

Affordable, Appropriate, Integrated Housing

a report prepared by Maine's Work Group for Community-Based Living

*Because of the need for physical shelter, housing is intricately intertwined with the core human experiences of relationship, security, respite, privacy, ownership, and community. The quality of housing and the health of the neighborhood in which it is located directly affect the physical and mental health of its inhabitants, their ability to raise a family, their ability to achieve employment and educational success, their ability to be engaged in civic life. What could be more fundamental to a caring and just society than assuring a minimum standard of housing below which no one will be allowed to fall?*¹

The *Olmstead* decision includes no explicit statement requiring states to assure that persons with disabilities have access to appropriate, affordable housing. Yet the vision of integration and choice embodied in the ADA (Americans with Disabilities Act) implicitly requires states to go beyond merely eliminating unnecessary institutionalization. Where you live has a profound impact on your life, where you work, who your friends are, and your sense of well-being and belonging in a community. Because housing is so fundamental to daily life, housing is a fundamental component of any plan to integrate persons with disabilities into the community.

In this report we address the housing needs common to many people with disabilities. In particular, we address the need for: affordable housing; supportive, person-centered housing services; and accessible, integrated housing.

A Right to Choose Where to Live

These are some of the shared core values of Work Group members:

- Individual choice is implicit in any framework that honors the dignity, equality and value of the individuals it serves.
- The choice of where and how one lives, and with whom, counts as the most fundamental of choices.
- Our government has a responsibility to open the door to choice by providing the services and information that make informed choice possible.

In light of these values we examine the gap between what we think we should be doing and what we do.

Affordability. Many people with disabilities are blocked from employment or earn very little relative to the general population. For those that depend on Supplemental Security Income benefits (SSI) for income, at \$545 per month, the “choice” of where to live is extremely limited.

¹ Crowley, S. (2001) Forward. In A. O'Hara and E. Miller, *Priced Out in 2000: The Crisis Continues*. Technical Assistance Collaborative, Inc. and Consortium for Citizens with Disabilities Housing Task Force, Available: <http://www.c-c-d.org/POin2000.html#a>.

Over 87 percent of a monthly SSI benefit is required to rent a one-bedroom housing unit in Maine.² For some communities in Maine, rent for a one-bedroom would consume all or more than all of a person's SSI benefit.³ In some cases, people have no choice but to accept poor quality housing as the only available option. For those with Section 8 vouchers, choice is limited by those landlords willing to accept the voucher. For those with very low incomes, a Section 8 voucher only solves part of the problem. Under Section 8, the renter is responsible for paying at least 30% of income, even when income is very limited. The cost of a security and utility deposit, and furnishings for a home must also be met.

In some communities, people have to wait for a voucher, sometime for a significant period of time (*i.e.*, years). According to the Maine State Housing Authority (MSHA), in 1999 the people receiving Section 8 rental assistance had waited 11 to 20 months to get help.⁴ The Bridging Rental Assistance Program (BRAP) provides some relief for people waiting for vouchers, by providing some interim rental assistance. However, BRAP is only available to persons with severe psychiatric disabilities served through the Department of Behavioral and Developmental Services (BDS).

In other communities, a healthy economy can mean that rents are so high, even vouchers are insufficient to put rental housing in reach. For example, in recent years Section 8 vouchers in Portland have gone unused because actual market rents had risen faster than the Fair Market Rent standard HUD (U.S. Department of Housing and Urban Development) uses to determine the rental subsidy. People holding vouchers could not use them because they could not find housing with low enough rents. The fact that housing shortages tend to be worse in urban centers, where access to jobs and transportation is best, means that some of the best opportunities for employment are unavailable to people shut out of the housing market.

Owning a home is often out of reach for persons with disabilities. Homeownership is the number one way for most Americans to accumulate wealth.⁵ Maine households have accumulated \$17.1 billion in assets by owning their own homes.⁶ In the face of poverty, owning a home is next to impossible for many people with disabilities. Less than 5% of people with disabilities who receive SSI own their own homes.⁷

In many cases, the only "choice" is homelessness. Homelessness is particularly acute for persons with disabilities. Forty-five percent of homeless people have a mental illness, 60% have an addiction disorder.⁸ Homelessness might also exacerbate the effects and symptoms of all types of disabilities, including mental illness. Research on homelessness for youths also shows a similar relationship between homelessness and addiction — the longer a youth is homeless the

² O'Hara and Miller 2001.

³ O'Hara and Miller 2001.

⁴ Maine State Housing Authority. (1999) *The State of Maine's Housing 1999*. Available: <http://www.mainehousing.org/reports.html>

⁵ O'Hara and Miller 2001.

⁶ Maine State Housing Authority. (1999) *The State of Maine's Housing 1999*. Available: <http://www.mainehousing.org/reports.html>

⁷ Dwyer, C. and Vogt, J. (2001) *Expanding our thinking on housing choice*. Advocacy Action News (44).

⁸ DeVos, M. (2001) *Ending homelessness: Maine's strategic plan*. A report submitted by Maine's Subcabinet on Homelessness to Governor Angus King.

more likely he or she will become addicted to drugs.⁹ Homelessness for persons with addiction disorders has increased since a change in federal law in 1996, denying SSI and SSDI (Social Security Disability Income benefits) (and with it health coverage) to people whose addiction is considered to be the cause of their disability status. Two-thirds of those who were paying for their own housing and lost benefits because of this change went on to lose their housing as well.¹⁰

Accessibility. Finding accessible housing is also a challenge. Federal and state laws only partially address physical barriers to access. While the federal Fair Housing Act requires all multi-family homes built after 1991 to comply with accessibility guidelines, it does not apply to single-family dwellings. Currently, there is no complete inventory of accessible housing in Maine. However, given that Maine has the 7th oldest housing stock in the nation¹¹ with 86% percent of Maine's housing stock was built before 1990,¹² it is safe to conclude that most housing units in Maine do not meet accessibility guidelines without modification. In addition to limiting the choice of where to live, inaccessible housing also limits whom one can visit, another barrier to being a participating member of a community. Modifying a home or apartment to increase access is not always possible. A tenant might be entitled to make a reasonable accommodation to an apartment, but some accommodations are at the tenant's own expense. It can also be challenging finding a builder who knows how to make modifications since implementation of some of the fair housing and civil right access standards come into conflict with local building and fire codes. An untapped resource for making modifications affordable for qualified individuals is the MPower Adaptive Equipment Loan Program. Through the MPower program, a person can obtain an affordable loan to purchase adaptive equipment. Other grant and loan programs also help qualified individuals purchase homes and make modifications.

Lack of Information or Awareness. Choice is limited by the lack of knowledge. Many people do not know about the options that are available to them or how to access those choices. Landlords do not always understand their obligations and tenants do not always understand their rights under fair housing laws. Some public housing authorities as well might not fully understand fair housing law.¹³ Often realtors, bankers, and other housing professionals are unfamiliar with the range of subsidies and assistance programs available to persons with disabilities. In many cases, the lack of awareness and understanding, means that funding and planning are directed away from where housing and services that could best meet the needs of persons with disabilities.

Discrimination. Discrimination can also limit choice. Some landlords might be reluctant to accept Section 8 vouchers because they attach a stigma to those people who use vouchers; or landlords might resist renting to a person with a disability, possibly because of prejudice, possibly because of fear of the unknown potential cost of accommodations. The "Not In My

⁹ DeVos, M. (2001).

¹⁰ DeVos, M. (2001).

¹¹ Maine State Housing Authority. (1999) *The State of Maine's Housing 1999*. Available: <http://www.mainehousing.org/reports.html>

¹² Calculated on 2/23/02 using summary tables accessed through the U.S. Census Bureau website. Available: <http://factfinder.census.gov/>.

¹³ Statewide Independent Living Council, 2001 Spring Summit, May 25, 2001, housing work group notes.

Back Yard,” or NIMBY syndrome, means neighborhoods resist housing developments that would integrate housing for people with disabilities into more community settings.

Range of Options. Maine has made much progress in recent years at expanding the range of affordable housing and services that permit more private and independent living. Yet shortages of both housing and services continue to make living in a large group setting the only option available for some people. Maine has over 5300 licensed beds in large residential care facilities, where residents have semi-private bedrooms and shared common areas. Over 80% of these facilities have more than 10 residents, with some having more than 100 residents. In our focus groups, we heard some people who live in a large boarding facility say they feel isolated, helpless and displaced; that they no longer have their personal belongings, have no opportunity to continue practicing basic life skills like cooking or shopping for themselves, and feel stigmatized in their community.¹⁴ Being uprooted from their community to live in a boarding facility far away has cut their ties to family and friends. One person said, “I don’t want to grow old here. I want to live closer to my home.”¹⁵

In our focus groups, we were told of the need for a range of housing supports in all communities, including independent living and assisted living, housing with more structured support services, and shared housing with other people with similar goals. Maine also needs to make sure that these housing options are available to all who need them. For example, through the focus groups and case studies, we heard about the unmet supportive housing needs of persons with traumatic brain injury and persons dually diagnosed with mental illness and addiction disorders. We heard about homeless children doing the “shelter shuffle” from short-term shelter to short-term shelter because no other options were available. We heard from parents concerned about where their adult child will go when they are too old to care for them, afraid of what will happen to their child in a residential facility.

Integration and Choice. At the same time that we do not want to promote segregation in large group homes, we do not want to deny people the right to choose where to live by forcing them to live in “integrated” settings against their wishes. Some people find support in living with other people with disabilities who have similar experiences or confront similar barriers. For example, some people who are hard-of-hearing or Deaf develop language skills more quickly through continuous access to American Sign Language (ASL). In Maine’s Portland and Bangor residential signing group homes, individuals are given that opportunity. Others want to benefit from the efficiencies of shared personal assistance services or other supports. Some people just want to be with those they care about, who might happen to be other people with disabilities.

Registering Choice. Some programs make sure that people make a choice between living in an institution or an alternative setting (e.g., the “choice letter” required under Medicaid waiver services). There are also requirements that people in institutional settings are reassessed periodically to make sure that the institutional setting is still necessary and appropriate. However, the State does not have a systematic way for registering the preferences of people in residential facilities to make sure that they live there by choice or that an alternative, more

¹⁴ Ormond, C., Ziller, E. and Richards, M. (2001) *Living in the community: Voices of Maine consumers*. Edmund S. Muskie School of Public Service: Portland, ME.

¹⁵ Ormond, C., Ziller, E. and Richards, M. (2001).

integrated setting might be preferable. (See the Coordination of Services Plan, the report of the Coordination Sub-Group, for a discussion of the State's need to develop a standard definition of "most integrated setting.") When an individual prefers to live in a more integrated setting, that option should be provided within a reasonable period of time.

Limited resources for enforcement, outreach and education. Currently, Maine does not have a Fair Housing Assistance Program or a Fair Housing Initiative Program. These are HUD programs, with federal funding attached, that would enhance Maine's ability to protect fair housing rights for its citizens and educate people about their rights.

Person-centered Housing

These are additional shared values of Work Group members:

Services should be offered in a way that not only permits but encourages people to maintain control over their lives, including maximizing the use of voluntary services. Each person's voice must be heard and all decisions and planning must reflect what is most important to the individual, and, when appropriate, supportive family and friends.

Housing services are examined relative to this standard.

The Link Between Housing and Services. In many cases, the landlord and service provider are one and the same. The link between services and residential setting creates a conflict for residents who might prefer alternative service providers. Some people are afraid to request an alternative provider because they are afraid they will lose their housing if there is retaliation.

The Link Between Services and Setting. Like many other states, for some services Maine has developed a continuum of settings with different level of services offered at each level. For example, a person leaving a psychiatric hospital might move to a residential setting with an intermediate level of service, then on to another setting when that level of service is no longer required. Moving might be a positive step for some people, seen as progress toward recovery. For others, it might be a setback, disrupting supportive relationships and jeopardizing the advances made. In some cases, rather than linking the services to the setting, the individual should have the choice to stay in the setting, while services are increased or reduced as needed.

Transitions Across Settings. Transitioning in and out of an institutional setting or across a range of settings can be disruptive in very practical ways. For example, in a focus group with five residents of the Bangor Mental Health Institute (BMHI), at least four of them had been rendered homeless by their stay, losing their apartments and possibly their belongings. Returning to the community will mean starting over.¹⁶ For someone transitioning out of a nursing facility or other setting, there is also the need for transition services. Home modifications, communications systems, transportation, assistance locating a home and furnishings, and linking with services, are just some of the assistance a person leaving an institutional setting might need.

¹⁶ Ormond, C., Ziller, E. and Richards, M. (2001).

Person-centered Focus in Planning. For many people with disabilities, a housing choice is closely linked to the availability of accessible transportation services, or even fixed route public transportation. If a person needs regular access to fixed route paratransit or other regularly accessible transportation services, that person will need to live in one of just a few cities in Maine. Yet, while transportation is critical, access to transportation is not always a priority when a housing developments are planned. Similarly access to other services, schools, and employment also need to be part of the planning process.

Recommendations

We recommend that, with the leadership of state government, state agencies and state and local housing experts take the following steps:

- Give people options about where to live and with whom and develop those options.
- Identify departmental representatives responsible for ensuring that the relationship between the location of housing, services and access to transportation are taken into account in the planning and development process.
- Break the link between housing and other services so that individuals do not feel they have to give up their choice of providers in order to keep their residence.
- Develop the option to “recover in place” so that, rather than moving from transitional setting to transitional setting, a person can stay in one place and the service level adjusts as needed.
- Review and modify regulations, as appropriate, to ensure that basic needs, such as home modifications, communications systems, transportation, and other transitional services are identified to meet the needs of people in institutions who wish to return home and that the services are available when they are needed.
- Make sure that service coordination, including case management services and community support services are available to assist in a transition, for up to 180 days before a transition from an institutional setting.
- Define “most integrated setting,” and track whether the people served are receiving services in the most integrated setting appropriate to their needs and preferences.
- Make sure that all people not served in the most integrated setting appropriate to their needs and preferences are provided that option within a reasonable period of time.
- Expand eligibility for the BRAP beyond those served by BDS, to all who need it.
- Educate bankers, realtors, and other housing professional about homeownership options for people with disabilities, available subsidies and assistance programs, and landlord/tenant issues.
- Increase the affordability of homeownership by supporting homeownership loan programs such as Coastal Enterprise Inc.’s now unfunded *Home Assistance Venture II*,

which assisted people with disabilities in making down payments and meeting closing costs.¹⁷

- Make sure resources are available to pay for modifying a home or an apartment when necessary. Make sure home modification is affordable.
- Support the recruitment and training of consumers to participate on public housing boards and in public housing authority annual or 5-year planning processes.
- Advocate to remove the federal barrier to housing assistance for persons in recovery who have a conviction for a drug-related offense.
- Expand legal resources to advise people on how to protect their housing rights.
- Support training programs to educate people about their housing rights and effective ways of educating landlords about rights and accommodations.
- Support training programs for landlords to educate them about disabilities and different accommodations.
- Examine all MaineCare options that impact on housing to ensure that only those that maximize integration (such as home and community-based services) are used.

¹⁷Coastal Enterprises, Inc. website, accessed 7/12/02. Available: <http://www.ceimaine.org/housing/home.htm>