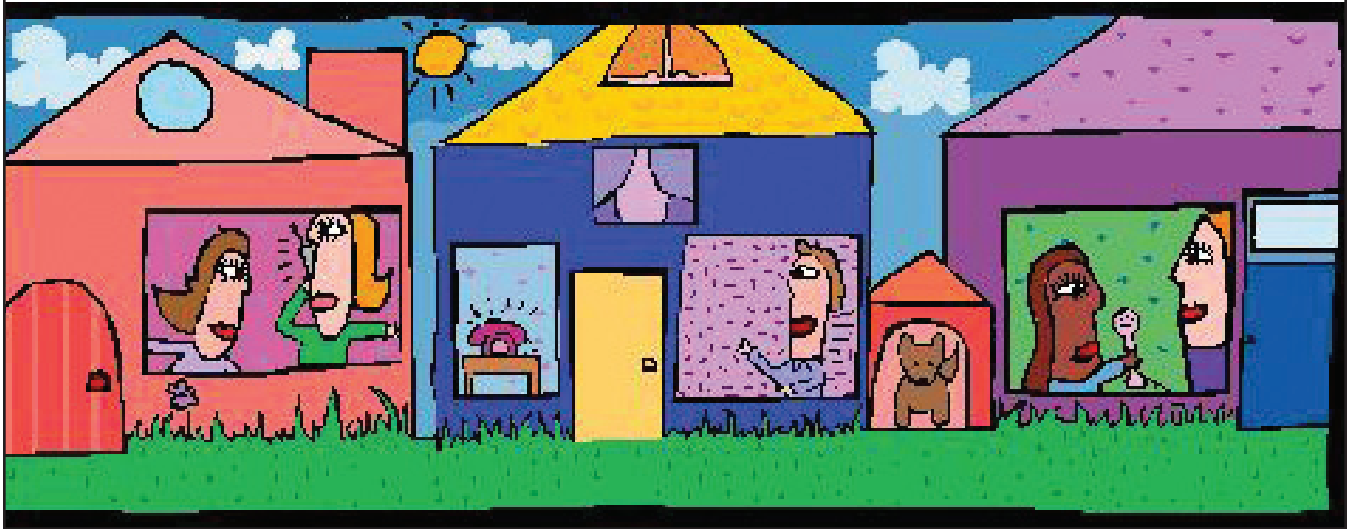


If You Build It, They Will Come

Present and Future Housing Options for Arizonans with Intellectual and Developmental Disabilities (ID/DD)



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ONE Community Working Together

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ARIZONA STATE UNIVERSITY

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EXECUTIVE SUMMARY

The Americans with Disabilities Act of 1990 and the Olmstead Decision of 1999 promised equity of opportunity, the right to live in the community, freedom from discrimination, and the right to be included in all areas of community life for people with disabilities. Years later, these promises have been a challenge to keep as people with disabilities continue to face barriers in accessing employment, transportation and housing — all functions needed to maximize choice, opportunity, and inclusion. Available housing with no access to transportation might as well not be available at all. Those with limited incomes from a lack of employment are often restricted to only a few housing options — living in a group home or living at home with loved ones who often worry about their futures.

This report examines the current state of housing in Arizona for people with disabilities. While it is one of the best states in the country in promoting community living options, there is more work to be done. Further examination reveals that most being served by the Arizona's Division of Developmental Disabilities (DDD) are living with their families, with the second largest group living in group homes, in the absence of other options. Those with limited incomes who opt to live on their own find that they are plagued with tremendous barriers that range from discrimination, to long waiting lists for HUD programs, to a shortage of accessible, affordable housing.

The federal government has recognized that these barriers exist and have initiated strategic partnerships and funding mechanisms to promote increased HUD-administered integrated housing options — strategies, which this report will demonstrate, are underutilized in Arizona. Conversely, some states have leveraged these opportunities to create a diversity of both specialized and integrated housing options, including shared living, home ownership programs, SMART homes, and a variety of supported living arrangements. Disability advocacy groups in these states have recognized the importance of the disability voice in the housing planning process and have collaborated with HUD officials to create more housing choices and opportunities for inclusion.

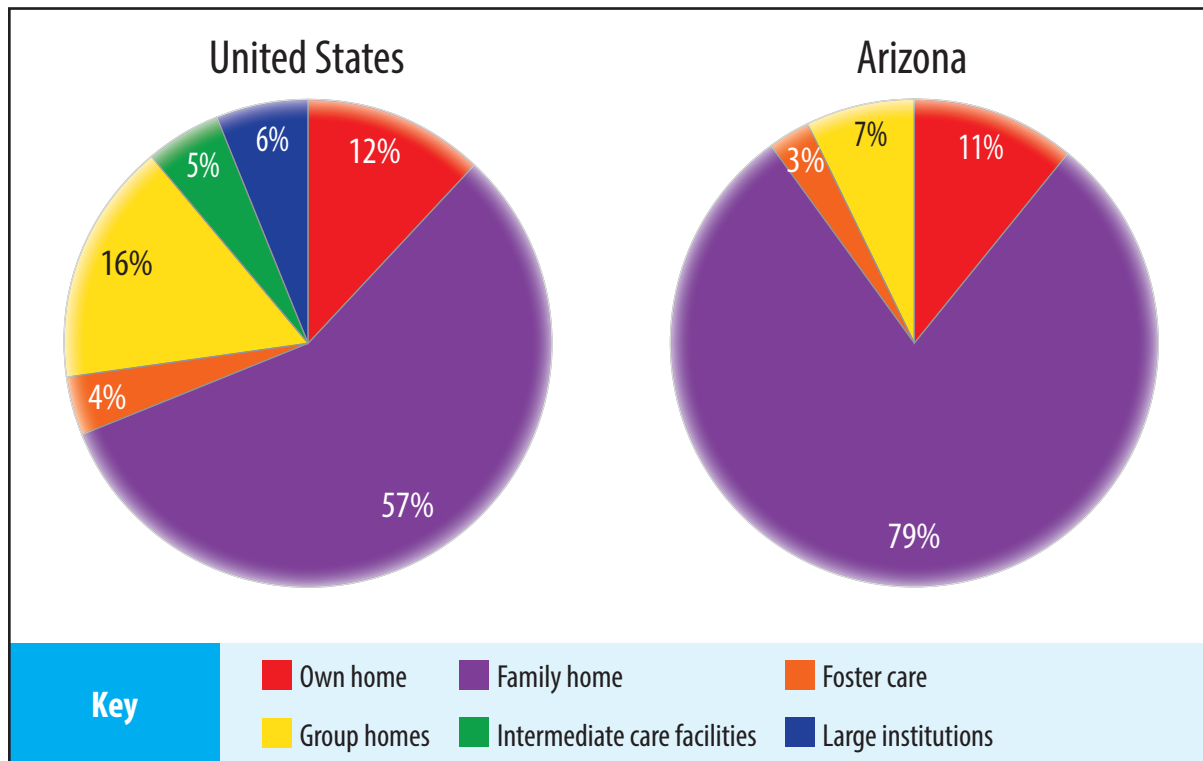
One step to making inclusion of people with disabilities a reality in Arizona is addressing the scarcity of affordable, accessible housing. Strategic collaborations with DDD, housing developers, non-profit organizations, HUD officials, city administrators, disability advocacy groups, and people with disabilities and their families will spark the change needed to innovate and promote housing options in this state. This report will assist these groups by identifying strategies, funding streams, and housing models that will help to reverse the tide of exclusion in housing that currently exists in Arizona.



INTRODUCTION

Like the rest of society, people with ID/DD have different desires of what they prefer in housing. Some desire to live in their own apartments or houses. Some would enjoy living with others with disabilities in small congregate settings. Some aspire to own their own homes, while others prefer to live with their families. As the following figures reveal, however, while Arizona shows a greater percentage of those with ID/DD living in the community than the national average, most are living with their families, but only 11 percent are renting or owning their own apartments or homes.

Figure 1. Percentage of People with ID/DD by Type of Residential Support Setting as of June 30, 2010¹



Source: S. Larson, A. Ryan, P. Salmi, D. Smith, & A. Wuorio, Residential Services for Persons with Developmental Disabilities, Status and Trends Through 2010, 2012.

While living at home with family may be the ideal option for some, for others it may be the only option if they do not want to live in a group home or other congregate setting. Additionally, a lingering worry among parents of children and adults with ID/DD is “what happens to my 50- year old son when I pass away? This home is all he has ever known.” There is a lack of affordable, accessible housing options for people with ID/DD in Arizona. And for many families, accessing the initiatives and options that are available remain complex, confusing and limited by funding restrictions.

¹ In this chart, intermediate care facilities (ICFs) house 7-15 residents, large institutions are ICFs that house 16+ residents, and group homes house 1-6 residents. Nursing facility residents are included under large institutions.

The Olmstead Decision of 1999 was a landmark U.S. Supreme Court decision that affirming people with disabilities have the right to live in the community with a variety of community-based options and not be institutionalized. This decision is often referred to as the ‘integration mandate,’ because it requires public agencies to provide services “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” Thirteen years since this ruling, people with disabilities are living in the community outside of institutions in large numbers and with their families — with almost one in three households having at least one person with a disability.² Yet, funding has not kept up with the need and desire of this population for independent living arrangements in Arizona. However, recent federal initiatives and innovative state models have been introduced to meet the diverse needs of this population.

This report will cover several areas in housing that need to be addressed to progress housing options in Arizona for people with ID/DD so that Olmstead goals are finally realized.

- Federal initiatives that are advancing community living options across the country will be described.
- It will discuss the most commonly used supported housing options for those with ID/DD in Arizona, and the strengths and weaknesses of these options.
- Next, barriers faced by those with ID/DD in obtaining scattered, integrated housing will be discussed, and recommendations on what individuals with ID/DD and families can do to address these barriers and promote housing through various funding options will be presented.
- Finally, the debate between specialized, congregate housing and scattered, integrated housing and national best practices of both models will be highlighted.

SECTION 504 AND THE OLMSTEAD DECISION — CATALYSTS FOR CHANGE

In addition to Olmstead, Section 504 of the Rehabilitation Act of 1973 has promulgated increased inclusion in housing practices.³ This legislation provides that no qualified individual with a disability should, only by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.⁴ Thus, a HUD funded public housing authority, or a HUD funded non-profit developer of low income housing is a recipient of federal financial assistance and is subject to Section 504’s requirements and may not deny or refuse to sell or rent to a person with a disability, and may not impose application or qualification criteria, rental fees or sales prices, and rental or sales terms or conditions that are different than those required of or provided to persons who do not have a disability.

Housing providers may not refuse to make repairs, or limit or deny someone with a disability access to recreational and other public and common use facilities, parking privileges, cleaning or janitorial

² United States Census Bureau, Americans with Disabilities: 2005, Household Economic Studies, December 2008.

³ http://portal.hud.gov/hudportal/HUD?src=/program_offices/fair_housing_equal_opp/disabilities/sect504faq

⁴ A qualified individual with a disability is any person who has a physical or mental impairment that substantially limits one or more major life activities.

services, or any services which are made available to other residents. They must also make reasonable accommodations to overcome barriers to participation to people with disabilities if doing so does not cause an undue financial and administrative burden on the provider or does not change the nature of the provider's operations.

Similar to the Olmstead decision, one of the basic tenets of Section 504 is that programs and services be conducted in the most integrated setting appropriate. In terms of housing, this means that the housing provided to people with disabilities is not separate or unnecessarily segregated. In other words, accessible units in a single elevator building should be located throughout the building and not just on the first floor. In projects having multiple buildings, accessible units should be interspersed throughout these buildings, rather than in just one or two buildings. Section 504 also mandates accessibility. For a federally assisted new construction housing project or one that has completed

alterations, Section 504 requires five percent of the dwelling units, or at least one unit, whichever is greater, to be accessible to persons with mobility disabilities. An additional two percent of the dwelling units, or at least one unit, whichever is greater, must be accessible for persons with hearing or visual disabilities.

Local efforts have been made as well in the spirit of Section 504. Numerous cities across the country have passed accessibility design standards on new constructions, and a number of states and towns have initiatives to encourage voluntary visitability construction, in which one zero-step entrance, an accessible bathroom, and 32-inch wide doorways are encouraged.⁵

Voluntary initiatives target both publicly and privately funded homes and include reimbursements, tax incentives, visitability certification procedures, and public awareness campaigns. However, Vermont is the only state with a mandatory visitability requirement.

While Section 504 guidelines ensure that the federally administered HUD program is implemented equitably among people with disabilities, the Olmstead decision was the spark needed to incentivize community living arrangements for people with disabilities, rather than institutions. Under the Supreme Court's ruling:⁶

- unjustified institutionalization of people with disabilities is considered discrimination and violates the Americans with Disabilities Act (ADA);
- states are required to provide community-based services for persons with disabilities otherwise entitled to institutional services when the state's treatment professionals reasonably determine that community placement is appropriate; the person does not oppose such placement; and the placement can reasonably be accommodated, taking into account resources available to the state and the needs of others receiving state-supported disability services;

5 J. Hayes, OLR Research Report, Federal, State, and Town Visitability Laws and Initiatives, 2010.

6 <http://www.acf.hhs.gov/programs/add/otherpublications/olmstead.html>

VISITABILITY IN PIMA

In February 2002, Pima County enacted the first mandatory visitability ordinance in the U.S. for all publicly and privately funded homes. It applies to all new homes and requires a no-step entry, doorways at least 30 inches wide, lever door handles, reinforced walls in ground-floor bathrooms for future installation of grab bars, and reachable electric controls for people in wheelchairs. Tucson adopted a similar ordinance in 2007.

- a person cannot be denied community services just to keep an institution at its full capacity; and,
- there is no requirement under the ADA that community-based services be imposed on people with disabilities who do not desire it.

The Court also said that states are obliged to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity.” The fundamental alteration test takes into account three factors: the cost of providing services in the most integrated setting; the resources available to the state; and how the provision of services affects the ability of the state to meet the needs of others with disabilities.

In effect, this decision has changed the way states have administered their long term care programs for the last ten years. Partnerships have been leveraged between the Centers for Medicare & Medicaid Services (CMS), Health and Human Services (HHS), and the U.S. Department of Housing & Urban Development (HUD); and funding streams for long-term care systems have been rebalanced so that housing and community supports are prioritized. The timeline in Appendix A highlights the activities by the various federal agencies to prioritize implementation and enforcement of the Olmstead decision. Clearly, there has been significant progress made among those who have been institutionalized, but there is still much work to be done for the larger population with disabilities who are still in need of housing supports.

THE STATUS OF SUPPORTED HOUSING IN ARIZONA

Those individuals in need of housing services or in-home supports apply through Arizona’s Division of Developmental Disabilities (DDD) and Arizona’s Long Term Care System (ALTCS). The goal of DDD and ALTCS is to honor individual choice and place individuals in the driver’s seat of their lives by offering living options and supports that advance their right to live in the community and not in an institution. Because of its innovative coordination of services through ALTCS and DDD and its flexible funding options for individuals with ID/DD, Arizona is a national leader in promoting community living. United Cerebral Palsy (UCP) confirmed this with its newly released report, “*The Case for Inclusion*,” in which Arizona was found to offer the best Medicaid services in the country for persons with ID/DD.⁷ Some criteria used to evaluate each state included lack of waiting lists for home and community-based services (HCBS), the availability of programs that support families who care for loved ones with DD, and residential services provided in small group settings.

DEFINING RESIDENTIAL SERVICES

Residential services directly provided or licensed by states for people with ID/DD include: nursing and residential care facilities; developmental (foster) homes; homes owned or rented by a person with ID/DD or his or her family, or a group of people with ID/DD living together through shared living arrangements. (In Arizona, this last option is not yet available.)

⁷ http://www.ucp.org/the-case-for-inclusion/2011/images/The%20Case%20for%20Inclusion%202012_Full%20Narrative_final%20.pdf

Arizona is one of three states to operate its entire Medicaid program through a federal 1115 waiver. This waiver funds the Medicaid managed care program, called Arizona’s Health Care Cost Containment System (AHCCCS), and the long term care system, ALTCS. It is unique to Arizona in that it allows the state to be exempt from federally approved budget amounts. The federal government has to match what Arizona spends at a 1 to 3 ratio with no cap in place. For this reason, Arizona has very short, if any, wait lists for services for ID/DD. Waiver-funded HCBS services may also be provided to eligible individuals as long as these costs are medically necessary and do not cost more than living in an institutional setting. ALTCS HCBS services allow people to live in the community, and include services such as personal assistants, respite care, transportation, and day treatment. As a result, Arizona is doing well assisting people with ID/DD to remain living in the community with their families.

However, there is room for advancement — since current funding streams only support a limited range of residential options for people with ID/DD through ALTCS.⁸ These residential options are listed below in the order of most to least restrictive setting:⁹

Institutional Settings

Institutional settings are licensed by the Department of Health Services, and ALTCS/DDD covers room and board.¹⁰

- **Nursing facilities:** Medicare/Medicaid certified skilled nursing or rehabilitation facilities that provide in-patient room and board and nursing care on a 24-hour basis to those who need it on a continuous basis but do not require hospital care. The majority of residents in these facilities are older adults; however some use these facilities as transitional housing or to recover from an illness/surgery. In 2010, 49 Arizonans with ID/DD were residing in nursing homes.¹¹ Complying with Olmstead and the Americans with Disabilities Act, people with ID/DD are only allowed to be admitted to these facilities if they require nursing care that they cannot find in a less restrictive setting.
- **Intermediate care facilities (ICFs):** Settings with more than six people that provide health and rehabilitative services through an active treatment program to individuals who require these services on a continual basis. The active treatment program includes “aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services that is directed toward the acquisition of the behaviors necessary for the consumer to function with as much self-determination as possible.” In 2010, there were approximately 185 Arizonans living in six ICFS across the state.¹²

Limitations: While these settings provide 24-hour care to those who need it, opponents claim that they are too costly and suffer from high staff turnover. The daily average costs of these settings per resident range from \$350 – \$400.¹³ These settings also limit the independence of residents, as

8 For those not eligible for ALTCS HCBS, DDD offers state funded case management services to help individuals with DDD locate housing.

9 Personal communication, Leah Gibbs, Contracts Management Supervisor, June 6, 2012.

10 The individual may be billed a share of the cost if there is additional income to SSI.

11 S. Larson, A. Ryan, P. Salmi, D. Smith, & A. Wuorio, Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010, 2012

12 Ibid.

13 Ibid.

what's best for the group supersedes individual options that are optimal in person-centered planning approaches desired by DDD. The trend has moved away from the utilization of these facilities. In December 2010, there were two ICFs located in Arizona, Hacienda de Los Angeles and the Arizona Training Program at Coolidge; Coolidge is the larger facility, housing 107 people in 2012. All other large state-operated institutions have been closed.

Community-Based Residential Settings

These settings are licensed to provide life skills training and room and board, and are paid for by DDD through federal Medicaid waivers. They are typically smaller, more “home-like” settings offering resident supervision and the opportunity to live in a neighborhood setting.

- **Group Homes:** This is the most popular residential option in Arizona, housing primarily adults at least 22 years old. Group homes house as many as six people with developmental disabilities; however the majority in Arizona house up to only three people. Average costs are \$400 per day per resident.¹⁴
- **Child/Adult Developmental Homes:** Up to three individuals with ID/DD live with a family other than their own. These “foster” homes provide care for children from birth to age 18 and for adults 18 years or older, are the second most requested living option after individually designed living arrangements.

Limitations: A 2010 report released from the Sustainability and Innovation Work Group facilitated by the National Association of State Directors of Developmental Disabilities found that group homes had a vacancy rate of approximately 11 percent, driving up per person costs to staff the home. It was discovered that, while the number of residents may be reduced, the staffing patterns don't change, leading to higher per resident costs. For example, staffing remains constant in a home designed for three people even after one resident moves out. Further, these vacancies remain unfilled as many residents have a difficult time locating housemates with whom they are compatible. In fact, the report contends that “the problem was not so much a vacancy problem as a program model problem. Individuals with disabilities, when given the choice, often reject the idea of living with two or more other individuals who also have disabilities.”¹⁵

As a result, only one out of five people participate in residential options in Arizona, while the rest tend to access in-home services. Subsequently, as Figure 2 reveals, residential services for ID/DD in Arizona are one of the lowest utilized in the country with only 68 per 100,000 individuals accessing services. The national utilization rate was more than twice that with 148 per 100,000 individuals accessing residential services.¹⁶

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14 S. Larson, et al., 2012

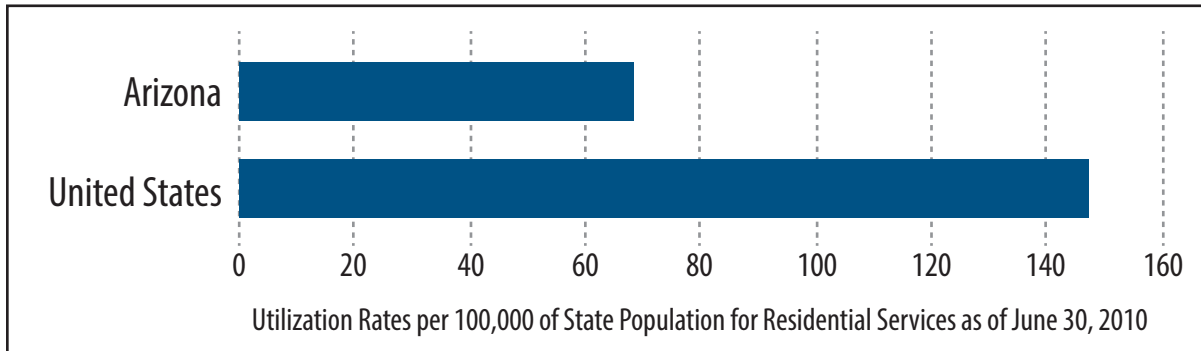
15 Report of the Sustainability and Innovation Work Group, NASDDD, October 2010, <http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/Report%20of%20the%20Sustainability%20&%20Innovation%20Work%20Group%20for%20AZ%20DDD%202010.pdf>

16 S. Larson, et al., 2012.

THE ARIZONA TRAINING PROGRAM AT COOLIDGE

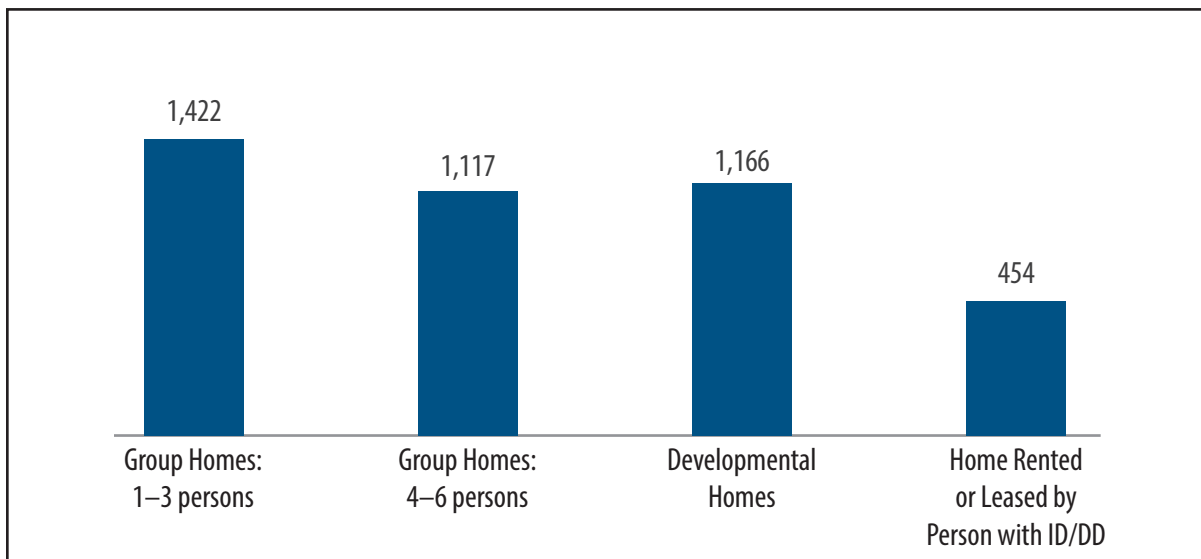
The only large state institution in Arizona is located outside Phoenix on 320 acres of land that is designated by state law for people with DD. As a result of a state mandate in 1979 declaring that no new residents could be admitted to Coolidge. The 1,200 residents in the 1950's has decreased to 115 by 2010. The average per diem costs are high, at \$382 per day. It functions primarily as a nursing home as those living there are predominantly over the age of 50 and have significant disabilities.

Figure 2.



Of those who participate in residential options in Arizona, (Figure 3), the choices made across these options are fairly consistent, with “homes rented or leased by person with ID/DD” the least utilized option. It can be assumed that this is due to significant barriers in accessing independent housing.

Figure 3. Number of Arizonans Living in Residential Settings by Type, 2010



Source: S. Larson, A. Ryan, P. Salmi, D. Smith, & A. Wuorio, Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010, 2012.

In spite of the low utilization of residential services, the Sustainability and Innovation Work Group found disproportionate spending in this more costly category:

“The fact that 43.7% of the program budget, when combining both ALTCS and state-only programs, is directed to services for 11.9% of the service population compels a review of residential services to determine if more cost-effective models of service delivery can be implemented for long-term sustainability.”¹⁷

.....
17 Ibid.

The recommendation was for an expansion of choices under individually designed living arrangements, specifically in shared living arrangements, discussed later in this report.

Individually Designed Living Arrangements

This option is less costly and not considered a residential service, but offers supports for individuals who choose to live by themselves or with their families in homes and apartments in the community. DDD offers different supports depending on individual need, but rent/mortgage is the responsibility of the individual. This is the most frequently utilized service offered through DDD. Some of the services offered include:

- **Attendant Care Services:** A qualified attendant assists the individual as needed with activities of daily living (i.e. bathing, dressing, eating, toileting, walking) and to maintain safe and sanitary living conditions, so that the individual may continue to live in his/her home and participate in community activities. Some attendant activities include housekeeping, cooking, laundry, shopping, help with personal care, and/or assistance with transportation. Unlike many states, Arizona incentivizes families to stay together by allowing attendant services to be provided by immediate family members for adults with DD for up to 40 hours per week; however, spouses/guardians are excluded as attendants, unless hired indirectly through home care agencies.
- **Respite care:** Provides short-term care to relieve unpaid caregivers. This service can be used in any setting, including institutions. Arizona is one of only a handful of states that has a formalized respite care program. The Lifespan Respite Care program can be provided in-home or through adult daycare services.
- **Home modifications:** Adapts the home/apartment so that it is accessible to the individual. These modifications must be medically necessary, cost-effective, and reduce the risk of institutionalization or the need for an increase in home and community-based services. These services may also be funded through programs from the U.S. Department of Housing & Urban Development (HUD).

Limitations: Because there are so many people receiving personal assistance services, a problem for DDD is turnover and the unreliability of some attendants. In *Ball v. Betlach* in 2010, the U.S. District Court ruled that Arizona failed to follow the Court’s previous orders in its Medicaid system by failing to address critical gaps, or “no shows,” in services, and not having a statewide hotline, or reporting critical gaps so that back-up workers could be substituted when these gaps occurred. It was stated that hundreds of gaps occurred every month. Sometimes, this would result in a person left in bed without food or water.¹⁸ Arizona has started a new monthly reporting system in response to the Court order.¹⁹ Services that are required to be reported are personal assistant, housekeeping and respite. Additional mechanisms have also been established to address the gaps in services, such as providing replacements within two hours and contingency planning.

Today, these gaps continue to occur. According to a DDD representative, in May 2012, there were 351 occasions when services were not provided as planned. This resulted in 42 gaps in services, meaning the individual did not receive any assistance at all due to “no-shows.” A statement by DDD reported that “on average, the monthly percentage of gaps in services is 0.04%.”

18 <http://www.azdisabilitylaw.org/pdfs/BallPressReleaseApr2010.pdf>

19 <https://www.azdes.gov/main.aspx?menu=96&id=5458>

Regardless of these issues, many Arizonans with ID/DD are choosing to stay at home with their families and receive services, which have proven to be less expensive than other residential options. Arizona serves the highest number of people with ID/DD through HCBS in the country, with approximately 22,000 served at a cost of \$606 million in 2010.²⁰ Yet, nationally, in that same year, Arizona also served the highest proportion of individuals with ID/DD living with their families compared with other residential options, posting one of the lowest annual HCBS expenditures per daily recipient of \$27,196.²¹ And if an individual with ID/DD does not have financial resources, living with his/her family becomes the only option as the next section will discuss.

HOUSING CHALLENGES NOT NEW FOR PEOPLE WITH DISABILITIES

Between 1994 and 2010, the proportion of people with disabilities receiving supportive services who lived in a home that they themselves rented or owned increased from 11 percent to 15 percent.²² Increasingly, people with ID/DD want to live on their own; however, nationally, there remains a lack of accessible, affordable, independent housing for people with ID/DD and other disabilities. Frequently cited problems, when searching for rental housing or buying homes, include discrimination, lack of funding supports, lack of housing options that address the house seeker's needs, and lengthy waiting lists for existing services.

Discriminatory Practices

Discrimination towards people with disabilities in housing has been illegal since 1988 when disability was added as a protected group to the Fair Housing Act. In spite of this protection, discrimination against people with disabilities persists. In 2012, disability discrimination tops the types of housing complaints filed among community-based organizations.²³ Further, the National Fair Housing Alliance reported that disability complaints were the most reported among all minority groups in 2011.²⁴ Complaints were often related to a landlord refusing to make an accommodation or developers designing and constructing inaccessible buildings that do not meet standards under the Fair Housing Act.

Similarly, a study conducted by the Urban Institute in Chicago found that almost one of every six housing providers who indicated that units were available to applicants refused to allow reasonable modifications in units needed by wheelchair users. Similarly, one of every five housing facilities with on-site parking refused to make the reasonable accommodation of providing a designated accessible parking space for wheelchair use. A third of advertised rental properties were not even accessible enough to visit.²⁵

20 S. Larson, et al., 2012.

21 Ibid.

22 Ibid.

23 Consumer Action, Consumer Action Housing Discrimination Survey, 2012, http://www.consumer-action.org/downloads/english/housing_discrim_survey_PR.pdf

24 National Fair Housing Alliance, Fair Housing in a Changing Nation: 2012 Fair Housing Trends Report, <http://www.nationalfairhousing.org/Portals/33/Fair%20Housing%20Trends%20Report%202012%20with%20date.pdf>

25 Discrimination Against People with Disabilities: Barriers at Every Step, conducted in 2005 by the Urban Institute, http://www.huduser.org/Publications/pdf/DDS_Barriers.pdf

There has been discrimination towards people with disabilities in home-buying as well. The Fair Housing Act makes it illegal to impose additional application or qualification criteria based on disability. Yet, in February 2012, HUD charged a large banking institution with posing unnecessary and burdensome requirements on borrowers who relied on disability income, such as requiring a physician statement.

Discrimination also occurs when community members see group homes as undesirable. The most common complaints include concerns over resident and staff turnover, increased traffic in the neighborhood, and fear of lower property values.

The City of Phoenix Equal Opportunity Complaint and Enforcement Division has reported similar trends. The division receives the highest proportion of complaints from those with disabilities, with the most cited issue being failure to make accommodations. In Tucson, the city's Housing and Community Development Department recently reached an agreement with HUD after an apartment complex failed to meet a one-bedroom unit reasonable accommodation request in a timely manner to a person with a disability. The conciliation agreement included an agreement to make reasonable accommodations by processing requests for transfers made by other tenants with disabilities as soon as appropriately-sized units become available.²⁶

Discrimination also occurs when community members see group homes as undesirable. The most common complaints include concerns over residents and staff turnover, increased traffic in the neighborhood, and fear of lower property values. DDD also stated that the most frequent complaints are from neighbors of group homes. However, a study conducted by the Furman Center on the effects of supportive housing on surrounding property values showed positive effects to surrounding home values.²⁷

Lack of Funding Supports

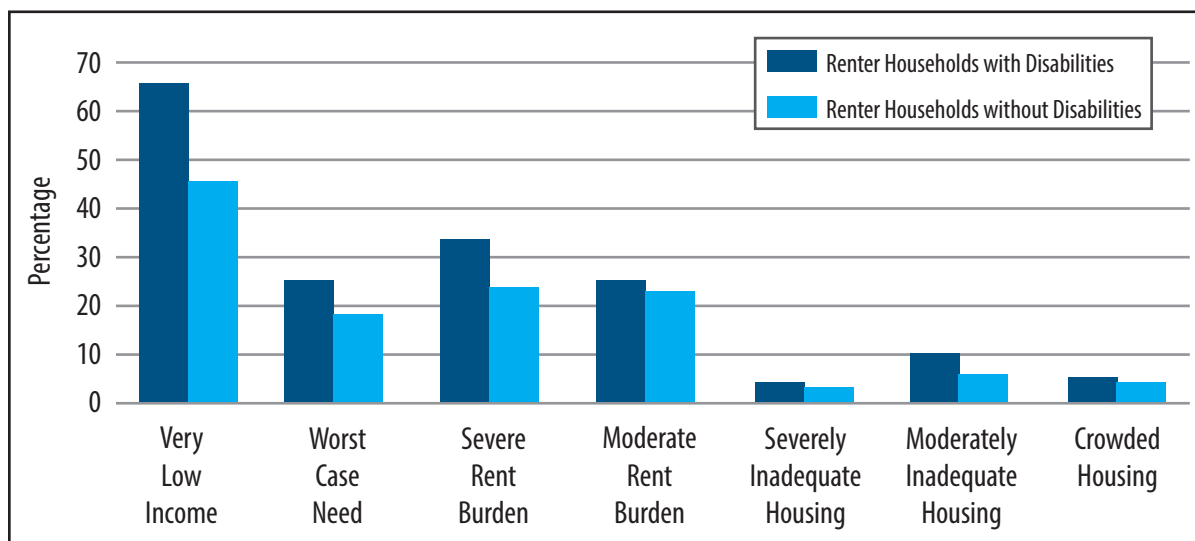
Poverty presents a formidable barrier to housing. HUD's report, "*2009 Worst Case Housing Needs of People with Disabilities*," found that households that include people with disabilities continue to face more economic barriers than the general population.²⁸ Figure 4 demonstrates the impact of these economic barriers. In 2009, 66 percent of renter households with disabilities had very low incomes, while only 46 percent of renter households without disabilities had very low incomes. Severe rent burden, in which over half of the renter's income is spent on rent, was found to affect about one in three households with disability, almost 50 percent more than renter households without disabilities.

26 <http://portal.hud.gov/hudportal/HUD?src=/states/arizona/news/HUDNo.2012-06-25>

27 http://www.furmancenter.org/files/FurmanCenterPolicyBriefonSupportiveHousing_LowRes.pdf

28 U.S. Department of Housing & Urban Development, 2009 Worst Case Housing Needs of People with Disabilities, Supplemental Findings of the Worst Case Housing Needs 2009: Report to Congress, http://www.huduser.org/Publications/pdf/WorstCaseDisabilities03_2011.pdf

Figure 4. Share of Renter Households with Selected Indicators of Income and Housing Options, 2009



Source: S. Larson, A. Ryan, P. Salmi, D. Smith, & A. Wuorio, Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010, 2012.

The report also shared some noteworthy statistics from the 2009 American Housing Survey:

- One in three very low income renter households were non-elderly with a disability.
- Two out of three renter households with a person with a disability were very low income.
- Very low income renter households with a person with a disability were more likely to spend over half of their incomes on rent.
- Very low income renter households with a person with a disability were two times more likely to receive housing assistance.

The same pattern of poverty prevails in Arizona.²⁹

- In 2008-2010, 96,000, or 26 percent, of people with disabilities between the ages of 18 and 64 received an income below poverty level in the last year.
- Approximately 40 percent of people with disabilities 16 and over earn less than \$15,000/year, within 150 percent over the federal poverty guideline.
- 41 percent of disabled households across the U.S. have difficulty paying their housing costs.³⁰ In the Phoenix metropolitan area, the average fair market rent for a 1 bedroom apartment for 1 year is \$8,652.³¹

According to these statistics, if the 370,000 individuals with disabilities between the ages of 18 and 64 want to live independently in Arizona, they would require housing assistance.³²

While non-institutionalized individuals with disabilities comprise 11.5 percent of Arizona’s population, they are overrepresented in HUD numbers.³³ The HUD Resident Characteristics Report indicates that from May 1, 2011 through August 31, 2012, 33 percent (1,963 residents) of the

29 American Community Survey, 2008-2010.

30 National Council on Disability, 2010, State of Housing in America in the 21st Century: A Disability Perspective.

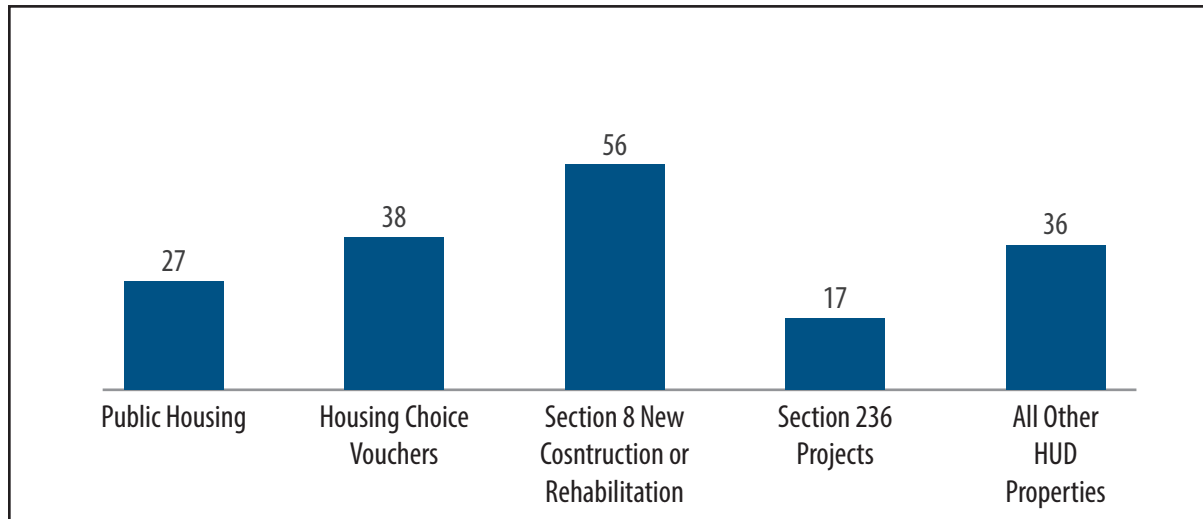
31 http://www.huduser.org/portal/datasets/fmr/fmrs/FY2012_code/2012summary.odn

32 American Community Survey 3 year estimates, 2008-2010, Disability Characteristics, Arizona.

33 Ibid.

public housing population in Arizona had a disability. Of 6,020 units, 21 percent were non-elderly with a disability.³⁴ Similarly, Figure 5 reports the results of a 2010 survey of HUD-insured and HUD-subsidized multifamily properties, showing prevalence in almost every housing assistance category among individuals with disabilities under 62 years of age.

Figure 5. Percentage of Arizona HUD Program Utilization by Non-Elderly Person with a Disability, 2009



Source: HUD MFH Inventory Survey of Units for the Elderly and Disabled, 2010.

HUD administers funding for public housing, privately owned subsidized multi-family housing, and tenant-based rental assistance programs. It also approves state and local coordinated plans that prioritize the allocation of federal funds towards housing and community development activities. Eligibility for HUD housing and programs is determined by income limits that are based on the family *Area Median Income (AMI)*.³⁵ These income limits determine if the person is extremely low income, very low income, or low income. In Arizona, for a one person household annual income, \$12,950 is considered extremely low income (30 percent of AMI) — a category in which many people with ID/DD fall into, \$21,550 is very low income (50 percent of AMI), and \$34,500 is low income (80 percent of AMI). However, the assistance provided to those eligible is very limited. These income limitations steer people with disabilities into public housing, which is in dire need of repair across the nation.

THE DISREPAIR OF PUBLIC HOUSING

A 2010 HUD study, *“Capital Needs in the Public Housing Program,”* reported that the nation’s 1.2 million public housing units are in need of \$26 billion (or \$23,365 per unit) for major, large-scale repairs — and with each additional year, that number grows by \$3.4 billion. These include accessibility modifications needed for residents with disabilities and roofing and plumbing repairs. Additionally, thousands of public housing units are lost each year and are not replaced.

Limited Housing Availability

The greatest challenges to HUD programs are too little subsidized housing, lengthy waiting lists, and

34 http://portal.hud.gov/hudportal/HUD?src=/program_offices/public_indian_housing/systems/pic/50058/rcr

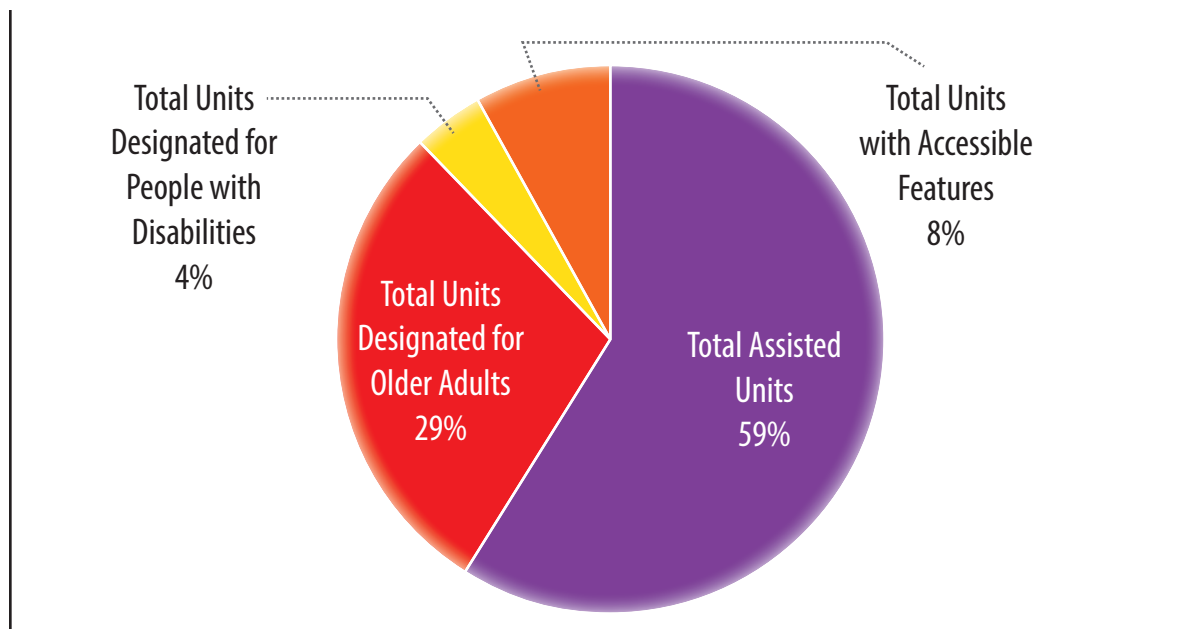
35 http://www.huduser.org/portal/datasets/il/il2012/select_Geography.odn

inadequate funding to bridge the gap between those with extremely low incomes and rental costs.³⁶ A majority of accessible housing is also age-restricted and not available to those under the age of 62. While HUD requires that those receiving HUD moneys make five percent of public housing units accessible to those with mobility impairments and two percent accessible to those with visual/hearing impairments, this doesn't necessarily mean that people with disabilities have access to them.

The affordable rental market is very tight. In 2009, Arizona public housing was 93 percent occupied, with 7 percent of units vacant, which may or may not be available or accessible to people with disabilities due to a number of reasons.^{37, 38} For example, as indicated in figure 6, in 2010, 8 percent of HUD-funded multi-family units had accessible features, but many of these units were restricted to seniors ages 62 and over, or were simply not affordable.

Out of 16,145 HUD units available across the state, only 489, or three percent of the available units designated for non-elderly people with disabilities, were subsidized by a federal, state or local government program and built with accessible features.³⁹

Figure 6. Arizona Multi-Family Housing Inventory, 2010



Source: HUD Multi-Family Housing Inventory of Elderly and Disability Designated Units, 2010

Darrel Christenson, Vice-President/Director of Community Integration, Arizona Bridge to Independent Living (ABIL), stated “the shortage of affordable, accessible housing has not improved in the last 25 years that I have been in the industry. We field about 100 calls per month on housing barriers in the Phoenix area. In fact, it is one of the most frequent needs reported by callers.” He further stated: “If there was more housing available, we would be able to move so many more people out of nursing homes. As it is now, many have to remain there waiting for their name to come up on waiting lists.”

³⁶ Also called bridge subsidies.

³⁷ <http://www.huduser.org/portal/picture/picture2009.html>

³⁸ Contrary to the posted vacancies, public housing has wait lists, as many vacant units are under renovation or are not ready for move in.

³⁹ http://portal.hud.gov/hudportal/documents/huddoc?id=DOC_13016.pdf

Housing Voucher Wait Lists

Federal funding of Housing Choice vouchers are the most popular option of all HUD housing programs accessed by people with DD. These vouchers can be given to the tenant or they may be project-based and tied to specific housing units. The tenant-based vouchers are flexible and may be used to rent townhomes, apartments, and single-family homes in the private market. A housing subsidy is paid directly to the landlord by the public housing authority and the resident is responsible for the difference between the subsidy and the rent, which cannot be more than 30 percent of the tenant’s adjusted monthly income.

Unfortunately, supply cannot keep up with demand. In most areas in Arizona, applications for these vouchers are not being accepted. Those that do have an open wait list tend to be in rural areas with limited access to transportation, and the wait list can be more than five years long. Some areas can choose to prioritize individuals on the wait list by disability status, but many do not.⁴⁰ In Phoenix for example, in April of 2011, the Housing Choice wait list was closed with 6,200 families on the list still to be served. Further, the Public Housing wait lists totaled 15,900 people.⁴¹

Streams of state and federal funding that may be used for accessible housing in Arizona, are being diverted for other purposes. Below are Public Housing Agencies (PHA) that have been previously funded for one or more special purpose voucher allocations and the number of vouchers each PHA received. Between 1997–2011, only 575 vouchers reserved for non-elderly people with disabilities were received.^{42, 43}

Housing Department	NED	Mainstream	NED Cat-2
Mohave County		50	
City of Mesa	150	100	
City of Phoenix		75	
Arizona Behavioral Health		125	
Pima County		50	25

Table Source: Data derived from Technical Assistance Collaborative, Database of Vouchers for People with Disabilities

NED: Non-Elderly Persons with Disabilities Housing Choice Vouchers

Mainstream: Section 811 tenant-based vouchers for non-elderly people with disabilities

NED Category 2: Rental Assistance for Non-Elderly People with Disabilities that are transitioning from nursing homes and other health care institutions into the community. Housing Authorities must partner with a state-level Medicaid or health and human services agency responsible for the state’s institutional transfer program.

40 For public housing and section 8 wait lists and preferences, visit www.hud.gov/local/az/renting/phwaitinglist.pdf

41 City of Phoenix, Consolidated Annual Performance and Evaluation Report, July 1, 2010 – June 30, 2011, available http://www.phoenix.gov/webcms/groups/internet/@inter/@dept/@nsd/documents/web_content/nsd_rp_caper.pdf

42 These numbers do not include vouchers targeted to homeless.

43 Caution should be paid to the previous numbers, as not all of the housing departments report the vouchers in use. When housing departments do not accurately report these numbers, however, these vouchers do not have to be returned to the non-elderly disabled population as they turnover. They can be used for other populations.

Arizona Behavioral Health Corporation (ABC) is a HUD-designated Public Housing Authority for purposes of administering the Mainstream Housing Opportunities for Persons with Disabilities Program. The Mainstream program provides housing choice vouchers for people with disabilities to lease private dwelling units in the community with tenant-based rental assistance. HOM, Inc. contracts with ABC to administer and operate the program, which includes maintaining the waiting list, determining eligibility, assisting clients with the housing search and leasing accessible, affordable housing in the community. Like other Section 8 programs, participants of this program contribute at least 30 percent of their adjusted income towards the cost of their rent and utilities. Funding is available for 125 vouchers for people with disabilities through HOM; however, all are currently in use in the community. Michael Shore, CEO/President of HOM Inc., stated:

“In 2000 in partnership with the Arizona Department of Economic Security Division of Developmental Disabilities, HOM, Inc. secured funding from the Arizona Department of Housing to provide tenant based rental assistance for people with developmental disabilities using HOME program funding. The program assisted eight (8) individuals over a three-year period but did not receive renewal funding. The intention of the program was to provide housing assistance for a two-year period with plans to transition assisted clients into other permanent housing options, which included obtaining Section 8, securing roommates, or attaining financial self-sufficiency and no longer requiring ongoing rental subsidies. Many clients were able to move on, but some were unable to do so and ultimately returned to living with their family members or remained in housing with severe rent burdens. The need for permanent rental assistance for these clients was illustrated in this program.”⁴⁴

Home buyer programs that will pay the down payment and closing costs of a house at zero percent interest are also available; however, there is very little affordable housing left to buy, so very few benefit from them. According to Michael Orr, Director of ASU’s Center for Real Estate Theory and Practice, many affordable and foreclosed homes have been snatched up by investors across the state who usually pay cash, effectively locking out of the housing market those home seekers who need to be financed. Some of the homes that are the most affordable have upwards of 90 bids on them. “Those who can pay the total sum by cash have a far greater chance of having their offer accepted,” stated Orr. For many with ID/DD with limited incomes, this is not an option.

HOUSING SHORTAGE AMONG NATIVE AMERICANS: CASE STUDY OF THE HOPI AND NAVAJO

Housing administration is administered differently from tribe to tribe. To respect tribal sovereignty, the federal government contracts with tribes to administer and structure their own housing programs

⁴⁴ After this program was terminated, HOME funds were diverted for other affordable housing projects.

so they are better able to respond to unique tribal needs. The Native American Housing Assistance and Self Determination Act of 1996 (NAHASDA) administers its housing programs through federal block grants. To receive this funding, an eligible tribe must submit an Indian Housing Plan (IHP) to HUD each year to receive funding and an Annual Performance Report (APR) on their progress in meeting the goals and objectives included in their IHPs. It is important to note that tribes do not have to comply with Fair Housing laws; however, they do have to comply with Section 504. Similar to other HUD programs, many of the tribes face a housing shortage.

The Arizona Developmental Disability Planning Council recognizes that the housing shortage is often magnified in all 22 federally recognized American Indian tribes across the state, yet the barriers are unique to each tribe. It is just beginning to interact with these tribes to learn about housing situations for people with developmental disabilities. This past year ADDPC contracted with the Native American Center for Disability Law to target housing issues experienced by Navajos and Hopis with disabilities.

It was discovered that although the housing situation is dire for people with developmental disabilities as a whole, for Navajos and Hopis, the situation is significantly worse. This is cause for concern as these additional barriers could result in higher rates of institutionalization in the absence of housing options. Some additional barriers these tribes face include:⁴⁵

- A shortage of adequate, accessible housing
- A shortage of affordable, accessible housing in the communities where they live
- A lack of electricity and plumbing
- Zoning restrictions which limit the number of people who can live in a house
- A shortage of land for constructing new housing
- Lengthy distances in accessing housing services
- Long waiting lists for housing
- Limited accessibility to the application process

⁴⁵ Personal communication, Theresa Yannan, Native American Center for Disability Law, August 8, 2012.

HUD'S FUNDING STREAMS AND THE CITIZEN INPUT PROCESS: WHAT YOU CAN DO⁴⁶

To increase the accessible, affordable housing supply, developers, advocacy organizations, and individuals with disabilities and their families, need to understand the different funding streams available and where they can make an impact in housing planning processes. In most cases, public input is required from citizens in order for HUD to approve the spending plan submitted by each housing department. It is critical that proactive relationships are established with these housing entities to create awareness of the needs of people with ID/DD in each community, so that they are addressed in each department's planning documents. There are also various HUD funding streams available that may be leveraged to increase housing options for people with developmental disabilities and their families and advocates. Following is a listing of these funds with avenues for citizen input:

HUD Section 811: Although limited and extremely competitive, this funding provides interest-free capital advances to finance construction, rehabilitation or acquisition of rental housing units for low-income person with disabilities. These funds have tended to be used for segregated, congregate living, including the development of group homes and independent living facilities. However, there is a push for a Project-Based Rental assistance approach that promotes scattered site, mixed use housing developments with more formal relationships with supportive services.

Low Income Housing Tax Credit (LIHTC): This credit allows qualified developers to apply for federal tax credits that they can sell to the investors and use the proceeds as equity for the development of apartment complexes for persons below 60 percent of area median income (AMI). Often, LIHTC housing is still not affordable enough for those living on Supplemental Security Income (SSI), but the state can allocate a certain percentage of units for people with disabilities

through set-asides or ensure that a certain percentage of units are accessible. Currently, the State's Qualified Allocation Plan (QAP) has no such priority scoring.

Housing Trust Fund: Although close to 2/3 of the budget was eliminated for FY 2013 from the state's Housing Trust fund, this is still a flexible funding source to assist in meeting the housing needs of low- to moderate-income families.⁴⁷ Local governments also may establish these funds to provide them with more flexibility in addressing critical housing needs. They have been used to provide homebuyer assistance, home rehabilitations and foreclosure assistance, and other gap funding to give access to affordable housing to people with ID/DD that are extremely low income.

ON THE CHALLENGES OF DEVELOPMENT

"You are adding more pieces to already complicated puzzles — particularly getting the rental subsidies and support services to work together with the capital financing. Our focus has been on integrating supportive housing into larger projects, which has been even more challenging. We have overcome this by developing real expertise with the various government programs that fund the operating and service studies. Another key to our success has been partnering with strong nonprofit supportive service providers..."

– Dunn Development

⁴⁶ These options reviewed in detail in J. Klein & D. Jones, *Funding Sources Successfully Used by States to Support the Development of Affordable, Accessible, and Integrated Housing*, Independent Living Research Utilization, Houston, Texas, 2008.

⁴⁷ <http://www.azleg.gov/jlbc/13AR/doh.pdf>

HUD also requires housing departments to consider the needs of their community in their annual application for the following HUD vouchers:

Housing Choice Vouchers: (Housing departments may establish preferences to give certain groups priority. For further information on cities that maintain vouchers, see Appendix B.)

- **Tenant-Based:** rental assistance provided to the individual to lease participating, privately owned, affordable rental housing, in which the person only pays approximately 30 percent of his/her income on rent.
- **Mainstream:** Vouchers targeted to families with a disability, which allows them to lease affordable private housing.
- **Homeownership Vouchers:** Tenant-based assistance that may be used for monthly mortgage payments and other monthly home ownership expenses. This program is not widely known or utilized by housing departments, but it is available through HUD.
- **Project-Based Vouchers:** Rental-assistance provided directly to the housing developments. Twenty percent of the units in each development may receive this subsidy.

HUD also requires public input on the 3- to 5-year housing Consolidated Plan (which every housing department maintains) from the housing departments in the following areas of funding, which may be allocated to people with disabilities:

Community Development Block Grant (CDBG):

Provides flexible formula funding to local governments to improve communities. Seventy percent of funds must be used to benefit low-and moderate-income households. Funds for people with disabilities are primarily used to make homes wheelchair accessible. In Arizona, few of these funds are allocated to non-elderly persons with disabilities.

Home Investment Partnership Program (HOME):

Provides very flexible formula grants to states and localities that communities use — often in partnership with local nonprofit groups -to build, buy, and/or rehabilitate affordable housing for rent or homeownership or provide direct rental assistance to low-income people. It can be used with LIHTC to set-aside accessible, affordable units for tenants with disabilities. It can also act as a subsidy to fill in gaps of 30 percent for tenants with extremely low income and rent set under 30 percent of AMI until the tenant obtains a Housing Choice voucher.

Organizations representing people with disabilities/developmental disabilities can assist housing departments by offering to organize participants for focus groups so that they can properly assess need and ensure that their input is included in the Consolidated Plan. To know the current plans and

FOCUS GROUPS CONDUCTED TO ASSESS NEED

As part of the five year consolidated plan process in the late-1990s, the Minnesota Housing Finance Agency (MHFA) held several focus groups. Recognizing that many outside the traditional affordable housing sector are deeply impacted by their policy decisions, MHFA used these focus groups to talk with constituents that would not normally attend an affordable housing public meeting. Typically, MHFA would partner with a trusted organization that would act as a liaison and host for the focus group. Through these partnerships, MHFA was better able to understand how affordable housing policy affects such diverse groups as recent immigrants, those with disabilities, and public health nurses.

citizen input strategies, review both the Consolidated Annual Plan and the Consolidated Annual Performance and Evaluation Report (CAPER) for your area. The contacts for these Housing Departments are located in Appendix B.

Fair Housing: People with ID/DD may also be heard through another planning document called the “Analysis of Impediments to Fair Housing (AI).” In this document, entities that receive federal monies through the Consolidated Plan process (i.e. with CDBG and HOME funds) are required to define problems, develop solutions, and be held accountable for meeting the standards they set for themselves in ensuring fair housing that is free from discrimination for everyone. All affected people in the community must be at the table and participate in making these planning decisions. These reports may also be accessed through each local housing department.

SPECIALIZED VERSUS INTEGRATED HOUSING: THE DEBATE

While all people with disabilities and their advocates agree there is a shortage of affordable, accessible housing, there is an ideological debate within the disability community over what type of housing should be made available. Should it be specialized housing that provides services and supports bundled together and targeted to people with specific disabilities, or should it be more integrated, individualized and scattered throughout the community among their counterparts without disabilities? Both sides of the debate offer positives and negatives that should be considered as the disability community considers various housing options in their local communities.

Specialized Housing

In specialized housing, groups of individuals with disabilities live close to each other in the same area of a building, or live together in the same house. Individual choice and control ranges from one specialized setting to the next, with some residents free to come and go as they wish and others unable to leave without staff supervision. Some specialized housing may also offer a bundled package of supportive services and/or services targeted to the needs of a specific disability. For example, with the rise in autism, proponents argue that the development of autism-specific housing with attention placed on the sensory environment in design and specialized training in its personal attendant support will be more successful at reducing behavioral problems and promoting independence of its residents. Similarly, apartment complexes are increasingly being designed and marketed for the deaf and hard of hearing community with visual communication systems and smoke alarms in every apartment. Proponents also state that specialized housing offers more opportunities for peer support, in which those with similar disabilities can learn from each other, build friendships and increase socialization. This more efficient delivery of services also reduces the risk of gaps in critical services, or personal attendants’ no shows, with a stable group of residents to serve.

On the other hand, critics of specialized housing believe that it stigmatizes people with disabilities since there is limited interaction with those without disabilities. The assumption within the general population then becomes “those people need to live with others like themselves.” The belief by critics is that specialized housing is typically segregated, professionally staffed, and congregate in nature, thereby replicating institutional programs of the past where resident compliance to house

rules overshadows self-determination and choice promised through Olmstead. Further, many with disabilities do not want to live with others with disabilities or want housing that is identifiable as “special needs housing” if they are given the option. Critics also disagree with catering to specific disabilities altogether in housing design and advocate for universal design principles in which the environment is accessible to residents of all ages and abilities. In the case of autism, they argue that designing “sensory havens” does not represent the neuro-typical environment of the community and can lead to further segregation of the people they are trying to include within the community.

Integrated Housing

Integrated housing is typical, residential housing that is scattered throughout the community among residents without disabilities. While specialized housing often delivers a bundle of services to a group of residents, integrated housing links individuals with disabilities ranging from moderate to severe to services that he or she needs to live in the community, i.e., personal attendants, transportation, and employment. Federal actions and initiatives stemming from the Olmstead Decision have targeted this individualized, person-centered approach, as its focus is integration over segregation and individual choice over compliance with rules and procedures. Proponents of integrated housing believe that inclusion of people with disabilities in the community among their non-disabled counterparts will improve outcomes in employment, community participation, empowerment, health, relationships, and overall life satisfaction. The stigma that people with disabilities have to be segregated to live in the community also fades with increased integration.

It is also found to be a less costly option. The Sustainability and Innovation Work Group found that people with similar significant disabilities, as measured by Arizona’s Pre-Admission Screening Process (PAS), were being served in all types of living arrangements, including individualized, integrated living arrangements, with higher costs associated with congregate, or group living, arrangements.⁴⁸

Most opponents also see the benefits of integrated housing, but they do not believe that this is an option appropriate for all people with disabilities for several reasons. The supportive services are not as efficient or as stable as a package of permanent, bundled services that are on-site. Other residents and housing managers may discriminate and not understand or have patience with residents who may exhibit what they perceive as troubling behaviors. Living independently with the many difficult decisions one faces may be too overwhelming without a case manager to assist. There is a very limited supply of integrated, accessible housing available, and community services support is not adequate to maintain the independence of a person with a significant disability, which is why many remain at home with loved ones.

POST-OLMSTEAD CMS LETTER OF GUIDANCE TO STATE MEDICAID DIRECTORS (2000)

“Our goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.”

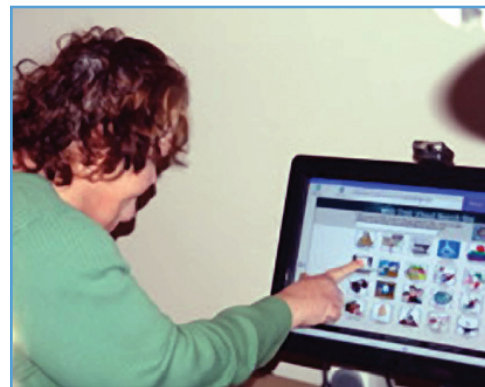
48 Report of the Sustainability and Innovation Work Group, NASDDD, October 2010. Available at <http://sonoranucedd.fcm.arizona.edu/sites/sonoranucedd.fcm.arizona.edu/files/Report%20of%20the%20Sustainability%20&%20Innovation%20Work%20Group%20for%20AZ%20DDD%202010.pdf>

TRENDS IN HOUSING⁴⁹

Regardless of where one stands on the issue, it is understood that people with disabilities, their families, and their advocates want to have a range of housing options from which to choose, which does not currently exist in Arizona.

Across the U.S. and internationally, there are numerous examples of creative ways funding is leveraged to develop innovative housing models that range from specialized to integrated. The following list of housing trends with illustrative examples can succeed with people of all types of developmental disabilities ranging from mild to severe. It is important to recognize that each option can be augmented with additional supports, as needed by the individual.

Smart Homes or Homes with Universal Design⁵⁰ may be offered in integrated or specialized settings. They are built or renovated to ensure full accessibility to a person with a disability. Features in these homes remove barriers to independence often found in traditional design. Common universal design elements include hard flooring, lever door knobs, 32 inch wide doors, and lowered countertops. Additionally, Smart Homes utilize technology that maximizes independence of those with significant disabilities. For example, a person with a wheelchair could control lighting, telephone, and cooling without having to rely on staff.



- Considered specialized housing, **Imagine's Smart Homes** owns two smart homes in Boulder, CO. One home houses six residents and the other, eight with significant ID/DD. The individuals living in these facilities would have been living in ICFs in most communities. Both homes incorporate cutting edge technologies to improve the quality and efficiency of service and supports for people with disabilities. Residents also use this technology as a means to access and interact with their community. For example, journaling software, communication devices, adapted email, and task reminders are commonly used throughout the home. Funding for these projects is provided by HUD, state and local funds, and individual and corporate donors. The residents in these homes actively participate in their local communities.

Shared Equity Home Ownership is a version of the cooperative and may be offered in integrated or specialized settings. A group comes together to purchase a home. The shared equity home ownership status ensures that the home remains affordable to lower-income households on a long-term basis by restricting the appreciation that the owner can retain. This occurs primarily through land trusts. Well over a hundred community land trusts exist across the country, from Burlington, Vermont to Santa Fe, New Mexico. Limited equity cooperatives, although predominantly an urban housing type, have

⁴⁹ Some models were extracted and follow-up interviews were conducted from the following sources: S. Ahrentzen & K. Steele, *Advancing Full Spectrum Housing: Design for Adults with Autism Spectrum Disorders*, Urban Land Institute, 2009; National Council on Disability, *The State of Housing in the 21st Century, a Disability Perspective*, 2010; and J. Klein & D. Jones, *Funding Sources Successfully Used by states to Support the Development of Affordable, Accessible, and Integrated Housing*, Independent Living Research Utilization, Houston, Texas, 2008.

⁵⁰ For more information on Universal Design principles, visit http://www.ncsu.edu/www/ncsu/design/sod5/cud/about_ud/udprinciples.htm

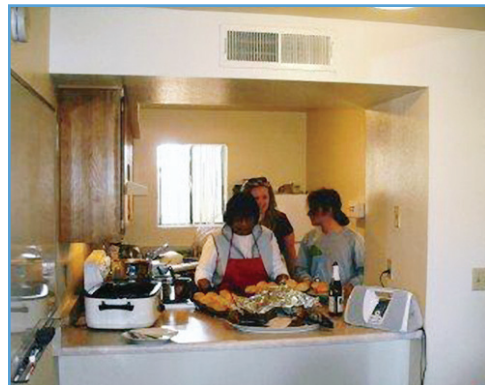
become a more widely used vehicle for building stable homeownership and preserving affordability.

- **Specialized Housing** in Massachusetts was the first housing program in the U.S. to help adults with special needs own their own homes with professional support. Families come together to purchase a house, and the management company helps locate housemates. Five people with ID/DD live in each house. Families purchase the home at a zero percent interest. The monthly mortgage that is owed is written off as a medical deduction expense. The rooms in the house are subsidized through Section 8, and the management company overseeing the house provides staff and clinical support. These settings offer more support for those who cannot live alone, yet allow more independence for individuals to live their lives.



Transitional Residential Programs are a form of specialized housing that offers a short-term residential experience to train individuals on the skills needed to live independently in their own homes for those not ready to live independently quite yet.

- **Chapel Haven** specialized housing programs offer a range of services for people with DD. Its three programs provide each person with a support coordinator who acts as a guide to building community relationships and to living independently. Mentoring is also available to those ready to live on their own from other individuals with DD who have successfully lived independently in the community for five years. Its programs reach out specifically to individuals with Autism Spectrum Disorders.
- **Chapel Haven West** in Tucson serves up to 30 students with autism or mild disabilities 18 years and older across the country. All roommates in this program live in apartments together and are taught the day-to-day living skills that will be necessary for independent living when they graduate from the two-year Residential Program and become members of the Supported Living Program, which involves living in their own apartments in Tucson. Many of these students live in non-subsidized apartments with other university students. Social security, college scholarships, and food assistance program can help subsidize their costs.



For students who still need a little extra support after the two-year Residential Program, there is the Bridge Program. Graduates live in the community, but receive extra support for one year, before their transition to more independent living. While the Residential Program and the Bridge program are tuition-based programs, Supported Living is a fee for service program. Annual program fees are approximately \$65,000. For those students who have day training on their individualized service plans, DDD reimburses the costs for a portion of this tuition amount.

- Similarly, the [Campus Based Program at Consaul Road](#) is a statewide transitional program for adults with autism. The program provides temporary, specialized services that are individualized to meet the more intensive treatment requirements for individuals with autism whose behavioral presentation prevents placement in a less restrictive community setting. The program ensures ongoing active treatment through the development of effective, proactive, behavioral strategies, skill development plans, and intensive clinical/medical monitoring and intervention. Since 2009, it has supported 13 individuals in successfully moving on to community-based services. The Program is partnering with two different voluntary agencies to develop community-based residential and day habilitation opportunities for nine individuals currently served by the Campus Based Program who are making progress toward their discharge goals.

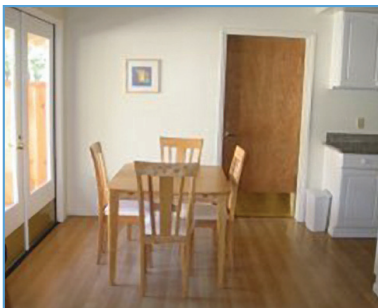
[Supported Living](#) offers independent living in apartments or homes with some supports from the community to maintain the person’s independence. To counteract the high turnover of caregiver staff in HCBS, increasingly newly developed buildings and duplexes that house people with ID/DD are allowing families (or caregivers and their families) of people with ID/DD to live on site. This option can be offered in both specialized and integrated housing models.

- [Options in Community Living](#) promotes integrated housing. It is a private, non-profit organization in Madison, Wisconsin, which provides residential support services to individuals who have developmental disabilities — 90 percent of whom have an intellectual disability. It assists individuals in finding and keeping a home of their own in the community. The home may be in an apartment, a townhouse, a condo or a single family house. Most are renters through the Section 8 Housing Choice voucher program. The options program has benefited from strong county support, including a commitment to self-directed services and the county’s exceeding the required match on Medicaid waiver funds available for services that promote dispersed, integrated housing. The organization also benefits from Wisconsin’s relatively minimal requirements for service providers to qualify for funds from Medicaid waivers. The organization’s director explains that this flexibility allows them to support people as active leaders in their own process, instead of having to follow conventional models that are focused on delivering services to passive clients.

- [Stoney Pine Villa](#), a 23-unit specialized housing development of Charities Housing designed for people with ID/DD and their families located in Sunnyvale, California, was built with Section 811 funding and received up-front financing from the state’s housing trust fund. People who live here are considered extremely low income. The residents pay 30 percent of their income for rent, in addition to utilities and phone. In planning this community, focus groups were conducted to determine what was most important to developmentally disabled adults seeking to live independently. Family members of developmentally disabled adults who will be eligible for residency have helped to select the service provider, Community Options.



- Located in Cupertino, California, the [Cupertino Duplexes](#) offers a hybrid approach of specialized and integrated housing. It offers four duplexes for twelve developmentally disabled individuals and four families responsible for



their care. This development is a collaborative effort between The Hallmark Group (developer), Bay Area Housing Corporation (owner and advocate for developmentally disabled population), Community Living Options (service provider) and Charities Housing Development Corporation (construction management agent). This project's funding source is the State of California Department of Developmental Services.

[Home ownership programs](#) may leverage HOME, 811, CDBG, housing trust funds, and/or local housing funds to help people with ID/DD purchase their own homes. Some funding provides down payment assistance in the form of a zero percent second mortgage. Title 19 Medicaid funds can also be used to pay a portion of an individual's mortgage when they have a roommate who does not have a disability and provides some level of support to the individual. This option is underutilized as the assumption is that people with significant disabilities cannot own their own home, but this is not the case. These programs can be administered in both specialized and integrated housing models.



- [Community Vision](#), located in Portland, Oregon, offers both integrated and specializing housing with its programs targeted to supported living, employment, home ownership and Individual Development Accounts (Matched Savings Accounts). This organization has helped hundreds of first time home buyers with ID/DD to buy their own homes and understand the different funding streams available to assist in financing. This organization also makes homes accessible and functional in relation to universal design.
- [The Arc](#), Central Chesapeake Region is specialized housing that offers a lease-to-own option. The Arc's homeownership efforts culminated in a 56-unit complex named Homes at the Glen. The residents who live there are low income earning 50 percent of AMI. Monthly rent payments include \$15 payments to accounts that will be used to help buy the unit at the conclusion of the 15-year lease. Service coordination and case management is provided by an agency funded by the Maryland Developmental Disabilities Administration. Direct grants came from private foundations, the Maryland Developmental Disabilities Council, and the Maryland Developmental Disabilities Administration. The Maryland Department of Housing and Community Development (MDHCD) provided a second mortgage to the project and an equity-generating tax credit.

On the local level, the Anne Arundel County Housing Commission granted a HOME loan, and the city of Annapolis and Anne Arundel County granted low payments in lieu of real estate taxes to make rent affordable. Another important state resource for this project was a 2002 MDHCD amendment to the State Qualified Allocation Plan. The amendment provides bonus points in the competition for federal Low Income Housing Tax Credits (LIHTCs), as well as gap financing to applicants who build units for people with disabilities.

Housing Cooperatives are another type of home ownership that allow residents to own and control their apartment through a corporation in which they own stock and are actively involved in management and programming. These also may be administered through integrated or specialized housing models. Maintaining affordability is difficult, but may be achieved by restricting resale prices, as in the case of Limited-Equity Cooperatives (LECs). Collectively owned and governed, LECs cap resale prices of shares by either regulating the resale price or the income levels of buyers. LECs enable stable affordable housing and the security this ensures, greater levels of tenant control and satisfaction, and neighborhood revitalization in economically depressed areas.

Services may or may not be offered on-site, can be informal or formal, and might involve either joint purchasing and/or scheduling of services or a coordinated and managed services program staffed by community agencies or the cooperative itself. Potential benefits for low-income people with disabilities include a relatively low financial investment and greater control over housing and the environment.

- **Penn South Co-Op** is an integrated setting that was built with 2,820 units for 6,200 residents. It has been in existence for 50 years. The low cost status of these units has been sustained after the city reclassified its tax status as “sheltered rent” allowing residents to continue to pay lower co-op fees. Taxes are based on property income as opposed to value. Fifty-five percent of residents here have incomes below \$40,000. The co-op has set up a collaborative program with community agencies so that residents may receive supportive services to remain independent. All buildings are accessible, and individual modifications are made as necessary.

Shared Living Arrangements/House Shares give people with ID/DD the opportunity to choose their own roommates and live in their own houses/apartments together. This was recommended as another option that should be considered by DDD from the Sustainability and Innovation Work Group. Supports from the state are through personal attendant support. This is an integrated housing model.

- **Onandaga Community Living** in Syracuse, N.Y. offers an innovative approach to live-in supports for people with DD. It utilizes housemates in its house shares. Housemates are typical members of the community who enter into a life-sharing situation with a person with a disability. Housemates not only share the home, it is their home as well. They live there as friends and companions to the person with a disability. The housemate is able to attend school or maintain his or her full time position elsewhere, and support is backed up with agency staff, reviewing each housemate’s personal work and social schedule to ensure that there is proper support at all times for the person with a disability. There is a one-year commitment and a three-month notice of intention to move. The housemate typically lives in the home rent free and free from the costs of utilities, but shares in the food expenses and pays for the extra phone line or long distance, if needed.

Onandaga Community Living introduces David, who had significant disabilities and wanted to move out of a group home arrangement:⁵¹

We met with him and his staff to try and get to know him and learn from them what worked or had not worked in his life. After careful planning it was determined that David would live with non-disabled housemates. We would combine the housemate support with regular daily residential staff support, personal care support each morning and vocational support Monday through Friday. This combination of services and housemate support equaled the 24-hour support that David needed.

David now lives in a home that he and his housemate chose. He lives there with two non-disabled housemates that he respects and loves. A Personal Care Attendant that has been chosen by David comes in each morning and helps him with his morning routine and ensures that he is ready for his day. He then either volunteers with horses, works with cars or delivers papers Monday through Friday. When he gets home from work, a residential staff member is there to assist him with his share of household duties, help him with any appointments or to support him in a social life that is separate from his home. Each evening he hangs out with his two housemates, and does things with them both at home and socially that they each enjoy. The key things for David are that his life is much more content. His behavioral problems are pretty much nonexistent. He is no longer restrained or on unnecessary medications. He now lives with people who he values.

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51 Excerpt can be found at http://www.oclinc.org/residential/residential%20_index.htm

CONCLUSION

The current housing system in Arizona is fraught with barriers to securing affordable, accessible housing for people with disabilities. There is ongoing discrimination, and many developers, housing officials, non-profits, family members and people with ID/DD are unaware of programs and services and what they can do to reverse these patterns.

This report has highlighted innovative housing models for people with ID/DD, in which existing funding streams, as well as strategic relationships with DDD were leveraged. While current funding mechanisms support individuals in the community and pay for family care, clearly Arizona has more work to do in expanding housing options for people with ID/DD. This demonstrates the need for DDD to develop closer relationships with developers, non-profit agencies, and housing departments so it may realize its goals of reducing costs of residential services while still helping its clients obtain self-sufficiency and independence — a seemingly unreachable dream for many at first glance, but one which can be made into reality with community action and involvement.

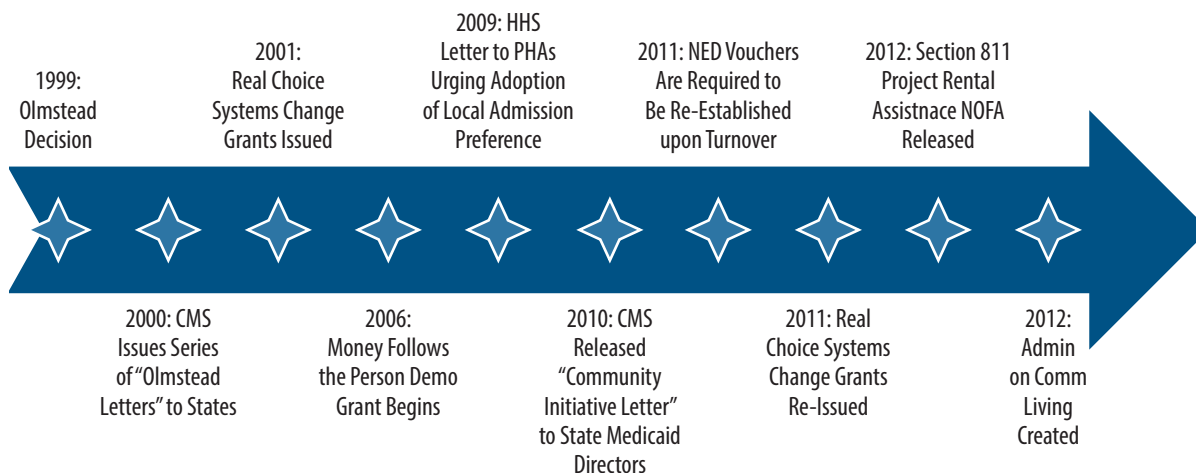
The climate of change is here and is encouraged by federal initiatives. Likewise, many housing departments and city officials are willing to work with the disability community, but remain unaware of the great need and barriers facing this population. In response, families, people with ID/DD, and the advocates who represent them should take this time to start building relationships with their local housing departments to initiate change.⁵² An official with Charities Housing Development Corporation stated:

“The disability advocates in California went to the housing authorities and planning departments and participated in community activities to re-write and review their planning documents. As a result, now housing funders can require that developers set aside a certain percentage of accessible units for people with disabilities/special needs. Now, some other developers even say that we have too many units designated for people with disabilities.”

Innovation in housing will take time, intention and the teaming up of groups that do not traditionally work together. But for people with ID/DD with limited housing choices and their families who worry about them and remain their sole support, it will be well worth the effort.

⁵² To begin this process, Appendix B lists the contact information for local housing offices.

APPENDIX A: TIMELINE OF FEDERAL HOUSING ACTIONS POST-OLMSTEAD DECISION



1999: Olmstead Decision handed down.

2000: CMS issues series of “Olmstead letters” that include technical assistance, policy changes and clarifications that will give states more flexibility to serve people with disabilities in different settings.

2001: Real Choice Systems Change grants begin to be administered to states to increase their home and community-based services programs.

2006: CMS’ Money Follows the Person pilot administered among the states, which allow funds paid to nursing homes to “follow” the consumer to the community and pay for the home- and community-based services consumers need to remain independent.

2009: Public Housing Authorities (PHAs) are urged to adopt local admission preference for persons with disabilities who are ready to exit institutions. In this same year, the U.S. Department of Justice doubled enforcement efforts of Olmstead with its involvement in 40 matters in 25 states related to housing discrimination to ensure that the right to live in the community was being advanced.

2010: CMS reaffirmed commitment to Olmstead through its “Community Initiative Letter” to State Medicaid Directors, which offered tools and technical assistance to help states advance housing and community options.

2011: Non-Elderly Disabled (NED) vouchers are now required to be re-established among the NED population as they are turned over. They cannot be used for any other purpose.

2012: HUD announced grants totaling \$85 million that would be awarded for project-based rental assistance through 811 vouchers to house extremely low-income persons with disabilities in integrated housing complexes, in which no more than 25 percent of the total units are designated for people with disabilities. It is expected that the housing authority will have a formal relationship with Medicaid and Health and Human Services agencies. About 2,800 people with disabilities across the U.S. will benefit from this program. Unfortunately, many authorities will not be able to apply because

of the immediate deadline; however, it may incentivize more authorities to build formal relationships with these entities so that they are ready for future funding cycles.

2012: The Administration for Community Living was created, which brought together key Health and Human Service offices, including the Administration on Developmental Disabilities, the Administration on Aging, and the Office on Disability. According to Health and Human Services Secretary, Kathleen Sebelius, “this agency provides leadership within HHS and across the federal government to make sure that people with disabilities have the opportunity to live in the community with the right mix of services and supports.”

APPENDIX B: ARIZONA PUBLIC HOUSING AGENCY CONTACT INFORMATION

Public Housing Authority Name, Phone & Fax Number	Address	Section 8 or Low Rent Program?
Cochise County Phone: (520) 432-8880 Fax: (520) 432-8890	Old Bisbee High School, First Floor 100 Clawson Ave. Bisbee, AZ 85603	Section 8
Pinal County HA Phone: (520) 866-7201 Fax: (520) 866-7235	970 N. Eleven Mile Corner Rd. Casa Grande, AZ 85222	Both
Chandler Phone: (480) 782-3200 Fax: (480) 782-3220	235 S. Arizona Ave. Chandler, AZ 85225	Both
Douglas Phone: (520) 364-8458 Fax: (520) 364-6462	425 E. 10th St. Douglas, AZ 85607	Section 8
Flagstaff HA Phone: (928) 526-0002 Fax: (928) 526-3734	3481 Fanning Dr. Flagstaff, AZ 86004	Both
Glendale HA Phone: (623) 930-3701 Fax: (623) 930-1064	6842 N. 61st Ave. Glendale, AZ 85301	Both
Gila County Phone: (928) 425-7631 Fax: (928) 425-9468	5515 S. Apache Ave. Globe, AZ 85501	Section 8
Mohave County Phone: (928) 753-0723 Fax: (928) 753-0776	700 W. Beale St. Kingman, AZ 86401	Section 8
City of Mesa Housing Authority Phone: (480) 644-3536 Fax: (480) 644-2923	20 E Main Street Suite 250 Mesa, AZ 85201	Section 8

Public Housing Authority Name, Phone & Fax Number	Address	Section 8 or Low Rent Program?
Nogales Phone: (520) 287-4183 Fax: (520) 287-4802	777 N. Grand Ave. Nogales, AZ 85621	Both
Peoria Phone: (623) 486-4375 Fax: (623) 486-0822	10950 N. 87th Ave. Peoria, AZ 85345	Both
Arizona Behavioral Health Corporation Phone: (602) 265-4640 Fax: (602) 265-4680	3829 N. 3rd St., Suite 101 Phoenix, AZ 85012	Section 8
Maricopa County HA Phone: (602) 744-4500 Fax: (602) 253-9268	2024 N. 7th St., Suite 101 Phoenix, AZ 85006	Both
Phoenix HD Phone: (602) 262-6794 Fax: (602) 534-4516	251 W. Washington St., Floor 4 Phoenix, AZ 85003	Both
Arizona Dept. of Housing Phone: (602) 771-1000 Fax: (602) 771-1013	1110 W. Washington St., Suite 310 Phoenix, AZ 85007	Section 8
Scottsdale Phone: (480) 312-7717 Fax: (480) 312-7761	7515 E. 1st St. Scottsdale, AZ 85251	Section 8
Yuma County HD Phone: (928) 627-8828 Fax: (928) 627-8715	8450 W. Highway 95, Suite 88 Somerton, AZ 85350	Both
South Tucson HA Phone: (520) 623-8481 Fax: (520) 770-0051	1713 S. 3rd Ave. South Tucson, AZ 85713	Both
Tempe Phone: (480) 350-8950 Fax: (480) 350-8902	21 E. Sixth St., Suite 214 Tempe, AZ 85281	Section 8
Tucson Hcd Phone: (520) 791-4171 Fax: (520) 791-5407	310 N. Commerce Park Loop Tucson, AZ 85745	Both

Public Housing Authority Name, Phone & Fax Number	Address	Section 8 or Low Rent Program?
Pima County Phone: (520) 791-4171 Fax: (520) 791-5407	310 N. Commerce Park Loop Tucson, AZ 85745	Section 8
Winslow HA Phone: (928) 289-4617 Fax: (928) 289-3848	900 Henderson Square Winslow, AZ 86047	Both



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