

The Key To My Own Front Door

"For every one person with a [disability] label who owns or leases their own home, twelve people who get residential services do not. This is a good start, but I'm worried about the other twelve people. Our group wants the President's Committee to ask the President to make it easy for people with disabilities to have a home that they control with a lease or ownership.

People need to have control of their front door.

-T.J. Monroe

Across the United States, at least 28,000 people with mental retardation and other developmental disabilities experience the rewards and responsibilities of having a home of their own. Most of these people lease their homes, but a small and growing number have the opportunity and assistance they need to become home owners. Their experience demonstrates that many people now housed in large and small residential facilities would, if offered the opportunity, chose and benefit from having the keys to the front doors of safe and decent homes that they select and control with the support of family and friends and the assistance of agencies dedicated to providing individually required personal assistance. They have shown that levels of initiative and commitment predict who can live successfully in their own homes far better than levels of apparent disability can.

While this working group focused on housing, it is vital to recognize that most people with mental retardation and other developmental disabilities can only live in a home of their own if effective, sufficient, flexible, individually focused personal assistance is available to them. The continuing, massive investment of federal and state funds in congregate residential facilities of all sizes constitutes the biggest single barrier to more people gaining control of their own front doors.

People with mental retardation and other developmental disabilities and their allies have found that many doors open when approached positively, with the expectation of collaboration. Landlords, property developers, and lenders have shown willingness to help people gain control of their own front door by joining in the negotiation of creative solutions to the many problems that arise as people whose incomes and savings are significantly restricted by federal and state income support and medical assistance policies. Families have shown willingness, within their means, to contribute effort, money, and property to assist their sons and daughters and brothers and sisters to establish and maintain control of a secure home. Most people who are asked to join in the effort at least

express willingness to explore the possibilities and a desire for more information, and many are glad to help.

Both those concerned with people with disabilities and those concerned with housing have found themselves interested and challenged by their encounter with another culture. Representatives of each culture have had to find their way through the changing complexities of the other. They have had to work to develop an understanding of the contending interests, organizational structures, issues, controversies, histories, vocabularies, and acronyms in the other field. They have found enough shared concerns and cross-cutting issues to make joint work interesting and satisfying.

Joint effort across public and private lines and across the boundaries of a variety of state and local housing and developmental disabilities agencies have shown strong mutual interest in developing the housing market for individuals with mental retardation and other developmental disabilities. Opportunities and creative solutions to common problems are widely distributed across the United States, and a broader, stronger network for sharing information and contacts would serve people with disabilities well.

While there is room for further debate and exploration, participants in this developing housing market believe that the protections offered by The Fair Housing Act and The American's with Disabilities Act, and the many opportunities to build coalitions with other people with disabilities and others concerned about affordable housing, offer people with mental retardation and other developmental disabilities fair chances to participate equitably in local, state, and federal housing programs. While there is a great need for information and organization, there does not seem to be a need to create special benefits for people with mental retardation.

Because local and state initiatives have already created many different ways to offer people with mental retardation and other developmental disabilities the keys to their front doors, no single federal policy initiative is necessary or desirable. What is required, from a number of federal agencies, is clear signals and strengthened incentives to enable people to find their way into their own homes. While some improvements may require Congressional action, PCMR's ex-officio members can take many helpful actions within their existing authority and their current agenda to insure more equal access to individually selected and controlled housing for all people, regardless of disability.

These actions would be particularly and immediately helpful.

- Assert vigorously that implementing The Americans with Disabilities Act means accepting a commitment to insuring that people with mental retardation and other developmental disabilities have equal access to all housing related benefits, especially to initiatives intended to assist people to own and control their own homes.

- Strongly promote the principle that affordable housing must be dispersed in all neighborhoods rather than concentrated in particular areas.
- Emphasize that all federal housing funds should be available to develop individual housing and not just congregate housing. This would begin to correct the current bias toward using federal housing money to finance facilities that group people together by design.
 - Allocate 50% of Section 811 funds to the support of individual home ownership.
 - * Provide strong and clear messages that Community Development Block Grant Funds can be used for individual housing.
 - * Focus HOME and HOPE3 programs specifically on individual home ownership.
- Actively promote building designs which make it easy for all homeowners to flexibly accommodate accessibility needs.
- Make it possible to apply all available housing funds to either rental or home ownership. For example, make Section 8 Certificates and Vouchers applicable to home purchase as well as to rent subsidy.
- Simplify application processes and improve their accessibility.
- Emphasize the opportunities arising from lending to people with mental retardation and other developmental disabilities for satisfying the obligations of the Community Reinvestment Act. Both information collection and the wide dissemination of positive examples among bankers and among people concerned with disability issues will serve this purpose.
- Clearly and widely acknowledge that income from SSI and other disability related benefits constitutes viable income for purposes of paying a mortgage.
- Encourage the desire of many people with disabilities to save for their own homes by creating an optional Plan for Home Purchase, which would expand the limits of savings allowed to SSI and medical assistance recipients for the purpose of allowing them greater control over their own housing.
- Insure that federally sponsored initiatives to provide people with counseling and advice regarding all types of home ownership and home improvement are fully accessible to people with mental retardation and other developmental disabilities and their families.
- Encourage the desire of many families to contribute to disabled family members having homes of their own by offering incentives through inheritance tax policy and by reviewing the implications of the {Medicaid Estate Recovery Act.

- Encourage states and disability service providers who want to reinvest by moving resources away from less effective forms of service and toward providing necessary assistance to people living in their own homes.
- Deal with the current inequity that allows reimbursement of the costs of housing in ICF-MR funded facilities but excludes such reimbursement from Home and Community Based (HCB) Waivers. Allow both recovery of excess housing costs and bridging costs incurred in closing congregate settings through HCB Waivers.
- Encourage re-negotiation of long term leases on properties developed for residential facilities with HUD funds. Allow development of alternate purposes for properties or, if no suitable alternate use can be found, provide for abandonment of the properties.