

HOUSING OPTIONS FOR ADULTS WITH AUTISM SPECTRUM DISORDER



pennsylvania

DEPARTMENT OF PUBLIC WELFARE

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**HOUSING OPTIONS FOR ADULTS
WITH AUTISM SPECTRUM
DISORDER**

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EXECUTIVE SUMMARY

In September 2008, the PA Department of Public Welfare's Bureau of Autism Services appointed the Housing Options Committee and charged them with the task of identifying and assessing housing options that will meet the varying needs, preferences and abilities of adults living with autism spectrum disorder (ASD)¹ at different points in their life cycle. The Committee included representatives from state agencies, county agencies, statewide disability organizations, elected officials, non-profit housing developers, and individuals with autism and their family members. The long-term goal of the group was to expand the number of viable housing options and models in order to maximize the choice and independence of adults with autism. The work of the Committee was facilitated by a consultant and staff from the Bureau of Autism Services.

The Committee held seven meetings during which it: defined the audience for the report; developed guiding principles; described the characteristics of the target population and their unique housing needs; identified barriers that adults with autism encounter in accessing housing or creating new housing opportunities; developed criteria for reviewing and selecting housing models for inclusion in the report; and reviewed numerous existing housing models for people with disabilities. The final step was the development of recommendations for addressing the barriers identified and the identification of "next steps" for accomplishing the Bureau's agenda.

The Committee was charged with an extremely challenging task. There is a very wide range of skills and needs among adults with autism, and their housing needs change over time as they move through different developmental stages. Further, one of the underlying principles for the Committee was to maximize housing choice. For some individuals, this may entail renting an apartment and receiving assistance with scheduling or bill paying. For others, it may entail creating a new housing opportunity such as a housing cooperative supported with service providers on a person-centered basis. Yet, for others, this may entail moving to a campus community with on-site staffing. In any case, attaining one's choice requires not only education in housing options but also a comprehensive housing needs assessment and plan for implementation.

As with any adult, an adult with autism will have differing housing needs and desires over the course of their life and may choose to move to a different setting as their needs and desires change. The key is to have housing opportunities from which to select that provide an affordable, quality home that meets the individual's current needs. Unfortunately, given the low incomes of many individuals with autism, public and private resources are needed to make most housing options affordable. That, too, is challenging in light of the current shortage of existing affordable housing throughout the Commonwealth and the competition for limited resources. In addition, although this report focuses on

¹ The term "autism" will be used throughout the report to refer to autism spectrum disorder (ASD).

housing, the Committee was constantly aware of the importance of having a range of services available to support individuals in the homes of their choice and the complexity of the current funding streams and waivers. The marrying of a variety of high quality housing options with appropriate services, although beyond the scope of the Committee's work, will be critical to adults with autism being able to actualize their housing choices and succeed in their homes.

The core of the report is the description of 22 housing models. A typology of seven different housing settings was developed. These include:

- Remaining at home
- Family living
- Renting an apartment or home
- Purchasing a home
- Shared housing
- Intentional communities
- Licensed facilities

The Committee members and consultants researched a number of models within each of these settings. All of the housing models identified have been options for adults with disabilities, but not necessarily for adults with autism, since there have been very few housing options developed specifically for this population. The Committee discussed each model in the context of its appropriateness for adults with autism; identified the strengths and unique characteristics of each model; and enumerated considerations/modifications needed for the model to best serve the target population.

Although numerous housing models exist, there are significant barriers to individuals successfully obtaining the housing of their choice in Pennsylvania. These barriers include: difficulty in accessing accurate information about housing and services; the scarcity of financial resources for creating new housing and the need for expertise in affordable housing development; the limitations imposed by both housing funding sources and local regulations; the need for appropriate services to support people in the housing of their choice; and characteristics of some adults with autism that require specific planning and housing design considerations.

This report identifies short- and long-term recommendations designed to remove these barriers and increase housing options for individuals with autism. The recommendations focus on: educational opportunities for adults with autism and their families to learn about housing options and service regulations; creation of new housing opportunities by taking advantage of federal, state and local housing funding sources; amendments to current regulatory policies on licensed residential programs and waiver funding; and creating increased public awareness, and awareness by the affordable housing industry, of the need for housing choices for adults with autism.

While some of the short-term recommendations can be accomplished with existing resources, it is imperative to recognize that successful implementation of other recommendations will depend upon two things. First, it will require advocacy by and partnerships with a host of public and private agencies and individuals, including persons with autism and their family members. Second, it will require the dedication of resources for both housing and supports. When the Bureau first embarked on this planning process, resources were available to create and test new and innovative ideas. Since then, however, resources have become extremely precious. Although this will not eliminate the Bureau's ability to carry out many of the recommendations, it may require that some recommendations be deferred. It will also require the Bureau to maximize coordination and collaboration with other public and private entities.

The report is an important first step in increasing housing choice and options for adults with autism. It is anticipated that some public officials, housing professionals, service providers, developers, public agencies, and individuals with autism and their family members will be able to readily use the information in the document. Others will need assistance in formulating and actualizing housing plans in areas such as: determining the most appropriate housing model; identifying partners to assist in pursuing the model; accessing housing financing; negotiating with service providers; and making sure the point of view of the individuals with autism is represented through the entire process.

In order to address the need for assistance, it is recommended that major next steps by the Bureau of Autism Services include: (1) designation of the Regional Autism Centers as the locus for housing and planning expertise and technical assistance, and (2) sponsorship or co-sponsorship of a pilot project to implement five to six of the above models specifically for individuals with autism. A technical assistance team would work with interested individuals and families on the model of their choice in order to test the feasibility of the model; determine the applicability of the model to adults with autism; identify barriers to implementation, and resolve barriers to the extent possible. This information will then inform a "How-To Guide" to provide step-by-step instructions and worksheets to assist housing planners and families in moving forward with their housing choice.

In releasing this report, the Bureau of Autism Services will not only be providing critical information on housing to a range of agencies and individuals, but also demonstrating yet again its national leadership in addressing issues designed to improve the lives of individuals with autism and their families.

SECTION 1: INTRODUCTION

Background and Objectives of the Housing Options Committee

The Bureau of Autism Services (BAS) was established in 2007 in response to the recommendations of the 2004 Autism Task Force Report. With respect to housing, the Task Force concluded: “Like typical Pennsylvanians, adults with autism will choose a variety of housing types, including continuing to live with their parents or other relatives, independent housing, group housing, or living within communities that are defined by educational or therapeutic approaches.”²

In September 2008, BAS appointed the Housing Options Committee. The Committee’s charge was to identify and assess housing options that will meet the varying needs, preferences and abilities of adults living with autism at different points in their life cycle. The goal was to expand the number of viable housing options and models in order to maximize the choice and independence of adults living with autism.

The work of the Committee was highly complex and challenging. While the group was charged with developing housing models, it is extremely difficult to separate housing from the supports needed for an individual to successfully find and maintain their housing. Indeed, many of the housing options identified and described in this report include the provision of services and, for this reason, they may be preferable to some housing seekers. However, while recognizing the importance of having services available to support an individual in their home, the Committee maintained its focus on presenting as broad a range of housing options as possible, regardless of the current availability of services. It also recognized that limited resources are available at the present time. Therefore, when services are described in this report it is because they are an integral part of the model being presented. Otherwise, it is assumed that the users of this report will address the provision of services through different resources.

Committee Process

The Housing Options Committee included representatives of state agencies, county agencies, statewide disability organizations, elected officials, non-profit housing developers and family members, and individuals with autism. A complete list of participants is provided as **Appendix A**.

The Committee held seven meetings from October 2008 through June 2009 to define the scope of the report, identify and review models, and make recommendations for housing models to address the needs of adults in Pennsylvania who are living with autism.

² Pennsylvania Autism Task Force Executive Summary, December 2004.

The Committee began its deliberations by reviewing the purpose of the committee, the timeline and proposed outcomes of the process. They then defined the target population to include all adults living with autism who needed housing assistance, followed by a description of their special characteristics and housing needs. This was followed by an initial listing of examples of housing models to be included in the report.

The next step was to craft a working definition of “community integration,” as this is a key term used in describing housing options for the target population. Once the committee agreed on a working definition, it turned to the identification of guiding principles for their work and criteria to be applied in selecting models for further investigation. However, it soon became clear that the Committee members did not want to eliminate any models. Rather, the group agreed to pursue all of the models and examples identified. Barriers were then identified that could impede the pursuit of the options being considered.

The Committee spent several meetings reviewing and discussing written summaries of a range of housing models. In addition, videos and guest speakers provided further information and insight into several models. In each case the Committee members determined whether the model would be desirable for adults living with autism and, if so, what modifications may be needed in order to make the model more feasible for their use. The last meeting was devoted to the identification of recommendations designed to remove the barriers to implementation of the various housing models.

Target Audience for the Report

The report is targeted to five different audiences:

- **Individuals living with autism spectrum disorder and their family members** who want to create or identify new housing opportunities for adults with autism.
- **Legislators, policy makers and other federal, state and local public officials** who are in the position to develop legislation, regulations, policies and programs that affect people with autism.
- **Service providers, including for-profit, non-profit, and faith-based organizations and agencies**, that work with people with autism and that want to expand the scope of their work or mission to include the provision of new housing opportunities for the people they serve or the provision of autism-specific services to support individuals in their home.
- **Housing developers**, including both for-profit and non-profit developers of affordable housing, who are interested in partnering with family members or service providers in the creation of new affordable housing

opportunities for people with autism, either as a specialized project or within their housing developments.

- **Public agencies**, including public housing authorities, redevelopment authorities and community development corporations, that engage in affordable housing development in their communities.

It is important to note that this report is targeted to agencies and individuals that have an interest in expanding housing options for adults with autism. It is not intended to provide an inventory of existing housing resources.

Organization and Use of this Report

This Report is divided into seven sections beginning with the background information provided in this introductory section followed by the following:

Section 2 provides the philosophy and guiding principles of the Housing Advisory Committee.

Section 3 describes the target population addressed in the report and their housing needs, especially the needs that are distinct from those of other populations. It also includes the criteria used to select and research housing models.

Section 4 is designed to educate readers about the key elements necessary to create new housing opportunities for people with autism. Each of the elements – such as sponsorship, ownership, and financing – is defined, and alternative approaches are described along with the considerations that must be taken into account when deciding among the alternatives. For example, the financing section includes a discussion of the considerations in determining whether to use private versus public financing sources for the development of housing.

The final housing element described within Section 4 is that of “Housing Setting,” which addresses the basic options for the housing arrangement – the type of home and the household members – whether a person lives alone, with their family members, other families or other unrelated individuals.

Section 5 of the report includes descriptions of each of the seven (7) types of housing setting and housing models within each. The following information is presented for each model: description; strengths of the model; its applicability to people living with autism; an example of housing currently available under the model; and location/contact information for the examples. *It is important to note that some of the models provide housing opportunities that include adults living with autism spectrum disorder, while others provide housing for individuals with other disabilities. However, each model was selected for its possible replication or modification for adults living with autism.*

Section 6 includes barriers and recommendations for removing the barriers in order to make the implementation of the models feasible.

Section 7 outlines next steps for individuals and agencies who, based on the information gained in the first six sections of the report, are ready and willing to proceed to the next step in creating new housing options for adults living with autism.

Finally, the appendices include participants on the Housing Advisory Committee, basic descriptions of key financing sources, and a glossary.

SECTION 2: PHILOSOPHY AND GUIDING PRINCIPLES OF THE COMMITTEE

Recognizing that people living with autism have a wide range of needs and challenges that will impact their housing preferences and needs and that those needs will change over time, the Committee identified the following guiding principles for their work. Models to be considered should, to the extent feasible:

Foster Community Integration: It is critical that housing models provide opportunities for community integration. The concept of community integration impacts many aspects of housing including scale, design, location, and ownership decisions. Since this is such a key principle in the discussion of housing opportunities, the Committee developed the following working definition:

Community Integration: Community integration is the opposite of isolation; it provides the opportunity to live in the community and be valued for one's uniqueness and abilities, like everyone else. Community integration is a right of all people and encompasses housing, employment, education, leisure/recreation, social roles, peer support, health status, citizenship, self-determination, and religion/spirituality. Community integration should result in community presence and participation of persons with disabilities similar to that of persons without disabilities.

Newly Constructed Units Should Be Adaptable/Visitable: Homes that are adaptable or visitable allow for flexibility in occupancy or visitation by people with physical disabilities or who may develop physical disabilities over time. The following are the features of an adaptable and a visitable housing unit:

Adaptable. A housing unit that has adaptable design can be easily adjusted to meet specific and changing accessibility needs of the occupants. It would have wide doorways and a no-step entrance like a fully accessible unit, but other features that can be easily modified as needed. For example, walls could have blocking to allow for grab bars to be added and removable covers could be placed over base cabinets to allow for knee space for a wheelchair user. Counter tops and closet rods can be installed on adjustable supports to change their height.

Visitable. Visitability ensures that everyone has basic access to visit homes with ease. Visitable design standards have the following features: at least one no-step entrance; a powder room on the first floor; wide doorways; and a clear path of travel on the main floor.

Enhance Informed Choice, be Individualized and Personally Fulfilling: Decisions around housing models should be person/family directed and respectful of individual desires and needs. They should also recognize that both needs and desires may change over time and that people may change

their homes to meet changing needs. Informed choice can be accomplished through allowing individuals to make their own decisions about the type and location of their housing, with whom they will live, which services they receive and by whom the services are delivered.

Provide Appropriate Housing Alternatives with Measurable Quality of Life Outcomes: It is important for a residential setting to fulfill an individual's unique needs and that there be a sufficient number of housing and service alternatives to address the broad range of people living with autism.

Safe-Guarded for Individual/Family Health and Welfare and Satisfaction: Housing models proposed should maximize the safety, health, and satisfaction of the residents. Models should be consistent with Individual Service Plan goals, designed to minimize reliance upon crisis resources, and help to decrease challenging and inappropriate behaviors.

Be Sustainable: All housing models must have the potential to be sustainable in the long term and have a plan for succession if and when one or more of the original residents leave.

SECTION 3: THE TARGET POPULATION AND THEIR HOUSING NEEDS

Characteristics

People living with autism have certain characteristics that may impact their housing needs. They may:

- Have difficulty with social skills, which may result in feelings of frustration, depression or anxiety
- Not be able to communicate through speech, which can result in the frustration of not being able to convey their feelings and ideas
- Lack such social skills such as flexibility and understanding motives that make it difficult for them to live with others
- Be vulnerable in the community because of their lack of understanding of their environment and other people's lack of understanding of their behavior
- Be at risk of having contact with law enforcement due to a lack of understanding of their sometimes, challenging behaviors in public by people in law enforcement and in the community
- Have cognitive and sensory issues that can have an impact on their housing setting
- Have co-occurring mental health and medical needs that may impact on their housing needs

Housing Needs

These characteristics create special housing needs. People living with autism may need:

- Support in finding and maintaining housing and in coordinating services at their housing site
- Extra space or amenities to accommodate their needs and preferences such as: their own bathroom, special lighting or noise barriers, an office for 24/7 staffing
- A secure location or security features to minimize risk from traffic and other hazards
- Living arrangements that are flexible enough to meet changing needs over time and life cycle
- Access to public transportation

Criteria for Selection and Research of Housing Models

Based on the specific characteristics and housing needs of the target population, the Committee identified the following criteria against which to choose and review models:

- **Affordable to the Target Population:** The housing should meet standard affordability guidelines: 30% of income including both utility costs and rent/mortgage. Services should meet individual needs with fees on a sliding scale according to income. All available public funding sources for housing and services should be leveraged to assure affordability.
- **Flexible:** The housing model should have adequate flexibility to meet the diverse needs of people living with autism and to allow the opportunity for residents to remain in their home as their needs change over time.
- **Attractive to Individuals Living There:** The housing model should be appealing and desirable to the individual who will be living there. This includes many factors such as location, design, other people living there, cost, and availability of appropriate services.
- **Utilizes Existing Housing Options:** To the extent possible, the housing proposed should build on currently available housing resources. This would allow for more rapid implementation and maximum acceptance by both funding sources and consumers.
- **Utilizes Available Community Resources:** The housing should foster the residents' opportunity to participate in community life and make use of its amenities and resources such as shopping, recreation, culture, faith community, banks, financial institutions, public agencies and other aspects of community life.
- **Simple, Replicable, and Easily Administered:** The basic components of the housing model should be easy to understand and replicable in various types of communities throughout Pennsylvania. In addition, to the extent possible, the ongoing administration, management, and fiscal accountability of the project should be easily understood and require minimal housing expertise.

SECTION 4: FUNDAMENTAL ELEMENTS IN PLANNING AND CREATING HOUSING OPTIONS

As stated above, many of the models in this document are directed to individuals and families and agencies who want to create new housing options. Since for many this will be their first such venture, we are introducing six fundamental elements that need to be assessed in planning and creating the most appropriate housing model. The following is a description of each of these elements, including alternative approaches to each.

1. **Housing Plan:** The first, and perhaps most critical, step to obtaining housing of choice for an individual with autism is to formulate a viable housing plan. This plan should identify the type of housing in which the individual wants to live, where he/she wants the housing to be located, whether the individual wants to share his/her home and if so, with whom, and the supports he/she will need to obtain and maintain that home. The plan should also identify the specific steps necessary for obtaining the housing of the individual's choice and a time line for carrying out those steps. For example, while an individual's housing goal may be to own her own home, she may want to find a roommate and try renting an apartment together as a first step.

Approaches: Housing planning can be carried out in any number of ways with any number of participants. The planning can be undertaken by the individual with autism with the participation of any or all of the following:

- Family members
- Friends
- Support Coordinators or other professional service providers
- Housing Experts
- Legal/Benefits Experts
- Members of a Self Directed Support Corporation (SDSC)

There are two keys to successful planning:

- The person with autism must be the central figure and decision-maker in the planning process;
- The housing choice must be informed, meaning the individual must be educated on the full range of housing options and the information be delivered in ways that he/she can easily understand.

Considerations: Most persons with autism who are currently receiving services participate in the development of an Individualized Service Plan or ISP. However, the individuals participating in the development of those Plans, including Service Coordinators and family members, are not housing experts and, therefore, may not be familiar with the range of housing options available. Second, there are many persons with autism who are not currently in the service system and have not participated in any formal planning.

Therefore, as further explored below, persons with autism and their family members must advocate for the availability of the following:

- Information on housing options and the advantages and disadvantages of each in a variety of easy to understand formats,
- Housing planning tools that guide the individual through a step-by-step planning process,
- Access to housing and service planners who can assist in the planning process.

2. **Sponsor:** This is the entity that originates or spearheads the housing development or option. This entity generally helps to determine the individual or group of individuals to be served, the model to be pursued and others who are needed to carry out the project. The sponsoring entity may be able to take these first steps alone or may seek assistance from an experienced individual or entity that understands the different housing models and funding sources and is able to help guide them through the process. The sponsor may go on to develop the housing themselves or work with a housing developer, consultant and/or other partner to bring their ideas to fruition.

Approaches: A variety of individuals or groups could sponsor a housing effort. (The examples referenced below are found in Section 5 of this report.)

- An individual with autism and/or his/her family members (See Model 1 under Setting # 4 Purchasing a Home)
- A group of family members of adults with autism working together to design a housing option that is appropriate for their family members (See Model 3 under Setting # 3 Renting an Apartment or Home)
- A service agency that works with adults with autism that chooses to expand their mission to provide a new housing opportunity (See Model 3 under Setting # 4 Purchasing a Home)
- A non-profit or for-profit housing developer who decides to sponsor a project for people with autism or to set aside units in an existing or proposed development in response to a community need (See Model 2 under Setting # 6 Intentional Communities)

Considerations: Several things must be considered when deciding upon a sponsor, including the entity's:

- Real commitment to the goal of providing housing for the individual(s) with autism,
- Willingness to dedicate considerable time and energy to the effort,
- Experience working with people with autism and “chemistry” with the specific individuals seeking housing,
- Understanding of the systems providing supports and services to people with autism.

Of critical importance is a lead individual to ensure that the necessary steps are followed in planning and carrying out the effort.

3. **Developer/Partner:** Depending on the complexity of the housing option under consideration, a professional housing developer, housing consultant or partnership with other housing professionals may be needed. If the “project” under consideration entails simple leasing of a property or a simple home purchase, the participation of a housing developer may not be necessary. On the other hand, this report includes housing options other than traditional group homes operated by service agencies. Under these options, funding for housing is generally not available from the same source as funding for services; therefore, additional funding sources for the housing must be identified. In most cases, this will require that the sponsor obtain expertise by reaching out to a public or private housing developer, finance agency or other entity. This experienced individual or entity takes the lead in guiding the development process, including organizing the development team (e.g. lawyer, architect, engineer, builder, property manager) finding and securing a property or location, putting the financing in place, and providing for construction management or oversight.

The success of a new housing option will depend upon the effectiveness of the collaboration among the people seeking the housing, those who will fund it or arrange for the funding, and those who will be coordinating the services. Therefore, the first step is usually for the individuals seeking the housing to identify and reach out to someone with expertise in housing. Partnership with, or at least cooperation of, one or more service providers will also be needed as described below in the discussion of services.

Approaches: Depending on the sponsor, there are several ways of bringing development expertise to a project:

- If the sponsor is a service or housing provider, it can use/engage in-house staff with expertise in development to carry out the project
- The sponsor can hire a consultant with expertise in affordable housing development
- The sponsor can partner with an experienced affordable housing developer. Potential partners include:
 - Local Public Housing and Redevelopment Authorities
 - Local Housing Development Corporations
 - For-profit housing developers

The sponsor may also contact the PA Housing Finance Agency (PHFA), the Housing Alliance of PA, their local planning or community development office or a local affordable housing coalition for assistance in identifying potential development partners.

Considerations: There are a number of factors to be considered when deciding among the above options:

- Most important is having an entity with a track record or expertise in developing affordable housing involved with the project, especially if public financing is desired. Public programs are not only complicated, requiring familiarity and expertise with funder requirements, but also extremely competitive.
 - A key issue is the amount of control the sponsor wants over the development process and the many decisions involved. Obviously, an in-house staff person provides the sponsor with the most control. The sponsor also has direct control over the consultant who, although not on site, answers to the sponsoring organization. A development partner brings a high level of expertise, but may require that the sponsor make compromises to meet the partner's objectives. When entering into a partnership, the sponsor must be diligent in learning about the partner's goals, objectives and mission and making sure that they are a good match to their own.
 - Extent of on-going commitment to housing development is another issue. Unless housing development is part of the organization's mission and the organization is planning on making a long-term commitment to the creation of new housing opportunities, it is probably best to work with a development consultant or partner rather than to expend the resources to develop in-house expertise.
4. **Site Control:** Site control can be through ownership or rental. The owner is the entity that holds legal title to the real estate. This could be a single individual or group of individuals, an agency, or a cooperative. The owner does not necessarily need to be the same as the sponsor.

Approaches: There are several forms of ownership to be considered:

- Fee Simple Ownership is the most common form of property ownership. Owners have full control and responsibility for the entire property including the ground and all buildings on it. However, if more than one individual is the owner, legal agreements should be executed to address what will happen in the event of one party desiring to terminate his/her interest, or to clarify other issues that may affect joint ownership.
- Under condominium ownership the individual owns, controls and is responsible only for the inside of his or her unit. The condominium association, in which the unit owners are members, controls all common areas including the roof, hallways and grounds. In addition to

carrying the costs associated with his/her unit, condominium members pay a monthly fee for upkeep of the common areas. They also may be charged extra assessments for major alterations or repairs to the common areas. Condominium ownership can be more affordable and entails less direct responsibility than fee simple ownership. However, if the majority of the association members vote to undertake a major improvement, such as building a new swimming pool, each owner is obligated to pay his/her share regardless of whether he/she voted for the improvement.

- Housing Cooperative is a form of ownership in which the entire property is owned by a single legal entity (i.e. the cooperative or “co-op”) authorized under a state statute (68 Pa CS §4101 et. seq.) and the individual unit residents hold shares in that entity. The Board of Directors, which is composed of shareholders of the corporation, make all decisions regarding property use and management, including who buys in. In a limited equity cooperative, the buy-in and appreciation of the shares is limited so that ownership remains affordable to low- and moderate-income households over time. The advantage of this approach is that it provides for long-term control and affordability to its members and also a means of succession that does not require dissolution of the ownership. When one shareholder/member leaves, his/her shares go back to the corporation for purchase by the next acceptable member. Since the decisions are made by the owners/shareholders, there is a range of approaches to property management. For example, in some cooperatives, the members themselves are responsible for chores such as snow and leaf removal. In others the cooperative pays for outside contractors to do the work. In certain situations, such as where the property is purchased or renovated using federal Low Income Housing Tax Credits, the co-op may not be the outright owner of the property but may hold a “master” lease for the entire property from the property owner who obtained the Tax Credits. This model allows access to capital the co-op does not have and compliance with Tax Credit requirements while providing a greater degree of control for the co-op members than possible under a standard individual lease.
- Limited Liability Company (LLC) is a hybrid business entity that has characteristics of both a corporation and a partnership. More flexible than a corporation, it provides limited liability to its owners. For example, Autism Living and Working, Inc. (ALAW), formed two LLC’s to own homes for young adults with autism. Governed by Operating and Management Agreements, each LLC owns a house. The parents of the adults with autism are the “members” of the LLC, ALAW is the manager, and the residents rent their home from the LLC. This model provides a vehicle that protects the families’ investments, assures

sustainability of the housing, and does not impact the residents' eligibility for SSI and Medicaid. For more information on this model, see the "Leasing an Apartment or Home: LLC Model" in Section 5 of this report.

- Self Directed Support Corporation (SDSC) is a corporation formed by an individual with disabilities and his/her family and friends for the sole purpose of supporting that individual in the community. The corporation can own or rent property and provide services, thereby giving the Board Members of the corporation a high degree of control but also a high degree of responsibility for management and operations.
- Long-term Lease is an option in some instances where obtaining ownership of an appropriate property is extremely difficult. In such cases, it might be desirable to secure a long-term lease (say 15, 30, 50 or even 100 years). Although this may be less desirable than full ownership, it can help a group or individual achieve their goal of providing affordable housing to individuals with autism. Religious and other charitable organizations are most likely to agree to lease properties for a long term, especially if they see it as a way of fulfilling their mission. Vacant land, rectories and school buildings can be prospects for long-term leasing.

Considerations: The issue of who controls the housing is a critical one for individuals and their family members, and ownership is a primary way of gaining and maintaining control over a property and its management. As can be seen from the above descriptions, each form of ownership has advantages and disadvantages. In general, the more control over the property and its use, the more the responsibility held by the individual owners. As such, the greatest control by an individual is through fee simple ownership. On the other hand, responsibilities are shared in the condominium and cooperative forms of ownership. Therefore, it is important to consider, that, for these forms of ownership, the members need to employ joint decision-making and be comfortable in accepting the decisions of the majority.

5. **Financing:** Financing for a housing project includes identifying sources for leasing or acquiring the building or site, constructing or rehabilitating the building(s), and ongoing operations of the housing, including money for maintenance, repairs, utilities, mortgage, taxes and insurance.

Approaches: Depending on the model selected, financing of the housing can be as simple as purchasing a single family home, or can require multiple sources with a myriad of rules and regulations. There are two types of financing sources: private and public. Private sources, primarily from local lending institutions, generally must meet standard lending criteria. Under

Community Reinvestment Laws, many local institutions have special programs that provide lower interest rates and other benefits to projects that meet local priorities and needs. You should contact the Community Reinvestment Act (CRA) Officer at the lending institution to determine if there are any special programs for which you may qualify. Talking with the CRA officer is also a good way to find out if there are any suitable foreclosed properties in your community that you might acquire for a below market price.

There are numerous sources on the state and local level that provide public funding for housing. All of these sources must meet a public purpose, which is generally to assist low- and moderate-income persons and/or those with special needs. Most of the models in this report will meet that requirement. However, many sources also have annual priorities and/or target areas for the use of their funds, so you must be careful to read all of their materials to determine if you are eligible. Your in-house developer or development consultant/partner will be familiar with these sources, their application requirements and deadlines, and how to access them. **Appendix B** lists those sources and websites for each source.

Considerations: While both public and private sources generally require a loan or mortgage backed by the value of the property, there are major differences in the rules governing them and in repayment requirements. If there is family or another source of funds available, it is probably more desirable to finance the housing privately and to avoid the requirements associated with public funding sources.

However, in many cases, public financing will be necessary. Many of those funding sources have complex requirements that should be carefully reviewed and considered. It is important to weigh the need for funds from a specific source against any requirement of that source that may counter your goals and objectives. For example, some financing mechanisms, such as the Low Income Housing Tax Credit Program, require that the property be owned by a separate legal entity for 15 years, which may make that source undesirable to an individual or group that does not want to give up ownership, even for a limited period. A “leasing co-op” may be a means of enabling a group to exercise some control over the property while complying with the 15 year ownership requirement. Yet, other programs require extensive legal documentation that results in hefty legal fees, which may not be supportable by a small project.

In addition to onerous requirements, due to the limited amount of funds available and the overwhelming need for those funds, the competition for many public programs is quite stiff. Therefore, it is critical that the applicant team has a high level of familiarity and expertise with the specific funding source.

6. **Management, Operations and Maintenance:** Every housing model, whether it is a single family home, apartment complex or congregate facility, must have a plan for the ongoing management and care of the building and grounds. Management functions include responsibility for the financial and legal matters, including: admissions and evictions; rent collection; payment of mortgage, taxes, insurance, utilities and other expenses; bookkeeping and tax preparation. In addition, the property manager or the owner's agent is responsible for maintenance and repair of all major systems including the roof, electrical, heating and plumbing, as well as for on-going operations such as cleaning, leaf and snow removal, replacing heating/air conditioning filters, and making minor repairs.

Approaches: Property management functions are the same, regardless of the size of the property, its location or occupants. The functions can be meted out in a variety of ways, depending on the characteristics of the property and the skills and abilities of its residents. For example, small properties are often managed entirely by their residents or family members. Larger properties often hire professional management companies to carry out all or most property management functions. In other properties, such as limited equity cooperatives, there is often a combination of the two — the members carry out certain routine functions such as cleaning the common areas and maintaining the grounds and then hire professionals to carry out the financial and legal functions.

Considerations: Property management is important for several reasons. It is not only important to ensure the maximum enjoyment by the residents, but also to sustain the long-term value of the property as an asset. Since deferred maintenance can lead to more expensive repairs and loss in property value, it is critical to engage professional help when needed. The key to successful property management and maintenance, however, is to make sure that all functions are listed and responsibility for each is clearly assigned. In addition, the residents, family members, board or shareholders must conduct periodic monitoring and inspections to ensure that each function is being carried out in a competent and timely manner. The need for support of the individual or his/her family in handling the responsibilities of managing their own property should be considered in service planning.

7. **Provision of Services:** A significant element of housing for people living with autism is a plan for the availability of appropriate and affordable services that are individualized to the needs of each resident. This may range from simple assistance such as assistance with paying bills to intensive personal and behavioral services. In planning for housing, the individual's service needs must be clearly understood and the provision of services needs to be coordinated with the type of housing selected.

Approaches: Meeting the service needs of people living with autism is a challenge, especially if the individual is moving from his or her family home for the first time and will need to access new services. Under the current system, individuals are eligible for services from a variety of sources depending on their need for services, their primary diagnosis, and other factors. Some individuals with autism may need very limited assistance, for example, with managing money and paying bills and could request assistance with these tasks from family or friends or formally designate a Representative Payee. Others may need support from friends or family with tasks such as time management or participation in social or community activities. Still others may need limited or large amounts of professional help funded through Waivers or private sources. There are also individuals who have significant service needs which may include personal care, assistance with mobility, behavioral and/or mental health services and medical care, requiring on-site and/or 24 hour staffing.

Under the Adult Autism Waiver, there are Home and Community Based Services that can support an individual in their home. Eligible services include but are not limited to: assistive technology, behavioral specialist services, community inclusion, community transition services, day habilitation, supports coordination, and supported employment. In addition, residential habilitation services are available to those who need round-the-clock supervision. At present these services are limited to individuals living in a PA Department of Public Welfare licensed program. Additional information about services available under the Adult Autism Waiver is available at <http://www.dpw.state.pa.us/ServicesPrograms/Autism/003677257.htm>

Considerations: Access to needed services may be critical to an individual's ability to live successfully in the community. The individual, his/her family members and supporters must identify the services needed and then educate themselves in where and how to obtain those services. Given the variety of sources and the complexity of the service systems, it is important that the individual and his/her family members and supporters understand all of the options for which they are eligible.

8. **Housing Setting or Arrangement:** The setting is the type of housing, which can vary by the characteristics of the housing structure, number of units in the building, number of people in the household and location of the home.

Approaches: There are seven basic housing settings or arrangements from which an individual can choose.

- 1- Remaining at Home
- 2- Family Living
- 3- Renting an Apartment or Home
- 4- Purchasing a Home
- 5- Shared Housing

- 6- Intentional Communities
- 7- Licensed Facilities

Considerations: Selection of an appropriate housing setting should be the outcome of an individual planning process that ensures that the person with autism and their family members and supporters understands the options and the positives and negatives of each. Individual choice should be maximized to the extent possible and feasible, depending upon available resources. For example, if resources allow, the individual should be able to choose among an urban, rural or suburban setting; whether he or she wants to live alone or with others; and whether in a single family home, large apartment complex, or farm community. Ideally, he/she should be able to choose whether to live with others with similar or different disabilities or with individuals without disabilities.

Descriptions of the range of housing settings followed by a list of the specific housing models that most closely fall within each type of setting is provided in Section 5.

SECTION 5: HOUSING SETTINGS AND MODELS

The following is a description of each of the seven settings, including the strengths of the setting for adults with autism and also the considerations/modifications needed for the setting to best meet their needs. Each setting includes descriptions of housing models that fall within that setting and examples of each model from Pennsylvania and elsewhere.

Some of the models require funding for the acquisition and construction of the housing, others make use of existing housing. They all require a source of funding for the on-going maintenance and operations of the housing, generally the residents' income along with additional sources. Lists of potential funding resources for rental subsidies and home purchase are provided in **Appendix B**. For those models or example projects that were created through an especially unique funding solution, this information is provided in the description of the model or example as appropriate.

It is important to note that in order to maximize choice, a very broad range of housing models is presented. They span from an individual with autism owning his or her own home to shared living in campus settings with 24-hour supervision. As with all adults, an adult with autism will have differing housing needs and desires over the course of his or her life and may choose to move to a different setting as their desires and needs change. The key to choosing a housing model is to select one that provides an affordable, quality home that meets the individual's current needs.

It is important to note that many of the models and examples presented here are a result of the tireless efforts of family members in creating new ways of providing housing, advocating for changes in how services are funded, and influencing public policy.

SETTING # 1: REMAINING AT HOME

Description of Setting:

Under this setting, a person living with Autism Spectrum Disorder would continue to live in his or her family home or the home of a relative. The ownership of the housing unit may change to benefit the individual. Alternatively, the house itself may be modified to provide increased autonomy for the adult with autism while enabling him or her to maintain connection to natural supports and familiar surroundings.

All of these models require the assistance of legal counsel to assure long-term sustainability of ownership for the person with autism after the death of their family member. Some mechanisms for achieving this are:

Self Directed Support Corporation (SDSC) This concept was developed by the Vela Microboard Association, Vancouver, Canada: www.microboard.org.

An SDSC is an incorporated organization, often a non-profit, composed of people who know and care about a person with a disability and is established to assist that person to plan for and obtain needed supports in his or her life, including housing. The SDSC facilitates the customization of services to meet the individual's unique needs and desires. Although to date, most SDSC's have focused on services, several SDSC's in PA rent and maintain properties, often ones owned by the individual's parent. SDSCs have also been used as a means of assisting homeowners with disabilities with their home maintenance responsibilities.

Put Property in a Life Estate or Trust with Siblings: The property may be put into a life estate in which the individual with a disability can remain a "life tenant" and retain the right to the property and responsibility for its maintenance for his/her lifetime, after which full ownership is granted to the "remaindermen," those who inherit the property upon the death of the individual with a disability. A trust could also be established that could own the property. This would keep the property for the individual's use while preventing unscrupulous persons from getting the individual to sign over his ownership rights. It would also protect the property from liens that might result from personal debts of the individual.

Strengths and Unique Characteristics of the Model:

- Enables the individual to remain in a familiar home and maintain connections with existing informal supports,
- Gives the parents and other family members the assurance that the individual will remain in familiar surroundings,
- Elder Cottage Housing Opportunity (ECHO Housing) and Accessory Apartments:
 - Foster autonomy for the person living with autism while maintaining family connections
 - Are relatively inexpensive and fast to develop

Considerations/Modifications:

- Depending on the needs of the individual, arrangements will need to be made for in-home supports and services and possibly accessibility and other modifications so that the house is suitable for the individual's behavioral needs, comfort and safety,
- The house may need to be shared in order to reduce the monthly costs for the individual,
- Issues of sustainability would need to be addressed as described above.

MODEL 1: HOUSE DONATED BY THE FAMILY

Description of Model: Either the parents of the individual with autism or another close family member or family friend may make arrangements for the individual with autism to continue to live in a family home as an adult, including after the death of his/her parents or after the parents move to a different residence. The details of estate planning should be discussed with an estate planning professional to assure that the transfer occurs as desired and does not negatively impact the parent's potential eligibility for Medicaid in the event they may need nursing home care. This planning should also include financial arrangements to meet the ongoing costs of operating the home including payment of taxes, insurance, utilities and maintenance as well as arrangements to assure that the property is properly managed. This would include such tasks as bill paying, maintenance, fuel delivery, and other day-to-day homeownership responsibilities.

Example: A couple in the Chicago area purchased their in-laws' home for their 22-year-old son with autism and then made numerous modifications to the house taking into account their son's behavior and needs. The house also provided space for a second special-needs person and a caretaker to be provided by an agency. They used the services of a specialized-housing consultant, Creative Housing Solutions LLC (gbcchs.com) in designing the modifications to the house for their son. Among the features in the house are sliding pocket doors with runners on the top and bottom instead of just the top to prevent the door from being kicked off the tracks. The complete article is archived in the Chicago Tribune. Visit <http://pqasb.pqarchiver.com/chicagotribune/advancedsearch.html>, then search for "A special house, a special solution" in the January 25, 2009 issue.

MODEL 2: ELDER COTTAGE HOUSING OPPORTUNITY (ECHO)

Description of Model: Elder cottages, also known as ECHO Housing, are separate small, manufactured residences placed in the side or rear yard of a family home. The cottage can be free-standing or attached to an existing house and can be customized for accessibility needs. This model enables a household to provide a nearby home for an elderly family member or a family member with a disability. In some cases, an elderly homeowner moves from the larger house to the cottage, providing a nearby home for other family members who can help with their care. In either case, the elder cottage allows autonomy for its resident along with easy access to family members to provide assistance as needed. A zoning variance will usually be needed to site an elder cottage and it is often only granted for the period of time the structure is occupied by the family member. In addition, issues of sustainability would need to be addressed in the event the housing status of the main household changes.

It is also relatively inexpensive and fast to develop an elder cottage. It can often be financed through the household's personal assets, by refinancing the main home, or through a line of credit based on equity in the main house. Many manufacturers of elder cottages have established relationships with banks that specialize in modular construction.

ECHO housing is most suitable in rural or suburban communities where there is adequate land for a second structure. However, some communities are concerned about the impact this may have on their property values and, if a zoning variance is needed, they may dispute the placement of the second structure.

Example: MSI of PA in Selinsgrove produces Elder Cottages that meet the PA building code requirements. As of January 2008, the purchase of an Elder Cottage was approximately \$35,000 for a 1-bedroom cottage and \$45,000 for a 2-bedroom cottage plus moving, foundation, and utility hook-up costs of approximately \$9,000.

Location/Contact Information:

Bradley J. Harvey
MSI of PA, Inc.
1910 North Old Trail
Selinsgrove, PA 17870
570-743-2012
bharvey@msiofpa.com

Ed Guion
Designer of Elder Cottages
1354 Honeysuckle Hollow Road
Elliottsburg, PA 17024
717-438-3659

Related Resources:

The HUD Office of Policy Development and Research published a report on "Accessory Dwellings" which includes examples of zoning ordinances. It is available at: <http://www.huduser.org/publications/affhsg/adu.html>.

MODEL 3: ACCESSORY APARTMENT

Description of Model: Also known as a "granny flat," "accessory dwelling unit," "secondary unit," "in-law apartment" or "single family conversion," an accessory apartment is a self-contained second living unit with its own kitchen and bathroom that is built into or attached to an existing single family dwelling. The

accessory apartment is smaller than the main unit and is intended to look like part of the main house. The addition of an accessory apartment generally requires a building permit and zoning variance (see **Related Resources** above).

Under this model, the adult living with autism can live in his or her own apartment but have easy access to family. The accessory unit could also be used to provide housing for a caregiver. The renovations can be funded through various personal financial strategies including a Home Equity Loan or refinancing of the main house. To help the family with operating costs, if the accessory apartment is used by an individual with a disability, he/she can, as a reasonable accommodation, use a Housing Choice Voucher (i.e. Section 8) towards the rent and only pay 30% of their income for remainder of the rent.

There are no specific examples of an accessory apartment provided.

SETTING # 2: FAMILY LIVING

Description of Setting:

Under this setting, a person with autism lives with a household other than his/her family of origin. This household is responsible for providing room and board and coordinating other services as appropriate to the needs of the individual. The host household may provide housing opportunities for one person or multiple people with autism.

Most family living programs are operated in accordance with public regulations. In Pennsylvania, there are two publically regulated programs. The first, Lifesharing, is administered by the PA Department of Public Welfare's Office of Developmental Programs, operates under PA's Code 6500 Family Living Home Regulations and is operated under contract with licensed provider agencies. The second, operated by PA Department of Aging, operates under PA Code Title 6, Aging, Chapter 21 Domiciliary Care and is administered through each county's Area Agency on Aging.

Strengths and Unique Characteristics of the Model:

- Provides an affordable homelike setting to consumers in need,
- No cost to develop new housing,
- Creates permanency of relationships,
- People can receive housing more quickly than a program that creates housing units,
- Provides more consistency than a group home because there is no change in staff over the course of the day or year.

Considerations and Modifications:

- Some adults with autism may have more complicated health needs than can be addressed by a lifesharing or Domiciliary Care (Dom Care) family,
- The lifesharing or Dom Care families and supervising staff must be properly trained on the needs and behaviors of adults with autism,
- Because the individual with autism will be living in someone else's home, it is important to give the individual opportunities to become acquainted with the host family before finalizing the placement to ensure a good match.

MODEL 1: LIFESHARING

Description of Model: Under the Lifesharing Program, a family, couple or individual makes a commitment to support one or two unrelated individuals with special needs in their home. In Pennsylvania, this is currently a resource under the PA Code 6500 regulations for individuals with intellectual disabilities under

the Consolidated Waiver and under the Autism Waiver for adults with autism who need more than 50 hours of service per week. For individuals not covered under either of these waivers, the county might use “base funds” although these funds are very limited.

The Lifesharing provider household and the individuals who live with them are carefully matched. The lifesharing family or companion assists the individual(s) with their “everyday lives” including: meal preparation, eating, shopping, money management, relationship building, social interactions, and personal appearance skills.

Lifesharing is stipend-funded by waiver dollars from the PA Department of Public Welfare, Office of Development Programs (ODP). In 2009, the average monthly stipend to lifesharers who provide services in their home was approximately \$1,750 for those serving one individual and \$1,950 for those serving two individuals. The stipend can be adjusted for individuals with special medical or other needs. This includes payment by each individual receiving services of up to 72% of their current SSI. A family with an adult child with autism could become a lifesharing family for another adult with autism, enabling them to remain at home to provide support and the family to have a source of income.

Examples: There are over 1400 people living in lifesharing homes across Pennsylvania. For example, Martha Lloyd Community Services in Tioga County offers the Life Sharing through Family Living program. They describe a key ingredient of successful Life Sharing as the compatibility between the family and the person with a disability. Families and individuals who provide family living services receive training from Martha Lloyd Community Services specific to the needs of the person sharing their home. A program specialist oversees and provides support for all aspects of the relationship.

Location/Contact Information:

PA Department of Public Welfare
Office of Developmental Programs
Carmen A. Donegan, Program Specialist
QI Initiatives Unit
717-705-7986

MODEL 2: DOMICILIARY CARE

Description of Model: The Domiciliary Care or “Dom Care” program, sponsored by the PA Department of Aging and Long Term Living, provides a homelike living arrangement in the community for adults age 18 and older who need assistance with activities of daily living and are unable to live independently. At this time, the Dom Care Program cannot be used with the Autism Waiver but this could possibly be changed in the future. While most

frequently used as a resource for elderly individuals and individuals with physical disabilities, Dom Care is an option for adults with autism. Individuals with extreme behavior problems or substance addiction are not appropriate for Dom Care.

Dom Care providers open up their homes to individuals who need supervision, support and encouragement in a family-like setting. Dom Care residents are matched to homes that best meet their special needs, preferences, and interests. A home may have no more than 3 Dom Care residents and is inspected annually to ensure they meet health and safety standards. It is a more homelike alternative to a personal care home. Dom Care is regulated under PA Code Title 6, Aging, Chapter 21 Domiciliary Care. Dom Care residents receive help with personal hygiene, meals, and housekeeping/laundry. In addition, the Dom Care provider makes sure the individual takes his or her medications at the correct dosage at the right time.

Location/Contact Information:

Local Area Agency on Aging
Information available at www.aging.pa.us

There are no specific examples provided.

SETTING # 3: RENTING AN APARTMENT OR HOME

Description of Setting:

Under this setting, an individual rents an apartment or a house either alone or with others. The rent may be subsidized through a public program or paid in full by the individual. In some cases, a service provider or non-profit organization owns the rental units and also either provides or coordinates services. This is frequently referred to as supported housing or supported living.

There are various public programs to reduce the amount of rent a household needs to pay for housing on the private market, typically down to 30% of their income. There are two general types of rental subsidies:

- **Tenant Based Rental Assistance (TBRA):** This is a subsidy that goes to the individual and can be used for the housing unit of his or her choice so long as the housing complies with program guidelines related to the market rent of the unit, the condition of the unit and sometimes the location. Unlike Project Based Rental Assistance (below), an individual who has TBRA can keep that assistance if he or she moves.
- **Project Based Rental Assistance (PBRA):** This is a subsidy that is connected to the housing unit itself. Generally, a household must meet the eligibility requirements for the housing unit in terms of income and other specific criteria, and then the rent is based on a percentage of the household's income, generally 30%.

A list of most commonly available rental subsidy programs is in **Appendix B**.

Strengths and Unique Characteristics of the Model:

- Housing is separate from supports,
- Participants live in homes in the community,
- Public funds are not necessarily required for the housing, although rent can be made affordable through various government subsidies,
- The residents have choice of where to live and with whom to live.

Considerations/Modifications:

- In some housing markets, if the individual does not have public rental assistance or assistance from their family, market rents may be too high for them to afford, necessitating them to share a home in order to make the housing affordable.

The models described below provide market-rate rental housing as well as housing subsidized through these various programs.

MODEL 1: LLC OWNED

Description of Model: Under this model, a group, generally parents or other family members, form a Limited Liability Company (LLC) for the purpose of acquiring a home that can then be leased by individuals with disabilities, generally their own children or family members. As the owner, the LLC is responsible for all bills and the upkeep of the property and the adults with autism have the same rights and responsibilities as renters of any housing unit. (See the Site Control in Section 4 for an explanation of an LLC.)

The LLC, using their own funds or grants, provides the funding for the down payment, renovations (including sweat equity), lawyer's fees, and closing costs. A larger down payment will result in lower monthly mortgage payments and lower monthly rental payments by the tenants (the adults with autism). As in other rental properties, the rent paid by the residents covers the monthly costs for mortgage, taxes, insurance, utilities, and minor repairs.

This model assures sustainability of the housing and does not impact the residents' eligibility for SSI and Medicaid.

Example: Autism Living and Working, Inc. (ALAW) is a non-profit organization committed to helping adults with autism to sustain households, hold jobs and contribute to community life. Several ALAW parents, with the help of a lawyer, formed two LLC's by applying to the Pennsylvania Department of State Corporation Bureau for a Certificate of Organization-Domestic Limited Liability Company and then applying to the IRS for an EIN number. The lawyer developed an Operating Agreement and a Management Agreement for each LLC. Each LLC owns a house and the participants rent from the LLC. The parents are the "members" of the LLC, and ALAW is the real estate manager.

One LLC owns a house for three adults with autism and the other owns a house for two adults with autism. Both homes are located within walking distance of shopping and stores and are on a public transportation route. Services are separate from housing and are individually determined depending on each participant's goals and needs outlined in their support plan. Services can vary from a few hours a week to around-the-clock supports. Services are funded through the OBRA waiver, which is a Home and Community Based waiver program that provides services to people with developmental physical disabilities, including some people with autism. These services allow them to live in the community and remain as independent as possible. Services provided include community integration, personal assistance, and behavioral therapy. It should be noted, however, that at the time of writing this report the OBRA waiver is not available for new participants.

The model was designed in accordance with ALAW's philosophy of Accommodated Living which enables adults with autism to live a regular adult life by supplying modifications, adaptations, supports and services which accommodate sensory/motor, communication, and social challenges.

The LLC provided a substantial down payment to make the units affordable for the residents. They obtained a mortgage from a local community bank. Family members manage the homes and pay bills as ALAW volunteers. To maintain affordability all residents have Housing Choice Mainstream Vouchers from the local public housing authority, enabling them to pay 30% of their employment and/or social security income towards rent, with the balance, up a maximum rental allowed by HUD known as "Fair Market Rent," paid by the public housing authority.

Location/Contact Information:

Autism Living And Working, Inc.
1528 Walnut Street, Suite 815
Philadelphia, PA 19102
267-322-5800
www.autismlivingworking.org

MODEL 2: NON-PROFIT OWNED

Description of Model: Under this model, a non-profit organization acquires and, if necessary, renovates a home and rents it to individuals with disabilities. Typically, the agency that serves as the developer and owner of the property also has an interest in the population to whom they rent. This may be a service agency or an affordable housing developer.

The non-profit organization raises the funds for the down payment, renovations, professional fees and closing costs. This may be from grants, low-interest or deferred loans, donations (including from family members), and/or sweat equity. In addition, the non-profit may need to obtain a mortgage from a lending institution.

The rent paid by the tenants covers the monthly costs for mortgage, taxes, utilities and minor repairs. The tenants may be able to obtain a Housing Choice Rental Voucher from the public housing authority which would enable these tenants to pay 30% of their employment and/or social security income towards rent, with the balance up to the HUD determined "Fair Market Rent" paid by the public housing authority. While the monthly cost to the tenants without the voucher would be higher, it can be made affordable by lowering the amount of principal borrowed through grants (from such sources as county Housing Trust Funds or the HUD HOME Program) and by provision of management services by the non-profit.

Public sources of funding are generally obtained by non-profit organizations in order for them to develop housing that is affordable to low and moderate income individuals. Another possibility is the HUD Section 811 program which provides funding for development and rental subsidies for housing for people with disabilities. Information on potential funding sources is found in Appendix B.

Example 1: In May 2002, Autism Living and Working (ALAW), a non-profit organization, applied for and was awarded a Pennsylvania Housing Finance Agency (PHFA) Special Initiatives grant for the purchase and renovation of two houses for adults with autism. Under this model, ALAW acquired, developed and now rents two houses, each providing a home to two adults with autism. The parents of the tenants helped support this project through donation of sweat-equity in the renovation of the houses. Both homes are located within walking distance of shopping and stores and are on a public transportation route. As in their LLC example above, services are separate from housing and are individually determined depending on each participant's goals and needs outlined in their support plan. Services can vary from a few hours a week to around-the-clock supports. Services are funded through the OBRA waiver and consist mainly of community integration, personal assistance, and behavioral therapy. ALAW's philosophy of Accommodated Living enables adults with autism to live a regular adult life by supplying modifications, adaptations, supports and services which accommodate sensory/motor, communication, and social challenges.

The substantial downpayment for these two homes was accomplished through a Special Initiatives grant from PHFA. Parents also contributed sweat equity for renovations. The balance of the development costs were financed through a mortgage. By keeping the mortgage principal as low as possible, the rent for those tenants who do not have a Housing Choice Voucher is lower than if a standard twenty percent down payment were used.

In 2009, ALAW was awarded funding under the HUD Section 811 Program to develop and operate 4 units of subsidized rental housing for adults with disabilities. This grant provides a major portion of the acquisition and rehabilitation costs as well as a forty year project based rental subsidy. When completed, this will provide additional rental housing with subsidized rents for four adults with autism.

Location/Contact Information:

Autism Living And Working, Inc.
1528 Walnut Street, Suite 815
Philadelphia, PA 19102
267-322-5800
www.autismlivingworking.org

Example 2: Waltham Forest Supported Living, located in a residential neighborhood in London, is a five-unit apartment complex developed specifically

for people with autism in terms of both its physical structure and its staffing. It provides five (5) self-contained apartment units and a unit for 24/7 sleep-in staff. This project was a collaboration among agencies with expertise in housing development, supportive services and assistive technology. The design took into account safety and security needs while maximizing the residents' participation in community life. Some of the project's design features are:

- Alarm system to alert staff about emergencies and to alert staff if residents leave their unit (this feature can be switched on or off as appropriate to time of day and the resident's risks),
- Sound-proofing,
- Anti-slam doors,
- Textures and color to provide a calming environment,
- A picture communication system,
- Durable fixtures and fittings,
- Located near open space,
- Good transportation and access to local amenities.

Location/Contact Information:

Debbie Richards, Assistant Commissioner
Learning Disability Partnership
47, Gainsford Road
Walthamstow, London
E.17
020-8496-1844
Debbie.Richards@walthamforest.gov.uk

SETTING #4: PURCHASING A HOME

Description of Setting: Under this setting, a person with autism would become a homeowner, either individually or along with others who may or may not also be living with autism. They could purchase a single family home or a condominium. The ownership can be structured in different ways. In some cases, each of the individuals is named on the deed and an Ownership Agreement is developed to account for changes such as one of the owners choosing to leave or if one of the owners dies. In others, the owners form a corporation and purchase shares in the ownership of their home.

There are various financing mechanisms designed to reduce the cost of homeownership for low and moderate income households. These may be government subsidized programs that reduce downpayment and closing costs or that reduce monthly payments. There are also numerous “first time homebuyer” programs offered through financial institutions that reduce costs to eligible buyers. These programs generally require the recipients to participate in pre-purchase homebuyer counseling. In some cases, programs can be combined to maximize assistance to the homebuyer. The most commonly used subsidy programs are found in **Appendix B**.

Strengths and Unique Characteristics of the Model:

- Makes use of mainstream financing resources,
- Can combine multiple funding sources to create an affordable housing option for low income buyers,
- Utilizes existing housing stock,
- Integrated into and indistinguishable from other homes in the community,
- Provides long-term control and affordability.

Considerations and Modifications:

- There needs to be a source of funding for “front money” including downpayment, escrows and move-in costs. These may include parents’ resources, public sources, or funds from a First Time Homebuyers Program,
- The owners need a credit history in order to be eligible for a mortgage,
- There must be a plan for on-going costs for maintenance, repairs, and utilities,
- Good legal assistance is important in establishing the ownership structure, especially if there will be more than one homeowner,
- There may be a need for technical assistance to help families and agencies utilize the various public funding programs.

MODEL 1: OWNERSHIP BY AN INDIVIDUAL

Description of Model: In this model, an individual with autism is the owner of his or her own home and responsible for the costs of purchase and home maintenance. In some housing markets, housing is more affordable than others and an individual can purchase a home without subsidies. In other areas, subsidies are necessary to make the home affordable. Yet, in other areas, even with subsidies, homeownership is not affordable for a low or moderate income individual. The following example shows how one individual combined multiple subsidies to become a homeowner.

While the combination of subsidies used by TM in the model below enabled him to become a homeowner in Lycoming County, this model may not work as well in more expensive areas. In addition, not all public housing agencies are willing to participate in the Section 8 Homeownership program and some programs, like those funded through USDA, are only available in particular communities.

Example: TM, now 43, has multiple disabilities including intellectual disability, autism, and cerebral palsy. He lived in a Community Living Arrangement (CLA) for several years but preferred to live by himself. His mother attended a conference about self-determination and learned about various subsidy programs that assist people with disabilities to become homeowners. Working with the Lycoming Area Office of USDA Rural Development and HUD, she helped her son obtain a Section 502 USDA loan which required no down payment. In addition, her son was awarded Section 8 through the local housing authority, which he used under the Section 8 Homeownership program to bring his monthly costs down to 30% of his income. He participated in pre-purchase counseling. Services are made available through Waiver funding.

Location/Contact Information:

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MODEL 2: TENANTS IN COMMON

Description of Model: In the Tenants in Common model, generally two to three individuals purchase a home together with all of their names on the deed. They each have equal ownership of the property. This is typically the form of ownership used by married couples. However, in the case of unrelated individuals jointly owning a home, there needs to be an Ownership Agreement that details what should happen under certain circumstances, such as when an

individual sells his/her portion of the property or for inheritance in the event of the death of one of the owners.

The purchase and renovation of the housing, as well as the operations, can be financed in different ways, depending on the resources of the homeowners, the cost of housing in their community and the availability of public programs. The two examples below provide innovative strategies to help adults with a disability own their own home.

Example 1: HomeWorks was created, with the assistance of their parents, by three adult men with physical disabilities. The men purchased a ranch house, called HomeWorks, in Merion, Montgomery County. Using a combination of public and private resources, the home was made fully accessible. The ownership is structured as Tenants in Common with a Tenants in Common Agreement to provide a mechanism for changes in ownership. Under this agreement, a person who leaves the house has six months to sell his share to another individual who needs the same services as those in the house. There are also additional options at various intervals. In order to assure the ongoing affordability of the house for future owners, the amount of the sale price must not exceed the original purchase price plus cost of modifications.

Also, in order to assure the sustainability of the house, a volunteer mini-board was created that includes the three owners, one family member from each household and two professionals who know the three owners, one with expertise in services and one with expertise in estates and trusts. New board members will be recruited as those on the original board age or are no longer able to perform their duties.

All three men qualify for PA Department of Public Welfare (DPW) OBRA Home and Community Based waivers which provide 24-hour attendant care with shared night supports.

The acquisition and development were funded through a number of sources. The PA Housing Finance Agency's (PHFA) First-time Homebuyer Program provided a reduced interest rate mortgage, down payment and closing cost assistance, and assistance with home modifications. The Self-Determination Housing Project (SDHP) also provided a grant for home modifications. The OBRA Waiver provided funding for modifications and assistive technology. Family resources, through Special Needs Trusts, were used toward the down payment to reduce the mortgage principal and thereby reduce monthly payments. This was necessary because under SSI regulations, if families supplement the owners' mortgage payments, their SSI payments would be reduced. Finally, there were corporate and congregational donations of household goods and additional renovations. The three owners make monthly payments from their SSI and other income towards the ongoing cost of operating and maintaining their home.

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Example 2: Another example is The Happening Place. In February 1999, three adults with developmental disabilities became homeowners. The Happening Place is located in Northumberland County. The three buyers purchased a two-family home and lived in one half and rented out the second half for additional income. Over time, they brought in a fourth owner and two of the owners now live in each unit. The house was part of a demonstration sponsored by the Self Determination Housing Project. The ownership is structured as Tenants in Common with all four names on the deed. Although the families have not finalized an Ownership Agreement, they are currently considering having the ownership share of the property pass to the remaining owner(s) upon the death of any of the current owners.

All four owners receive services under PA DPW waivers; two are eligible for 30 hours per week, and two are eligible for 24 hour staff. Because all three of the initial owners were receiving services under the mental retardation system, the house had to be licensed as a group home requiring such safety features as inspections, fire drill training, railings and alarms.

The acquisition of the property was funded through a combination of three sources: PA Housing Finance Agency's (PHFA) First-time Homebuyer Program which provided a reduced interest rate mortgage, downpayment and closing cost assistance; a grant for technical assistance from the Self-Determination Housing Project (SDHP) under a demonstration program; and family resources including sweat equity.

Each of the owners puts \$500 per month into a checking account for household costs including maintenance and repairs. One of the parents assists with paying the bills. Three of the owners are employed in a workshop and the fourth is a consumer speaker.

Contact Information:

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MODEL 3: LIMITED EQUITY COOPERATIVE

Description of Model: A housing cooperative (or co-op) is a legal entity authorized under a state statute (68 Pa CS §4101 et. seq.), which owns one or more residential buildings. Each resident is a shareholder in the legal entity and is granted the right to occupy one housing unit. Units can be group residences or individual apartment units. There is an Occupancy Agreement, which is similar to a lease, which specifies the co-op's rules.

In most cooperatives, the value of the shares appreciates with the fair market value of the real estate. To the contrary, a limited equity housing cooperative (LEHC) is designed to provide affordable housing to low- and moderate-income households. In an LEHC, the legal entity is a non-profit corporation and the term "limited equity" refers to the low, initial investment a new member of the cooperative makes compared to the private market value of an unrestricted cooperative interest. Since purchases of memberships/shares are income restricted, LEHC bylaws limit the resale price of membership/shares in order to keep the housing permanently affordable to incoming members. The resale value of shares is not determined by what the market will bear, but it follows a pre-determined formula that limits that maximum resale value over time.

In housing cooperatives the shareholders are actively involved in all decision-making about property maintenance and upkeep as well as household rules and policies. Maintenance and upkeep responsibilities range from being totally contracted out to being completely handled by the cooperative members themselves.

In addition to the other benefits of homeownership, this model also provides the benefits of peer support and the opportunity for co-op members to participate in decision-making for the management of their home.

There are some considerations that go beyond those for other forms of homeownership that need to be addressed. Most significantly, establishing a co-op is complicated and requires specialized legal assistance. In addition, the members of the Co-op Board may need support in their decision-making role, from family members or professionals. Finally, there are potential zoning issues when a group of unrelated individuals choose to live in a single property.

Example: Milestones Community Healthcare, Inc., a subsidiary of Salisbury House, Inc., developed the 626 Co-op in Montgomery County for adults with serious mental illness. Milestones financed the conversion of a church rectory into a home for nine individuals with serious mental illness. Each resident has his/her own room clustered with two other rooms around a sitting area and bathroom. All nine residents share a large dining and living area as well as the basement recreation room.

All nine residents were previously living in Milestones-owned group homes (i.e. Community Residential Rehabilitation (CRR) facilities). Residents receive support services from Milestones through a team model based on a mental health recovery model.

Following rehabilitation of the building, Milestones sold the property to the 626 Co-op, which was incorporated as its own non-profit organization. Each resident received a \$1,000 forgivable loan, which was used to buy his/her share in the co-op. When a co-op member moves, the loan is forgiven and passed on to the next co-op member. Seventy-two percent of each resident's Social Security Income is used for room and board. Since a mortgage was needed to meet the costs of the building renovations, the co-op was also licensed as a personal care home to take advantage of the state personal care home supplement to help cover the mortgage cost.

The acquisition and rehabilitation of the 626 Coop was financed through a one-time PA Housing Finance Agency Special Initiative Program and a mortgage from William Penn Savings Bank. The residents each pay 72% of their SSI and the co-op receives a monthly PA DPW Personal Care Boarding Home Supplement for each resident.

Location/Contact Information:

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SETTING # 5: SHARED HOUSING

Description of Setting: Shared Housing is a model in which two or more unrelated individuals share a home. Generally each individual has his/her own bedroom and shares a kitchen, dining room, living room and other common areas with the other residents of the house.

Strengths and Unique Characteristics of the Model:

- Opportunity for peer support and interdependency,
- More cost effective than individual living units,
- Reduces isolation and provides opportunities for companionship and socialization for the homesharers,
- Flexible and adaptable to a variety of populations and communities,
- Makes use of existing housing stock.

Considerations and Modifications:

- Zoning may be a barrier, depending on the definition of “family” in the municipal zoning ordinance. This definition establishes the number of unrelated individuals that are permitted to live together as a single housekeeping unit.
- Best for people who like joint decision-making and have good negotiation skills, which may not be typical of people with autism,
- For people with autism, two or three people would be preferable; the more people, the more opportunity for challenging behaviors of some to impact other house members,
- The dynamics of the residents needs to work – a common interest could be a good starting point,
- There needs to be planning around issues of privacy and personal space.

MODEL 1: GROUP SHARED RESIDENCE

Description of Model: A Group Shared Residence is a living arrangement where up to eight unrelated people share a home or apartment to their mutual advantage. Each person has a private room and shares the kitchen, dining and other common areas. Many residences are sponsored by non-profit organizations and may involve the provision of meals, laundry, and housekeeping services. The members of shared housing choose the other members of the household and as such the members are often referred to as a “family of choice.” Members of a shared residence make policy decisions and manage the day-to-day operations of the home. They decide on rules around such household issues as pets, guests and smoking and often buy food, cook, and eat meals together.

Residents' rental payments are used toward operating costs. Housing Choice Vouchers/Section 8 may be used in a Group Shared Residence. The public housing authority must include shared housing as a "special housing type" in its Administrative Plan in order to use Housing Choice Vouchers in the home.

Screening is key for this to be a successful model for adults with autism. Some existing shared residence programs use a trial period to determine compatibility of homesharers. Also, the selection of the house itself is important. Often an older home is used for a shared residence. If this is the case, maintenance can be an issue and, if it is a rental property, the maintenance of the house is dependent on the quality of the landlord. Since a large number of people sharing a home may be difficult for adults with autism, an alternative would be two separate houses side by side that share a yard that would provide the economies of scale of a larger house but enable fewer people to share their living space.

Example: CHAPS, a non-profit organization serving Crawford County, has operated two group shared residences for people with mental illness since 1993. One residence serves three women and the other serves four men, many of whom were formerly homeless. Each homesharer has his/her own bedroom and shares the common areas. The homes, which CHAPS rents from a private landlord, come fully furnished. Although there are no subsidies, the rents are quite affordable: \$140 per month for individuals receiving public assistance and \$275 for individuals receiving SSI, including all utilities, laundry facilities and cable. All homesharers sign a Shared Housing Contract that sets basic household rules including an agreement to maintain a level of physical and mental health.

Although there is no on-site staff, most residents receive case management or services of a Supported Living Worker through the County Mental Health Office and participate in the drop-in center. In addition, CHAPS staff assists with household issues on an as needed basis. In Crawford County, the shared housing program has been serving as a stepping stone to other affordable housing opportunities because the residents establish a housing record that can later serve as a landlord reference. In fact, following their stay in shared housing most of the former residents have successfully moved to their own apartments. At the present time, both shared residences are adding vocational components to foster their conversion to Fairweather Lodges. (See Model 3 below)

Location/Contact Information:

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CHAPS
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MODEL 2: SHARED HOUSING – MATCH UP

Description of Model: Shared Housing – Match Up is a living arrangement where two or more unrelated people share a home or apartment to their mutual advantage. Each person has a private room and shares the kitchen, dining and other common areas. In the Match Up model, a “home provider” shares his/her home with a “home-seeker”, who pays rent. Most match-up programs are either sponsored by a public agency such as a city or county aging or housing agency or a private non-profit organization. A staff person conducts intake, screens applicants and introduces potential home sharers to each other. Both the housing provider and the applicant need to be carefully screened for compatibility and a pool of applicants generally must be established before matches can be made. Trial periods for home sharers are strongly recommended in order to ensure a compatible match. This trial period is also a time to better understand types of behaviors that are relevant in a shared housing setting that may not be apparent in the initial screening. Since this model would often match people with and without autism, it provides an opportunity for inclusion.

The property owner is responsible for operating costs of the house. Their income is supplemented by the rent paid by the home seeker who would be fully responsible for his/her rent or could use a Housing Choice Voucher, reducing his/her rent to 30% of income. As noted above, some public housing authorities have Shared Housing as a “special housing type” in their Administrative Plan. If it is not in the Plan, a person with a disability can request a Housing Choice Voucher in shared housing as a reasonable accommodation.

Although this is a relatively inexpensive program to start and administer and does not entail the creation of any new housing, funding is needed for the staff person who conducts intake, screenings and introducing potential home sharers.

Example 1: One example of a Match Up program is Homeshare Alliance jointly operated by the YWCA of Chester County and the Home of the Sparrow. Over the past 20 years, the program has made hundreds of matches including people with disabilities.

Example 2: The second example, operated through Residential Living Options, Inc. (RLO) is targeted to people with disabilities in Chester and Delaware Counties. They hold meetings in each county to provide an opportunity for potential homesharers to meet socially and to identify someone with whom they would like to share. RLO has developed a Roommate Questionnaire to help focus the discussion around housing preferences.

Location/Contact Information:

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YWCA Chester County

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MODEL 3: FAIRWEATHER LODGE

Description of Model: Fairweather Lodge is a housing and employment program that enhances the lives of adults with a mental health disability. The goal of the program is to help people reintegrate themselves into the community by providing peer support, a place to live and employment. A Fairweather Lodge operates under “Fidelity Standards” relating to housing, employment, social interaction, and autonomy.

Typically lodges are groups of four to eight people who share a house and own or are employed in a small business. Lodge groups’ businesses have included lawn care, janitorial or laundry services, printing, furniture building, shoe repair, transportation service, car detailing and catering. However, to be true to the Fidelity Standards, the employment does not necessarily have to be a group business. The employment component of the Lodge model provides an opportunity for both vocational and social skill-building while also increasing the individuals’ sense of self-worth.

There is no live-in staff at a lodge but a lodge coordinator is available to assist the lodge members. The members of the lodge make decisions as a group and meet regularly creating a system for feedback and problem solving. The primary role of the lodge coordinator is to be a teacher, coach, mentor and group facilitator. Staff is also on-call 24 hours a day for emergencies.

Funds are needed for acquisition and renovation of the lodge. If the creation of the lodge is fully funded through grants, without debt, the operational costs of the house can be covered through the rents paid by the lodge members from their SSI and employment income. Generally, lodge members pay 30% of their income for rent and utilities. Lodge members also pay a food and transportation fee. These fees are determined by the lodge membership.

Currently, the Lodge model has only been utilized for individuals with mental illness; however, there is interest in expanding the model to include adults with autism, either through integration into an existing lodge or creating a new lodge focused on their needs. There is expertise on the Fairweather Lodge model in

Pennsylvania and the potential for technical assistance in starting a lodge from Stairways Behavioral Health. (See contact information below.)

Example: A split level ranch house is the location of the first Fairweather Lodge in Erie. This lodge is located in a residential urban neighborhood and is home for five lodge members. Several stores and a bus stop are located close by. Each lodge member has his/her own bedroom yet there are multiple areas where people can gather together including the kitchen, living room and family room. The home also features a back deck and small yard for picnics. Several vehicles are parked in the driveway with people coming and going all day long. Week-days, lodge members attend classes, go to work in their janitorial business and participate in medical/mental health services. On weekends, lodge members may choose to go to the mall, take a walk on Presque Isle or stay home and host a movie night. Being involved in the lodge gives its members lifestyle choices that had been financially out of reach to them in the past.

Location/Contact Information:

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MODEL 4: L'ARCHE

Description of Model: L'Arche, which began in 1964 in France, is now an international federation of more than 130 communities in over 30 different countries. "L'Arche enables people with and without disabilities to share their lives in communities of faith and friendship. Community members are transformed through relationships of mutuality, respect, and companionship as they live, work, pray, and play together." While starting in the Catholic community, they are now ecumenical.

In a L'Arche Community there are members who have a developmental disability and members who do not. They live together in ordinary houses. The individual with a developmental disability is referred to as a "core member" and "assistants" are those who come to share their life with the core member. Assistants work to build a relationship of mutual care and support with persons with disabilities; foster a home life of unity, mutual respect and participation by all members; provide direct care supports and skill building for core members' personal care needs, money management, medical care, appointments, family and work connections, household chores, laundry, medications, meal preparation, and transportation. The core members and assistants are also friends with each other, building relationships based on trust. They make decisions together and share responsibility for what happens in the house.

Because they are part of the International L'Arche program, L'Arche communities benefit from additional volunteer or stipend-paid staff to supplement their regular staffing. However, becoming a L'Arche community and receiving their support requires a long process of community building and prayer. This process can be slow but contributes to the stability of the L'Arche Community.

Example: L'Arche Erie which began in 1972 is the first L'Arche community in the US. It operates eight houses and two apartments with a maximum of four people per home. They are licensed by the PA Department of Public Welfare under the PA 6400 regulations. L'Arche purchased the houses, using the State funds toward mortgage payments and services. While the L'Arche homes operate according to the same regulations and staffing patterns as other group homes, they operate under the organization's philosophy.

Location/Contact Information:

L'Arche Erie
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Erie, PA 16505

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Also a new L'Arche Community is being planned in Richmond, VA. An article on their efforts can be found at
<http://www.catholicvirginian.org/archive/2008/2008vol84iss4/pages/article2.html>.

SETTING # 6: INTENTIONAL COMMUNITIES

Description of Setting: Under this setting, people live together in a community that is built around a shared belief system. Some communities are specifically established to provide a shared commitment to caring for people with disabilities. Others are focused on other types of shared interest or life style. These can be located in urban, suburban or rural areas.

Given the nature of Intentional Communities and their uniqueness, each model described below has its own strengths and unique features as well as modifications and considerations that are specific to the model. They are provided with the description of each model.

MODEL 1: INTERGENERATIONAL COMMUNITY AS INTERVENTION (ICI)

Description of Model: An Intergenerational Community as Intervention (ICI) is an intergenerational neighborhood where some of the residents are facing a specific challenge around which the entire community organizes. The basic strategy of an ICI is to facilitate and support natural relationships and lifetime commitments across generational lines. The younger families in the community provide a home to a particular special-needs population, such as children adopted out of foster care or the juvenile justice system. Seniors in the community receive reduced rent and act as “volunteers” to help support the families. As the seniors age in place, the younger families also provide support to the seniors. The model is based on a ratio of one family to 3 to 4 “volunteer” households.

Because of the scale of an ICI, the development cost for site assembly and construction can be very high unless existing housing becomes available as in the example below, where the site was acquired from the closing of a military base. ICIs are also being explored on the site of a religious order or a closed institution.

Strengths and Unique Characteristics of the Model:

- Multi-generational approach to addressing a social need,
- It is more than housing – it is a supportive community that has benefits to all of its members,
- Technical support is available from Generations of Hope (see the example below) in designing and planning an ICI as well as grants for start-up.

Considerations/Modifications:

- Could be a community for adults living with autism in a lifesharing model with other adults,

- Funding is needed for the acquisition of the homes near each other and for rental subsidies to rent to the volunteers at below-market rents.
 - There are military bases that are downsizing and closing that should be investigated. A list is available in the February 20, 2009 Federal Register
http://www.access.gpo.gov/su_docs/fedreg/a090220c.html.
- A model of what a community is – it creates meaningful connections,
- Provides support to parents,
- This is a major undertaking requiring expertise in:
 - ICI principles and practices
 - The target population
 - Real estate development
- Individuals with extremely challenging behaviors could be dangerous for the seniors.

Example: The concept of an ICI was developed in 1993 by Generations of Hope, a non-profit corporation based in Rantoul, Illinois. Hope Meadows, developed by Generations of Hope, is an ICI for families that adopt multiple children from the foster care system. These families are supported by the community “volunteers,” seniors who also live in the community and serve as surrogate grandparents for the children. At Hope Meadows, the families receive free housing and the senior volunteers lease their homes at below-market rent in return for a commitment of 6 hours per week of volunteer time. Both the families and the seniors are responsible for their own utilities. This rental structure was only feasible because the site and houses were acquired at nominal cost from the federal government as part of a base closing.

Location/Contact Information:

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MODEL 2: COLLABORATION WITH A COLLEGE OR UNIVERSITY

Description of Model: Under this model, the housing is developed in collaboration among a college or university, adults with disabilities and their family members and a non-profit housing developer to provide housing units for both adults with disabilities and for students. There is shared space for group and social activities to foster all the residents learning from each other. The example provided is a large property with complex financing. This model can also be replicated on a smaller, less expensive scale.

Strengths and Unique Characteristics of the Model:

- Collaboration among parents, adults with disabilities, a university, and a non-profit affordable housing developer,
- Includes space for interaction and social activities between the residents with disabilities and the students,
- Location allows for participation in community life,
- Involvement of students facilitates relationships within the community by the residents,
- Provides a learning experience for university students,
- The University connection could also work with other housing arrangements since students are often looking for ways to enhance their learning experiences.

Considerations/Modifications:

- Supports would need to be in place as university students do not replace professionals,
- Need a developer and manager experienced with Low Income Housing Tax Credits and affordable housing finance,
- Would need to incorporate design features needed for a person with autism,
- Lack of continuity of the student volunteers since they leave during breaks and upon graduation, affecting the formation of lasting relationships.

Example: Trinity House is a proposed housing development in Bloomsburg, Columbia County. It is being planned collaboratively by parents, adults with disabilities, Bloomsburg University and the Columbia County Housing Corporation (CCHC). It entails the renovation of a vacant church into housing for 19 adults with disabilities in eleven 1- and 2-bedroom units and the renovation of two adjoining residential homes which will house ten students attending Bloomsburg University. The model was designed around the concepts of integration and choice. The building is located in close proximity to shopping and community activities, allowing the residents to participate in the day to day activities of the broader community. Engaging Bloomsburg University and its students will provide a broader range of opportunities and supports and a bridge to the community. The students' role will be as "buddies," not caregivers. The building will have a large common area where the residents with disabilities and the students can get together to work, learn and socialize.

Because the ownership of the building is to be structured as a leasing housing co-operative, and the co-op members are therefore homeowners (see Setting # 4 – Limited Equity Cooperative), Trinity House will not come under the PA Department of Public Welfare's 30-Hour Rule for Residential Habilitation which states, "If the person owns or leases the home, then the home does *not* have to be licensed even if the person needs more than 30 hours of supports per week." As a leasing co-op, each resident will be a member of the organization that holds a master lease with the non-profit that owns the property. In addition, it will not

be a “community home for people with mental retardation” because only housing and the opportunity for informal natural supports will be provided through this model – no paid staff will be provided by the “home.”

Trinity House has wide community acceptance both because it is a collaborative effort and because the community was brought into the planning process in the early stages of planning. As a result, this collaborative project has not encountered community opposition often encountered by affordable housing developments. Because of the scale of the project, it required multiple funding sources, many of which have complex application and reporting requirements and require the expertise of a housing development professional. The Columbia County Redevelopment Authority has played a very active role in obtaining funding for the project.

Location/Contact Information:

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MODEL 3: FARMSTEADS

Description of Model: The farmstead model for providing housing for people with disabilities incorporates both residential and vocational opportunities in a rural setting and has been used specifically to provide housing for individuals living with autism. The concept originated in England in the 1970s and has been adapted in the US. At these farm communities, the residents are involved in meaningful work that has been adapted to their specific strengths and needs.

Strengths and Unique Characteristics of the Model:

- Has been successfully used to provide housing specifically for people living with autism
- The individual with a disability is a full participating member of the community
- Provides meaningful work
- Encourages safety
- Provides long-term housing stability
- Because it is a campus setting, the staff can trade responsibilities if one is having difficulty with a particular resident or there can be a change in activity for the resident if that is causing an issue

Considerations/Modifications:

- Requires staff with skills in working with the residents as well as in the farm work,
- Need a source of operating funds beyond what the farm can support,
- Could possibly be replicated in an urban setting with a different type of meaningful work,
- In Pennsylvania, there is currently a policy favoring smaller community-based settings,
- Cost to families can be high,
- A large piece of land is needed,
- Start-up capital expenses are high,
- Requires a farm manager and if animals are raised, inspections by the Department of Agriculture.

Example 1: Bittersweet Farm in Whitehouse, Ohio is one of the best-known farmstead programs. They purchased their 80-acre site in 1981 and opened their doors two years later. They now have three houses providing home to 20 adults living with autism. Bittersweet Farm is licensed as an Intermediate Care Facility for people with mental retardation (ICF/MR). It also supports 60 adults who come to the farm for day programs. The program is based on Applied Behavioral Analysis, which focuses on individualized skill development.

Its mission is “to address the needs of autistic people for growth in every area of life, using the rural, extended family community as the model...some staff and residents live and work together every day.” They grow their own food and make wood products. By learning skills within the context of their everyday life, rather than in a classroom, the skills are more readily incorporated into their life. The farm also has hiking trails and other activities demonstrating their emphasis on recreation. The residents also interact with the wider community through a mobile landscaping crew, a hand bell choir which performs at community events, an engine repair shop, a tearoom and the sale of their produce to the community. Residents shop and eat in restaurants in the community as important social and skill-building events.

Location/Contact Information:

Bittersweet Farm
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Example 2: The Camphill model was founded by Dr. Karl Koenig based on the philosophy of Rudolf Steiner. The Camphill communities are based on a comprehensive therapeutic way of life for people with cognitive disabilities. The model combines a supportive setting for people with cognitive disabilities with a commitment to sustainable agriculture and creating social arrangements that nurture the growth and development of the members of the community. All community members contribute their time and skills according to their capabilities. There are slightly different models in different locations.

Located in Chester County, PA, Camphill Village at Kimberton Hills is part of the international Camphill movement. The Kimberton Hills location is a rural community that provides housing and services for adults with developmental disabilities, including autism. The community members, with and without disabilities, live and work together as expanded families in homes throughout the village, forming a supportive community based on shared responsibility and caring. There are 11 lifesharing households which include 42 adults with developmental disabilities. Each household prepares and participates in meals in their individual homes. The community focuses on wellness, working together, social and cultural life, and commitment to caring for the environment. The entire community participates in the community's farm, bakery, and café. In addition, there are many communitywide celebrations.

The farmstead site was donated to Camphill with the houses already in place. The operating funds for the housing come from a combination of the residents' families, the residents' own income (typically SSI), agriculture, rental of the other buildings on the site, and fundraising. In order to replicate this model, there needs to be front-end money for a site or the donation of a suitable site and a full community of people interested in participating in this lifestyle.

Location/Contact Information:

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www.camphillkimberton.org

Example 3: Safe Haven Farms, located outside of Cincinnati, Ohio, is currently under development. Occupancy by the first 16 residents is planned for the first quarter of 2010. Safe Haven Farms, Inc. was founded by a group of parents with young adult children with autism in response to the lack of residential and vocational services available. They designed Safe Haven Farms after extensive research on other farmstead programs. During the fall of 2009, they purchased a 60-acre working farm to intentionally serve individuals with autism. Phase I will consist of four homes for four adults each. Phase 2 planned for early 2011 will entail the construction of two more homes for an additional eight adults. All of the homes will have community and private space, will be universally accessible and will be energy efficient.

The farm will have 24/7 staffing to be provided by a state licensed agency. It will serve individuals with ICF/MR level of care needs using a combination of funding from Medicaid and County MR/DD funds. Residents will pay a room and board fee. All staff will receive extensive training on autism and will receive specific instructions for each individual resident and participate in day services.

In addition to the residential program, Safe Haven Farms will have day programs for individuals who live off-site, a therapeutic horseback riding program open to the community, as well an educational program and volunteer opportunities for local college students.

Location/Contact Information:

Dennis Rogers, President
Safe Haven Farms, Inc.
Dennis.Rogers@safehavenfarms.org

MODEL 4: CO-HOUSING

Description of Model: Co-housing is a type of collaborative housing in which residents actively participate in the design and operation of their own community. Co-housing can be developed around common interests, but not necessarily. It is often called an “intentional neighborhood.” The design encourages social contact while providing individual space. Co-housing incorporates private homes along with access to common facilities, including a common house, open space, and play areas. Community decisions are made through consensus. Community meals are often available but not required. Some co-housing neighborhoods have explored mechanisms to use affordable housing financing strategies.

Strengths and Unique Characteristics of the Model:

- Provides the opportunity of integrating the individuals with disabilities into the community,
- It is a “safe” neighborhood.

Considerations and Modifications:

- Diversity must be an initial, core principal,
- Other residents may be unlikely to engage residents with autism,
- The participating families must have access to development capital and sophistication in real estate development,
- Could work in a tax credit rental project provided that appropriate supports are in place.

Example: Coho Ecovillage in Corvallis, Oregon has a commitment to diversity. Six of their 34 units are reserved for people who earn under 80% of area median income and one unit is dedicated to an individual with a disability. Occupancy began in early 2008. All one-floor units are fully accessible and all two-floor units are visitable. The community was developed by Willamette Neighborhood Housing Services, an affordable housing developer. Each household is represented on the Co-Housing board, which governs the operations of the community.

One unit is owned by a non-profit and rented to an individual with physical disabilities. When this individual leaves the unit, it will be rented to another individual who needs the accessibility features. The inclusion of this unit was spearheaded by family members who were involved in the initial design of the community and it was built into the planning of the community.

A 4-bedroom, accessible unit was purchased by a local provider of residential services, Home Life, Inc. to provide housing for three adults with developmental disabilities and an overnight service person. For this to be a successful model for community integration, the service provider that leases the unit(s) and its staff need to take an active role in the operations of the community, as a board member and in helping the residents become part of the community. This would work best if there is continuity of staff.

Willamette Neighborhood Housing Services, the developer, is a county and state approved Community Housing Development Organization (CHDO). They used numerous funding sources including local and state HOME funds, state housing trust funds, and a state first-time homebuyers program. Each individual unit is maintained and supported by its owner. CoHo Ecovillage is structured as a condominium, charging an association fee based on unit size, typically under \$200 per month. All maintenance and management functions are conducted by the residents, resulting in lower monthly fees than are typical of a condominium community.

Location/Contact Information:

Colleen
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541-758-8210
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Douglas McRae, Director of Housing Development
Willamette Neighborhood Housing Services
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Douglas.Mcrae@w-nhs.org

SETTING # 7: LICENSED FACILITIES

Description of Setting: Licensed Facilities are those that must comply with the specific licensing requirements of their funding source. For those facilities that serve people living with autism, these licenses are typically those issued by the PA Department of Public Welfare, Office of Developmental Programs for people that meet the eligibility requirements of programs targeted to individuals with intellectual disabilities. The housing licensing requirements relate to such factors as the number of people living on a specific site, level of services provided, and health and safety standards.

Strengths and Unique Characteristics:

- Funding for 24/7 staffing,
- All costs, housing and services are covered,
- Availability of experienced residential providers,

Considerations and Modifications:

- Pennsylvania policy limits the size of new licensed facilities to four people,
- Residents and their families have limited input in and control over how the homes are managed or the training/expertise of the staff,
- Existing resources are limited, restricting these as options to those with the most critical needs.

MODEL 1: PRIVATE LICENSED FACILITY

Description of Model: Private Licensed Facilities (PLFs), also called “private community campuses” provide a wide range of programs and services including education, adult work and vocational services, residential services, and health care and rehabilitation on college-like campuses. The PLF can have, within or in close proximity to its campus, homes for individuals with developmental disabilities.

The proximity of the residential facility to a full campus gives the residents access to 24-hour healthcare and a range of professional staff able to address behavioral emergencies. In addition, as part of a larger institution, the program benefits from economies of scale in staffing and services. However, the typical size of the houses used for this purpose and their proximity to a campus make them ineligible, in Pennsylvania, for ICF or Waiver funding.

Example: In 2007, Melmark, in Chester County, began to provide residential services for adults with autism. They operate two homes with six residents each. The houses are located near their Berwyn campus, indistinguishable from other houses in the community. This model is targeted to adults with autism who have significant behavioral challenges. Many of the participants also have co-

occurring intellectual disabilities. The residents of the house have access to the Adult Autism Day Program available on the Melmark campus including specialized clinical programming using Applied Behavioral Analysis, medical services, and educational/vocational services. The services promote independence, choice, support, individual well-being, improved functioning and skills, and expanded opportunities for community involvement.

The program is funded under MR Base Funding.

Location/Contact Information:

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Berwyn, PA 19312-2307
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gplj@melmark.org

MODEL 2: INTERMEDIATE CARE FACILITY FOR PEOPLE WITH MENTAL RETARDATION (ICF/MR):

Description of Model: An ICF/MR provides residential services for people with mental retardation or other related conditions. They are an optional benefit under Section 1905(d) of the Medicaid portion of the Social Security Act to fund “institutions” with four or more beds. In Pennsylvania, most ICF/MRs are homes serving four to eight people. An ICF/MR must provide “active treatment”. In Pennsylvania, the basic principles of ICF/MR facilities are:

- Each individual has capacity for growth and development
- Each individual should have access to services that enhance his/her development, well-being and quality of life
- Each individual should have access to the most normal and least restrictive social and physical environments consistent with his/her needs
- Each individual’s services should be delivered in accordance with a single, comprehensive individual rehabilitation plan that is developed, monitored, coordinated, and revised by members of a duly constituted inter-disciplinary team

To the maximum extent possible, services and supports reflect person-centered planning, inclusion in community life, and control and choice by the person served. Values for the persons as reflected in the supports and services offered under the ICF/MR funding stream include choice, control, permanency, security, freedom, prosperity, individuality, relationships, recognition, privacy, and citizenship.

Example: Jubilee House, which opened its doors to six adults with intellectual disabilities in April, 2009, is the only new ICF/MR funded in Pennsylvania in the

past 15 years. It is located on the campus of Rockhill Mennonite Community, a continuing care retirement community in Souderton, PA. The house is staffed 24/7. The land was donated by Rockhill and the program is operated by Peaceful Living. Jubilee House is the result of very aggressive advocacy on the part of a group of parents who felt their adult sons' and daughters' needs would be best met in this setting. They began planning Jubilee House approximately 12 years before it became a reality. The ICF/MR funding covers the cost of Rockhill's mortgage for the approximately \$1 million development cost and for staffing. Each resident has his or her own bedroom and there is also a living room, dining room, kitchen and screened porch. As the parents age, they have the option to move to the Rockhill continuing care community.

Location/Contact Information:

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Peaceful Living
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MODEL 3: COMMUNITY LIVING ARRANGEMENT (CLA):

Description of Model: A community living arrangement (CLA), also known as a group home or community home, provides a home in a residential neighborhood. The homes are supported by staff providing supervision and assistance in the home 24 hours a day, seven days a week. Funding is typically through the Consolidated Waiver for people with intellectual disabilities and can be through base funds (i.e.: the county's allocation of funds) when available, plus 72% of the resident's SSI. If the CLA is funded through the Consolidated Waiver, it can only serve a maximum of four individuals. A CLA is an eligible housing choice under the Residential Habilitation service in the Adult Autism Waiver for adults who need round-the-clock supervision.

CLA beds are very limited and as a result, individuals often move to one in an emergency situation such as the serious illness or death of their caregivers. When this happens, they may need to be placed in the first available home, which may be far from natural supports or familiar locations.

Example: There are numerous CLAs throughout the state. A searchable listing is available at:
<http://www.dpw.state.pa.us/PartnersProviders/MentalRetardation/003670755.asp>

SECTION 6: BARRIERS THAT IMPEDE THE IMPLEMENTATION OF HOUSING MODELS AND RECOMMENDATIONS FOR OVERCOMING THOSE BARRIERS

The Housing Options Committee identified a number of barriers that need to be addressed to successfully provide new housing opportunities for adults living with autism. Following is a brief description of each barrier identified as well as short and long-term recommendations for addressing that barrier. *It is anticipated that the short-term recommendations can be accomplished within 18 months assuming at least the current level of staffing and resources at the Bureau of Autism Services and the formation of collaborations with other state agencies. The long-term recommendations are intended to inform future initiatives for increasing housing options for adults with autism in Pennsylvania. If resources permit, actions on some of the long-term recommendations might start concurrently with the short-term recommendations.*

MYTHS AND DIFFICULTY ACCESSING ACCURATE INFORMATION

Many adults with autism and their family members have inaccurate and/or insufficient information about existing and potential housing options and how to access those options. In addition, many family members are living with the stress of managing the day to day needs of their loved one and have little time to research new information. As a result, they may not take advantage of all the resources available to them. Further, without full information, individuals may make decisions that are not in their best interest. For example, an individual may not apply to his local public housing authority for a Section 8/Housing Choice Voucher to reduce rental housing costs because he has inadequate knowledge of the eligibility criteria, purpose and availability of this housing resource.

In addition, there are a host of myths about the potential impact of employment, homeownership, and Section 8/Housing Choice vouchers on an individual's SSI and other public benefits. These myths cause people to fear a loss of benefits, which results in their rejecting options that could be beneficial and desirable. For example, adults with autism may not consider homeownership due to a lack of understanding of the current rules governing the accumulation of savings in excess of \$2,000 by people receiving SSI. This, however, is an option as illustrated in the models described above.

RECOMMENDATIONS:

A range of mechanisms needs to be developed to disseminate accurate information to adults with autism and their families. This information will increase their understanding of the housing options included in this report and help dispel fears based on myths about the impact of various decisions on public benefits. This will enable them to pursue the housing options of their choice with an accurate awareness of the implications of their decisions on their public benefits.

SHORT TERM

We recommend that:

- 1- The Bureau of Autism Services (BAS) staff and Housing Consultants work with the PA Department of Developmental Programs (ODP) to develop/distribute a series of training modules on housing planning and housing options for individuals with autism. This activity would start with reviewing and modifying existing resources to the extent possible and would include such topics as: individual assessment and planning; an overview of housing options; how to prepare to be a renter or homeowner; and creation of Self-Directed Support Corporations and other legal tools such as special needs trusts. These modules could then be made available through the most appropriate medium as part of the Bureau of Autism's Spectrum Training Series so that they can be accessed by individuals with autism seeking housing alternatives, family members, and supports coordinators.
- 2- BAS request that the PA Health Law Project assemble accurate information on rules and regulations to dispel common myths. This could include information on savings and real estate ownership that could potentially affect SSI and other public benefits. The information should then be disseminated through fact sheets, websites, webinars, training and other means.
- 3- BAS add a link on its website to the Self-Determination Housing Project of Pennsylvania website (www.sdhp.org) to provide adults with autism and their families information currently available in Pennsylvania concerning housing for people with disabilities. This information includes such relevant topics as fair housing and home modifications as well as articles in their newsletter, *Homewards*. This information will also be of value to service providers and supports coordinators.

LONG TERM

We recommend that:

- 1- BAS, using the ASERT Regional Centers as a clearinghouse, work with consumers and families to develop a speakers' bureau of individuals with autism who are living in various housing settings and their family members. Speakers would share their experiences with families and individuals considering a move or change, either in person or through e-mail or phone contact.
- 2- BAS staff and consumers, using the Bureau of Autism's Spectrum Training Series, provide training for PHFA, HUD-Approved Housing Counseling Agencies and other appropriate entities on the housing needs

of people with autism with the goal of more effectively helping them to obtain the housing of their choice.

FINANCIAL BARRIERS TO THE CREATION OF NEW HOUSING OPPORTUNITIES

Many individuals with autism have low-incomes and cannot, therefore, afford housing at fair market rents or pay fees for services. They need subsidized housing and/or publicly funded services. Specifically, in relation to housing, individuals who want to rent may need rental assistance or subsidized housing in order to afford the monthly costs. In addition, in many areas of the Commonwealth, those who want to purchase a home will likely need assistance with down payment and closing costs. Finally, people living with autism may have no credit history or poor credit, which creates a barrier to their qualifying for rental housing as well as purchasing a home.

Unfortunately, there is a shortage of federal, state and local subsidized housing resources, resulting in extremely long waiting lists for rental subsidies as well as for affordable rental units and homebuyers' assistance. Further, although most communities do have homebuyers' programs, the maximum amount of down payment and closing cost assistance is well below that needed to make a home purchase affordable for many individuals with disabilities.

This situation is exacerbated by the shortage of funding for services in many communities. This results in limiting housing options to situations in which services are bundled with the housing or in which services are not needed. This deficit is described further below under the service considerations section.

RECOMMENDATIONS:

Since there is such a great need for affordable housing by both people with disabilities and those who do not have disabilities, the creation of new housing resources for individuals with autism will require targeted advocacy on the part of interested parties. There also needs to be an assurance to developers that once built, these units will be quickly occupied and appropriate services will be available to those who need them.

The creation of new housing opportunities will require efforts to create additional resources for the development and operations of rental housing and for increased financial resources to make home ownership affordable.

We therefore make the following short and long-term recommendations:

SHORT TERM

For rental housing, we recommend that:

- 1- BAS advocate with the PA Office of Long Term Living (OLTL), PA Department of Public Welfare (DPW), PA Housing Finance Agency

(PHFA) and the PA Department of Community and Economic Development (DCED) to expand the Tenant Based Rental Assistance pilot program now being used for Nursing Home Transition to include the provision of rental assistance for individuals with autism.

For potential homebuyers, we recommend that:

- 2- BAS advocate with DPW, PHFA and DCED to develop strategies for increasing the amount of down payment assistance available to accommodate low income individuals with autism pursuing home ownership. This could include providing incentives for family members and/or other private sources to provide additional sources of down payment assistance.

LONG TERM

We recommend that:

- 1- BAS advocate with housing agencies to make resources more available for new housing opportunities for people with autism. It is important to begin the dialogue with housing agencies around the following recommendations as soon as possible in order to put these long-term changes in motion. Areas for housing resource advocacy include:
 - Identifying additional sources of flexible capital funding to develop housing for individuals with autism. One potential resource is a set-aside in the State Housing Trust Fund, which has been legislated but not yet funded.
 - Creating a priority within funding competitions for family-driven models, since to date, most of the successful models of affordable housing for people with autism in Pennsylvania have been family driven.
 - Establishing a statewide financial mechanism to assure funds for on-going management/operating expenses of housing for individuals with autism.
 - Encouraging lenders to develop criteria to enable potential homebuyers with no credit (as opposed to poor credit) to qualify for a mortgage or for mortgage assistance programs.
 - Establishing a mechanism that will enable homebuyers to save for home maintenance and repair without jeopardizing their SSI and other benefits. Alternatives to be investigated include how to use Medical Assistance for Workers with

Disabilities (MAWD), Self Directed Support Corporations, a new nonprofit, remainder trust, special needs trusts, or consumer run credit union for this purpose.

- 2- BAS advocate with the Office of Developmental Programs (ODP) to redirect existing or new PA 6400 Group Home funds to other types of community-based housing opportunities, including funding of rental assistance and/or housing operations for the types of models described in Section 5.
- 3- BAS develop and implement strategies to encourage persons with autism and their families, where applicable, to work with other individuals with autism and other disabilities and their families together with housing developers to replicate housing models described in this report or to develop new models.

HOUSING PROGRAM LIMITATIONS AND ZONING RESTRICTIONS

For those individuals with autism who want to live in the community, there is often a preference for small scattered site housing options that are well integrated into the community, rather than large housing developments. In fact, many of the housing models in this report involve small scale options. Unfortunately, the financing for the development of new affordable housing often favors large scale development, since such projects benefit from economies of scale in both development and management. For example, many of the up-front planning costs and fees are almost the same for small or large projects, which increases the per-unit costs of smaller projects and makes them less attractive to funding sources. As a result, developers of new housing are often hampered in their ability to meet the preferences of people with autism for small scattered site housing.

The largest source of subsidies currently available for the development of affordable housing is through the Low Income Housing Tax Credit Program administered by the Pennsylvania Housing Finance Agency (PHFA). This program is highly competitive and, for the above and other reasons, small specialized housing development projects often do not fare well. For example, one of the scoring criteria for PHFA funding is “Community Impact,” which may be difficult to document in smaller communities that do not have Community Revitalization Plans. In addition, even with substantial development loans/grants, additional subsidies are frequently needed to cover operating costs for the term of the mortgage due to the very low incomes and small number of the anticipated residents.

PHFA also operates homebuyer mortgage and mortgage assistance programs. The amount of subsidy under their HOMEstead Program, which provides down payment and closing cost assistance, is per property, not per individual. This

means that three unrelated individuals purchasing a home together can only qualify for one homebuyer subsidy rather than three, and a single subsidy is generally not enough to make the monthly payments affordable. Further, PHFA has financed few limited equity cooperatives, which is an affordable housing model that could be desirable to individuals with autism.

Local zoning restrictions pose another barrier to implementation of certain housing models introduced in this report. For example, numerous local zoning codes have definitions of family that restrict occupancy in certain residential neighborhoods to a maximum of three unrelated individuals, which may impede the ability to execute shared housing models. In addition, zoning ordinances are also often used to exclude or limit the creation of accessory apartments, elder cottages, and other non-traditional housing models suitable for persons with autism.

RECOMMENDATIONS

In order to increase the affordable housing options available to people with autism, current housing regulations and funding mechanisms need to be reviewed and modified to better address their housing needs.

SHORT TERM

We recommend that:

- 1- BAS advocate for PHFA creating a mortgage product that would permit assistance to be based on the number of individual households purchasing a property. This would make purchase by unrelated individuals more affordable.
- 2- BAS advocate for the PA Department of Community and Economic Development, the PA Planning Association, universities, and/or Regional Housing Legal Services to identify, develop, and disseminate model zoning ordinances that support alternative housing options such as ECHO housing or group shared residences.

LONG TERM

We recommend that:

- 1- BAS request that PHFA review its current programs in order to remove impediments and develop clear guidelines for groups interested in financing limited equity housing cooperatives. This would include revising its Community Impact scoring criteria to recognize the unique impact small projects serving targeted underserved populations have and acknowledge that large projects that would score well for Community Impact are often inappropriate for persons with disabilities.

- 2- BAS make developers and advocates aware of current fair housing laws (<http://www.hud.gov/offices/fheo/FHLaws/>) that protect people with disabilities and can be used to support the creation of certain housing options. For example, a community cannot restrict the number of unrelated individuals sharing a home if the same number of related family members is permitted to occupy a similar property.

SERVICE CONSIDERATIONS

First, there is a major gap in the availability of housing assessment and housing planning for individuals with autism. Although many adults with autism have Individual Service Plans (ISPs), most plans do not include long-term planning with informed choice about a range of housing options. Other adults with autism do not even have an ISP. It is critical, therefore, that all individuals with autism be an active participant in a meaningful process that results in a housing plan reflecting their needs and preferences. This planning is especially important to ensure that the individual is prepared in the event of such crises as the serious illness or death of a family member or turnover in staff.

The second major issue is how to best provide long-term, consistent supports for people with autism, whether they are living with family members or in other settings. Presently, there are a number of different programs/Medicaid waivers through which services may be funded for adults with autism depending on their primary diagnosis and their specific needs. These include the new Adult Autism Waiver administered through the PA Bureau of Autism Services, the OBRA Waiver administered through the PA Office of Long Term Living and the Person/Family Directed Support Waiver (PFDS) and the Consolidated Waiver administered through the PA Office of Developmental Programs. In addition to waiver funded services, the Adult Community Autism Program (ACAP) was recently initiated in several counties. ACAP provides skill development along with individualized behavior support and medication management. Unfortunately the eligibility for and services available through each of the above sources differs, resulting in confusion among adults with autism and their families.

In addition to confusion about coverage, there are gaps in the eligible services. The Adult Autism Waiver provides funding for a number of services to help support individuals in their own home who do not require 24/7 staffing. These include, but are not limited to: Adult Day Habilitation, Assistive Technology, Behavioral Support, Community Transition Services, Supports Coordination and Personal Assistance Services. In addition, individuals who require awake support 24 hours a day, 7 days a week are eligible for Residential Habilitation. However, this can only be provided by an agency that is licensed by the DPW Office of Developmental Programs as either a Family Living Provider (Title 55 PA Code Chapter 6500) or a Community Home (Title 55 PA Code Chapter 6400).

At the present time, a considerable number of adults with Autism Spectrum Disorder who also have a diagnosis of Intellectual Disability are accessing services through the Person/Family Directed Support Waiver (PFDS) or the Consolidated Waiver. There are, however, barriers when these services are being applied to housing options for adults with autism. Specifically:

- Under PA 6400 Regulations, the “30 hour rule” requires licensing of residential settings in which an individual with an MR Waiver receives a yearly average of 30 or more hours of service per week *unless* the person receiving the services owns the home or is living in a relative’s home. However, there is inconsistency in the application of the 30 hour rule, with some persons on Consolidated Waiver who own or rent their own homes being required to license them while others are not. Licensing, while a safeguard to the health and safety of the individual, increases the cost of providing housing opportunities because of both the paperwork and the physical requirements for the property.
- The current four-person limitation for new Community Living Arrangements (CLAs) and ICF/MRs is an obstacle to housing options that may be the choice of certain individuals and/or that require a minimum number of people to make the operating costs viable.
- In most counties, slots are limited for the more comprehensive Consolidated Waiver, and the cost of licensed residential services is not eligible under the PFDS Waiver.
- Under the Consolidated & PFDS waivers, family members can be paid for habilitation services that they provide in their home or can receive Habilitation Aides to care for an adult with autism in their home. However, there are several problems. First, many families are unaware of this opportunity or have misinformation about when these options apply. Second, in order to be paid under the waiver, services provided by family members must be for tasks that the family members “would not ordinarily perform.” Unfortunately, this is interpreted differently by different counties. Third, in order to qualify for payment, the family member must be an employee of a vendor who serves as the fiscal agent, which can be a significant obstacle to their participation.
- Current regulations prohibit aunts, uncles, siblings, nieces, nephews and grandparents of an individual in the Mental Retardation system from being paid under the family living (lifesharing) program to provide housing to their relative (55 Pa Code §6500.4). While these non-parent relatives may be more suitable to provide housing and support to their relative with autism than a complete stranger under the family living program, they often cannot afford the additional expense of housing and caring for that individual while they take care of their own immediate family as well.

RECOMMENDATIONS

There is a need for the service system to be reviewed and modified to better support adults with autism in their own home in the community.

SHORT TERM

We recommend that:

- 1- BAS work with the Office of Developmental Programs (ODP) to develop a housing assessment tool specifically for people with autism, to be used along with the above housing options training module to provide current information about potential housing options and how individuals with autism can best ascertain their individual housing preferences and choices.
- 2- BAS work with ODP to assess the current application of the 30-hour rule to ensure that it does not impede the creation of new community housing options for individuals with autism.
- 3- BAS work with ODP to explore a relief from the four person limitation for a new ICF-MR if it is clearly the housing of choice for the residents and if there is no other feasible way to provide that housing.

LONG TERM

We recommend that:

- 1- BAS advocate with ODP to determine the extent to which allowing non-parent relatives (i.e.: siblings, step-parents, grandparents, aunts and uncles) to be paid under the family living program would expand housing opportunities for persons with ASD in the Intellectual Disabilities system,
- 2- BAS advocate with DPW, DCED, PHFA, ODP, constituents and others to identify alternative resources for ensuring the availability of housing related services for individuals with autism who are not eligible for waivers, especially those who have social rather than functional limitations.

SPECIAL BARRIERS ASSOCIATED WITH AUTISM

While many of the barriers listed above affect a range of individuals with disabilities, adults with autism face some unique barriers. As described above in Section 4, people with autism have certain characteristics that may present obstacles to meeting their housing needs. For example, some people with autism may need an extra room for a live-in aide. Some cannot communicate verbally, which presents special challenges to housing planners and providers

attempting to ensure that individual choice is respected. Other individuals have difficulty with social skills, have cognitive differences and/or sensory integration issues, which can eliminate housing models that involve sharing with others and/or require special accommodations such as extra space or amenities. Other individuals may have behavioral issues that require on-site credentialed behavioral clinicians.

Some individuals may need special attention to environmental factors such as special lighting or noise barriers, or need to be located far from noisy fire departments or major highways. These features may add extra cost to the home, especially if it means retro-fitting an existing home rather than construction of a new one.

Finally, some adults with autism have health related issues that may further limit their housing choices. This can affect them in several ways: extraordinary health costs can limit their ability to pay for housing; they may need to be close to medical facilities and services, and/or they may need to live in a place that provides on-site medical care.

RECOMMENDATIONS

There needs to be a concerted effort to create housing options designed around the specific needs of an individual with autism and increased public awareness of these needs.

SHORT TERM

We recommend that:

- 1- BAS and its staff and housing consultants develop and test alternative methods of conducting housing assessments and communicating housing information and options to ensure full participation and choice by all individuals with autism, including those who are non-verbal.

LONG TERM

We recommend that:

- 1- BAS request that DCED and PHFA research, pilot and disseminate information on innovative and affordable design solutions for housing units occupied by individuals with autism, including units with special lighting or sensory features and units accommodating live-in aides. The dissemination of information could be done through the media and with special showcases, including regularly scheduled open houses/home visits to housing occupied by individuals with autism and/or the creation of “virtual tours” showing people with autism living in various settings/models. These videos could be posted on the BAS website through YouTube or other appropriate venues.

- 2- BAS request that the Self-Determination Housing Project, DPW, DCED and PHFA compile an inventory of architects, builders, developers and others who have experience developing, building and renovating housing for people with autism.
- 3- BAS support the development and implementation of a public awareness campaign to change cultural and housing industry norms about housing opportunities for people with autism.

CAPACITY/TECHNICAL KNOWLEDGE

This report presents a number of housing options that could be pursued by individuals with autism and their family members. However, many of the options described are complex. Implementing them would require a great deal of knowledge and expertise in housing finance and development and/or extraordinary advocacy on the part of the families or self-advocates. Although some individuals and family members have successfully advocated for their chosen housing options, many families are not equipped to do so. They have neither the background needed nor the time to embark on a complicated housing venture. It is important, however, that all individuals with autism and their families have equal access to housing options regardless of their knowledge level and advocacy skills. Families need access to information and professionals who are experienced in both conducting housing assessments and in implementing individual housing options.

While “Home Finder” is an approved service under the Consolidated Waiver to assist individuals in locating the housing of their choice, this service is neither widely known nor utilized. It is also not currently included in the Autism Waiver.

Finally, there are still unresolved issues, such as how specific models can be sustained when there is a change in the needs or status of the resident. Consequently, a number of these models will require “tweaking” to accommodate the unique needs of the individual residents or persons being served and to continue to meet needs as they evolve over time.

RECOMMENDATIONS

There needs to be a plan to help adults with autism and family members to use the information provided in this report, especially to determine which model is most appropriate for them and then how to pursue that model.

SHORT TERM

We recommend that:

- 1- BAS work with ODP to ensure the availability of Housing Technical Assistance to adults with autism and their families. This can be achieved

by adding a service to the Autism Waiver and ACAP similar to “Home Finding” in the Consolidated Waiver. This will enable those with expertise in housing and benefits to assist individuals and their families to develop a housing plan/model that best meets the needs and desires of the adult living with autism. This will require a clear service definition, provider qualifications that ensure expertise, and a reimbursement rate that will attract persons with the requisite qualifications.

LONG TERM

We recommend that:

- 1-** BAS make Housing Technical Assistance Providers (HTAPs) available through the Autism Services, Education, Research, and Training (ASERT) Regional Centers or other viable locations. The roles of the HTAPs would include training of Support Coordinators, people with autism, family members and others in housing options and housing planning; and assisting individuals, families and groups of families to select among and implement various housing options, both traditional and creative.
- 2-** Over time, BAS develop a broader cadre of people who can provide Housing Technical Assistance. In order for this to happen, BAS needs to work with DPW, ODP, DCED and PHFA to create a system that helps people to develop the skill sets to take on this role. In addition to an actual training program, there needs to be a training manual that would enable people to develop housing planning skills through a web-based interactive training program.

SECTION 7: NEXT STEPS AND CONCLUSIONS

This report has been directed to a number of readers including state and local officials, policy makers, service providers, developers, and individuals with autism and their family members. While many of these groups probably have the capacity to use the information provided, some, including individuals with autism and their family members, may need assistance in taking the next step. For example, an individual with autism may find three of the models presented of interest, but may need assistance in understanding the advantages and disadvantages of each as it relates to his/her individual situation. Or three families may want to work together on a housing option but do not know how to form a partnership that both achieves their goals and protects their interests.

We anticipate that these families and individuals will fall into one of three categories:

1. Those who can use the report as is and who have the ability to pursue options on their own with little or no help:

This group will identify their preferred housing option and be able to proceed, but may need assistance with difficult issues or advocacy with state agencies to obtain waivers or special considerations in order to implement a specific initiative.

2. Those who will be overwhelmed and/or disinterested and not want to pursue anything in the near future:

This group will need continuing education and information on successful models and how they are accomplished in order to bring them to a comfort level to consider undertaking an initiative. This type of education should be provided to local governments, housing authorities, developers and other partners as well as to adults with autism and their family members.

3. Those who are interested but who do not know how to proceed or who need help representing their point of view/interest to possible partners:

This group will probably represent the majority of families and will need the most assistance, particularly in the following:

- **Determining the most appropriate housing model:** This would begin with a housing assessment, education on housing options and discussion of the pros and cons of various models in terms of the individual's desires and needs.
- **Identifying appropriate partners:** Partners may include other individuals with autism, a group of families working together to pursue a model or

local housing agencies and/or developers. It is important that all participants' roles are clearly defined and that the individual with autism continue to be an active participant in the planning process and have his or her desires be heard throughout the planning process.

- **Identifying the best organizational and legal structure:** Once the housing model is determined, there may be a need to create an organization to carry out the development and/or ownership of the housing or other legal structures to assure the ongoing affordability and sustainability of the housing.
- **Accessing housing finance sources:** In most of the models, there is a need to identify and obtain financing for purchase, construction or rehabilitation, housing operations, or rental assistance.
- **Negotiating with services systems and providers:** For many people with autism, services need to be in place to assure success in their home.

Next Steps:

The above short-term recommendations fall into two general categories as follows:

- 1. Information, Training and Technical Assistance**
- 2. Regulatory and Program Modifications**

We recommend that the Bureau form three Work Groups, the first two to follow up on the recommendations under their purview and the third charged with developing a pilot project. Following are specific suggestions for the three Work Groups:

Work Group 1: Information, Training and Technical Assistance

This work group would focus on the following short-term recommendations:

- The Bureau of Autism Services (BAS) staff and Housing Consultants working with the PA Department of Developmental Programs (ODP), develop/distribute a series of training modules on housing planning and housing options for individuals with autism.
- BAS request that the PA Health Law Project to assemble accurate information on rules and regulations to dispel common myths.
- BAS put a link on its website to the Self-Determination Housing Project of Pennsylvania (www.sdhp.org) to provide adults with autism and their

families information currently available in Pennsylvania concerning housing for people with disabilities.

- BAS work with ODP to develop a housing assessment tool, specifically for people with autism, to be used along with the above “housing options” training module to provide current information about potential housing options and how individuals with autism can best ascertain their individual housing preferences and choices.
- BAS work with DPW and ODP to ensure the availability of Housing Technical Assistance to adults with autism and their families.
- BAS and its staff and housing consultants develop and test alternative methods of conducting housing assessments and communicating housing information and options to ensure full participation and choice by all individuals with autism, including those who are non-verbal.

The key to success of this Work Group will be the development of capacity on both the state and regional levels to assist families and individuals in moving forward. We suggest that the Work Group develop recommendations for making the ASERT Centers the locus of housing and planning expertise. It should also take the lead in identifying a pool of interested partners (e.g. developers, consultants, provider agencies, family members) to be trained to work with interested individuals and families. In carrying out their charge, the Work Group should use the Regional Housing Coordinators of the Self Determination Housing Project as excellent resources for coordinating the interested parties with existing housing groups and committees. Finally, the Work Group should work closely with Work Group 3 in identifying groups and individuals interested in participating in the pilot projects.

Work Group 2: Regulatory and Program Modifications

This Work Group would focus on the following short-term recommendations:

- BAS advocate with PA Office of Long Term Living (OLTL), PA Department of Public Welfare (DPW), PA Housing Finance Agency (PHFA) and the PA Department of Community and Economic Development (DCED) to expand the Tenant Based Rental Assistance pilot program now being used for Nursing Home Transition to include the provision of rental assistance for individuals with autism.
- BAS advocate with DPW, PHFA and DCED to develop strategies for increasing the amount of down payment assistance available to accommodate low income individuals with autism pursuing home ownership.

- BAS advocate for PHFA creating a mortgage product that would permit assistance to be based on the number of individual households purchasing a property.
- BAS advocate with the PA Department of Community and Economic Development, the PA Planning Association, universities, and/or Regional Housing Legal Services to identify, develop, and disseminate model zoning ordinances that support alternative housing options such as ECHO housing or group shared residences.
- BAS work with the Office of Developmental Programs (ODP) to assess the current application of the 30-hour rule to ensure that it does not impede the creation of new community housing options for individuals with autism.
- BAS work with ODP to explore a relief from the four person limitation for a new ICF-MR if it is clearly the housing of choice for the residents and if there is no other feasible way to provide that housing.

In order to be effective, this Work Group needs to include representation from the key program and regulatory decision makers in the appropriate state departments. Assuming buy-in regarding the need for change, this Work Group should be charged with drafting program and regulatory amendments and/or with identifying impediments to changes needed to implement the housing options in this report. It should work closely with Work Group 3 as it selects and carries out its specific pilot projects.

Work Group 3: Pilot Projects

This report is a critical first step in addressing housing choice for people with autism living in Pennsylvania. It provides a wealth of information on a comprehensive range of housing options that can be considered by persons with autism and their families. However, while many of the models in this report are interesting, innovative and inspiring, some have not been implemented in Pennsylvania and others have not been implemented specifically for persons with autism. As a result, families attempting to implement them may face regulatory, political, financial or other obstacles. Also, as described above, the implementation of many of the above housing models are complex and will be difficult for families without a background in affordable housing.

Therefore in order to identify and test the various regulatory and program modifications identified in this report, Work Group 3 should be charged with selecting five to six of the models for implementation in Pennsylvania for individuals with autism. Interested individuals and families would be chosen specifically based on the model in which they express interest, geographic location, skill level and other criteria established by the Bureau of Autism Services. A technical assistance team could work with the individuals selected

on specific models in order to test their feasibility and applicability to people with autism. This process would also aid BAS in identifying and addressing state and local barriers to the implementation of each model. At the end of the demonstration period a “How-To Guide” could be developed to provide step-by-step instructions and worksheets to assist in replication by future housing planners and users.

Conclusion:

The information in this report was developed through the hard work and interest of a broad range of people including adults with autism, family members, and those with expertise in housing, social services, and government regulations. This same range of expertise and energy will now be needed to create successful housing solutions for the many adults in Pennsylvania with autism who are hoping to have their own home.

APPENDICES

APPENDIX A

HOUSING OPTIONS COMMITTEE MEMBERS

Robyn Arva	PA Bureau of Autism Services
Michael E. Bomberger	Keystone Service Systems
Eboni E. Braxton	Pennsylvania Department of Public Welfare (DPW)
Claire Choutka	PA Bureau of Autism Services
Roy Diamond	Diamond & Associates
Carmen Donegan	DPW - Office of Developmental Programs
David Gates	PA Health Law Project
Barbara Hodas	Diana T. Myers & Associates, Inc.
Gail Hoffmann	Self-Determination Housing Project of Pennsylvania (SDHP)
Rich Kisner	Columbia County Redevelopment Authority
Leo LaPlante	DPW - Office of Long Term Living
Ginny Leonard	Autism Living and Working (ALAW)
Carol Lynch	PA Bureau of Autism Services
Nicole Matero	PA Bureau of Autism Services
Mary Maurer	Parent
Diana T. Myers	Diana T. Myers & Associates, Inc.
Gelene Nason	Pennsylvania Housing Finance Agency (PHFA)
Pia Newman	PA Bureau of Autism Services
Dana Olsen	DPW - Office of Developmental Programs
Mike Piccuch	State Representative O'Brien's Office
Melody Ranck	State Representative O'Brien's Office

Charles Scalise	Housing and Neighborhood Development Services, Inc. (HANDS)
Rae Unger	Autism Living and Working (ALAW)
Shirley Walker	Pennsylvania's Service Network for Autism and Intellectual Disabilities
Nina Wall-Cote	PA Bureau of Autism Services
Ryan Walters	PA Bureau of Autism Services
Becky Willmot	Autism Living and Working (ALAW)
Lisa Yaffe	Pennsylvania Housing Finance Agency (PHFA)

APPENDIX B

HOUSING FINANCING SOURCES

Rental Housing:

- **US Department of Housing and Urban Development (HUD) Housing Choice Vouchers (formerly Section 8):** This is a TBRA program, under which, an individual or household applies to their local public housing authority for a Housing Choice Voucher. When the voucher is approved, the individual or household can then use the voucher in a rental unit of his or her choice so long as it meets the rental and quality standards of the program. There is often a waiting list for Housing Choice Vouchers. However, some public housing authorities have a “preference” for people with disabilities. Under this preference, a person with a disability would move to the top of the waiting list. A list of public housing authorities in PA is available at: <http://www.hud.gov/offices/pih/pha/contacts/states/pa.cfm>. Contact your public housing authority to see if they have any waiting list preferences.
- **Special Purpose Tenant Based Rental Assistance:** On occasion, HUD makes funding available on a competitive basis for Housing Choice Vouchers for particular population groups. In particular, the Mainstream Housing Choice Voucher Program is targeted specifically to people with disabilities. Contact your public housing authority to see if they have an allocation of Mainstream Housing Choice Vouchers and how to apply for them.
- **HOME TBRA:** The HUD HOME Program allows communities to use a portion of their funds for short-term (up to 2 years) for TBRA. This is not commonly used but in some communities, groups have advocated for the availability of these rental subsidies.
- **US Department of Housing and Urban Development (HUD) Section 811 Program – Supportive Housing for People with Disabilities:** Under the 811 Program, HUD provides funding to nonprofit organizations to develop rental housing with the availability of supportive services for very low-income adults with disabilities. HUD provides project based rental subsidies to help make the units affordable to the occupants. As described below, ALAW recently received funding under the Section 811 Program.
- **Local Public Housing Authority Project Based Section 8:** HUD makes project based rental assistance available on a limited basis through the Housing Choice Voucher Program. This enables developers of affordable housing to make a portion of their units affordable to the lowest income renters, typically those with disabilities.

Home Ownership:

- **Pennsylvania Housing Finance Agency (PHFA):** PHFA has several different programs, based on the income of the homebuyer, to help make homeownership more affordable. Information on their programs is available at <http://www.phfa.org/consumers/homebuyers/loans.aspx>.
- **PA Accessible Housing Program:** Provides grants to local entities to carry out home modification programs that will enable low-and moderate-income persons with physical disabilities of all ages to make their home more accessible. Full program guidelines and county contacts for the program can be found at: <http://www.newpa.com/find-and-apply-for-funding/funding-and-program-finder/funding-detail/index.aspx?progId=88>.
- **First Front Door Program of the Federal Home Loan Bank of Pittsburgh:** Although this program was not funded during 2009, it is a potential resource in the future for downpayment and closing cost assistance for first-time homebuyers with incomes at or below 80% of area median income. Information is available at: <http://www.fhlp-pgh.com/housing-and-community/programs/first-front-door.html>.
- **US Department of Housing and Urban Development (HUD) Section 8 Homebuyers Assistance Program:** The homebuyer pays 30% of his/her income toward mortgage payments and the Section 8 Program, administered by the local public housing authority pays the difference. For this to be feasible, the monthly payments must fall within the local Fair Market rents established by HUD. More information is available at <http://www.hud.gov/offices/pih/programs/hcv/homeownership/>.
- **US Department of Agriculture (USDA) Section 502 Program:** This program provides low and no downpayment loans to income eligible homebuyers in eligible rural communities. More information is available at http://www.rurdev.usda.gov/rhs/sfh/brief_rhguar.htm
- **PA Department of Community and Economic Development (DCED) Neighborhood Assistance Program (NAP):** This is a tax credit program to encourage businesses to invest in projects which improve distressed areas. They can use it to donate property to a non-profit, including foreclosed properties. Information about the program is available at: <http://www.newpa.com/find-and-apply-for-funding/funding-and-program-finder/funding-detail/index.aspx?progId=82>.
- **County First Time Homebuyer Programs:** Many counties use their HUD Home Investment Partnership Program (HOME) funds and or local Housing Trust Funds to subsidize homeownership for first time homebuyers. Information is available from county community development offices.

- **Lender's First Time Homebuyer Programs:** Many lending institutions operate first time homebuyer programs. Interested households should contact the lenders directly for additional information.

APPENDIX C

GLOSSARY

- **Affordable housing:** Affordable Housing is generally defined as housing where the occupant is paying no more than 30 percent of his or her adjusted gross income for housing costs, including utilities. Households paying greater than 30% of their income for housing are considered cost burdened and those paying greater than 50% of their income for housing are considered severely cost burdened.
- **Area Median Income (AMI):** Area Median Income (AMI) is the midpoint in the income distribution within a specific geographic area. By definition, 50% of households earn less than the median income, and 50% earn more. HUD calculates AMI levels for different communities annually, with adjustments for family size. AMI is used to determine the eligibility of applicants for both federally and locally funded housing programs. For example, HUD defines very-low income as below 50% of the Area Median Income.

A chart of the AMI for every county in Pennsylvania is available on the PA Housing Finance Agency (PHFA) website at:

<http://www.phfa.org/developers/developer/housingapplication.aspx>.

Note: Under the Application Instructions section of the page – click on “06B - Rent and Income Limit Chart”

- **Consolidated Plan:** The Consolidated Plan is the annually-updated plan submitted to HUD by DCED and each Participating Jurisdiction, describing how HUD funds will be used. May be referred to as: “con plan” or “state plan” or “local plan.”
- **Cost Burden:** Cost burden is the fraction of a household's total gross income spent on housing costs. For renters, housing costs include rent paid by the tenant plus utilities. For owners, housing costs include mortgage payment, taxes, insurance, and utilities.
- **Development:** A housing development is any number of housing units constructed or renovated with or without subsidy programs. May be referred to as: “property” or “site” or “apartment complex.”
- **Development Subsidies:** Development subsidies are funds used to reduce the cost of developing affordable housing.
- **Fair Market Rent (FMR):** Under the Housing Choice Voucher (a/k/a Section 8) Program participants can only rent units that do not exceed the Fair Market Rents (FMRs) in their community. FMRs are gross rent estimates that

include the cost of the actual rent plus the cost of utilities, except telephone. The Department of Housing and Urban Development (HUD) sets FMRs to assure that a sufficient supply of rental housing is available to program participants. To accomplish this objective, FMRs must be both high enough to permit a selection of units and neighborhoods and low enough to serve as many low-income families as possible.

The FMRs are recalculated annually. The FMRs for every county can be found at: www.huduser.org/datasets/fmr.html.

- **HOME Program:** The HOME Investment Partnership Act was authorized under the National Affordable Housing Act of 1990. It is a formula-based allocation program intended to support a wide variety of state and local affordable housing programs. The formula funding allows state and local governments flexibility to use the money in ways that best meet locally-defined needs. Funds can be used for acquisition, construction, reconstruction and moderate or substantial rehabilitation activities that promote affordable rental and ownership housing. HOME funds can also be used for tenant-based rental assistance programs.
- **Home Modifications:** Modifications to the structure of a housing unit for accessibility and ease of use, based on the disability-related needs of the individual. Examples: grab bars; no-step entrances; flashing doorbells; widened doorways.
- **Housing Choice Voucher Program (Formerly called Section 8):** These rental subsidies are available through local Public Housing Authorities (PHA's). Some PHA's have a "preference" for people with disabilities which enables people with disabilities, including those with mental illness to receive priority for obtaining Housing Choice Vouchers.
- **Housing Trust Fund:** A Housing Trust Fund is a dedicated capital pool established by legislation, ordinance, or resolution to receive specific on-going revenues from sources such as taxes, fees, or loan repayments. Proceeds can be used for a range of affordable housing including housing for people with serious mental illness and co-occurring disorders.
- **Housing unit:** A housing unit can be a house, apartment, condominium, or other living space intended for occupancy by a single individual or family.
- **HUD Section 811, Supportive Housing for People with Disabilities:** Under the Section 811 Program, HUD provides funding to nonprofit organizations to develop rental housing for very low-income adults with disabilities to provide on-going rent subsidies for the projects to help make them affordable. Projects may be targeted to a single disability and supportive services are available.

- **Low Income Household:** A Low Income Household is a household whose income does not exceed 80 percent of the median income for the area, as determined by HUD, with adjustments for smaller or larger families.
- **Low income Housing Tax Credits (LIHTC):** The Low Income Housing Tax Credit Program became law through of the Tax Reform Act of 1986. LIHTC does not provide loans or grants but rather a tax incentive to owners of affordable rental housing. The incentive is an annual tax credit (a dollar for dollar reduction in the tax payer's federal taxes) earned in the initial ten years following when the units are placed in service assuming program requirements are met. A developer markets or "syndicates" the credits allocated to the development to investors whose contributions are used as equity in the development's financing plan.
- **Moderate Income Household:** A Moderate Income Household is a Household whose income is between 81 percent and 95 percent of the median income for the area, as determined by HUD, with adjustments for smaller or larger families.
- **Public Housing Agency (PHA):** A PHA is any local, regional, or state agency that receives federal funds to operate such housing programs as Public Housing or the Housing Choice Voucher program, as described in their PHA Plan. They may also be referred to as "Public Housing Authority."
- **Project Based Rental Assistance (PBRA):** PBRA is a rental subsidy that is associated with specific housing units to make them affordable to low income households.
- **Rental Subsidies:** Rental subsidies are funds that supplement rental income, either through tenant-based rental assistance or project-based rental assistance.
- **Subsidized Housing:** This is housing in which tenants pay less than the going market rate for rent, typically 30% of their income. Subsidized housing receives financial assistance from one or more public agencies to build or operate the development, or to help pay for some of the rent and utility costs. Rents are typically set according to Fair Market Rents (FMRs). Household income guidelines, based on Area Median Income (AMI) determine eligibility to live in subsidized housing.
- **Tenant-Based Rental Assistance (TBRA):** TBRA is used to assist low- and very low income families to obtain decent, safe, and sanitary housing in private rental accommodations by making up the difference between what they can afford and the approved rent for an adequate housing unit.

- **Very low Income Households:** Very low income households are those whose incomes do not exceed 50 percent of the median area income, as determined by HUD, with adjustments for family size.