

# The Housing Resource Guide



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

**Supported, in part, by the Organization for Autism Research**



University Center for Excellence in Developmental Disabilities



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## Introduction

In 2012 Westchester Institute for Human Development (WIHD) was awarded a grant by the Organization for Autism Research (OAR) Applied Research program to create a Resource Guide for families seeking housing for their adult sons and daughters with Autism Spectrum Disorder and other Intellectual and Developmental Disabilities (ASD/I-DD) in Westchester County, New York. The creation of this guide was supported, in part, through this grant.

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 lawsuit<sup>1</sup> and the de-institution related reforms in the 1970s. 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 and in our region, the system that has developed is expensive, segregated and exclusionary, and is no longer economically or socially sustainable<sup>2</sup>. People with ASD/I-DD and their families are compelled to seek alternatives.

Westchester County is home to just under one million people<sup>3</sup>. For the purposes of this project we estimate the number of people in Westchester County with significant support needs, people who need some level of support all day every day, to be approximately 3,700. Approximately 20,000 additional people need less comprehensive care, across a wide spectrum of need. NY State currently supports approximately 2,800 people with ASD/I-DD in congregate and community housing in Westchester County, with an additional 500 people on a waiting list. In the forty years since the Willowbrook Consent Decree, NY State has developed a group home system that serves some 30,000 people<sup>4</sup>. Funding for this system, primarily from Medicaid and Medicaid Waiver 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. 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, segregated and increasingly out of line with best practices. Federal and state reforms are pointing the way to more self-determination, individualized plans and budgets 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 flexibility of the provider agencies.

The Guide begins with an overview of housing options in Westchester County 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. 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 funding that made this guide possible, and for their continuing commitment to the vital issues that affect people with ASD-I/DD.



## I. First Steps: Eligibility and Entitlement

The path to housing starts with finding out what resources an individual might already have. We begin by helping to determine 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 services, and these should include plans to become qualified wherever they are eligible for the adult services and opportunities listed below. Whereas children are entitled to a Free and Appropriate Education, adult services 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.

- (i) 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 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 \$1070 income per month, 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.
  
- (ii) An individual may also qualify for **Social Security Disability Income (SSDI)**. Social Security is an insurance program, so it requires that an individual 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<sup>5</sup>. 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 an individual and their service coordinators need to monitor the SSDI level. SSDI by itself does not qualify an individual 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 people with disabilities. While people with ASD-I/DD may be enrolled in Medicare it is not directly involved in housing.

**(iii) Medicaid** is a health insurance program for people with disabilities, as well as senior citizens and people with low income. 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 and in NY State counties 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).

**(iv) 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 a person seeking employment support from OPWDD<sup>6</sup> first seek support from ACCES-VR. 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. ACCES-VR services can be applied for directly from the regional office, and the application process should begin when a student enters their last year of High School. Application should be included in the student’s Transition Plan and school counselors should connect the student with the ACCES-VR process.

- (v) Apply to the **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). Westchester is in Region 3 of the state, and the DDRO has offices in Thiells, in Rockland County, and in Tarrytown in Westchester County. Once deemed eligible by OPWDD, the current route to obtain services is through the “**Front Door**” Process<sup>7</sup>, 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<sup>8</sup>.

The Front Door process includes an assessment of a person’s needs. Since the 1980’s NY State has used an assessment instrument called the **Developmental Disabilities Profile (DDP2)**. The instrument is deficit based and implicitly incentivizes applicants to highlight their disability 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 instrument<sup>9</sup> 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 **Personal Resource Account (PRA)** (see (vii)). The PRA is critical to developing a service plan, and is based on the principle that “**Money Follows the Person**” (**MFP**).

- (vi) 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, 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 obtaining a flexible budget for housing.
  
- (vii) **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)**” Waiver. HCBS waivers allow for funding to be directed to the individual need rather than to an agency program. NY is currently negotiating a new waiver, the “People First” waiver<sup>10</sup>, (more technically a 1915 (b) (c) waiver). Under the waiver CMS requires that Medicaid funded programs be more individualized; specifically
  - a. Waivers should encourage **Self Direction**
  - b. Waivers should include **Person centered Planning**
  - c. Every participant should have an **Individualized Service Plan (ISP)**
  - d. Every participant should have an Individualized Budget, and a **Personal Resource Account (PRA)**
  - e. The state must provide Information and Assistance in support of Self Direction
  - f. The state must monitor for Quality Assurance and improvement.

The reforms that OPWDD is initiating coupled with the freedom “Waiver” creates, allow for a much more flexible path to housing<sup>11</sup>.

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.”

**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.”<sup>12</sup>

**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.”<sup>13</sup> 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 Consolidated Support Services (CSS) their MSC is required to be a member of the Circle of Support.

**(viii) Individual Supports and Services (ISS).** ISS funds are “state only” funds, and are independent of Medicaid funding. As such they can be used at the 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 in to account the individual's income. ISS funding can be included in an individual's plan along with their CSS day funding, but if an individual is using CSS for their residential plan ISS may not be used.

- (ix) 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 CSS an individual 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 CSS the DDRO will provide them with a list of "Start-Up" brokers. The Start Up 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 CSS the MSC must be a member of the Circle of Support. Once the budget has been approved by the DDRO and by the Division of Budget in Albany, the Start-Up broker hands off to the "Support Broker" who will continue to work with the individual to implement and sustain the plan. Under CSS the individual 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. CSS 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 CSS - Money Follows the Person - is essential to realizing housing independence, and CSS, sometimes

coupled with ISS, is the current mechanism within OPWDD services that is built around that principle.

- (x) **Department of Social Services (DSS)** can provide funding for personal aides, nursing care and other support through **Consumer Directed Personal Assistance Services (CDPAS)**. These funds cannot be used to purchase housing services but they expand the options for residential supports. Application is made through the Department of Social Services using a 1050 form. Eligibility is based on the level of need, and applicants must have Medicaid.
  
- (xi) **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:
  - **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 Department of Social Services. The person’s MSC should coordinate this application.
  - **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<sup>14</sup>. 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.

- **ConEd CONCERN, Low Income Rate, and Energy Share.** 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 is in a "turn off" situation, and it can only be used once every 5 years<sup>15</sup>. These programs are available to those receiving SSI/Medicaid. The application process begins in mid-January, and is the responsibility of the individual.
- **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.<sup>16</sup>

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."

## 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 in to the community other sources of income and support have become available.

- (i) **Employment.** As described by the US Dept. 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.”<sup>17</sup> 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<sup>18</sup>, 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 most definitely meet with a Disability Benefits Specialist to learn about how to retain benefits while earning income. There are several agencies in the County that are funded through OPWDD, or ACCES-VR, or through private fees to provide this service.

- (ii) **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 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 NY Special Needs or Elder Law attorney before creating or joining a trust.

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

- a. **Third Party/Supplemental Needs Trust (SNT).** These are usually established by a parent or other guardian or relative. They can be funded immediately, funds may be added over time, or they may be funded through an insurance policy payable upon the death of a parent.
- b. **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.”

- c. **Pooled Trust.** A Special Needs Trust for an individual that is managed by a not-for-profit 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, consultation with a specialized attorney is essential.**

**(iii) 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.

- a. **Housing Vouchers.** Section 8 of the US Housing Act of 1937 administered by the US Dept. of Housing and Urban Development (HUD)<sup>19</sup> 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. Of Westchester’s 48 municipalities there is only one that currently (February 2014) has an open waiting list. One other has 250 vouchers outstanding with a wait list of 3,000. All other waiting lists are closed, and funding is currently constrained by federal budget 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, and **Very Low Income** as 50 % of the area median income.<sup>20</sup> The median household income in Westchester is \$81,093.<sup>21</sup> Housing agencies must provide 75% of their vouchers to applicants whose incomes do not exceed 30% of the area median income,<sup>22</sup> in the case of Westchester that is \$24,328. 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 or the CVR New York (which covers all of Westchester) Section 8 offices at 112 East Post Road, White Plains.

- b. 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 the 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 publication, “The Voice” issue of March 2011 described the impact of an SNT on eligibility.<sup>23</sup> 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.<sup>24</sup> As with any legal matter the individual should consult an attorney.

- c. **Section 9** of the Housing Act provides for funding for **Public Housing Authorities (PHAs)**. HUD funds both capital and operating expenses for the 21 PHAs in Westchester. PHAs provide housing for low income individuals (80% to 50% of median income). 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.
  
- (iv) **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.

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.

### 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.

#### (i) HUD resources for Developers.

a. **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 Non-Profit 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.<sup>25</sup> The section 811 approach has successfully been applied to recent developments in neighboring Rockland County, and in Westchester.

b. **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:

- c. **The Public Housing Agency Plan** which 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.<sup>26</sup>
- d. **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 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 neighboring 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.
- e. **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 Westchester 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.<sup>27</sup> This is a subject that merits further examination.

- f. **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 non-profit 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.<sup>28</sup>

(ii) **US Department of Agriculture (USDA)**<sup>29</sup>:

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. While there are many rural areas in New York State, Westchester County in particular is very developed with little opportunity to access these funds.

- (a) **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, and while there are no locations in Westchester there are locations in the neighboring counties of Ulster, Sullivan and Putnam beyond the larger cities and towns of those areas.

- (b) Housing Preservation Grants** are made to local municipalities, state agencies or non-profit organizations to repair or rehabilitate rental units to benefit low income individuals.
- (c) 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.
- (d) 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).

**(iii) Internal Revenue Service: (IRS)**

The IRS is not directly involved in housing but is a major factor in its creation, in particular through:

- (a) 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 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 Westchester County.<sup>30</sup>

**(b) New Markets Tax Credit (NMTC)** was established as part of the Community Renewal Tax Relief Act of 2000<sup>31</sup> 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.<sup>32</sup> 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.

**(iv) 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.<sup>33</sup>

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.

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

### (i) 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. 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.<sup>34</sup>

#### ***“Access to Residential Services:***

- *Westchester County Department of Community Mental Health (DCMH) is the Single Point of Entry (Central Registry) for placement on the residential waitlist following OPWDD eligibility. There is a new “Front Door” procedure being developed to address eligibility and identify needs.*
- *Enrollment on the waitlist may be initiated by an individual or a family member, a Medicaid Service Coordinator (MSC), a provider agency or school district by contacting DCMH directly at (914) 995-5276.*
- *DCMH works collaboratively with provider agencies, families, advocates and MSCs throughout the referral process to gather all the necessary information. After eligibility has been established with the Developmental Disabilities Regional Office (DDRO) of the Office for People with Developmental Disabilities (OPWDD), it is important for the individual and his/her family to identify the types of supports that are needed to transition to a new housing option.*



- *At this time, development of **new** certified residential opportunities is limited to those individuals who are aging out of residential schools and to those who are being deinstitutionalized.<sup>35</sup> However, OPWDD is currently exploring additional, i.e. Non-traditional, community living options to accommodate new residential housing opportunities.*

**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 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.*
  - 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. 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.”*

Certified Group Home settings are not for everyone. As noted above they are not available to all, and 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, 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.

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.

- (ii) **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.”<sup>36</sup> 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.

- (iii) **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 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. Creating a Housing Plan

**Person Centered Planning.** 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.”*<sup>37</sup>

An excellent publication from The New York Self Determination Coalition “Self Direction in New York” describes the process in lay terms: **Person Centered Planning** is:

- *“An open and on-going exploration of what is important and meaningful to the person*
- *A frank discussion of necessary supports and safety concerns*
- *A practical discussion of how day-to-day life can reflect an individual’s preferences and desires*
- *A process to be approached with an open mind, creativity, and without arbitrary assumptions.”*<sup>38</sup>

Person Centered Planning needs to acknowledge the hopes and aspirations of the individual, while being firmly rooted in the practical. 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 reduced.

Following the path laid out in this guide, the first step is to review and inventory what are the assets, income from private and public sources,

eligibilities and entitlements that an individual 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 an individual and their family to answer one of the most important questions in their search for 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?”

**(i) 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 the individual and their family. 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 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 the individual, 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.

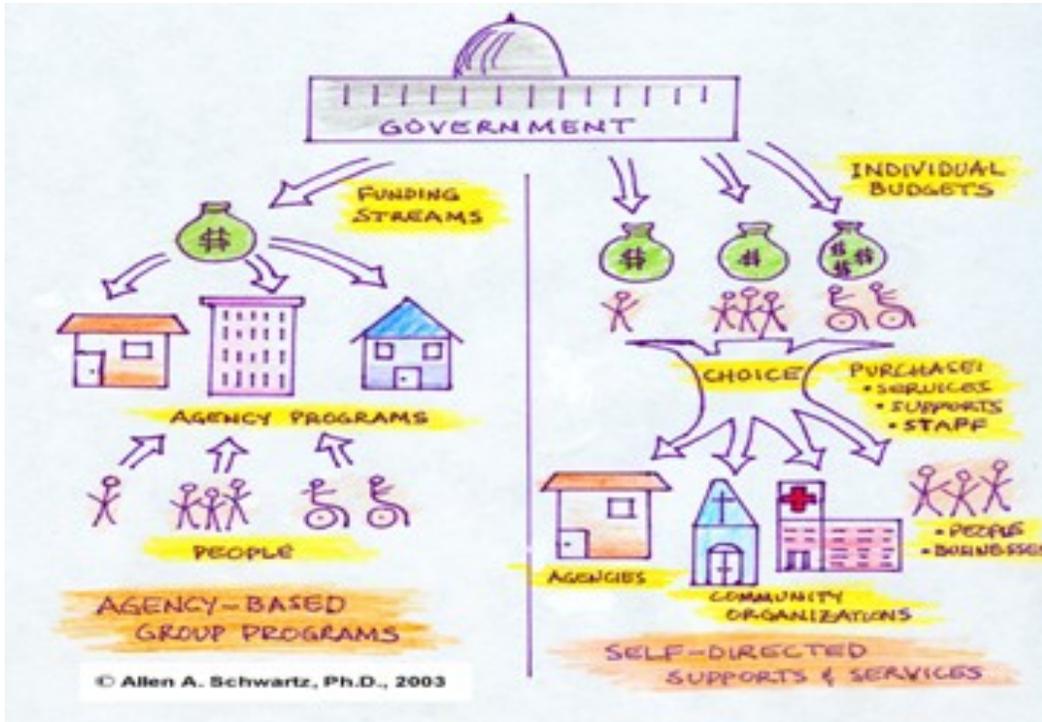


Figure 1

**(ii) Planning for Independent Housing.**

If after a careful review of the pros and cons of Certified Housing settings in contrast to Independent Housing an individual chooses to seek Independent Housing they should consider the steps we have outlined so far:

- a) Review the resources that are available to them, including employment plans and prospects, and seek help from a Benefit Advisor.
- b) If eligible, apply for SSI, Medicaid, ACCES-VR, and OPWDD services, MSC, Medicaid Waiver and CSS. 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.
- c) 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.

- d) 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.
- e) 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 of course, but 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 PRA for services can exceed 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?

**(iii) 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.

**a) 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. Our region encompasses areas that fit all three criteria.

**b) 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 an individual or more than one individual living with others 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.

**A room of your own.** Having one's 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.

**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.

**(iv) Other Considerations.** This guide is focused on obtaining accommodation rather than the provision of LTSS, but In addition to the cost of rent or mortgage, there are other related costs to consider when creating a plan and a budget, whether for one person living alone or for a group of people.

(a) For most people with ASD-I/DD the cost of support staff is the largest item in their budget. Their CSS Residential plan, created in collaboration with their Circle of Support and their Start-Up or Support broker will include a projected amount of staff support time. If an individual is living with other people who are also receiving CSS funding they can combine their staffing hours. They may need to include a “Live-In Caregiver” (LIC) for overnight safety and as a way to control staff costs. Careful planning to optimize staff time is essential not simply to conserve funding but also to comply with overtime and labor laws.

(b) Staff can be hired in two primary ways:

- i. through Self –Direction the individual or individuals can recruit their own staff, and the FI becomes the employer of record. This may result in reduced costs but requires more management by the person receiving services and their Circle of Support. Or,
- ii. the individual or individuals contract with a provider agency to provide and oversee staff. This may be more expensive but will take care of much of the management, compliance and training tasks.

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.

**(v) 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.

**(a) Self Advocates.** WIHD is home to an active group of Self Advocates, many of whom are in various stages of planning for their housing, or who have achieved their own housing, singly or with others. The Self Advocacy group can be reached through WIHD, and is keen to help people seeking housing to connect with each other.

**(b) GROW.** GROW is a parent and family run organization whose members have volunteered their time for over thirty years to advocate for a full range of support services to enhance the lives of people with developmental disabilities. It was founded in 1981 when a small group of

families felt the need to band together to assure that their loved ones receive residential and other services in the community. GROW ( <http://www.growny.org/docs/about.htm>) has created a committee comprised of parents who will be acting to facilitate connections between families who are seeking to find other families who might collaborate on the creation of housing for their sons or daughters with ASD-I/DD. The committee parents are members of the Housing Learning Community.

- (vi) 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.
  
- (vii) 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 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.”<sup>39</sup>

- 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. Westchester County enacted “Source of Income legislation” in December 2013 partially protecting county residents from such discrimination, but effectively exempting small landlords.<sup>40</sup>
- 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 to 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 are not readily available at this time.
- d. Utilities.** Some rentals include the cost of utilities and perhaps superintendent services in the rent, some 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 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 visit the

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

- (viii) Renting a home.** People with disabilities and people with low incomes have several programs and options open to them to assist with rental payments.
- (a) 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 in Westchester. Currently the waitlists are long, and many offices have simply closed their waitlists. When available, the voucher allows the individual to pay only a 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. The wait list for HUD vouchers has its counterpart in the county waitlist for certified housing.
- (b) 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.
- (c) 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 that will undertake to provide support services to the people living in the “set aside” units, and the agency will 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 2014<sup>41</sup> 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.

**(d) To Rent an Affordable house/apartment.**

In addition to newspaper advertisements, personal contacts etc. there are several websites that allow you to search for affordable rental housing in New York and Westchester:

- <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&region\\_id=32865](http://www.socialserve.com/tenant/NY/Search.html?type=rental&region_id=32865)
- <http://homes.westchestergov.com/homeseeker-housing>
- <https://secure05.westchestergov.com/housingintake/jsp/language.jsp>
- <http://www.nyshcr.org/topics/home/renters/opportunitiestoapplyforaffordablerentalunits.htm>

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

**(a) 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.

**(b) 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 school taxes at a lower rate through a School Tax Relief (STAR) exemption.<sup>42</sup>

**(c) 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 CSS 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 HCR<sup>43</sup> or a Community Development Financial Institution (CDFI) such as the Disability Opportunity Fund which is headquartered in Long Island but is active in Westchester County.<sup>44</sup>

**(d) 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 one of the individuals involved is 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.

**(x) 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 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.

**(a) 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 a failing boiler/water heater/roof. Expenses can be significant, unexpected and untimely. As previously noted, state based budgets (e.g. CSS 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.

**(b) Realtors.** An individual may want to contact a real estate agent to assist with the housing search. 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 WIHD Housing Learning Community includes realtors who have experience with the needs of people with ASD-I/DD.

- (xi) **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.
- (a) **Down payment.** There are state programs that will help with funding for down payment and closing costs when purchasing a home.<sup>45</sup> In a “Matching Grant” program an individual’s own savings towards a down payment, typically to a maximum of \$1,000 but in some cases more, are matched by the state at a ratio of from 4 to 1 to as high as 8 to 1. Savings of \$1,000 can lead to a down payment of \$9,000.
- (b) **SONYMA Down Payment Assistance program (DPAL)**<sup>46</sup> 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.<sup>47</sup>
- (c) **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 a \$1000 may receive a match of \$8000 for a total of a \$9000 pool of funds to be used for a down payment on a home. This program is administered through OPWDD and M&T Bank.<sup>48</sup>
- (d) **First Home Club Savings for Down Payment .**<sup>49</sup> 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 \$7500 in matching funds.
- (e) **Home of your Own (HOYO).** HOYO is a program created in the mid 1990’s to encourage home ownership for people with developmental disabilities and in NY State is run by OPWDD. Through SONYMA and M&T Bank, the HOYO program offers homeownership support services, such as homeownership counseling, as well as low interest rate mortgages.<sup>50</sup>

- (f)** In 2013 **Community Housing Innovations (CHI)** received a grant from the New York State Affordable Housing Corporation and may provide up to \$25,000 toward down payment assistance via the Westchester County Home Ownership Initiative to eligible low income individuals.<sup>51</sup>
- (g)** **Hudson Valley Home Ownership and Revitalization**<sup>52</sup> program offers first-time homebuyers purchasing a property in Westchester or the Hudson Valley \$25,000 in program funds for the acquisition and renovation of an identified property for low income individuals. The funds are provided as a forgivable loan, which is waived if the property is lived in for over 10 years. A minimum of 51 percent of the \$25,000 - \$12,750 - must be used for renovation or repairs of the property.
- (h)** **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 Westchester where house prices are relatively high, and you may need to borrow from more than one source, or to combine grant funds with a mortgage.
- (i)** **State of New York Mortgage Agency (SONYMA).**<sup>53</sup> 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.
- (j) **Smart Move Loan (through HDF Connects).** This is a second mortgage product for first time homebuyers with incomes below \$83,400 in Westchester. Loans can be for a term of up to 20 years at a low fixed rate. Applicants must receive homebuyer education and counseling to qualify for the loans.
- (k) **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. In Westchester, the program is administered by CVR New York.<sup>54</sup>

- (xii) **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.



**(a) 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.



**(b) 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. Westchester Residential Opportunities (WRO) based in Mount Vernon is the lead agency in the county coordinating the program. Applicants are screened by either of the county’s two Independent Living Centers, Westchester Independent Living Center in White Plains (WILC) and Westchester Disabled on the Move (WDOMI).



## VI. 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. 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	
<b>I. Eligibility and Entitlements Benefit Review</b>			
		<b>YES</b>	<b>NO</b>
SSI			
SSDI			
Medicaid			
ACCES-VR			
OPWDD	DDP2		
MSC			
Medicaid Waiver			
ISS			
CSS			
DSS			
Income Assessment			
	SNAP		
	HEAP		
	ConEd		
	Lifeline		
<b>II. Individual Resources</b>			
Employment			
Supplemental Needs Trust			
HUD			
Credit Score			
<b>III. System Resources and availability to the Individual</b>			
HUD 811			
HOME			
PHA Plan			
CDBG			
CoC Plan			
SHOP			
USDA			
IRS	LIHTC /NMTC		
FHLB			

IV. State Agencies that support Housing			
OPWDD Certified Group Home			
OMH Supported Housing			
Administration on Aging			
V. Creating a Housing Plan			
Decision on Independent Housing			
Planning for Independent Housing			
Determining factors for location and collaboration			
	Urban, Suburban or Rural?		
	Alone or with others		
	A room of your own		
	With whom?		
Other considerations	staffing		
	Self hire or		
	Agency hire?		
How to connect			
Rent or buy	<b>AFFORDABILITY</b>		
	Accessibility		
	Availability		
	Utilities		
	Rent control		
	Section 8 rental		
	Public Housing		
	Multifamily housing		
	Real estate taxes		
	Maintenance		
	Ownership partnership		
	Budget sustainability		
Purchasing assistance	Loan Programs		
Environmental Modification			

## **Appendix B.**

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 renewal 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 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..

Each homeowner’s room is their private area. No other person in the house may have access to their room without their permission

Each homeowner will participate in household chores to the best of their ability.

All household upkeep expenses and maintenance expenses are borne equally

All food costs are borne equally

Each homeowner will pay an equal sum in mortgage, taxes, upkeep and utility costs to Agency. This sum will be periodically reviewed by the House committee

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**

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.

Each homeowner, their family and circle of support are responsible for the individual’s health and wellbeing, and will work through the house committee to allocate support worker time.

Are responsible for repairing any damage to the house or other property caused by themselves or their guests.

Will respect each other’s privacy

Are committed to independent living and will work to maintain that goal.

Will perform the household chores to the best of their ability and fairly.

### **(ii ) Agency**

Will pay the mortgage, tax, car lease, house upkeep and utility bills on behalf of the homeowners.

Will act as a fiscal intermediary for the homeowners.

Will pay all bills due in a timely fashion.

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.

Will be the employer of record for any paid caregivers.

Will ensure the maintenance of insurance policies to protect the homeowners, their property and their employees.

Will maintain accurate, and easily understood records of all transactions.

Will recruit and review all support personnel.

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.

Will review the upkeep of the house and budgetary matters.

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.

Will work with the homeowners to establish a fair share of household chores for each person, set bathroom schedules etc.

Will set menus and shopping lists

Oversee household costs and major expenses

Will review any damage done to the house by the homeowners or their friends or their support staff

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.**

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.

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.

There will be no overnight guests.

There will be no internal locks in the house.

No pets are allowed unless agreed to by each of the homeowners

The house is smoke, alcohol and drug free.

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, with the first renewal due on May 1<sup>st</sup> 2000.

Signed by all homeowners, families and house liaison

## **Appendix C.**

### **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

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  
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

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

PRA. Personal Resource Account

QEI. Qualified Equity Investments

RETC. Renewable Energy Tax Credits

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

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<sup>2</sup> The Group Home system is described in section IV of the Resource Guide.

<sup>3</sup> Per the US Census Bureau 2010 report pop. 961,670 2013 estimate <http://quickfacts.census.gov/qfd/states/36/36119.html>

<sup>4</sup> 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

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<sup>6</sup> It is a sad fact that in order to advance to 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.

<sup>7</sup> Refer to OPWDD Front Door site. <http://www.opwdd.ny.gov/welcome-front-door/home> retrieved February 2014

<sup>8</sup>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](http://www.clmhd.org/img/uploads/file/507_Final_1_4_12.pdf). Accessed May 2014

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<sup>14</sup>Office of Temporary and Disability Assistance, (OTDA) website <http://otda.ny.gov/programs/heap/> retrieved February 2014

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<sup>54</sup> <http://www.nyshcr.org/Programs/section8hcv/hcvp00.htm>, [http://portal.hud.gov/hudportal/HUD?src=/program\\_offices/public\\_indian\\_housing/programs/hcv/homeownership](http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/programs/hcv/homeownership) (March 2014)

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