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Access to Housing for Persons with Disabilities: Lessons Learned from Three Demonstration Projects, Cutler, Disability and Aging

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Access to Housing for Persons with Disabilities

**Lessons Learned from
Three Demonstration Projects**

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■ Executive Summary

Between 2001 and 2004, Maine conducted the Quality Choices for Maine project. This project was supported by a three-year grant from the U.S. Department of Health and Human Services to improve services for people with disabilities. This grant was part of the Real Choice Systems Change Initiative funded by the Centers for Medicare & Medicaid Services (CMS).

Access to Services was one of four major areas of focus for the Quality Choices for Maine project. This report focuses on the work related to Access to Services, and specifically the development of increased access to housing for individuals with disabilities in Maine. The report includes a summary of grant activity, lessons learned throughout the project, and recommendations for next steps to sustain the work of this grant.

The specific goal related to housing was “To improve access to community housing for people with disabilities of all types.”

Project activities were overseen by both the Access to Services Technical Assistance Group (the “Access TAG”) that included a variety of stakeholder representatives. (Access TAG members are listed in the APPENDIX A.)

Three housing demonstration projects were funded. The successes and challenges of each project are discussed below.

■ Background

In 2001, the Maine Department of Human Services received a three-year grant from the U.S. Department of Health and Human Services to improve services for people with disabilities. This grant was part of the Real Choice Systems Change Initiative funded by the Centers for Medicare & Medicaid Services (CMS). Called Quality Choices for Maine, the goals of the grant were to:

- make services and supports more consumer-centered by incorporating greater choice and control for consumers in the system;
- ensure the quality of Maine's community-based living options by building community-relevant quality management structures that incorporate the consumer perspective;
- focus attention on services and supports identified as weak links in the system; and
- facilitate inter-departmental collaboration by developing integrated data capacity.

The grant provided funds for work in four major areas: Person Centered Services; Quality; Access; and Data Integration.

This report focuses on the work related to Access to Services, and specifically the development of access to housing for individuals with disabilities in Maine. The report includes a summary of grant activity, lessons learned throughout the project, and recommendations for next steps to sustain the work of this grant.

■ Goals

One of the overall goals of the Quality Choices grant was to focus attention on services and supports identified as weak links in the system, either because they are inconsistently available, or are inaccessible to people with disabilities. These include the short supply of personal assistance workers, lack of housing in many areas of the State, patchy access to transportation, and low participation among people with disabilities in existing community recreational and cultural events.

The specific goal related to housing was “To improve access to community housing for people with disabilities of all types.”

■ Funded Housing Demonstration Projects

The budget for the Quality Choices Access to Housing project was quite limited, at least in the sense that real changes to housing and related supports would require a tremendous capital investment. The Access TAG helped to shape the design of a demonstration project activity that would identify, and test, relatively low-cost ideas for increasing access to housing for Maine citizens with disabilities.

A Request for Proposals (RFP) document was developed and issued in November 2002. The decision was made to solicit proposals for up to three project awards at one time, and to allow applicants to propose project activities for as long as one year. The RFP incorporated the opportunities for improvement identified by the Work Group for Community Living, Maine's Olmstead planning group, and the overarching Consumer Taskforce for the Quality Choices grants. These opportunities include:

1. *Affordability.* Buying or renting housing is unaffordable for many people with disabilities, especially in more populated communities in Maine.
2. *Accessibility.* Maine's housing stock is very old, making most housing inaccessible to those with mobility impairments.
3. *Lack of information or awareness.* Choice is limited by lack of knowledge about options and rights.
4. *Discrimination.* Some landlords might discriminate because a person has a housing subsidy or because a person has a disability.
5. *Shortage of housing and service options.* A shortage of both housing and services make living in large group settings the only option for some people.
6. *Integration and choice.* While some are concerned that people with disabilities who live with other people with disabilities might not live in an "integrated" setting, all people should have the right to live with whom they choose.
7. *Limited resources for enforcement, outreach and education.* Maine does not have a Fair Housing Assistance Program or a Fair Housing Initiative Program with federal resources to educate people about their rights and enhance enforcement of fair housing law.
8. *Service provider tied to setting.* Often the landlord and provider are one and the same. Some people are afraid to request an alternative provider because they are afraid they will lose their housing.
9. *Level of services tied to settings:* Many residential services currently offered in Maine require a person to move when they no longer need the level of service provided in that setting, rather changing the level of service.
10. *Disruption caused by transitioning across settings.* Transitioning in and out of an institutional setting is disruptive, if a person loses an apartment and belongings.
11. *Person Centered Focus in Housing and Transportation Planning.* Long-range planning for housing should consider access to transportation, services, schools, and employment.

Seven applications for funding were received, and were read and evaluated by a review team comprising members of the Access TAG, a housing specialist from the former Department of Behavioral and Developmental Services, and a member of the Statewide Independent Living Council. Three awards to conduct housing demonstration projects were made:

- *Greater Portland Housing Choices*, Ingraham, Inc. and Amistad
- *Making Our Own Place*, Tri-County Mental Health Services
- *Affordable Housing and Homeownership Center for People with Disabilities/Opportunity Grants*, Coastal Enterprises, Inc.

Each of these three proposals is described below.

Greater Portland Housing Choices

Ingraham, Inc. and Amistad submitted a proposal to develop Greater Portland Housing Choices, an information toolkit that would provide comprehensive information about accessing housing in Portland. Ingraham is a mental health provider and Amistad is a social club for persons with mental illness. Both agencies are located in Portland. These partners proposed using grant funds to hire two part-time Resource Educators, who would be persons with disabilities, to develop the toolkit. Grant funds would also be used to pay stipends to members of a consumer-directed advisory committee and for production costs for the toolkit.

This proposal was funded in the amount of \$13,086 for a period of March 15, 2003, to September 15, 2003. Under the direction of Amistad staff, a steering committee was convened in April, 2003. The steering committee included consumers from several local service agencies providing services to persons with mental illness. Attempts to recruit participation from other agency providers, including agency providers serving persons with other types of disabilities, did not meet with success. Steering committee members were each paid \$20 per meeting.

The steering committee hired two consumers to write the toolkit. Early in the process, it became apparent that one of these individuals was not able to stay on task and was let go. Because only one person would be writing most of the toolkit, the project timeline was extended to March 31, 2004.

The toolkit has three chapters. The first chapter provides a guide to the intake process at many housing agencies as well as a directory of the housing resources in the Greater Portland area. The second chapter provides practical information about obtaining housing and setting up an apartment, as well as fair housing laws and tenants' rights. The third chapter describes the skills people need to cope with the personal, social, and physical challenges of living independently and responsively. An excerpt from this third chapter is included in APPENDIX B.

The author of the toolkit spent close to 300 hours on this project. The editor spent approximately 40 hours on the project. Both of these positions were charged against this agreement. Project coordinators contributed 100 hours of their time. When completed, the toolkit was printed, publicized and distributed in hard copy and electronically on the AccessMaine.org website.¹ Financial administration of the grant by Ingraham totaled about 15 hours.

Successes

Amistad and Ingraham used a number of strategies that were very successful:

Consumer Involvement. Amistad and Ingraham wanted to make sure that the project empowered those who live with a mental illness or a long-term disability to let their voices guide the project. To that end, the project relied heavily on consumer participation. Most significantly, the primary author of the toolkit was a person who has experienced a mental illness, as well as homelessness as a result of his mental illness. The content of the toolkit was informed by the consumers steering the project and contributors to the toolkit.

The Right Skill Set. The primary author of the toolkit had the writing and organizational skills necessary to pull the resources together. Other needed skills, including editing and graphic design, were also purchased with grant funds.

Collaboration. In developing content for the resource tool, project staff were successful in accessing existing expertise. For example, a major collaborator was Pine Tree Legal Services, which helped to explain fair housing law and other legal protections.

Publicity for Toolkit. Amistad was very successful in attracting publicity for the housing resource toolkit. The author and the publication were featured in the primary newspaper in Portland and on local television.

Coordination with AccessMaine.org. The housing toolkit was incorporated into AccessMaine.org, a website created under the Quality Choices grant. By putting the toolkit on the website, the toolkit was more broadly disseminated.

Challenges

The primary challenge identified by project staff was cultivating and sustaining consumer input. Recruiting members from outside agencies met with limited success, particularly when the efforts to recruit were outside the mental health field. For those that did participate on the steering committee, input and participation was mixed.

¹ AccessMaine.org was also created under Maine's 2001 Real Choices Systems Change grant and provides information to Maine citizens with disabilities, their families, and providers. The toolkit can be accessed at: <http://www.accessmaine.org/Toolkits/HousingSource/housing.htm>.

Making Our Own Place

Tri-County Mental Health Services (Tri-County) submitted a proposal entitled *Making Our Own Place*. Tri-County's goal was to support community efforts to improve access to housing services and supports for persons with disabilities wishing to live in Franklin County. Tri-County perceived a general lack of housing and supports for persons with disabilities. At the same time, as it discussed options for addressing these shortages, Tri-County found a lack of information about the needs and preferences of persons with disabilities and the best way to meet individual needs. Tri-County believed that there was a need for organized advocacy and funding sources to better meet the housing needs of Franklin County residents. To address these needs, Tri-County proposed to use grant funds to conduct a survey of housing needs and preferences for persons with disabilities wishing to living in Franklin County. Tri-County would work with other community members to bring these resources into play.

The funding award to Tri-County was for \$17,434 for a one-year period from April 2003 through March 2004. As discussed below, due to a series of challenges with this project, the grant period was extended through February 2005. Additional grant funds were also allocated to Tri-County to fund stipends for consumers participating in the survey.

A steering committee was formed to guide grant activities, with consumers, Tri-County staff, and interested community members invited to participate. The steering committee elected to use a housing survey developed by Elizabeth Tanzman, et al. The survey consists of 50 questions and takes about 30 minutes to administer. The survey was designed to be administered to persons with mental illness by persons with mental illness. The committee also elected to open recruitment for participants to anyone with a disability residing in Franklin County. In May of 2003, the steering committee hired a half-time Consumer Housing Advocate to conduct the survey. As a sub-contractor to the University of Southern Maine, Tri-County sought and obtained approval of its research plan from the University's institutional review board.

The Consumer Housing Advocate's outreach and recruitment efforts included meetings with area providers and social service agencies, letters to agencies and area churches, as well as placement of more than 50 recruitment posters in these locations and in town offices. Prospective survey participants were given a toll-free number if they were interested in participating. The initial response only produced four respondents. After a \$10 gift card to a local grocery was offered as compensation for participation, an additional 26 respondents were recruited.

Of the 30 respondents, 22 were women and eight were men. The average age was 45. Fifteen described themselves as having a mental or emotional illness, six described themselves as having a physical illness, and nine described themselves as having both. The survey results showed the number living in an apartment or a home, the number living in a temporary setting, the number living alone, with family, or with others, and the number wanting to live in their own space. Respondents were also asked whether they wanted to live with other people with disabilities. Respondents were asked how long they had lived in their current residence as well.

To further its effort to develop “one-stop” access to housing, Tri-County staff linked their efforts with the Franklin County Aging and Disability Resource Network demonstration, funded under the Aging and Disability Resource Center grant to the Department of Health and Human Services from the Administration on Aging and CMS.

Successes

While the survey did not produce representative results, it did identify characteristics of housing that are important to respondents, which can inform the community-level efforts to address housing needs. In general, respondents expressed satisfaction with their current housing. (Because the survey is not representative of all Franklin County residents, Tri-County is not confident that housing is generally satisfactory.) While most had stable housing, some respondents experienced homelessness or moved multiple times in the last year. People who described themselves as satisfied with their living conditions identified their homes as quiet and secure, and at a good location. Those who were dissatisfied talked about the location, the neighbors, or the costs associated with the rent or utilities. The most important considerations related by participants were the ability to do what they wanted to do, when they wanted to do it, that there was privacy and space, and that “It’s not a psychiatric hospital.” These responses are consistent with those of consumers who are looking for an apartment in the community and have decided not to live in a group home.

When respondents were asked about their greatest need, 22 said that reliable transportation was always a problem, and that they would like to be able to reach help, day or night. Fourteen said they would like to have someone come to their home, day or night.

Challenges

Tri-County reported a number of challenges and delays in implementing this project. These include:

Complying with Human Subjects Research Protections. The first challenge for Tri-County was complying with the human subjects research protections. As a subcontractor to the University of Southern Maine, Tri-County’s survey required the review and approval of the University’s institutional review board (IRB). Although Tri-County appreciated its value, the process delayed Tri-County’s start date and imposed a certain amount of rigidity on its recruitment process.

Recruitment. Tri-County experienced significant challenges recruiting survey participants. The steering committee theorized that people did not volunteer to participate for a number of reasons:

- People who did not have a problem with housing saw no need to participate.
- People were reluctant to communicate personal information to an interviewer they did not know. (Because the recruitment and survey were governed by the IRB-approved research protocol, flexibility on who could conduct the interviews was not permitted.)
- People who had a problem with housing may not have been in contact with the agencies or towns to whom recruiting materials were sent.

- People were unhappy that participation would not immediately assist them in securing housing.

When participants were offered a \$10 gift certificate, recruitment efforts were much more successful. However, because of the small sample size, Tri-County's findings were not representative or as robust as they had hoped.

Affordable Housing and Homeownership Center for People with Disabilities/Opportunity Grants

Coastal Enterprises, Inc. (CEI) is a private, non-profit community development corporation. CEI proposed to use demonstration funds for two related programs:

The Affordable Housing and Homeownership Center for People with Disabilities/Opportunity Grants. CEI proposed the development of a resource center to provide information to consumers, service providers, and state agencies. The resource center would offer books, periodicals, brochures, and video and audiotapes to be housed at CEI, with electronic resources made available on CEI's website. The center was also to offer counseling and training to assist persons with disabilities in finding housing to serve their individual needs.

Opportunity Grants. CEI proposed funding five to seven "Opportunity Grants," or scholarships to train persons with disabilities to act as housing activists in their communities around the state. Opportunity Grants would also be used to train consumers to fulfill their personal housing needs, including homeownership, credit repair, and landlord/tenant relationships.

CEI received a grant for \$20,500 for a nine-month grant period starting April 1, 2003. The initiative was named People with Disabilities Center for Housing Information in Maine (PWD CHIME).

The project coordinator conducted outreach through several strategies. He used different email lists, including lists likely to be used by people with disabilities, people who are poor, advocates, providers, state agencies, and people in the housing community. In response he received requests for direct assistance as well as opportunities to speak to groups and further disseminate information. He compiled homeownership materials, information for renters, home modification and design materials, and other resources for use by developers, renters, and prospective homeowners. He provided direct assistance to people seeking housing and trained advocates to attend public meetings, etc.

Successes

Synergy within CEI. CEI already had considerable expertise on creating affordable and accessible housing. This expertise made it possible to support demonstration activities. In return, demonstration activities enhanced CEI's understanding of the needs of persons with disabilities, and increased the availability of resources and information at its disposal.

Successful Homeownership. Through outreach and direct assistance, the project coordinator reports that a number of people were successful in pursuing homeownership. In one instance, materials made available through the demonstration project made it possible for a person with a visual impairment to attend and understand a homeownership class. That person went on to obtain approval for a loan.

Advocacy. The project coordinator reports that advocates trained through demonstration activities have appeared at community meetings and public hearings, providing input on housing issues of concern to persons with disabilities.

Challenges

Resistance to Disability Advocacy. The project coordinator reported that some prospective partners resisted his overtures. He believed that, among agencies serving persons with disabilities, there seemed to be a resistance to advocacy, perceiving that some professionals are annoyed when a person or program asserts the individual rights of a person with a disability. Within the broader community, he perceived a resistance to dealing with people with disabilities. In one instance, a quasi-state agency refused to provide a program brochure in an alternative format. In other cases, attempts to communicate were rebuffed with unreturned phone calls and email messages.

Insufficient Resources. The project coordinator cited insufficient resources as preventing him from completing some of his intended goals. In particular, developing a formal curriculum for training advocates, a web presence and completed catalog for information and resources, and a stronger connection with the commercial community (*e.g.*, bankers, lawyers, and real estate professionals) were all identified as activities requiring more than that provided by demonstration resources.

Organizational Turbulence. The project coordinator reports that during the life of the project, CEI experienced downsizing and changes in its organizational structure. As a result, progress in implementing demonstration activities was negatively impacted and the PWD CHIME project was unable to achieve a sustainable basis.

■ Conclusions

As the Work Group identified, there are numerous barriers to housing for persons with disabilities. The small amount of funding offered under these demonstration projects was insufficient to meaningfully impact the affordability or accessibility of Maine's housing stock, perennial barriers to access that require sustained incremental steps and concerted, long-term planning and investment. The lasting impact of these efforts is not found in more accessible and affordable housing, but in the better information about housing, better understanding of housing needs, and the increased capacity of project participants to speak to housing needs.

Central to all three demonstrations was the focus on the consumer: the consumer's need for information, the consumer's need for housing, the consumer's need for assistance. All three demonstration projects were solidly committed to seeking out the consumer voice to develop or shape products, to define needs, or to advocate for change. There were multiple roles through which persons with disabilities could provide input: as paid staff, advisor, survey respondent, or as trainee. While each of the demonstrations encountered challenges in reaching out and successfully engaging consumers, the barriers to participation in certain demonstration activities were comparable to some of the barriers that limit participation in the community generally: trust, isolation, transportation, and the disability itself. No effort to create consumer-centered housing options can avoid confronting these challenges.

■ Appendices

- A. Access Technical Advisory Group (TAG) Members
- B. Excerpt from Greater Portland Housing Choices Toolkit: *Living Alone and Overcoming Isolation*
- C. Excerpt from *Making Our Own Place: Final Report*, by Peggy Cope Mascher, Tri-County Mental Health Services
- D. Excerpt from PWD CHIME Presentation

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Excerpt from Greater Portland Housing Choices Toolkit

Excerpted from *Greater Portland Housing Choices Toolkit*,² written by Alex Myhaver, edited by Patrick Quinlan, under the direction of Brian Wallace of Amistad. Portland, Maine (April 2004).

Living Alone and Overcoming Isolation

Living alone has its advantages and its disadvantages. When you live alone you have privacy and you don't have to answer to anybody else. This can be great. When you live alone you don't have anyone to talk with and you can get lonely and bored. This can be depressing. Living alone is a challenge. You can learn to have your freedom and not be lonely.

Being Socially Responsible

When you live alone you need to be socially responsible. This means that you need to try hard to be with other people. Being socially responsible means that you need to pay attention to what other people are doing and saying. Being socially responsible means you have to share things about yourself with other people. Being socially responsible does not mean you have to be intimate with strangers. It does not mean you have to suddenly make all kinds of new friends. It does mean you have to make an effort to build trust with others.

Being socially responsible means you should meet with other people and do things at the times you say you will. This can be a challenge. When you live alone there is nobody home to encourage you to follow through with your plans.

Avoiding Social Isolation

There are many ways to avoid social isolation. It's good to find a way to be involved with the community. There are things you can do to make sure you are involved with others. You can volunteer, join a fitness club, or get a paying job. You can become a member of a club that does things you like. It's a great way to have fun and meet friends. You can go to the library, take a class, or go to the movies. You can even take a bus ride to the mall. These are some suggestions. There are many things you can do to be social. Be imaginative and try.

Enjoying Your Freedom

When you live alone your privacy and your freedom is important. This might be your only opportunity to live alone. So take advantage of it. Become your own best friend. Do things that you would like to do if others did not constantly surround you.

Make sure you take care of yourself. Eat regular meals. Have that cup of tea in peace. Do your apartment cleaning. Listen to music and exercise. Play pool. Work on your computer if you have one. Read books. Have quiet time and meditate. Call the person you would like to date! Start a

² The complete toolkit is available at AccessMaine.org:
<http://www.accessmaine.org/Toolkits/HousingSource/housing.htm>

dream journal. Pray! Yes, you can even watch television and talk on the telephone. Just don't sit home and do nothing all day long.

The important thing to remember is that the time you're alone should be quality time. It can be a time you look forward to. This will help you get your own needs met. It will also make it easier to be around others again.

Living alone will have advantages and disadvantages. Get involved with your community and avoid social isolation. Appreciate the time you are alone and do things that are important to you. You will have a sense of accomplishment. This will improve who you are.

■ Excerpt from *Making Our Own Place*

Excerpted survey results from *Making Our Own Place: Final Report*, Peggy Cope Mascher MSN, RN, BC, Tri-County Mental Health Services (February 22, 2005)

Demographics: n=30; 22 women; 8 men; average age was 45±17 yrs.

Disability Status: Fifteen described themselves as having a mental or emotional illness (participants were not asked about their specific diagnoses), six described themselves as having a physical illness and nine described themselves as having both (n=30)

Living arrangements

- 27 live in an apartment or home
- 2 live in what was described as a >temporary= setting
- 1 lives with family
- 9 live alone
- 19 live with others
- 1 had children under the age of 18
- 13 participants wanted to live alone in their own space
- 10 said they would not want to live with other people with disabilities, but 7 said it didn't matter or they had friends with disabilities

Longevity

- 19 have not moved this year
- 3 moved once
- 1 moved three times
- 1 moved four times
- 3 described themselves as being homeless at least once during the last year

Comments

- “Labels do not define people and their value.”
- “I have all can do to take care of myself.”
- “As long as I get along it doesn't matter.”

Satisfaction about living space

- Things people liked best in their current living situation: quiet, location, security.
- “I can come and go as I please.”
- “It's not a psychiatric hospital.”

Dissatisfaction about living space

- Difficult to get to or there is too much lifting and carrying.
- Utilities cost too much.

There's not enough room.
It's too far from town.
I don't like the neighbors.

Most important considerations in choosing a place to live

The ability to do what I want to do, when I want to do it,
Privacy and space.
Fifteen people would like to have a pet.

Choice of services: Where do you go first when you need help?

- 16 used Tri-County services (case management, psychiatrist).
- 18 stayed home alone and relied on self care methods
- 16 used friends and family for support (the choices were not mutually exclusive so the totals exceed the n).

Frequency of use: How often do you use resources when you need help?

- 8 reported calling their case manager “often.” This data is flawed by a lack of definitional specificity
- 13 called friends “sometimes.”
- 9 called family “sometimes.”
- 11 called their psychiatrist or their primary physician “sometimes”
- 8 called other mental health staff “sometimes”

Greatest Areas of Need Expressed by Participants

- 22 participants said they had difficulty accessing reliable transportation to get around.
- 22 participants said they wanted to be able to reach help day or night.
- 14 said they would like to have people come to them day or night.
- 15 participants were dependent on SSI or SSDI (range of income was listed as \$400-\$1,200 average \$667.00) 11 said that their money was barely enough or not enough to live on.

■ Excerpt from PWD CHIME Presentation

Excerpt from June 9, 2004 presentation by Steve Hoad, project coordinator for PWD CHIME, to the Quality Choices Technical Advisory Group

Lessons Learned? Briefly...

Accomplishing change takes persistence, time, money, and collaboration plus cooperation. Acceptance of change is neither quick nor straightforward within the agency mentality. Service to People with disabilities often takes a back seat to administrative details. Accommodations are often viewed as “special rights” and cause anger, foot dragging, and roadblocking.

Don't count your chickens before they hatch!

Create the project with success in mind and success will follow.

A positive spin can still create collaborative spirit even in the worst times!

Advocates can create change and opportunities if they are trained in their subject area and advocacy.

People are proud, sometimes to their own detriment.

Success is always just a few thousand dollars away!

Some interesting numbers:

Referrals by E-mail and telephone 54

Contacts by agencies looking for information 38

Requests by Orgs and Agencies for Outreach 5

Valuable resources provided by National groups 10

Information requests from and outreach presented to agencies or their representatives:

BDS mental health

BDS mental retardation

Disability Rights Center

Elder Independence,

Peoples' Regional Opportunity Program

Midcoast United Way

Vocational Rehabilitation

Division for the Blind and Visually Impaired

MS Society

Pinetree Society

Maine Association of Peer Support and Recovery Centers

Advocacy Initiative Network of Maine

100 Pine Street in Lewiston

Speaking Up For Us

Good Will,

The Iris Network

Many homeless shelters

Many domestic violence groups

Portland Tenants' Union

Lewiston Downtown Neighborhood Association

Maine Association of Independent Neighborhoods
Headstart organizations
Maine Equal Justice Project
Many Community Action Projects
Maine State Housing Authority