Rate**," where the account holder can receive a discount on the monthly Basic Service. The discount can range from \$7-\$12 per month. The **Energy Share** program is a \$200 grant, which works in tandem with HEAP. This program is only to be used in an emergency; it requires that the customer has an active “disconnect notice”, and it can only be used once every 5 years.²⁷ These programs are available to those receiving SSI/Medicaid. The application process begins in mid-January, and is the responsibility of the individual.

²⁵ Contact information for County DSS at NYS DOH website.

https://www.health.ny.gov/health_care/medicaid/ldss.htm retrieved June 2014

²⁶ Office of Temporary and Disability Assistance, (OTDA) website <http://otda.ny.gov/programs/heap/> retrieved February 2014

²⁷ <http://www.coned.com/customercentral/brochures/Customers%20With%20Special%20Needs.pdf>,
<http://www.coned.com/energyshare/>

4. **LifeLine.** This is a basic phone service which is supported by the Federal Communications Commission, and also by the Universal Service Fund. The program provides discounts on monthly telephone service (landline or wireless) for low income individuals. Income levels need to be below \$15,755 p.a. and only one LifeLine is available per household. The application may take up to 90 days to process for approval and it must be renewed annually. As an example, Verizon offers a landline base rate of \$1/month for the dial tone (monthly service) vs. its standard fee of \$15.80/month, plus \$0.09 for each local call.²⁸

In addition to the support an individual may receive from public sources like the Social Security Administration and OPWDD, they need to consider the resources that they and their family can generate to help to obtain housing. We have termed these “Individual Resources.”

²⁸ <http://www.fcc.gov/guides/lifeline-and-link-affordable-telephone-service-income-eligible-consumers>
http://www.verizon.com/Support/Residential/phone/homephone/billing/special+billing+services/information+about+your+service/95830.htm?CMP=DMC-CVZ_ZZ_ZZ_Z_ZZ_N_Z103

II. Individual Resources

Public benefits can help to provide long term sustainable support, but as people with ASD-I/DD have increasingly become more integrated into the community other sources of income and support have become available.

A. Employment As described by the US Department. of Labor, “**Employment First**” is a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community. Under the Employment First approach, community-based, integrated employment is the first option for employment services for youth and adults with significant disabilities.”²⁹ Since 2012, NY State has been an Employment First state, and its principles have been adopted by OPWDD.

In the past a person with ASD-I/DD might have been directed automatically towards a “Day Program” of segregated enclave work in “Day Habilitation.” They may have worked in a “Sheltered Workshop” for wages, or received “Supported Employment” (SEMP) services or “the Employment Training Program” (ETP) funded through OPWDD. As part of the Transformation agreement with CMS,³⁰ Sheltered Workshops are closing. Day Habilitation services will be encouraged to be “without walls,” not center based, and to increasingly emphasize “Pathways to Employment,” a new program with the goal of paid work for as many people as can achieve it. This major social, cultural and financial transition will take many years. Its impact will be that people with ASD-I/DD who in the past were not expected to earn their own money will now be able and expected to do so.

A significant impediment to increasing employment for people with disabilities has been the perception that earning an income will reduce or eliminate benefits. Much publicly available information concerning this issue is misleading or false. The reality is that most people receiving benefits will add to their net incomes if they are paid for the work that they do. Anyone who is aspiring to paid employment and who receives benefits should meet with a Disability Benefits Specialist to learn about how to retain benefits while earning income. Benefit Advisement is a service offered through OPWDD and/or ACCES-VR funded agencies, or through private fees to agencies that provide this service.

B. Supplemental Needs Trusts (SNT) An SNT holds funds that can be used to supplement the public benefits received by a person with a disability without compromising their public

²⁹ Employment First at the US. Department of Labor. <http://www.dol.gov/odep/topics/EmploymentFirst.htm> retrieved April 2014.

³⁰ NY OPWDD agreement with CMS, <http://www.opwdd.ny.gov/transformation-agreement/home>. Retrieved April 2014

benefits, including SSI and Medicaid. Funds may be used to pay for personal items and necessities with limitations on their use to buy food or shelter. Trusts are not solely for people of means, and can be used to provide for housing support and, with restrictions, for housing itself. Trust Law is a specialized field, the laws vary from state to state and it is essential that an individual and their family consult with a New York licensed Special Needs or Elder Law attorney before creating or joining a trust.

There are three primary types of SNTs that are established for individuals with ASD-I/DD.

1. **Third Party/Supplemental Needs Trust (SNT).** These are usually established by a parent or other guardian or relative. Funds may be invested immediately or over time, or they may be funded through an insurance policy payable upon the death of a parent. Upon the death of the beneficiary funds revert to the trust to be disposed of at the trustee's discretion.
2. **First Party Trust.** Established by an individual, their parent or guardian or court, and funded with the assets of the beneficiary, for example from an insurance or lawsuit settlement. When the beneficiary dies, the state has a right to be paid back for medical assistance (e.g. Medicaid) if there are any assets left in the trust. This is sometimes referred to as Medicaid "Claw-back."
3. **Pooled Trust.** This is an SNT for an individual that is managed by a nonprofit organization and established by a sponsor, such as an OPWDD provider agency. The sponsor manages the trust for the beneficiary in the same way as the other SNTs, with the difference that when the beneficiary dies any remaining funds may revert to the sponsor rather than to Medicaid.

As noted above, Trust law is complex, and creating or funding a trust requires significant qualifications and expertise. A consultation with a specialized attorney is essential.

C. The "Achieving a Better Life Experience" (ABLE) act.

At this writing the ABLE Act was passed by the House and Senate in December 2014, and was signed into law by President Obama. The next stage will be for each state to create their own governing law and regulation, similar to the way "529 plans" were created for college savings.

Per the summary on Congress.Gov website³¹ the "Achieving a Better Life Experience Act of 2013 or the ABLE Act of 2013 - Amends the Internal Revenue Code to establish tax-exempt ABLE accounts to assist an individual with a disability in building an account to pay for qualified disability expenses. Defines

³¹ <https://www.congress.gov/bill/113th-congress/house-bill/647>. Retrieved December 2014

"qualified disability expenses" to include expenses for education, including higher education expenses, a primary residence, transportation, obtaining and maintaining employment, health and wellness, and other personal support expenses.

Treats a qualified ABLE program and an ABLE account in the same manner as a qualified tuition program for income tax purposes (i.e., allowing a tax exemption for such program and an exclusion from gross income of amounts attributable to a contributor to or a beneficiary of a program account). Defines "qualified ABLE program" as a program established and maintained by a state agency under which a person may make contributions to an ABLE account established to pay for qualified disability expenses.

Requires amounts in ABLE accounts to be disregarded in determining eligibility for Medicaid and other means-tested federal programs. Suspends the payment of supplemental security income benefits under title XVI (Supplemental Security Income) of the Social Security Act to an individual during any period in which such individual has excess resources attributable to an ABLE account"

Essentially the ABLE Act is a 529 plan for people with disabilities, similar to the exemption from IRS code section 529 that allows for special tax treatment for savings that go towards higher education. In allowing individuals and families to save funds of their own to provide for their disability related needs it is revolutionary and has the potential to change how we plan for services and supports in the future.

D. United States Department of Housing and Urban Development (HUD).

HUD has a range of programs that help individuals to pay for housing and housing developers to create it.

1. **Housing Vouchers.** Section 8 of the US Housing Act of 1937 administered by the US Dept. of Housing and Urban Development (HUD)³² was created "For the purpose of aiding lower-income families in obtaining a decent place to live and of promoting economically mixed housing, low income housing support and Housing Choice Vouchers." Section 8 vouchers allow for a person with low income to limit their housing cost to 30% of their gross income with the balance paid by the program. Housing Choice vouchers also allow for a tenant to save towards the purchase of a home. Each municipality in each state has a quota of vouchers. Waiting lists can be long, many are closed to new entrants and funding is currently constrained by federal budget

³² Section 8 of the US Housing Act of 1937 as amended,
<http://portal.hud.gov/hudportal/HUD?src=/programdescription/cert8> retrieved February 2014

sequestration. Notwithstanding these constraints an individual should seek to be included in any open list where they live; vouchers are portable, and waiting lists are not infinite.

Housing vouchers are intended to be used by people with lower incomes. While the HUD guidelines are complex in detail, broadly, **Low Income** is defined as 80% of the Area Median Income, (AMI), and **Very Low Income** as 50 % of the AMI.³³ Housing agencies must provide 75% of their vouchers to applicants whose incomes do not exceed 30% of the area median income.³⁴ To determine your AMI you should visit the US Census Bureau website and sort by your county or municipality. There is a wide range of income in the state; median household income in Lewis County is \$45,187 in contrast to Nassau County's at \$97,049. The median value of owner occupied housing in Westchester County is \$533,400, that of Cayuga County is \$101,400. Per capita income in New York County is \$61,951, while in adjacent Bronx County it is \$18,048. These contrasting levels of wealth are relevant to the provision of housing and services. Housing costs, including local taxes, help to determine where people live. The availability of Direct Support Personnel ("DSPs") and other service providers is influenced by the cost of housing and commuting, and affected by potential earnings from other work in the region. The reimbursement rates paid to providers vary from region to region depending on the service provided. By contrast, the rates paid under the "State Plan" for MSC providers, and under the Medicaid Waiver for Start Up and Support Brokers are the same statewide, regardless of local labor market or of the local cost of living. As noted above the typical income from SSI is \$9,696. Most people with ASD-I/DD whose income is primarily from SSI will qualify for Section 8 vouchers. While these vouchers are intended for those with low incomes there may additionally be "preferences" for people with disabilities. To apply for a Section 8 voucher an individual should contact their municipal Housing Authority directly.

2. **Does having a Trust or other Assets impact Section 8 Eligibility?** In general, some assets, particularly those that could be used to pay rent or pay medical expenses, often known as "investable" assets, can be considered part of an individual's resources. The Section 8 office may calculate an annual hypothetical income from those resources at a 2% rate. Even though a Third Party Trust is not under the control of the individual beneficiary, it could be included as one of these assets. The Special Needs Alliance

³³ HUD Schedule of income guidelines.

http://www.huduser.org/portal/datasets/il/il14/IncomeLimitsBriefingMaterial_FY14_v2.pdf retrieved February 2014

³⁴ HUD website.

http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/about/fact_sheet retrieved January 2014

publication, “The Voice” issue of March 2011 described the impact of an SNT on eligibility.³⁵ The Evelyn Frank Legal Resources program of the NY Legal Assistance Group has a helpful publication, “Supplemental Needs Trusts, Impact on Medicaid and other public benefits” (2013) which has up to date information on how public benefit oversight agencies view trusts.³⁶ As with any legal matter the individual should consult an attorney.

3. **Section 9** of the Housing Act provides for funding for **Public Housing Authorities (PHAs)**. HUD funds both capital and operating expenses for the PHAs in NY State, 25 of which are listed on HUD’s website.³⁷ PHAs provide housing for low income individuals (80% to 50% of AMI). As with the individual Section 8 vouchers, the individual pays approximately 30% of their income for rent with the balance assumed by the PHA. PHAs maintain their own separate waiting lists.

E. Credit and Credit Score. As with anyone else who will be purchasing or renting a home the lender or landlord will want to see if an individual is creditworthy. The lenders will look at income, whether from an entitlement, a trust, or from work. They will also look to see if there is a sound history of paying back any credit owed and that the individual is reliable with their bills and obligations. There are companies that track individual credit history and it is important to have developed and demonstrated a good credit history if an individual wants to obtain a mortgage or other financing. Obtaining a “Secured Credit Card”, or being an “Authorized User” on another person’s such as a parent or guardian’s credit card, and having a history of making regular payments (rent, etc.) are all ways that an individual’s credit usage can contribute to building a credit history. It can take one or more years of payment history to build a credit history but it is a helpful way to learn money management skills and to build independence. The sooner an individual gets started the better.

In addition to the resources that an individual may have access to, there are resources at the “system level” that will affect their opportunities and the availability of housing. We will review those in the next section of the guide.

³⁵ <http://www.specialneedsalliance.org/the-voice/the-impact-of-special-needs-trusts-on-eligibility-for-subsidized-housing-2/>

³⁶ Available online at ; <http://www.wnyc.com/health/afile/44/9/> Retrieved May 2014

³⁷ Look for your closes PHA on the HUD site http://portal.hud.gov/hudportal/HUD?src=/states/new_york/renting/hawebsites. Retrieved November 2014

III. System Resources

In addition to benefits and supports that are directed towards the individual, there are state and federal programs that are intended to incentivize public and private creation of affordable housing. These incentives may not necessarily be directly involved in an individual housing search, but they form part of the background; they exist to create more affordable housing for our community and mobilizing these incentives forms part of our communal agenda.

A. HUD Resources for Developers

1. **Section 811.** The Section 811 program aims to expand the supply of affordable housing that includes units specifically intended for people with disabilities. Low cost mortgages are applied for by nonprofit organizations in collaboration with developers. Each project must have a Supportive Services plan developed by a provider agency that includes, for example, case management, training in independent-living skills and assistance in obtaining employment. Nonprofit organizations with a Section 501(c) (3) tax exemption from the Internal Revenue Service can apply for a capital advance to develop a Section 811 project. These funds are applied for by developers and nonprofits via the Grants.gov website.³⁸ The section 811 approach has successfully been applied to recent developments in Rockland and Monroe Counties.
2. **HOME Investment Partnerships Program (HOME).** HOME is the largest federal block grant to state and local governments designed to create affordable housing for low-income households. Funding may be used for building, buying or rehabilitating affordable housing for rent or homeownership. The funds can also be used to provide rental assistance directly to low income individuals through local governments. Each state also develops a Five year Consolidated Plan that articulates how the funds will be used. There are opportunities for public comment on the five year plan as it is developed and also during the Annual Action Plan review.

HUD has several other programs that support housing at the state and local levels:

3. **The Public Housing Agency Plan** requires the Public Housing Authority to outline the approach to meet low income housing needs in their area. A 5-year plan is required, with annual updated plans. The Plan for a local PHA can be obtained from the HUD website.³⁹
4. **Community Development Block Grant (CDBG).** CDBG funds are also developed as part of the five year plan. These funds are allocated to states and then on to counties and

³⁸ http://portal.hud.gov/hudportal/HUD?src=/program_offices/administration/grants/fundsavail/2014gensec (March 2014)

³⁹ http://www.hud.gov/offices/pih/pha/received/view_received_plans.cfm#NY042 Retrieved November 2013

municipalities. Funds are available for building, renovating or other projects relating to development. These funds are typically used to facilitate access, e.g. by maintaining or installing new sidewalks and sewers. In a recently built development in Rockland County NY the funds were used to improve the municipal supply of fresh water to the site. Typically funds are not directly used for housing construction. The planning process for the Consolidated Plan is open to the public and individuals and advocates should participate if they have the opportunity to do so when their community's five year plan is up for renewal and during the annual review. You should check with your municipality as to when the next Consolidated Plan revision is planned.

5. **The Continuum of Care Program** focuses on the reduction of homelessness (those living in shelters, emergency housing, etc.). Continuum of Care is a competitively awarded grant process whereby the local housing consortium agrees on which homeless support programs should be funded. While the level of homelessness among people with ASD-I/DD in New York State is hard to determine there is evidence from a small UK study that people with "High Functioning" ASD are over represented in the ranks of the homeless.⁴⁰ This is a subject that merits further examination.
6. **Self-help Homeownership Opportunity Program (SHOP)**. SHOP is a grant program authorized by the Housing Opportunity Program Extension Act of 1996, Section 11 that awards funds to eligible national and regional nonprofit organizations to purchase home sites and develop or improve the infrastructure needed to set the stage for "sweat equity" and volunteer-based homeownership programs for low-income persons and families. SHOP funds must be used to develop housing for low-income persons and families who otherwise would not become homeowners. Homebuyers must be willing to contribute significant amounts of their own sweat equity toward the construction or rehabilitation of their homes. Grantees include organizations such as Habitat for Humanity and the Housing Assistance Council.⁴¹

B. US Department of Agriculture (USDA) ⁴²

The USDA provides financing to developers, municipalities and nonprofits to build housing for elderly, disabled, or low-income rural residents in multi-unit housing complexes. Despite being home to the most populous city in the country, NY State ranks 7th in overall density, with extremely low density in some parts of the state in particular in the Finger Lakes and Western NY region.

⁴⁰ Report in Autism Daily news, February 2014. <http://www.autismdailynewscast.com/are-people-with-autism-at-a-higher-risk-for-homelessness/6784/laurel-joss/> Retrieved May 2014

⁴¹ http://portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/affordablehousing/programs/shop . retrieved February 2014

⁴² <http://www.rurdev.usda.gov/Home.html> retrieved February 2014

1. **Rural Rental Housing Loans (Section 515 financed housing).** Section 515 loans can be extended to for-profit or nonprofit organizations, as well as public agencies. Certain communities are targeted for the loans. The extent of USDA eligibility for rural areas can be seen from the map on page 27.
2. **Housing Preservation Grants** are made to local municipalities, state agencies or nonprofit organizations to repair or rehabilitate rental units to benefit low income individuals.
3. **Site Loans: Section 524** loans are made to nonprofit organizations to purchase land (the “site”) for the building of housing to benefit low income individuals.
4. **Section 502** loans help low income individuals or households purchase homes in rural areas. Funds can be used to build or renovate.⁴³
5. **Guaranteed Rental Housing Loans** are designed to increase the supply of moderately priced multi-family housing in rural areas for low income individuals. Public agencies or other entities can apply for these funds. Under this program, the USDA guarantees funds that are provided through the larger semi-government lending programs (Federal National Mortgage Association (FNMA), Federal Home Loan Mortgage Corporation (Freddie Mac, FHLMC), HUD, or Government National Mortgage Association (Ginnie Mae, GNMA).

C. Internal Revenue Service: (IRS)

The IRS is not directly involved in housing but is a major factor in its creation. While we don’t commonly think of the IRS as creating housing, mortgage interest tax deductibility and capital gain exemption provide, by some estimates, up to \$100 Billion in housing stimulus annually. Some argue that this stimulus unfairly benefits the privileged and the real estate industry, but there are also housing exemptions and credits that can stimulate affordable housing in particular through;

1. **Low Income Housing TAX Credits (LIHTC).** The LIHTC Program is an indirect federal subsidy used to finance the development of affordable rental housing for low-income households. The LIHTC Program, which is based on **Section 42 of the Internal Revenue Code**, was enacted by Congress in 1986 to provide the private market with an incentive to invest in affordable rental housing. Federal housing tax credits are awarded to developers of qualified projects. Developers then sell these credits to investors to raise capital (or equity) for their projects, which reduces the debt that the developer would otherwise have to incur. Because the debt service burden is lower, a tax credit property

⁴³ USDA website Rural Development Housing & Community Facilities.
http://www.rurdev.usda.gov/rhs/sfh/brief_rhguar.htm retrieved July 2014

can in turn offer lower, more affordable rents. This is a very important incentive in building housing. Ninety percent of all new affordable housing in the United States is developed with funding incentives from this tax credit. There are qualified Low-Income Housing tracts in every part of the state.

2. **New Markets Tax Credit (NMTC)** The NMTC Program was established as part of the Community Renewal Tax Relief Act of 2000⁴⁴ to encourage investment in low income urban neighborhoods and permits individual and corporate taxpayers to receive a credit for making **Qualified Equity Investments (QEIs)** in qualified **Community Development Entities (CDEs)**. The private investor receives a 39% federal tax credit. Areas that have a poverty rate of 20% and median family income at or below 80% of the area median are eligible.⁴⁵ These funds are to foster development in low income communities for low income individuals. NMTCs can be combined with other programs to further increase the incentive to attract capital to these low income areas, such as the **Historic Tax Credits (HTCs)** and **Renewable Energy Tax Credits (RETCs)**, but not with the LIHTCs.

D. Federal Home Loan Bank (FHLB) The FHLB funds the **Affordable Housing Program (AHP)**, which directs member banks to partner with developers and community organizations and can also utilize other programs such as the LIHTC and CDBGs to develop housing for low income populations. In addition, the **Community Investment Program (CIP)** provides funding to member banks to be used for long-term projects that create low-income housing.⁴⁶

Understanding the role of the federal and state governments in creating housing involves a great deal of information, some of it complex, and the brief review here does not by any means depict the whole range of activity. An individual and their family do not need to become experts in order to make their own plans; however it is important that they be aware of the range of options that may be available, especially when collaborating with others to create a home or working with a provider agency or a developer to find ways to finance a home. The system is complex, no one has all of the answers, and the more informed the individual is, the broader their range of choices will be.

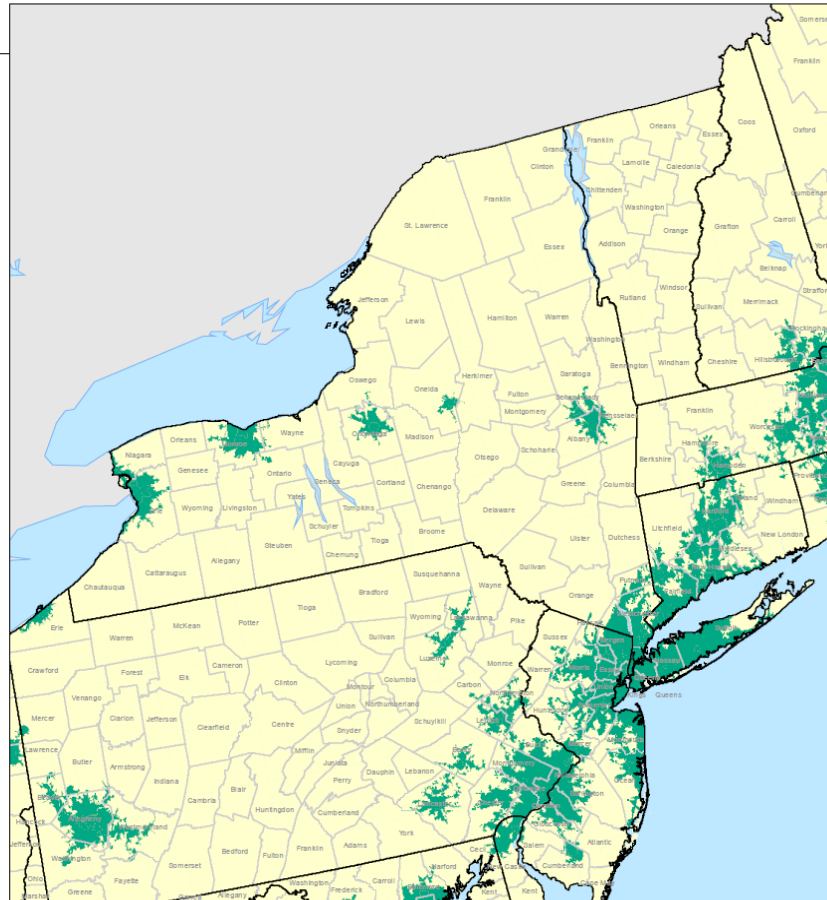
⁴⁴ Community Renewal Tax Relief Act of 2000 retrieved May 2014
http://portal.hud.gov/hudportal/documents/huddoc?id=19129_actof2000.pdf

⁴⁵ <http://nmtccoalition.org/2012/01/09/nmtc-fact-sheet/>

⁴⁶ <http://www.fhlbny.com/community/community-lending-programs/cip/index.aspx>. Retrieved January 2014

New York

The USDA Business and Industry ineligible locations are Census Places greater than 50,000 people and their adjacent and contiguous Urbanized Areas



For more information on definitions, see documentation

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E. Affordable Housing “In order to thrive, lower income families need housing in healthy neighborhoods with low crime rates, access to quality education, meaningful job opportunities and affordable and reliable transportation options”. (National Housing Trust).

In addition to the housing available through rental and purchase subsidies from HUD section 8 and Public Housing agencies through section 9, there is a wide range of housing created by for-profit and not-for-profit housing developers that people with low incomes and people with disabilities may qualify for. The initiatives that create affordable housing take different forms but their common goal is to help communities to sustain diversity. This goal might be framed as maintaining economic diversity, permitting people who work in a community to live there - municipal workers, teachers and other essential professions. It might also be to help people who are aging to remain within their communities when they can no longer afford high real

⁴⁷ Rural NYS per the USDA http://www.ers.usda.gov/datafiles/Rural_Definitions/StateLevel_Maps/NY.pdf retrieved July 2014

estate taxes, or for people with disabilities to remain in familiar and supportive communities. Public policy nowadays seeks to encourage inner town, inner village density and to reduce sprawl, creating more vibrant downtowns. Affordable housing is an essential element in creating a cohesive community,

1. **What is Affordable?** The term “Affordable” means different prices in different places. Generally, affordable housing vacancies are allocated on the basis of a range of income tiers that reference the Area Median Income (AMI). For example, a development might consist of 100 dwelling units (“du”s) of which 80 are to be sold at market rates, 10 are reserved for rental for people earning 80% of AMI, and 10 for people earning 50% of AMI.⁴⁸ It is important to remember that the properties are allocated to people with low income, not no income, but people with ASD-I/DD who have SSI and some earnings and a housing allowance through ISS or other means will qualify for the lower income levels. The rents they will pay may be as low as 50% of the market rent for the property, allowing them to live in a decent home and remain part of the community, while making the property more accessible and financially viable for them and for the taxpayer in the event they are receiving a residential subsidy.

For some, “Affordable” might imply that the housing is of poor quality or in an undesirable neighborhood. There is some historical basis for that prejudice, but the world of affordable housing has changed as the breadth of need has changed. In a series of case studies examining ways to create affordable housing⁴⁹ the nonprofit organization Business and Professional People for the Public Interest highlighted six important observations:

- Affordable housing can be built in character with the rest of the community
 - Affordable housing can be constructed with little public subsidy
 - Affordable housing will work in affluent areas
 - Affordable housing does not have to be constructed in high rise or dense developments
 - Affordable housing can reach a mix of household incomes
 - Affordable housing can be built without a decline in real estate values
2. **How is Affordable Housing Created?** Government has a long history of intervention in the real estate market. The federal government has provided infrastructure to facilitate

⁴⁸ NY State HCR Publishes a listing of AMI levels by county ranging from 30% AMI to 166%. List is available at <http://www.nyshcr.org/Topics/Home/AHCIIncomeLimits.pdf> retrieved November 2014

⁴⁹ A Community Guide to creating Affordable Housing. BPI Regional Affordable Housing Initiative 2005 available at www.bpichicago.org.



The Picture above shows Mason's Ridge, a development in New Windsor New York that includes 84 units of mixed family and special needs, including 70 affordable and 14 affordable special needs units with services coordinated by several social service agencies. The picture has been provided by Regan Development, the creator of the Housing.

development, tax abatements to encourage employment in construction trades, tax deductibility of mortgage interest and other incentives through HUD. Much of the affordable housing creation however takes place at the local level. Local authorities have a range of zoning tools to encourage development. These include "Mandatory zoning" – requiring that any new development include affordable units, or less formal voluntary guidelines that are negotiated with each new development. Sometimes these "set-asides" rely on the market rate unit sales or rentals to offset the affordable units without public subsidy; sometimes there are direct rental subsidies or property tax incentives. The field requires considerable expertise and experience but there is a mature industry of for-profit development companies that are well versed in the structuring of incentives, zoning, community needs and preferences and federal and state subsidies. From the perspective of people with ASD-I/DD, the question is less about how to create affordable housing and more about how to connect with developers and realtors and nonprofit groups that act as the gatekeepers to affordable housing.

3. **Where to find Affordable Housing?** State Housing and Community Renewal (HCR, formerly

DHCR) has an interactive website that provides information on available rental housing, "NYHOUSINGSEARCH.gov" <http://www.nyhousingsearch.gov/> The site lists properties by city and county, across different sizes and includes developments that have reduced rents as low as 50% AMI.

As described above, affordable housing is a very local affair. Your community may already have an Affordable Housing corporation, a Community Land trust, a Housing Partnership or a Redevelopment corporation. The municipal or regional administrator of HUD section 8 programs can be a resource for connecting with developers and property managers of affordable housing.

F. Supportive Housing

1. **What is Supportive Housing?** The group home system for people with ASD-I/DD that we have now was created in the 1980s and subsequent years in large part by the then newly established Office of Mental Retardation and Developmental Disabilities, (OMRDD now OPWDD), the requirements of the Willowbrook Consent Decree, and the advocacy of provider organizations and families. The mid 1970s furor over Willowbrook and other institutions for people with ASD-I/DD was happening at the same time that deinstitutionalization was scaling down psychiatric hospitals and mental health institutions. People with mental health needs did not receive the same level of support as people with ASD-I/DD. People with mental illness who had been discharged from institutions in the late 70s and the 80s frequently had little discharge planning or support and became homeless, with meager resources to provide for their daily needs or their long term care. The rapid deinstitutionalization period coincided with a shrinking of available housing stock and Single Room Occupancy (SRO) hotels in New York City that had formerly been a housing option, but which had degenerated over time. The emergence of Supportive Housing was in response to this desperate need and is itself a triumph of practical advocacy.

To quote the Supportive Housing Network of NY website⁵⁰ “Supportive Housing is just that; Housing plus support.” Originally created to address the housing needs of the elderly it has since evolved as an effective way to address the housing and long term supports and services needs of a broad range of people. The primary format is for a nonprofit organization to own the property, rent the accommodation to tenants at an affordable rate, and to either import services from a separate organization or to provide them themselves. Services include benefit optimization and physical health and mental health care, but may also include recreation, food services and other support. NY State now has some 45,000 units of supportive housing, most of them in New York City but also elsewhere in the state.

2. **How is Supportive Housing created?** Provision of housing for people with ASD-I/DD from the 1970s until today has followed a different path to the supports provided to people with mental health and substance abuse as well as chronic health conditions including HIV-AIDs. In some ways people with ASD-I/DD have been provided for more generously because there was more funding per capita than that provided to some other people with long term support needs. That picture is beginning to change, and in particular for people who have significant needs but who are not eligible for OPWDD

⁵⁰ <http://shnny.org/learn-more/what-is-supportive-housing/> retrieved November 2014

services or who will receive little support from OPWDD. As a community we have to learn about other housing options, and supportive housing is a model that is already serving thousands of people effectively and sustainably. As is the case with Affordable Housing, it is a mature industry with professionals who know how to negotiate the system. Families, advocates and ASD-I/DD provider agencies would do well to reach out to the Supportive Housing industry, to understand how Supportive Housing can be created and to collaborate with existing providers.

We have reviewed public and private individual resources and the resources the affordable housing system might offer. The next section will describe the group home or supported living options from the state agency, OPWDD, and from other state entities.

IV. State agencies that support housing for the aging or for people with disabilities

A. Traditional Group Homes

When most of us think of housing for people with ASD-I/DD the image that first comes to mind is that of a group home. Group homes come in several different forms, and while they are not the main focus of this guide, it is important to understand the principal types. Bear in mind that a Group Home is primarily an economic construct, the primary reason for people with ASD-I/DD to be congregated is to save money on services, rather than because people with disabilities necessarily desire to live with other people with disabilities. The following description of traditional housing services is taken with kind permission of the creators from “A Brief Guide to Residential Services,” published by GROW Inc., a housing advocacy organization in Westchester County that has been advocating for people with I/DD for over 30 years.⁵¹

“Types of Residential Housing Options:

There are two major types of housing options:

1. **Non Certified Residential Opportunities:** (which will be discussed later) and

2. **Certified Residences:** These are programs licensed by OPWDD to provide housing and services and, when appropriate, overnight supports to individuals; they may be operated either by OPWDD or by a nonprofit /“voluntary” agency whose programs are certified by OPWDD.

a. Individualized Residential Alternative (IRA): provides room, board and individualized service options.

i. Supportive IRA – provides varying levels of staff support, according to the needs of each individual; this is typically for a more independent person.

ii. Supervised IRA– provides 24 hour staff support and clinical supports as needed by the individuals living in the residence.

b. Intermediate Care Facility (ICF): provides 24 hour staffing and clinical services for individuals with specific medical and/or behavioral needs. (An individual living in an ICF will not receive MSC support)

⁵¹ We recommend the brochure, copies may be obtained from GROW <http://www.growny.org/docs/info.htm> or from WIHD. Creation of the brochure was sponsored by Westchester County Department of Community Mental Health (DCMH). Spring 2013

c. Family Care: provides a family living experience in a structured, stable home environment.

Selection Process and Transition:

“At this time, for those people who need a certified setting, there is one way to access this opportunity and that is through an opening or vacancy in an existing residence. [Westchester County] Department of Community Mental Health (DCMH) is notified by a provider agency when there is an available opening and they will then match an individual from the residential waitlist with the general characteristics of the other people who live in the house. There is a screening process which consists of an exchange of both written and verbal information and of time spent getting to know each other through observation, interviews and visits.”

[This description was designed to describe how things work in Westchester County where applications are made through a Single Point of Access (SPOA) at the County level. In most counties in the State the primary point of access is the regional DDRO]

Certified Group Home settings are not for everyone. As noted above they are not available to all, and are not necessarily the right fit for the majority of people with ASD-I/DD. However, people with significant needs or who require substantial support may wish to pursue this route. Financial incentives to certified housing operators that are not available to people living independently make the creation of certified settings simpler in some ways than the creation of non-certified settings. These include a congregate supplement to the residents’ SSI which is paid to the provider agency, funding for property maintenance, exemption from local taxes and assistance in low cost borrowing needs. These subsidies, sometimes termed “institutional bias” are one reason that the movement to more independent housing has taken so long.

B. OPWDD “Family Care”

OPWDD Family Care is the oldest of OPWDD’s community based residential programs, founded in the 1930’s, and originally intended to move people from institutional settings into the homes of people living in the community adjacent to the institution, mostly DSPs who worked there. The provider family cannot be related to the individual resident. Since those early days the program has since been adopted by voluntary providers, and there are now two parallel programs, one operated by the state (SOFC) and the other by the voluntary providers (VOFC). Family Care residences are certified by the state. Family members are trained and oversight is provided by the state itself or by voluntary providers funded by the state. Family care providers are paid a (tax free) stipend for each resident, with a maximum of four residents to a home.⁵²

⁵² For more information on Family Care see OPWDD site <http://www.opwdd.ny.gov/node/402>

Family Care operates successfully for many people, but some express concern that it can be akin to “Adult Foster Care” and that there is something amiss when families cannot receive support for their own son or daughter in their own home, while such support would be provided to a non-relative. This latter concern is increasingly relevant now that the IRS has ruled that “Difficulty of Care” payments, i.e. in home support funding, may be made to family members, including parents.

People with ASD-I/DD may be eligible for services from providers other than OPWDD. As the paths to housing change it becomes clearer that people with ASD-I/DD need to understand these other services and forge alliances with other groups that seek to find LTSS and housing.

C. New York State Office of Mental Health (OMH)

The NYS OMH is charged to assist those with Mental Illness with medical care and related support services. Historically OMH provided housing through its Community Residence Program which ranged from highly supported “Congregate Treatment” settings, through less restricted settings with all day support, to Single Room Occupancy (SRO) settings with varying levels of support. In the past the emphasis has been on transition back to the community wherever possible, with several of the housing options designed to enable that transition rather than to provide permanent housing. More recently, recognizing the importance of permanent housing in providing a predictable and stable environment, the state implemented the Supported Housing program in 2012 to increase permanent housing options and with “recipient specific support services designed to assist people in succeeding in their housing.”⁵³ This model is designed to reduce the “revolving door” effect of transitional and institutional mental health programs. This is a stipend program, when section 8 or other sources are unavailable that limits housing cost to the individual to approximately 30% of their income. The stipend is paid to the rental agency, not to the individual. A diagnosis of a Mental Illness is required in order to be eligible for these programs.

D. Administration on Aging (AoA)

AoA programs, funded under the Older Americans Act of 1965, provide assistance to older persons and their caregivers and support services that help older adults remain independent and involved in their communities. The Section 202 Supportive Housing for the Elderly program (Similar to Section 811) is provided by private, nonprofit housing and service-oriented organizations that have received capital advances from HUD to finance the construction and rehabilitation of housing for the low income elderly. This program provides rent subsidies, and

⁵³ “Supported housing” from OMH website.

<https://www.omh.ny.gov/omhweb/adults/SupportedHousing/supportedhousingguidelines.html> retrieved April 2014

the supportive services include meals, transportation, and accommodations for residents with disabilities.

The New York State Office of the Aging assists older individuals with living independently and accessing necessary resources. For those wishing to continue to live independently, the Office of the Aging directs individuals to the NYS Housing Websites

(<http://www.nyhousingsearch.gov/>) and <http://www.nyshcr.org/AboutUs/affhsg.htm> , which are funded through the NYS Homes and Community Renewal (HCR).

We have reviewed the range of supports, benefits and eligibilities that an individual may qualify for and have access to. The next stage is to use that knowledge to create a plan for housing.

V. Supports and Services

What do we mean by Supports and Services? In addition to the physical building that the adult with ASD-I/DD will live in, the other aspect of housing that is equally or more important is to secure the services and supports that the individual will need to live independently. In the traditional group home the provider agency will own the property and will also provide the services. In an independent setting the provision of residential support services is separate from the provision of property. Support services are required across a spectrum of need for people with ASD-I/DD. Some individuals require a nominal amount of support –an occasional visit to make sure that the person is safe and healthy and that they are sustaining themselves. Some require an oversight of budgets, food shopping, home maintenance, monitoring of medication, while others need 24/7 support for help with daily needs, ensure safety and provide health related care. There are different routes through which to obtain these services. The first step to services is thoughtful planning.

A. The Circle of Support. In pages 14-15 we described the requirement that a Circle of Support (Circle) be created for any participant in OPWDD’s SDSO funding.⁵⁴ The MSC is required to be a member of that Circle, but the other members are invited at the discretion of the individual and their guardians or advocates. While the SDSO regulations require a Circle, the creation of a Circle should not be driven solely by compliance, and the principles apply to providing for any one with significant support needs, regardless of ability or age. A well-constructed and sustained Circle is a powerful way to ensure that the focus remains on the individual.⁵⁵

The Circle should include family and friends and non-professionals as much as possible, people who will bring a “real world” perspective and who have a sense of the person’s character and knowledge of their personal history rather than their “case file”. OPWDD stresses the role of the volunteer in the Circle, but to be comprehensive and sustainable the Circle should also include professionals involved in the individual’s life. They bring their knowledge and experience, but by being included they also gain a more intimate perspective on the individual and are less inclined to see them as a “case”, and get a chance to learn about the individual’s family life, their childhood, their progress and the things that matter most to them.

⁵⁴ Some OPWDD regulations now refer to the Circle of Support as “the Planning Team”, but we will continue to use the term Circle of Support, which is a term of art, in this guide.

⁵⁵ Amado, A. N. and Mc Bride, M. (2001), *Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning: A Manual for Person-Centered Planning Facilitators*. Minneapolis, Minnesota: University of Minnesota, Institute on Community Integration. Includes helpful material on creating a circle of support and a listing of relevant publications

Non-professional Circle members are not paid for their time and currently there is no provision for payment for the professionals in the Circle, other than the MSC and the SDSO broker.⁵⁶ Meetings tend therefore to be called during the working day when the professionals can be paid. However, the context and setting for a planning meeting matter, so, as much as possible, meetings should be in the person's home, at a time convenient to them and to the other non-professional members of the Circle.

B. Service Planning. The starting point for service planning should be the Circle, whether a person is receiving services through OPWDD or from elsewhere. The Circle addresses the person's needs, their health and safety, risks, goals and desires. The formal OPWDD system is primarily funded through Medicaid, and even with the flexibility of the Waiver the plan follows the prescriptive path of a medical model. People living in the traditional congregate care system will tend to have highly prescriptive plans, created by professionals to address the structure of the institutional system. People living outside the congregate care system have more flexibility but need to be mindful that Medicaid funding will always be contingent upon a prescribed plan of services.

The MSC takes the goals and activities and desired outcomes from the Circle and creates an Individualized Service Plan (ISP). The plan includes medical information and a health and safety plan in addition to setting out the individual's Activities of Daily Living and a description of their home and work life.

C. Services delivered per an ISP. These include "Habilitation" OPWDD defines Habilitation thus:- *"services are designed to provide general assistance to persons, in accordance with their individualized service plan, to acquire and maintain those life skills that enable them to cope more effectively with their environments. Habilitation services are directed toward acquiring, retaining, and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings. Services offered are designed to correspond to the person's strengths and needs. These services include activities and tasks required to design, implement and support the individualized service plan. The individualized service plan includes specifically stated objectives and tasks related to physical, social, psychological, and pre-vocational skills or supports which are designed to achieve performance levels associated with the specified objectives"*⁵⁷

⁵⁶ Wittingly or unwittingly our systems seem unable to shake off Institutional bias, both in soft forms such as this instance and in more identifiable regulations. For comment on "Institutional Bias, see Appendix D

⁵⁷ Taken from NY Codes Rules and Regulations Title 14 Dept. of Mental hygiene Chapter XIV OPWDD Part 635 General Quality Control and administrative requirements applicable to programs, services or facilities funded or

- a. Hourly Community Habilitation. The delivery of habilitation services in a non -certified setting, where the service delivery is recorded in 15 minute intervals, and billed per hour.
- b. Day Habilitation Primarily out-of- home training and assistance in skill development

D. Service Settings

1. IRA Certified Settings and Agency operated non certified settings. In an IRA setting support services are funded by Medicaid Waiver “ funds. The individual’s MSC will develop their ISP which will set out what services are provided and how they will be delivered. The Provider Agency will create a “Residential Habilitation Plan”⁵⁸ based on the ISP, and Direct Support Professionals (DSPs) employed by the agency will provide the services and the management of the property. The agency will typically become the representative payee for all SSI and SSDI funds and will apply for and administer the individual’s SNAP and HEAP funds. They will also receive funding from the state to assist with establishing the home, any necessary conversions or modifications, and a letter known as a “Prior Property Approval” (PPA) which is an implicit state guarantee of funding that is critical in obtaining a commercial mortgage to purchase the property. A “Supervised IRA” (as described on page 37) is a 24/7 support setting while a “Supported IRA” provides a more limited level of support depending on the individual’s level of need.

2. Agency operated non certified settings. In a non-certified setting support services can be provided for in a variety of ways. At the most simple level they can be provided in exactly the same way as they are in a certified setting, (-i.e. by an agency that owns the property and employs all of the staff). The only distinction is that they are not certified, and thus will, in theory, have less oversight than a certified setting, and will also not receive the Congregate Care Supplement to the resident’s SSI payments. In addition they will also not receive the funding for start-up costs, or the PPA.

3. Agency services in an independent home. An agency may also provide services to an individual or group of individuals living in a home that is not owned by the agency. The property could be owned through any of the mechanisms described elsewhere in the guide. In this setting the agency may, for example, provide a full array of services as

certified by the OMRDD (sic) Subpart 635-10 provision of Home and Community Based Waiver Services.
[https://govt.westlaw.com/nycrr/Document/IS0397e72cd1711dda432a117e6e0f345?viewType=FullText&originati onContext=documenttoc&transitionType=CategoryPageItem&contextData=\(sc.Default\)](https://govt.westlaw.com/nycrr/Document/IS0397e72cd1711dda432a117e6e0f345?viewType=FullText&originati onContext=documenttoc&transitionType=CategoryPageItem&contextData=(sc.Default)). Retrieved August 2014

⁵⁸ “Community Habilitation” funding used to be known as “Residential Habilitation” funding. The term is still used when creating the plan.

described above. Funding for the services would be provided through the same mix of funding which is directed through the agency but which is “unbundled”. In such a setting the funding for services is derived from an individual’s Self Directed Services budget which can include Community Habilitation funds and funding from ISS (see page14).

4. The Live In Caregiver. The plan may include funding for a Live In Caregiver (LIC) which in the past was only fundable through an ISS contract but which is now a Medicaid service. Per OPWDD the LIC “is an unrelated care provider who resides in the same household as the waiver participant and provides as needed supports to address the participant’s physical, social or emotional needs in order for the participant to live safely and successfully in his or her own home.” This person may have outside employment or they may be employed by a provider agency to provide Community Habilitation services in addition to their LIC duties. Agencies have to monitor the number of hours spent on both tasks carefully, in particular if the LIC is required to be awake for much of the night as the federal Department of Labor (DOL) rules limit the number of hours that can be provided “in kind” and require overtime payments above a certain number of hours worked.⁵⁹ These rules, designed to protect workers have the potential unintended consequence of pricing out people who are seeking self-directed services or non congregate care. The situation is still under discussion but the rules are scheduled to be implemented.

5. Services through Shared Living. The term “Shared Living” is used to describe arrangements where a person or persons with a disability lives with other people who do not have a disability. Typically the person without a disability is provided with a lower rental cost or a (possibly tax exempt) stipend in exchange for providing agreed upon supports to the person with a disability. These arrangements can be fostered by a provider agency who can assist in finding room mates and in providing training and back up, or they can be negotiated privately. There are many examples of such relationships working extremely well, but to be successful they require significant planning and relationship building, and also an exit strategy in the event the relationship is not working. Agencies have adopted some of the funding methods used in Family Care to create Shared Living environments in which the person or persons with a disability moves in with an individual or family. In the event that the relationship doesn’t work there needs to be an exit strategy with an alternative home for the person with a

⁵⁹ In December 2014 DOL announced that it will publish a *Federal Register* notice announcing a time-limited non-enforcement policy toward the Final Rule amending regulations extending Fair Labor Standards Act (FLSA) protections to most home care workers. The rule will become effective on January 1, 2015, but for six months, from January 1, 2015, to June 30, 2015, the department “will not bring enforcement actions against any employer as to violations of FLSA obligations resulting from the amended regulations.” Advocates need to monitor progress.

disability. If the person with a disability is the homeowner/lessee and the relationship sours they may be required to evict their support person. In some cases there may be personal risk to living with the support person and the homeowner may even have to leave their own home until a solution is found. Shared living has worked in many instances and is used in other states but requires significant scaffolding and planning to be practical. The National Association of State Directors of Developmental Disabilities Services (NASDDDS), the American Network of Community Options and Resources (ANCOR), and the National Association of States United for Aging and Disabilities (NASUAD) have developed a model shared living contract designed to be used as a template by providers entering into certain shared living arrangements. The contract is available at www.nasddds.org/uploads/files/Model_Shared_Living_Contract_-_FINAL.pdf

6. Self-Directed Services. An Individual's resources also include SSI/DI, SNAP and HEAP funds which are controlled by the individual. In some settings these funds can be paid directly to the agency, or they can be paid through the individual's Fiscal Intermediary. One of the virtues of this latter approach is that if the individual wishes to change the service provider they are able to do so. Such a change is a complex undertaking and would only be contemplated in the event that the provider signally failed to provide adequate services.

People who have a Self-Directed plan that includes funding for residential services and who want to be more independent may seek to purchase some of their services from an agency, but may also seek to hire support personnel themselves. They may do this in one of two ways- they can typically work with their broker, or in some cases collaborate with their Fiscal Intermediary (FI) to advertise for, interview, train and hire their staff, or they can do so personally, becoming the employer themselves. In the event that they work with the FI, it will be the FI who becomes the employer of record and provide payroll, benefits, insurance, Workmen's' Compensation, liability coverage, scheduling, training and background checks.⁶⁰ In exchange the FI is paid a percentage of the individual's budget. If individuals choose to become the employer of record themselves they are required to fulfill all of the same requirements. While it is important that this latter option be available, the level of paperwork and knowledge required and the compliance risk involved make it inadvisable as currently formulated.

7. Individual Directed Goods and Services (IDGS). IDGS is a new waiver service under Self-Direction which provides funds that can be used to purchase equipment or supplies

⁶⁰ A state authorized criminal background check is required of any employee whose employment is funded through OPWDD funds, whether they work for an agency or for an individual directly.

that are related to an identified plan-goal, will increase independence and promote inclusion. For example these funds can be used for training programs, summer camp, employment related community classes, health club memberships, and Assistive Technology. The funding stream is still evolving and at present each expenditure is subject to individual capping with an overall annual cap of \$32,000.⁶¹

8. Other Than Personal Services (OTPS). OTPS can fund items that are not eligible under Medicaid, for example phone service, software and staff training, but may not be used for any medical support. OTPS funds are capped at \$3,000 annually.

9. Consumer Directed Personal Assistance Plan. Funding for support services can also be obtained through CDPAP (see page 16). These funds require that the DSP work for an agency and that they be subject to a background check, and the individual is responsible for all aspects of hiring and employment and compliance.⁶²

While we commonly think of people with ASD-I/DD living in group homes the fact is that many of them would like to live alone or with other people who do not have ASD-I/DD. After all a group home is primarily an economic construct rather than a social one.

10. Paid Neighbor program. This is a Medicaid funded program that provides additional support to an individual. The Paid Neighbor (PN) can be any person other than an immediate family member not residing at the same address, and can be as far as 30 minutes away, although they should be available to respond on foot if needed. The PN receives a monthly stipend of up to \$800/month to be "on call". If they are needed to help the recipient, they may also receive funding through Community Habilitation for additional Direct Support work.

This program offers companionship and support to individuals who want to live on their own but would benefit from having immediate access to 24-hour supports. Paid neighbors can provide 24-hour emergency supports. They are hired by the person they support and provide individual services depending on needs. Employment and screening requirements are performed by the FI.

⁶¹ OPWDD Self Direction Guidance September 1 2014 MSC training

⁶² See the link here for an excellent write up on staffing: <http://nyseld.org/wp-content/uploads/2013/10/nys-self-directed-services1.pdf> retrieved October 2014

Family Concerns

One of the questions that every parent asks is “what will happen when I am unable to support my son or daughter?” In a traditional group home the individual’s welfare is the responsibility of the agency and the person’s guardian if the family is unable to provide support. There is an assumption of limited self-advocacy. Families take comfort in the permanency that an agency might provide and they believe that they can rest easy now that their loved one is provided for. This is an understandable emotion, and rings especially true for the generation that saw how terribly neglected some of the patients discharged from institutions were in the ’70s and ’80s. They live with fear as to what might happen once they are no longer alive to advocate for their son or daughter. However experience shows that while some agencies do this work very well, there are risks. Agencies change, merge with others, leadership changes, founders retire, funding changes, standards shift. Given the Institutional Bias embedded in NY’s residential system an agency has little incentive to foster independence or self-advocacy. An individual becomes more institutionalized if they lack contact with the outside world, and this institutionalization compromises both their quality of life and their lifespan. Whether or not they live in a certified or in a more independent setting, it is paramount that they and their family and advocates create a Circle of Support which can look out for their interests and advocate for them as their parents become less able to do so. This is especially important for people living in non-certified or non-agency based settings.

VI. Creating a Housing Plan

Person Centered Planning (PCP) In its Waiver creation guidance to states, CMS states the following; “CMS encourages and supports the use of person/family-centered planning methods in service plan development. Such methods actively engage and empower the participant and individual selected by the participant in leading and directing the design of the service plan and, thereby, ensure that the plan reflects the needs and preferences of the participant (and/or family, if applicable). Person/family-centered planning is an integral element of participant direction of Services.”⁶³

According to the Health and Human Services Administration “PCP assists the person to construct and articulate a vision for the future, consider various paths, engage in decision-making and problem solving, monitor progress, and make needed adjustments to goals and HCBS in a timely manner. It highlights individual responsibility including taking appropriate risks (e.g. back-up staff, emergency planning). It also helps the team working with the individual to know the person better.”⁶⁴

PCP needs to acknowledge the hopes and aspirations of the individual, while being firmly rooted in the practical. True Person-Centered approaches are not confined to planning, they should infuse all aspects of services and supports. The Self Advocacy slogan “nothing about us without us” sums up the approach perfectly.

Planning for housing begins with the individual. As the plan takes shape it will need to address some fundamental housing questions – “Rent or Buy?”, “Alone or with others?” and as those choices are addressed and expressed in practical terms, the range of options is progressively defined and simplified.

Following the path laid out in this guide, the first step is to review and inventory the assets, income from private and public sources and eligibilities and entitlements that individuals may be able to mobilize in their search for their own home. It is recommended that they consult with a Benefit Specialist to ensure that they have optimal access to all of the options available to them. “Benefits Advisement” is a service provided through ACCES-VR, through OPWDD’s Family Support Services and through Fee for Service providers. This evaluation will help individuals and their families to answer one of the most important questions in their search for

⁶³ Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]

Instructions, Technical Guide and Review Criteria, January 2008. Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations. Centers for Medicare & Medicaid Services, Department of Health and Human Services <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/Technical-Guidance.pdf> p.178

⁶⁴ HHS Guidance for Implementing Standards for person-Centered Planning and Self Direction in Home and Community-Based Services Programs. June 2014. HHS.

housing: “Is it in my best interest to obtain housing through the certified group home system or will I be better served by putting together my own plan for Independent Housing?”

A. Deciding on Independent Housing

Independent or non-certified housing can take as many forms as there are people seeking it. The primary differences from the certified settings described above are that supports tend to be less intensive, although not universally so. Settings tend to be smaller, typically three to four people or less. Property is independently owned, either by a commercial landlord or by the individual themselves or by a housing corporation. The provision of accommodation is separated from the provision of services, meaning that the agency that provides support services does not also own the house where services are provided. This means that if a person likes where they live but they are not satisfied with the services provided by a provider agency, they can choose to have services from a different provider. Conversely, if they want to move to a different location but wish to retain the service provider, they have the option to do so. People are not locked into a traditional group home model. There are people with ASD-I/DD who live alone and receive a few hours a week of support, and there are people who live in partnership with two or three others, with caregivers living alongside, and who receive around the clock support. The key is flexibility, and the ability to adjust service and support levels when necessary, or to fade them out if the needs become less critical.

The choice as to whether to opt for the traditional or the independent route is to some degree left to individuals and their families. Families should do their own due diligence on both types of housing. The traditional congregate model tends to be more costly to the taxpayer and as such is increasingly rationed in an era of attention to budgets and growing demographic pressures on supported housing. While OPWDD describes congregate care as a “choice,” it is a choice dictated and rationed by the state budget and regulatory considerations, rather than an option that is available to all.

In 2003 Allen Schwartz Ph.D. created a graphic (figure1) that illustrates the change in how services will be delivered in the future. In the traditional model on the left, funding is directed to provider agencies that create programs which people with ASD-I/DD attend. Programs may be well designed and implemented but they will be from a set menu. In the Self Directed environment on the right, the funding flows to individuals, and they have the choice as to whether they purchase services from an agency, or use alternative means to provide their support. Given the direction of best practice research, financial demands of a broadening demographic, and federal and state policy the agency based model of home ownership and service provision is unlikely to continue for much longer.

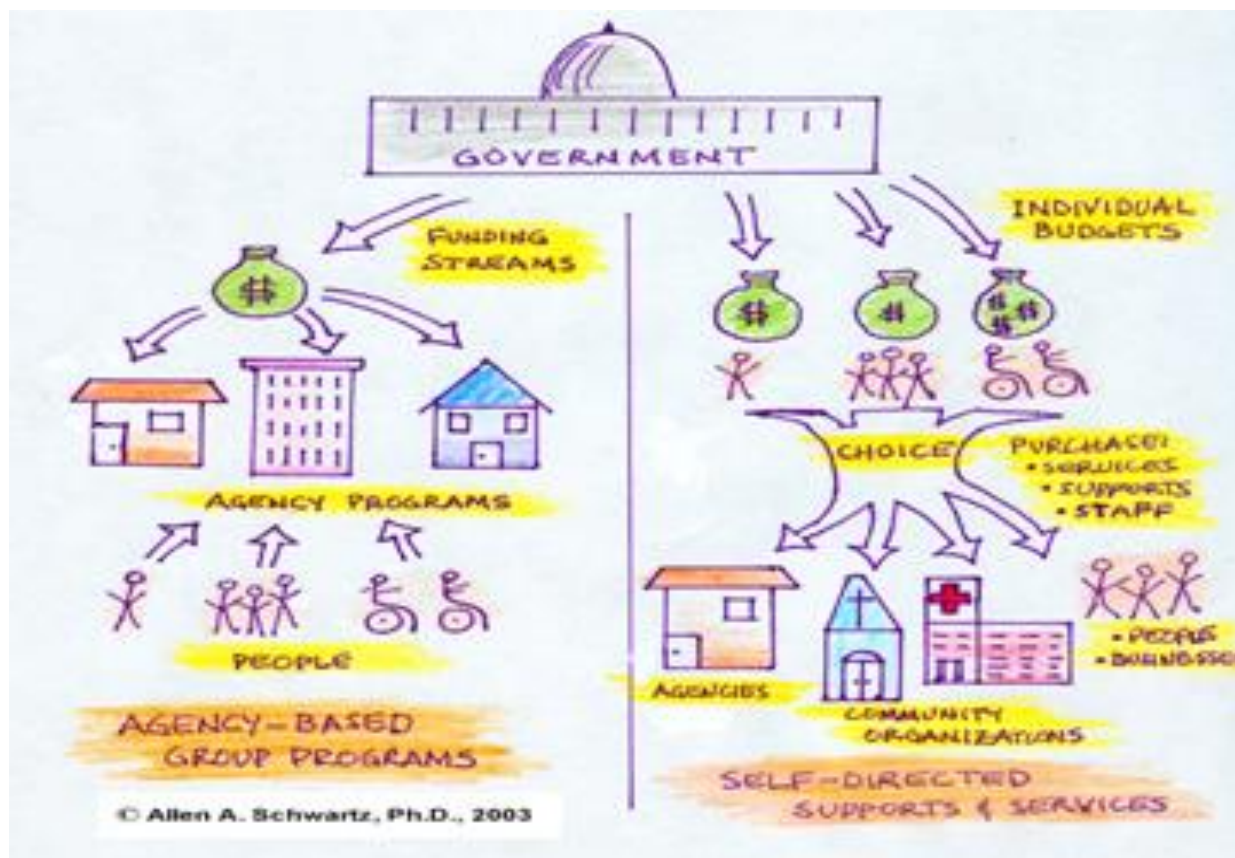


Figure 1

B. Planning for Independent Housing.

After a careful review of the pros and cons of Certified Housing settings versus Independent Housing, if an individual chooses to seek Independent Housing they should consider the steps we have outlined so far:

1. Review the resources that are available to them, including employment plans and prospects, and seek help from a Benefit Advisor.
2. If eligible, apply for SSI, Medicaid, ACCES-VR, and OPWDD services, MSC, Medicaid Waiver and SDSO. Establish qualification for HUD benefits and other low income benefits, and the level of availability. These steps are vital, and while cumbersome they can be negotiated with the help of qualified eligibility specialists, funded through OPWDD, or available on a private pay basis.
3. Whether eligible for all of the above or not, every person seeking independent housing should conduct a thorough review of their resources from government benefits, private income from work, and support from a trust or from friends and family in cash or in kind. Bear in mind that support in the form of in-kind food, rent or shelter may compromise public benefits.

4. In the event that an individual has assets, is likely to receive assets, is the beneficiary of a trust or seeks to establish a trust they must seek the advice of an attorney. There is much misleading information bandied about regarding trusts and housing. In order to have reliable and sound information the advice of an attorney specializing in NY Elder or Disability Law is essential.
5. While this guide focuses on finding the right accommodation there are other important elements to consider when making a housing plan. These include the need for staffing support , but also consideration of daily living skills (shopping, cooking, self care), transportation needs etc., as well as the emotional aspects of living away from family and living with others (roommates, staff, etc.) will need to be taken into account.

A thorough review process is necessary to establish how much funding is available to pay for accommodation. Typical householders are advised to spend no more than 30% of their income on housing. People with ASD-I/DD are not typical; their income from all sources may include a mix of benefits that are tied to specific need (e.g. SNAP), or housing (HUD) and they are likely to have very low incomes, even if their Personal Resource Account (PRA) for services can reach the low six figures. That said their income is likely to be stable. Public benefits, while occasionally in political jeopardy and subject to administrative error, tend to be stable and to keep pace with inflation. The key element is sustainability. How much will consistently be available to pay for rent or a mortgage payment and other housing costs?

C. Determining factors for location and collaboration

In addition to financial considerations a person with ASD-I/DD will need to consider other factors in determining where and how they live.

1. **Urban, Suburban or Rural?** Each has their advantages and disadvantages. Urban areas tend to offer greater options in employment, services, transportation infrastructure and social opportunities. They also tend to be more crowded and expensive. Suburban areas offer a slower pace of life, perhaps less expensive, but with fewer support and employment options, socialization, and access to labor for provision of Direct Support Personnel (DSPs). Rural areas may offer peace and quiet, connection to nature, lower costs and access to USDA benefits, but they can be isolated, lack services or transportation and be lonely. Idealized rural life can disappoint when the weather is gloomy and the work is hard
2. **Alone or with other people?** An individual might like the peace and quiet of living by themselves, or they might relish the opportunity to spend time with others. Ultimately the decision as to whether to share an apartment or a house is an economic one. The economics are not simply determined by how much rent or mortgage one or more

individuals can afford, but on the cost of the support staff they might need. The greater level of staff support required, the larger the impact on the budget, and the more important the task of finding and retaining staff or working with a provider agency to ensure staff continuity. In many instances it is more effective for two or three people to pool their support resources and to share staff services. The reality is that a group home is a financial construct as much as it is a social one. Sharing services requires planning for staff time, the range of services that each person receives, time spent etc.

3. **A room of your own.** Having your own room and the privacy it affords is an essential element of adult life. CMS requires that settings that receive HCBS funding have privacy, including lockable doors, but “a room of one’s own” is more than just the opportunity to get peace and quiet; it is a statement of a person’s independence and adulthood. Congregate care facilities will often have more than one person in a room, as it is a way to optimize revenues, but most people prefer to have their own room.
4. **With whom?** While the factors that determine who we live with are both financial and social, there is no need to be encumbered by stereotype. People with ASD-I/DD do not need to live with other people with disabilities, or with other people whose diagnosis matches their own. While budgetary limits might necessitate collaboration with people with similar needs it is important to have as diverse a group as possible, for one person’s strengths to complement another’s needs. The more people are able to support each other, the less need there is for paid support, and the richer the quality of social interaction.

There are helpful guides and checklists to address these aspects of planning for a home. We have attached one such list that is a helpful starting point as Appendix A.

D. How to Connect?

An individual may have grown up with a group of students with special needs, attended the same schools and the same programs. Sometimes groups form around those familiar relationships, but sometimes the individual may want to make new friends or to live with a different kind of person. Making those connections can be facilitated by social groups and social media, but there are other resources to help families to get together.

Self Advocates. Self Advocacy of NY State (SANYS)⁶⁵ can identify a regional or local group of Self Advocates, some of whom may have experience with housing or may be interested in combining their efforts with others.

⁶⁵ SANYS can be reached at <http://sanys.org/> retrieved November 2014

E. Rent or Buy?

Now that the individual and their family have thought about issues concerning budget, housemates and living costs, the next decision is whether to purchase a property or to rent. For a typical person or family seeking accommodation the decision as to whether to rent or to buy represents an assessment of their economic security, and a judgment as to the state of the property market and the cost of borrowing. They will also consider whether they are putting down roots in a community, convenience to their employment, quality of schools, and level of taxes and so on. People with ASD-I/DD will have additional considerations.

1. **Renting Considerations** In addition to the economic issues that have to be taken in to consideration there are other specific factors that people with ASD-I/DD need to consider.

- a. **Accessibility** Newer rental properties, particularly housing that has been built with federal or state subsidies or tax concessions may be more physically accessible to people with disabilities than older housing stock will be. In 2012, Westchester County NY adopted a Universal Design protocol. The Law requires that “no-step entries, one story living spaces, wider doorways and hallways, turn-around floor space, grab bars, removable cabinets and reachable switches and controls—be designed into at least 50% of the construction of residential housing that receive support from Westchester County fair and affordable housing programs and all entities seeking to improve new residential housing units with support from County “Fair and Affordable” housing programs.⁶⁶ This ordinance should serve as a model for other regions of the state, and possibly a statewide initiative. It has been demonstrated that if accessibility and environmental considerations are included in the earliest stages of a development the additional cost can be offset through incentives in some cases and be immaterial in most.

- b. **Discrimination** In much of New York State it is still permissible for landlords to discriminate on the basis of “Source of Income.” This allows for other forms of “Not In My Back Yard –NIMBY” style discrimination to be cloaked in an economic mantle. “Source of Income” may be a HUD voucher, or an SSI check, and the landlord may choose not to accept a tenant who relies on such public funding. New York City Human Rights Law prohibits discrimination in housing based on (among other things) disability or lawful source of income.⁶⁷ Westchester County enacted “Source of

⁶⁶ See more at: <http://westchesterlegislators.com/district-14/1928-westchester-legislators-adopt-universal-design-standards-for-county-residential-housing.html#sthash.jf4o513B.dpuf> retrieved April 2014

⁶⁷ NYC Fair Housing law <http://www.nyc.gov/html/fhnyc/html/protection/income.shtml> , Retrieved December 2014

Income legislation” in December 2013 that partially protected county residents from such discrimination, but effectively exempted small landlords. Other counties including Nassau, and the cities of Buffalo, Hamburg and West Seneca have enacted similar legislation.⁶⁸

c. **Availability** If the service and economic reality mean that people with ASD-I/DD need to share their accommodations, then they will typically need a three, four or five bedroom home to accommodate each person with a room of their own, and to allow for a live in caregiver or other staff. They will seek a long lease. Properties that fit this description may not be readily available in the higher cost regions of the state.

d. **Utilities** Some rentals include the cost of utilities and perhaps superintendent services in the rent while others do not. Renters need to be clear as to what costs are included in the rent, and if energy costs are not included they should plan for potential energy price increases and seasonal fluctuation.

e. **Rents may inflate** Rent subsidies provided through OPWDD or DSS are based on guidelines set down by NY State Homes and Community Renewal (HCR) on behalf of HUD and are generally modest. Private landlords are free to raise rents at each lease renewal based on rates varying between 2.5% and 4%. There is no such requirement embedded in HUD subsidies. A tenant must be careful not to be trapped by rising rents without sufficient income.

The decision as to whether to rent or to buy is one that requires considerable deliberation and supporting advice. HUD counselors and social service agencies are able to provide first time homebuyers with guidance and social service agencies can also help. For a listing of HUD approved Housing Counseling Agencies please visit the HUD website at:

<http://www.hud.gov/offices/hsg/sfh/hcc/hcs.cfm?webListAction=search&searchstate=NY>

F. Renting a home

People with disabilities and people with low incomes have several programs and options open to them to assist with rental payments.

1. **Section 8 Housing Choice Vouchers.** As discussed above these are also known as Housing Choice Vouchers, and are applied for through the municipal and county level Section 8 offices. Currently the waitlists are long, and many offices have simply closed their waitlists. When available, the voucher allows the individual to pay only a

⁶⁸ Re the bill and the background, especially Westchester’s discussions with HUD see <http://westchesterlegislators.com/media-center/2330-westchester-legislators-approve-source-of-income-legislation.html>. Retrieved April 2014

maximum of 30% of their income (or SSI if they have no other income) for rent. The remainder of the rent is paid to the landlord by the Housing Authority.

2. **Public Housing.** There are separate Public Housing offices in each municipality through which an individual can apply for public housing units. There are also waitlists for public housing. An important distinction between public housing and Section 8, is that with public housing, the landlord is the Public Housing Authority and with Section 8, the landlord is the owner of the property that accepts the voucher.
3. **Multi-family Subsidized Housing.** There are also affordable housing units known as Multi-family subsidized housing that have typically been created through the LIHTC benefit to the developer. These units may have a certain number of units set aside for the elderly or for people with disabilities. If the funding is through section 811 (see above) then the units may be exclusively for “non-elderly” people with disabilities. The landlord is the property owner and sometimes there is a property management company that acts as the primary contact. If the housing has been developed using Section 811 the developer or landlord may be required to work with a provider agency to provide support services to the people living in the “set aside” units, and to also be liable for the rent. The developer has the protection of knowing that the rent will be paid and that the people in the apartments will not be neglected. The tenants have the comfort of knowing that they will have secure tenancy and that their support needs will be addressed. However, the tenants are required to receive their services through the same single agency and may not readily have the option to switch providers. CMS in its HCBS Settings ruling of January 2014⁶⁹ leaned very strongly towards the provision of smaller scale settings, and while the “811” type of setting may create more affordable and sustainable housing the concentration and limitation of options must still be addressed.
4. **To Rent an Affordable house/apartment.** In addition to newspaper advertisements, personal contacts etc. there are several websites that can help you to search for affordable rental housing in New York State.
 - <http://www.nyhousingsearch.gov/>
 - <http://www.hud.gov/apps/section8/step2.cfm?state=NY%2CNew+York>
 - http://www.socialserve.com/tenant/NY/Search.html?type=rental®ion_id=32865
 - <http://www.nyshcr.org/topics/home/renters/opportunitiestoapplyforaffordablerentalunits.htm>

⁶⁹ HCBS Settings ruling CMS Jan 20 2014 <http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html>. retrieved April 2014

- Independent Living Centers (ILCs) may provide registries and other housing connection opportunities. To find the ILCs in your area check the ACCES-VR website <http://www.acces.nysed.gov/vr/lsn/ilc/locations.htm>

G. Expanded opportunities under the Melville Act. In December 2014 HUD issued a notice of proposed rulemaking to implement amendments made by the Section 202 Supportive Housing for the Elderly Act of 2010 (Section 202 Act of 2010) and the Frank Melville Supportive Housing Investment Act of 2010 (Melville Act) to the authorizing statutes for HUD's supportive housing for the elderly program, known as the Section 202 program, and the supportive housing for persons with disabilities program, known as the Section 811 program. The Melville Act provides for additional methods of financing new supportive housing for persons with disabilities, as well as supporting the preservation of affordable rental housing for individuals with disabilities and nonelderly disabled families. The proposed rule would also implement several other changes to align with the amendments made by the two statutes. The rule would "establish the requirements and procedures for the use of new project rental assistance for supportive housing for persons with disabilities;" implementation an "enhanced project rental assistance contract;" and "modernize the capital advance for supportive housing for persons with Disabilities." The proposed rule is available at www.gpo.gov/fdsys/pkg/FR-2014-10-07/pdf/2014-23276.pdf

H. Buying considerations. Home ownership is within reach for many people with ASD-I/DD, but as with renting there are unique considerations:

1. **Owning a home does not compromise social security or Medicaid benefits.** If an individual chooses to purchase a primary residence it does not affect their eligibility. However if they sell the property at a future date and do not reinvest the proceeds in a primary residence, the gain on the sale may be subject not only to tax but also to a potential "claw back" from Medicaid.
2. **A person with a disability may qualify for lower taxes.** Certified group homes operated by nonprofit corporations do not pay local taxes, a privilege that can sometimes become a source of community friction and "NIMBYism." Individual homeowners do pay taxes, although people with permanent disabilities may be able to pay taxes at a lower rate through a School Tax Relief (STAR) exemption.⁷⁰

⁷⁰ For information about the STAR and Enhanced STAR exemption visit <http://www.tax.ny.gov/pit/property/star/index.htm> Retrieved April 2014

3. **Maintenance.** OPWDD provides funding to certified group home operators to maintain their property. However the state is not permitted to provide funds that improve property values for an individual homeowner, and so the funds it provides for routine maintenance are limited to very basic tasks. Housing support budgets through SDSO may include some modest funding for upkeep but the homeowner is liable for any significant repairs. There are several programs that can provide Home Equity style loans to help with repairs for low income homeowners, such as the Neighborhood Preservation Company grants, available through NY State HCR⁷¹ or a Community Development Financial Institution (CDFI) such as the Disability Opportunity Fund which is headquartered in Long Island but is active throughout the state.
4. **Owning in partnership.** Some people with ASD-I/DD have established home ownership in partnership with others. This shares the cost, but requires careful planning for an exit strategy to address what will happen when one or more of the homeowners want to move and to sell their share. After all, very few of us spend all of our adult lives in the same house. Each home ownership situation will be unique. Several home ownership groups have created their own agreements to govern how property is owned, and how a property partnership can be changed or dissolved if one member of the partnership needs to leave. A partnership agreement should be created by an attorney, and may need to be reviewed by the Surrogate's Court in the event that any of the individuals involved are subject to guardianship.

Home ownership is the American dream for many people. There are also economic incentives to purchase such as assistance in down payments, deductibility of interest and potential accumulation of equity. For people who are reliant on public funding though, the accumulation of equity is not necessarily a significant benefit at this time, given that they may forfeit such equity to Medicaid. Interest deductibility from income taxes is irrelevant if income is extremely low. Property ownership in partnership with others requires significant effort at the outset to ensure that each partner's interests are protected in the event that one partner wishes to sell their share. Considerable attention must be paid to providing for conflict resolution, and to governance. This guide includes a specimen document that addresses the issue, "The Social Contract," which is attached as Appendix B.

I. Buying a home

After a thorough review of an individual's assets, income and choices of where to live, with whom, and how to obtain services, the person may decide they want to buy their own home

⁷¹ NY State HCR Neighborhood Preservation Companies Program (NPP) <http://www.nyshcr.org/Programs/npp/> retrieved March 2014

rather than rent. Or they may have spent some time renting, and decided that they want to put down deeper roots and that they are ready to own their own place.

1. **Budget sustainability.** An individual's budget will need to address not just the costs of a mortgage, but the cost of real estate taxes, insurance to cover each homeowner and partners, and perhaps to cover any liability to visitors. The most significant additional item is the cost of maintenance. "Murphy's law" holds that if something can go wrong it will, and it seems that every new homeowner inherits an (unexpected) failing boiler/water heater/roof. Expenses can be significant and untimely. As previously noted, state based budgets (e.g. SDSO or ISS) do not allow sufficient funds for maintenance. The homeowner needs to begin with some funding set aside, ensure that necessary maintenance is performed, and put away a portion of funds each month to save for the eventual need to replace a major item. Sensible homeowners also carry a line of credit to be able to draw on in an emergency. For condominiums and cooperatives there are typically common charges and Home Owners Association (HOA) fees that must be included in the budget.
2. **Working with Realtors.** An individual may want to contact a realtor to assist with the housing search. Real Estate Sales professionals who have a realtor designation have the credentials and training and are required to maintain a higher level of ethical standards. Bear in mind that realtors are paid on commission from the property owner, the seller, and represent their interests. There are also "buyer's agents" who will work for a fee for the purchaser. Realtors are in business to buy and sell real estate, and will tend to want to move properties as promptly as possible. They will not readily adjust to the lengthy processes that we are accustomed to in the social services field so before engaging with a realtor an individual should know their budget, their financing options and be ready to act if presented with an opportunity. The individual should speak with the broker in the office, and ask if there is anyone in that office that has experience working with people with disabilities or with specific experience working with accessibility issues. The relationship with the broker is important, as the client will be working closely with them for the duration of the housing search which could take many months. The New York State Association of Realtors recommends interviewing at least three agents to make sure that there is a personality and skill set fit.

J. Assistance for First time home buyers. People with disabilities and people with low incomes can access a range of supports and financial incentives to help them to achieve home ownership.

1. **Down payment.** There are state programs that will help with funding for down payment and closing costs when purchasing a home.⁷² In a “Matching Grant” program the state matches an individual’s own savings towards a down payment, at a ratio of from 4 to 1 to as high as 8 to 1. Typically an individual can contribute a maximum savings of \$1,000 but in some cases a higher amount is allowed. Savings of \$1,000 can lead to a down payment of \$9,000.
2. **SONYMA Down Payment Assistance program (DPAL)**⁷³ is one such program that provides funds to home buyers for down payment assistance. The funds provided are the greater of either \$3000 or 3% of the home’s purchase price, to a maximum of \$10,000.⁷⁴
3. **Assets for Independence/Individual Development Accounts (AFI/IDA).** Savings for Down Payment. This program allows an individual to save earned income (not SSI) and provides an 8:1 match. Savings of \$1,000 may receive a match of \$8,000 for a total of a \$9,000 pool of funds to be used for a down payment on a home. This program is administered through OPWDD and commercial banks.⁷⁵
4. **First Home Club Savings for Down Payment.**⁷⁶ This program was first launched by the Home Loan Bank (HLB) in 1995 to offer an incentive for low income households to save towards a home purchase. Any of the 300 NYS Home Loan Banks can originate the mortgage. Savings are matched 4:1 up to \$7,500 in matching funds.
5. **Home of your Own (HOYO).** HOYO is a program created in the mid 1990s to encourage home ownership for people with developmental disabilities and in NY State is run by OPWDD. Through SONYMA and commercial banks, the HOYO program offers homeownership support services, such as homeownership counseling, as well as low interest rate mortgages.⁷⁷
6. **The Affordable Housing Corporation (AHC)** issues grants to municipalities and non-profit organizations for the building or renovating of housing for those with low incomes. They provide funds to promote home ownership and to revitalize neighborhoods. There are AHC Grantees across the state, and the list of these can be found at the NYSHCR.ORG website.⁷⁸

⁷² <http://homes.westchestergov.com/down-payment-and-closing-cost-assistance> retrieved March 2014

⁷³ [http://www.nyshcr.org/Topics/Home/Buyers/SONYMA/DownPaymentAssistanceLoan\(DPAL\).htm](http://www.nyshcr.org/Topics/Home/Buyers/SONYMA/DownPaymentAssistanceLoan(DPAL).htm) retrieved March 2014

⁷⁴ [http://www.nyshcr.org/Topics/Home/Buyers/SONYMA/DownPaymentAssistanceLoan\(DPAL\).htm](http://www.nyshcr.org/Topics/Home/Buyers/SONYMA/DownPaymentAssistanceLoan(DPAL).htm) retrieved March 2014

⁷⁵ http://www.opwdd.ny.gov/opwdd_community_connections/housing_initiative/assets_for_independence_individual_development_accounts retrieved March 2014

⁷⁶ <http://www.fhlbny.com/community/housing-programs/fhc/> Retrieved March 2014

⁷⁷ http://www.opwdd.ny.gov/opwdd_community_connections/housing_initiative/home_of_your_own_hoya (March 2014)

⁷⁸ <http://www.nyshcr.org/Topics/Municipalities/AHCGrants/AHCGranteeList.htm>

7. **Federal Housing Administration (FHA) Mortgage.** These mortgages are administered by the Federal Housing Administration through commercial banks. They feature lower interest rates, low down payment options, and both fixed rate and adjustable rate options. Some lenders/banks may also provide grants that can offset closing costs. Whereas most of the low cost mortgages above are limited in the amount that may be borrowed, and do not permit the addition of a second mortgage, an FHA loan has more scope and permits the addition of a second mortgage. This is especially important in areas where house prices are higher than average, such as NY City and the downstate counties.
8. **State of New York Mortgage Agency (SONYMA).**⁷⁹ SONYMA provides a Low Interest Rate Program for first time home buyers. Up to 97% financing is available to low income individuals and for property within a purchase price limit, which is approximately \$665K in target areas or \$813K in non-target areas. The annual income limit is \$127K. These mortgages are offered through participating lenders.

Other SONYMA programs include:

- a. **Achieving the Dream** provides for low down payments and the individual may also be able to combine purchase and renovation in one loan.
- b. **The Construction Incentive Program** provides up to 97% long term fixed financing on newly constructed or rehabilitated homes.
- c. **Remodel New York Program** also combines purchase and renovation funds in one low interest rate long term fixed loan.
- d. **Own it, Fix it New York!** Home Mortgage is designed to provide streamlined mortgage financing to homebuyers for the purchase and repair of homes requiring \$25,000 or less in repairs.

9. **Section 8 Home Ownership Program.** This program allows individuals who are already in possession of a Section 8 Housing choice voucher to “convert” it to (first time) home ownership through a Public Housing Agency. The monthly tenant payment is generally 30% of the tenant’s adjusted family income. People with disabilities receive certain preferences, for example, they do not have to be working full time to qualify, and there is no time limit on the duration of the housing subsidy.

⁷⁹ <http://www.nyshcr.org/Topics/Home/Buyers/SONYMA/SONYMAProductsforFirstTimeHomebuyers.htm>

K. Modifying a home.

Environmental modifications allow people with disabilities to remain in their own homes and to have access to the community. In addition to providing for accessible physical environments, homes can be adapted to provide an environment more suitable for an individual's needs for privacy, quiet and support for activities of daily living.

1. Environmental Modifications (E-mods). Once an individual has identified a potential home, they may need to make modifications to ensure accessibility. NY State Department of Health defines E-mods as "internal and external physical adaptations to the home, which are necessary to ensure the health, welfare and safety of the waiver participant. These modifications enable the waiver participant to function with greater independence and prevent institutionalization." E-mods may include ramps, lifts, widened doorways, hand rails, roll-in showers and modifications to a vehicle. In order to qualify for E-mods through OPWDD the individual must be receiving services through the HCBS Waiver. Application for funding is coordinated by the MSC in collaboration with the DDRO.
2. New York State Access to Home. NY State HCR provides financial assistance to homeowners and landlords who qualify for loan assistance through their municipality or not-for-profit entity under the following criteria: the occupant is physically disabled or has substantial difficulty with an activity of daily living because of aging; the dwelling unit is a permanent residence; and total household income does not exceed 80 percent of area median income, or 120% of area median income if the person in need of modifications is a disabled veteran. Loans to homeowners can be up to 100% of the total cost of the adaptations to a maximum of \$25,000. Loans will be at 0% interest with payments deferred on the condition the customer resides in the modified residence. The entire loan will be forgiven at the end of a regulatory period of up to five years.

VII. Conclusion

Finding an affordable and desirable place to live is always a complicated business. For people with disabilities it can be made more complicated by additional needs, and by the maze of eligibility and funding options that they have to navigate. NY State agencies, in particular OPWDD, are changing how they do business. What emerges will hopefully be more person-centered, fairer, more transparent and sustainable than the current certified housing model. While this change is underway, no new system resources have been created to help people to find a home. It is up to the individual and their Circle of Support, including their family, their friends and their service coordinators to create their housing plan and to put it into practice.

Throughout the guide we have referred to “independent housing” but the reality is that future housing will be “interdependent.” People with ASD-I/DD will rely on their Circle of Support but will also connect with their peers, with their employers, and with all of the housing related professions: bankers, realtors, attorneys, developers and contractors. Their housing advocacy issues will have much more in common with those of people with other disabilities, people with low incomes, and the elderly. It will require all of us to collaborate with others rather than focusing solely on our own needs.

At last, Money is Following the Person, but with that new freedom comes more work and more responsibility. Although supported by Law, Regulation and Best Practices people who have sought independent housing have nonetheless experienced frustrating obstacles. These range from the institutional bias embedded in law and regulation, (see Appendix C) to family and provider unwillingness and trepidation when confronted with change. WIHD created this guide to help individuals and families understand the issues and learn how to negotiate the path to housing. We will continue to refresh our knowledge and to work with families who set out on this sometimes intimidating but always worthwhile journey.

Appendix A - Housing Checklist

This list is by no means exhaustive but is a starting point to help an individual and their family develop a plan.

Name		Date	
I. Eligibility and Entitlements Benefit Review			
		YES	NO
(i) SSI			
(ii) SSDI			
(iii) Medicaid			
(iv) ACCES-VR			
(v) OPWDD	DDP2		
(vi) MSC			
(vii) Medicaid Waiver			
(viii) ISS			
(ix) SDSO			
(x) DSS			
(xi) Income Assessment			
	(a) SNAP		
	(b) HEAP		
	(c) ConEd		
	(d) Lifeline		
II. Individual Resources			
(i) Employment			
(ii) Supplemental Needs Trust			
(iii) HUD			
(iv) Credit Score			
III. System Resources and availability to the Individual			
(i) HUD 811			
(ii) HOME			
(iii) PHA Plan			
(iv) CDBG			
(v) CoC Plan			
(vi) SHOP			
(vii) USDA			
(viii) IRS	LIHTC /NMTC		
(ix) FHLB			

IV. State Agencies that support Housing			
(i) OPWDD Certified Group Home			
(ii) OMH Supported Housing			
(iii) Administration on Aging			
V. Creating a Housing Plan			
(i) Decision on Independent Housing			
(ii) Planning for Independent Housing			
(iii) Determining factors for location and collaboration			
	(a) Urban, Suburban or Rural?		
	(b) Alone or with others		
	(c) A room of your own		
	(d) With whom?		
(iv) Other considerations	(a) Staffing		
	(b) Self hire or		
	(c) Agency hire?		
(v) How to connect			
(vi) Rent or buy	AFFORDABILITY		
	(a) Accessibility		
	(b) Availability		
	(c) Utilities		
	(d) Rent control		
	(e) Section 8 rental		
	(f) Public Housing		
	(g) Multifamily housing		
	(h) Real estate taxes		
	(i) Maintenance		
	(j) Ownership partnership		
	(k) Budget sustainability		
(vii) Purchasing assistance	Loan Programs		
(viii) Environmental Modification			

Appendix B – The Social Contract

The “Social Contract” below is taken from a contract drawn up between three men who live together in a house that they own. The contract has been in effect since 1999 and while subject to periodic revision has served them well.

The Social Contract

The Homeowners

This agreement is between XX,XX,XX, (collectively “the homeowners”), their parent /guardians, and “Agency” Inc. The homeowners and their families and Agency Inc. are all actively committed to promoting independent living for people with disabilities, and this agreement’s purpose is solely to facilitate and support that goal

The House Committee

Consists of the homeowners, plus one individual nominated by each homeowner to assist them in their representation. The House Liaison worker from the Agency, and the Live in Caregiver. Each member of the committee shall have one vote.

Agency

Is a nonprofit corporation formed to act as a fiscal conduit in supporting individuals with disabilities who seek to increase their independence in housing work and daily life.

I Principles

The undersigned have agreed to the following..

1. Each homeowner’s room is their private area. No other person in the house may have access to their room without their permission
2. Each homeowner will participate in household chores to the best of their ability.
3. All household upkeep expenses and maintenance expenses are borne equally
4. All food costs are borne equally
5. Each homeowner will pay an equal sum in mortgage, taxes, upkeep and utility costs to the Agency. This sum will be periodically reviewed by the House committee
6. The disposition of any real estate that is shared, or any transfer of real estate, and any and all matters related to the property rights of the homeowners is governed by the “Real Estate Contract” separately agreed to by the homeowners.

II Responsibilities and Obligations.

(i) The Homeowners

1. Each homeowner will create and maintain a “Circle of Support” to include friends, family and community members who can advise and support them in matters relating to all aspects of independent daily living.
2. Each homeowner, their family and Circle of support are responsible for the individual’s health and well-being, and will work through the house committee to allocate support worker time.
3. Are responsible for repairing any damage to the house or other property caused by themselves or their guests.
4. Will respect each other’s privacy
5. Are committed to independent living and will work to maintain that goal.
6. Will perform the household chores to the best of their ability and fairly.

(ii) Agency

1. Will pay the mortgage, tax, car lease, house upkeep and utility bills on behalf of the homeowners.
2. Will act as a fiscal intermediary for the homeowners.
3. Will pay all bills due in a timely fashion.
4. Will maintain all records and abide by all regulations required to retain its status as a Medicaid Waiver provider and its approval by NY State as a fiscal intermediary.
5. Will be the employer of record for any paid caregivers.
6. Will ensure the maintenance of insurance policies to protect the homeowners, their property and their employees.
7. Will maintain accurate and easily understood records of all transactions.
8. Will recruit and review all support personnel.
9. Agency will not be paid by the homeowners for any of the above services.

(iii) The House Committee

Day to day concerns involving the running of the household will be resolved by the committee. The committee will meet bi-weekly for the first three months after the homeowners move in to the house, and thereafter no less than bi-monthly.

1. Will review the upkeep of the house and budgetary matters.
2. Will arrange for training in conflict resolution techniques for its members. Will establish a written arbitration process for resolving issues that it cannot resolve itself, using the Ombudsman program of GROW, and with financial support from Agency.
3. Will work with the homeowners to establish a fair share of household chores for each person, set bathroom schedules etc.
4. Will set menus and shopping lists
5. Will oversee household costs and major expenses
6. Will review any damage done to the house by the homeowners or their friends or their support staff
7. Will coordinate the allocation of staff time on a compatible basis with each homeowner’s ISP.

III Other House rules to ensure peaceful daily living.

1. The car is to be used primarily to get to and from work and social events for the homeowners. It is not for the use of the support staff unless travelling with one of the homeowners.
2. The phone is communal property and to be used sensibly. If the monthly bill exceeds a level determined by the house committee to be reasonable, then the costs will be allocated to each user.
3. There will be no overnight guests.
4. There will be no internal locks in the house.
5. No pets are allowed unless agreed to by each of the homeowners
6. The house is smoke, alcohol and drug free.
7. Television usage should be planned ahead, with the homeowners agreeing to a fair breakdown of time. When a program has not been planned the TV should be turned off.

This agreement will be renewed every six months,

Appendix C - Institutional Bias

As people with I/DD and their families move towards more Self Directed services they and their Service Coordinators report that they are encountering numerous obstacles and hurdles that were not evident when they were applying for services from traditional legacy sources.

In discussion with these stakeholders in Self Direction it is clear that there are indeed systemic biases that seriously impede their ability to obtain Self Directed services in the most integrated setting. These barriers tend to fall into six categories:

I. Legal Barriers to independent living.

Nurse Practice Act. The act prohibits HCBS workers from administering medication in non-certified settings and requires the hiring of a nurse to come to the home once or even multiple times per day. The recent passage of the exemption to the Nurse Practice Act should be used as an opportunity for OPWDD to negotiate with the State Education Department (SED) to set individualized and common sense training requirements for direct support staff to safely allow them to administer medications and perform simple procedures at home and in the community.

The SED is reviewing possible amendment to the regulation that would allow for training to be provided to DSPs in non-certified settings.

II. Structural issues that reinforce institutionalization.

- (i) **Dormitory Authority of the State of New York (DASNY).** The DASNY issued bonds over many years to fund institutions and large ICF and other facilities, with the funding being provided to the state and to provider agencies. Unravelling the financing is a complex task and is a major impediment to NY State and its provider agencies that are getting out of the property business and focusing on services. Some of the bonds have highly restrictive covenants and high interest rates and high fees were paid to the underwriters.

Financial Expertise should be applied to assist in repurposing and defeasing /refinancing existing bond issues to free up funding and remove constraints from large properties.

- (ii) **Union activity** to keep institutions open. There have been reports of scare-mongering and alleged misuse of confidential health information by some union members designed to keep institutions open and the current workforce in place. The interests of the people “serviced” seem to be secondary.
- (iii) **Compensation** for Home Health staff is low compared to union based institutional pay levels, and excludes or minimizes benefits. *Under Self Direction, rates can be made more competitive as overheads are lower.*
- (iv) **Benefits.** Agencies can achieve economies of scale and can pay benefits. Self-Hires cannot. *This issue may be ameliorated by the implementation of the Affordable Care Act.*
- (v) **Support.** The Circle of Support works for free. In the Self Determined world we rely on Circles of Support to help make life decisions. These circles rely on volunteers which is all good, but unsustainable. Circles may lack experience in hiring practices, workers compensation, payroll taxes and other issues. We are promoting Self Hiring without providing people with education and training. *Accessible, straightforward training on being an employer, including hiring, retaining, and training staff should be made available to individuals and families. MSCs and brokers should identify training opportunities and funds for training may be available under IDGS, and should include training in employer responsibilities and other hiring concerns.*

III. Regulations that incentivize congregate care.

- (i) **SSI Allowable Income Limits last changed 1/1/89.** Earned income limits are too low, and savings limits are unrealistic if we want people to acquire independent assets. *Sens. Warren and Brown introduced legislation in 2014 to increase the SSI savings limit to \$10,000.*

(ii) **Preferential treatment for people returning from residential schools**

discriminates against those who have been supported at home. Those in residential facilities are fast tracked from child services to adult services. Those living at home tend to get put on waitlists. The system is ripe for gaming. The new template rate awarded to nonprofits establishing new houses for those aging out of residential schools is called "Specialized Residential Care" and the rate per person/year is \$166,400. In addition the state awards these providers capital funding of \$145,000 per person to purchase the house, significant incentives for congregate care. *This process should be made more open and transparent in order for families seeking self-direction to understand that the process is fair.* These individuals should also receive the option to be self-directed rather than remain in an institutional setting.

(iii) **Department of Labor (DOL) overtime ruling.** Makes the provision of "Live in Caregiver" difficult to implement. *The ruling implementation will be delayed until late 2015 and there is still active discussion between DOL and disability advocates.*

(iv) **Tax.** Certified houses come off the tax rolls and the operating agency pays no taxes. People living in their own homes or other settings may qualify for reduced taxes under the STAR program but still pay taxes like every other citizen. *This is unlikely to change – on the plus side non-certified settings do not have to endure the Padavan process.*⁸⁰

IV. State Practices that incentivize congregate care and subsidize provider agencies.

⁸⁰ Section 41.34 of the Mental Hygiene Law, also known as the Padavan Law, provides that licensed community residences and family care homes⁸⁰ for the mentally disabled are deemed a family unit for purposes of local land use regulation. The Padavan Law also sets forth dispersion guidelines and notification guidelines for the siting of licensed community residences.⁸⁰ Anna Georgiou, Pace Law School 1998 retrieved from Pace Website November 2014 landuse.law.pace.edu/landuse/documents/.../RegGroupHomesInNY.doc

- (i) **Congregate Care Supplements.** NY State provides supplemental payments for congregate care, but does not do so for people with the same needs who seek to live outside of certified settings. This practice incentivizes congregate care by providing financial supplements to agencies. *DSS Should consider an MFP incentive that would ease transition back into the community,*
- (ii) **Hard copy/signatures.** State practice requires that a person engaged in Self Directed Services sign off that they have received all services. The vendor is not paid until a hard copy of the note is submitted. In no other business does the vendor have to have approval of the client once services have already been provided. (Try this in a restaurant!) Hand signed hard copies are archaic, wasteful and inaccurate, and no such requirement is made in provision of services by an agency in congregate settings. *Fixing this using electronic signatures would seem to be relatively straightforward.*
- (iii) **Pooled Trusts.** While beneficial in many ways they often have unfavorable terms for the individual including high penalties and fees. Public information on the size of funds is limited. Some operators use trust income to supplement Fee For Service (FFS) business without clear benefit to the trust investor. *The DOH and other regulators of trusts should encourage greater transparency in particular around fees and use of funds.*
- (iv) **Transportation via Medicaid van.** Van operators are paid high Medicaid rates to transport between certified sites, but not for general transportation. *This system is expensive and not scalable. In the age of Ride-Sharing and app-driven car services this system is ripe for transformation.*
- (v) **MSC and services from the same agency.** In principle people should receive their Service Coordination from a different agency than the one that provides day or residential services, avoiding conflict of interest. In practice more than 60% of MSC recipients receive MSC from the same agency that provides their services. *There should be an acknowledgement that even the most well-trained staff have a*

bias towards the services they know (within their own agencies), and a requirement that agencies affirmatively address the bias.

- (vi) **No transparency for funding.** Budget streams are obscure, service pricing is fragmented and budgets are opaque. While confidentiality should be respected, equity for people with I/DD, the interests of providers and taxpayers alike should be aligned when funding streams are more transparent.
- (vii) **RISK and rights and responsibilities.** There is a regulatory emphasis on the exclusion of all risk, past any rational purpose, to the detriment of individual rights. *OPWDD has undertaken considerable work on re-thinking risks and agencies should be trained in risk principles.*
- (viii) **Moving from ICF to IRA etc.** Who decides who prefers to live in an ICF or an IRA vs. living in the community? – The individual? Their guardian? The ICF operator? Their staff? *Current efforts to provide decision making to the residents are limited in scope and need to be upgraded.*
- (ix) **Roommate – who chooses?** In a congregate setting – not the people who are sharing a room. HCBS settings principles require that the individuals have a choice. *This needs to be implemented.*
- (x) **Dispute resolution.** How do you resolve disputes or friction between residents and between staff if an agency owns the home? There is no route other than punitive to staff and segregation for resident. *Residences should create and adhere to a “Social Contract” between the owners of the property, the residents and the service provider to cover dispute resolution.*
- (xi) **Maintenance.** Certified houses are funded for house maintenance and repairs. Uncertified homes are not. Funding for reasonable maintenance is an even more acute need for those who use “Home of Your Own” or other innovative methods to build or acquire housing. *OPWDD should reexamine its guidelines for what constitutes property improvement and what is necessary maintenance.*

V. Excessive bureaucracy associated with the introduction of Self Direction

- (i) **Laborious process.** To obtain housing an individual must (1) provide evidence of that they have partners, (2) that they have executed a lease, (3) they must submit a plan – and (4) wait. Given the realities of the real estate market these requirements make obtaining housing almost impossible. The present requirement under self-direction for those utilizing transition stipend funds for housing support is that they submit all four transition stipend forms with copies of all receipts. This is difficult for most individuals or families who may not be able to finance several thousand dollars up front to get an apartment ready. *This process needs to be redesigned.*
- (ii) **FI Choice.** Individuals should have a choice to change their FI agency at any time just like their broker support if they are not satisfied with their support services. This is central to the principle of informed choice. Current guidelines limit the option to change FI to once a year on their “annual date”. The high risk to providers associated with the FI Employer liability has limited the number of agencies willing to provide the service. In much of the state there are only one or two FIs. *OPWDD should consider how FI employer risk can be capped or mitigated.*
- (iii) **Over Compliance.** The contemporaneous note and 15 minutes billing increment that OPWDD is requiring is going to create more paperwork and less support to the individual in a Self Directed setting. *This is a process that cries out for simplification and automation.*

VI. Unaddressed Needs of people seeking independence.

- (i) **Everything is fine!** There is a perception by the affordable housing community that ASD- I/DD is “taken care of”. Not surprisingly given the OPWDD budget, many advocates for other communities resent the resources devoted to people with ASD- I/DD without understanding how challenged the current system is. *OPWDD needs to be proactive with other groups and agencies.*
- (ii) **Legislature ill informed.** There is a perception by NY Legislators that the large agencies know what is best for the people they serve. There is also a lack of

interaction with self-determined people with I/DD and their families. *Families involved in self-directed services need to organize and educate their representatives.*

(iii) **Parental and guardian decision making** vs. supported decision making.

Guardianship is absolute, and contrasts with efforts to promote self-determination and dignity. *The state is examining how the guardianship statutes should be amended to provide for supported decision making and more involvement by people who may be subject to guardianship restrictions.*

(iv) **Benefit Advisement.** Myths abound as to what happens when a person starts to earn money, or move to less restricted settings, - myths perpetuated by people who benefit from institutional business. *Improved benefit consultation will give people more options.*

Appendix D - Acronyms

Acces-VR. Adult Career and Continuing Education Services- Vocational Rehabilitation

AFI/IDA. Assets for Independence/Individual Development Accounts

AHP. Affordable Housing Program

AoA . Administration on Aging

ASD. Autism Spectrum Disorder

CAS. Coordinated Assessment System

CDBG. Community Development Block Grant

CDE. Community Development Entities

CDFI. Community Development Financial Institution

CDPAP. Consumer Directed Personal Assistance Program. Formerly -

CDPAS. Consumer Directed Personal Assistance Services

CHI. Community Housing Innovations

CIP. Community Investment Program

CMS. Centers for Medicare & Medicaid Services

CSS. Consolidated Supports and Services

DCMH. Westchester County Department of Community Mental Health

DDP2. Developmental Disabilities Profile

DDRO. Developmental Disabilities Regional Office

DOF. Disability Opportunity Fund

DPAL. Down Payment Assistance Program

DSS. Department of Social Services

ETP. Employment Training Program

FHA. Federal Housing Administration

FHLB. Federal Home Loan Bank

FI. Fiscal Intermediary

GROW. Advocates for People with Developmental Disabilities

HCBS. Home and Community Based Services

HCR NYS. Department of Housing and Community Renewal

HEAP. Home Energy Assistance Program

HLB. Home Loan Bank

HOME. HOME Investment Partnerships Program (not an acronym)

HOYO. Home of Your Own

HTC. Historic Tax Credits

HUD. US Department of Housing and Urban Development

ICF. Intermediate Care Facility

ICS .Individualized Community Supports

I/DD. Intellectual or Developmental Disability

IRA. Individualized Residential Alternative

ISP. Individual Support Plan

ISS. Individual Supports and Services

LIC. Live in Caregiver

LIHTC. Low Income Housing Tax Credit

LTSS. Long Term Supports & Services

MSC. Medicaid Service Coordinator

MFP. Money Follows the Person

NIMBY. “Not in My Backyard”

NMTC. New Markets Tax Credit

OAR. Organization for Autism Research

OPWDD. Office for People with Developmental Disabilities

PCP. Person Centered Planning

PHA .Public Housing Authority

PPA Prior Property Approval

PRA. Personal Resource Account

QEI. Qualified Equity Investments

RETC. Renewable Energy Tax Credits

SDSO. Self Directed Support Options.

SEMP. Supported Employment

SGA. Substantial Gainful Activity
SHOP. Self-Help Homeownership Opportunity Program
SNAP. Supplemental Nutrition Assistance Program
SNT. Supplemental Needs Trusts (also sometimes Special Needs Trusts)
SONYMA . State of New York Mortgage Agency
SRO. Single Room Occupancy
SSDI. Social Security Disability Income
SSI. Supplemental Security Income
USDA. US Department of Agriculture
WDOMI. Westchester Disabled on the Move
WIHD. Westchester Institute for Human Development
WILC. Westchester Independent Living Center
WRO. Westchester Residential Opportunities