

HOUSING OPTIONS FOR ADULTS WITH AUTISM SPECTRUM DISORDER



pennsylvania

DEPARTMENT OF PUBLIC WELFARE

Bureau of Autism Services

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

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prepared by:

**Diana T. Myers and Associates, Inc.
6 South Easton Road
Glenside, PA 19038
215-576-7970**

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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.