

NATIONAL  
HOME OF YOUR OWN  
ALLIANCE

*ISSUES IN HOUSING*

*Based on a presentation  
to the  
1995 National Collaborative Academy on Mental Retardation  
conducted by  
President's Committee on Mental Retardation*

*September 8-11, 1995*

*by  
Jay Klein, Director  
National Home of Your Own Alliance*



## Issues in Housing

Written by

Jay Klein, Director

National Home of Your Own Alliance

Institute on Disability/UAP

University of New Hampshire

Based on Presentation to

1995 National Collaborative Academy

on Mental Retardation

Conducted by PCMR September 8-11, 1995

*“As you rely less and less on knowing just what to do, your work will become more direct and more powerful. You will discover that the quality of your consciousness is more potent than any technique or theory or interpretation.” -John Hieder*

Most people with developmental disabilities who are recipients of residential services live in institutions, group homes or community-based settings. Individuals obtain a package of services in which housing and support are linked. Even in so-called community-based settings, such as adult foster care or supervised apartments, a service provider is compensated for both housing and support as one service. For people who live in these settings, their associations and the daily pattern of their lives are dictated by their address. People must buy the package whether or not they like all of its components.

Because people are often congregated based on their support needs, a person's address determines the level and type of support received. If support needs change, the person is moved to another residence. This linkage between support and housing is one factor that has made it difficult, if not impossible, for individuals to decide where to live and to develop roots within their communities.

Home ownership provides a sense of control and belonging unachievable in the living arrangements typically available to people with developmental disabilities. Support can become more personalized when it is not dictated by the rigid protocols required when many people live together in a facility. With home ownership, the agency responsible for

providing support no longer owns or leases the house; the individual does. As needs change, support can be modified accordingly in the person's home. People are not relocated when the need for a new service or support arises and are thus more able to maintain stable and typical connections to their new communities. In this way, ownership serves as the platform for community membership.

On September 1, 1993, the Institute on Disability, a University Affiliated Program at the University of New Hampshire, entered into a five year cooperative agreement with the United States Department of Human Services' Administration on Developmental Disabilities to create a national technical assistance center on home ownership and control for persons with disabilities. The Alliance, was born as a result of the realization that 92% of Americans want to live in their own homes. Not only is this desire for personal space a basic human drive, but in our culture, it's a basic human right. Our five-year cooperative agreement with ADD represents their continued commitment to home ownership.

There are three primary goals of the Alliance. The first is to include people with disabilities in everything that we do.

The second primary goal is technical assistance to states. Over the five years of the program's funding, the Alliance will negotiate technical assistance agreements in 23 states, building coalitions of housing and disability organizations, lenders, and service providers. As we conclude our second year, we are currently in eight states: Arizona, Connecticut, Idaho, Illinois, Michigan, New Hampshire, New York, and Oregon. By October 1, 1995, we will have completed our review of the eleven proposals submitted this summer in response to our request for proposals. The National Home of Your Own Alliance Advisory Board, comprised of people with disabilities from around the country, is charged with the formidable task of selecting five from among those eleven proposals. Each state receiving technical assistance from the Alliance agrees to institute a demonstration project to assist a specified number of people to own or lease their own homes.<sup>12</sup>

The third goal of the Alliance is information and referral through a national information clearinghouse. The National Home of Your Own Alliance Toll-Free Information Line is 800-220-8770. In addition, we publish materials which describe our initiative, provide guidance for state coalitions, and describe our guiding beliefs, the most important of which is that all people deserve and desire control over their lives. Our future publications will offer information about our policy research and evaluation related to people with disabilities owning and controlling their own homes.

One of our publications, titled “Extending the American Dream” outlines the stories of 16 people in New Hampshire who bought their own homes and describes their experiences from a financial perspective. This publication addresses some of the questions that people typically ask about interest rates and home prices, where to obtain funding, and what types of supports people need to accomplish their home ownership goal. The report is available by calling our toll-free number.

The New Hampshire project outlined in the American Dream report is just one of the successful state pilot projects which is working to chip away at the misguided paradigms of traditional services for people with disabilities. From a national numbers perspective, we have seen a huge decrease in institutional living for people with disabilities. In 1990, the population of state institutions decreased to about 84,000 and five years later, it’s down approximately fifteen percent. While we applaud this reduction in institutionalization, it is critical to note that this still means that 70-75,000 people are still living in large state institutions in 47 states throughout this country.

And for those who have been allowed to move on, what do the changes in their living situations look like? The fact is that most people with developmental disabilities who are recipients of residential services still live in institutions. They are smaller, but they are still institutions, with parking lots and nurses stations, designated smoking areas, day rooms, and fire escapes. The reason is that traditional services are based on program and professional paradigms which imply that professionals know best and that programs are based in buildings. The person is not the basis for the program. It’s based on a building. It’s driven by funding. It’s guided by regulation. It’s based on readiness and movement. When a person earns the right to move to the next level, they may get to move to the next level. The real problem is that in trying to move through this arbitrary progression from one step to the next step, from one program to the next program, from one facility to the next facility, from one level to the next level, people end up jumping through hoops for other people. The hoops are determined by the hoop holders, and since the hoop holders change all the time, so do the hoops.

We have assessments to figure out where people belong. We have criteria that drive expectations and arbitrary and artificial rules. We have models that have become molds rather than tools.

As service providers and others came to realize that the big state institutions were not the answer, traditional services turned to something called “community-based” services. This is not a real paradigm shift, however, it truly means that the facility is **based** in the community, like an army base is “community-based”. But, there are still big barbed wire fences around it. The community is not let in. It’s just based there.

Our terminology is what has changed mostly. We now use terms such as “home-like” to describe these places. “Home-like” .... *like* a home? “Family-like” ... *like* a family? How many people want to live in a place that’s *like* a home, with a group of people, not of our own choosing, that are labeled family-*like*?

A lot of service providers sensed the need for a change in our traditional service approach so they changed their program names. Now we hear some very fancy, wonderful names. Popular words are “options” and “dreams.” It’s “community dreams,” “community options,” “community independent living,” “community independent living with options and choices and dreams.”

But, of course, people realized we have to do more than just change the name. So we reduced the sizes. Smaller became better, *per se*. But what does that really mean? Look at the numbers. Two hundred thousand people in “six beds or fewer.” It’s still “six beds or fewer.” It’s still a facility. It’s still a program. It’s still someplace where we put people and where we control people.

We have manipulated language. We have changed the language around so that we disguise what we are talking about. The fact is we are talking about tailoring programs to fit new funding streams. Every time there is a new funding stream, service providers start spending it by fitting people into the slots for which the funding stream was created.

The HUD 811 Program is a good example. It used to be the Section 202 Loan Program and then it became the Section 811 Grant Program. It’s the same program under a different number. Now it’s scattered site grant funding, but it’s still for 40 years ... a 40-year grant instead of a 40-year loan. It’s still based on disability categories and only accessed by non-profits, not by individuals. There were a billion dollars in requests last year to give out 387 million Section 811 dollars ... funds which will continue to institutionalize people.

Thirty-six states currently use more than two-thirds of their Federal ICF/MR (Intermediate Care Facility for the Mentally Retarded) resources to support placements in large, congregate care settings greater than 15 beds in size. These services are designed for specific disability categories. So, for example, people with cerebral palsy should live here, and people with autism should live there. To facilitate the process of moving from one facility to another, we have invented new levels of readiness to correspond with new types of facilities. But this is the same thing only with new labels. Whether they have 6 beds or 66 beds, they're still facilities. People want to live in homes, not facilities!

The essential dream is to support people to have *their own* homes. And, believe it or not, this doesn't mean asking for more money. It means being creative about defining an individual's support needs and effectively reallocating existing resources to meet those needs.

The key is that it must be about an individual. It is about one person's resources, one person's support requirements, one person's home. The person controls the home and controls their own support network. It truly must be the person's own home. Whether they own or lease the home doesn't matter. The issue is *who controls it?* How do we tell...? Whose name is on the mailbox? Who hires the supports? Just think about it ... how many people would want somebody that they don't even get to hire touch their body?

Besides the name on the mailbox and who hires the support, the other fundamental changes are also straightforward. For example, earlier we referred to manipulating the language we use. The essential language change, however, is simply that we need to use everyday language, language that we can all understand. It's a matter of avoiding acronyms and other program-based names, titles, jargon, and lingo. It's a simple shift ... "Don's house" not the "Adobe Independent Living Group Home." We simply need to remember that we all have "friends" with whom we share support, not "volunteers." We focus on a person's "capacity" not their "deficiency." We are concerned with "care and love" not "programs and services."

Paradoxically, we need to shift our emphasis away from the concept of "independence." As Bishop Desmond Tutu has said, "The fundamental law of human beings is interdependence. A person is a person through other persons." We are people who live together, with each other, as part of a community.

We are talking about being adults, about being ready to live in our own places and figuring out how we can get the support that we need in order to do so. *Being* ready, not *getting* ready.

Let's dispel the notion of matching or grouping based on disability. People live together because they are in love, or in lust, or for convenience, because they like one another, because they choose to live together, not because they have a disability. People don't live together because they knew each other from the group home or even because they happen to be good friends. If I were to ask you right now to make a list of the ten people you are closest to, with how many of those people would you want to buy a house? Just because you're close to someone, doesn't mean you want to live together or make a financial investment with them.

It's about choices and it's also about realistic expectations. We have unintentionally set people up to fail by assuming that they would, could, and should get along with roommates we chose for them. In many cases, these roommates were taken from a waiting list for a particular program service. Typically, we tried to match people who scored the same on our assessment, believing that people who could not do the same things would get along. Once we made the match, we expected people to get along. If they did not get along, we tried teaching them conflict resolution strategies or put them on a social skills development program. Of course, if this did not work, we assumed the person had failed. Somehow, we had forgotten that the national divorce rate is between 50% and 60% and this frightening statistic applies to people who choose their own partners.

Another major shift is to dispel the notion of 24-hour supervision. People don't need 24-hour supervision. People need support. Sometimes they need access to support on a 24-hour basis; so 24 hours a day they need to be able to know that support is close by. But that is different from being supervised 24 hours a day.

Another paradigm shift involves focusing on what people can do, not what people can't do, what makes sense for people to learn, not what other people think they should learn. Some people place such value on domestic skills that they think everybody should learn to make their bed before they can live in their own home. How can I possibly agree with this when the truth of the matter is that I never make my bed ... and you can't make me. Why should we insist on such arbitrary criteria?

Planning and collaboration with others is really important. This means not only planning with professionals, but planning with everyone, including people's friends, family, neighbors, and assistants. We need to provide support to people by truly becoming their agents. Listening to the dreams and goals of people means spending time with them, walking with them to find out not only what their needs are but, also, what their desires and preferences are, listening to their pain and looking injustice in the face.

Home ownership is only one vehicle to having control over your life, but it happens to be the vehicle that I am very excited about because it is a direct affront to the real issues ... poverty, isolation, and control. These are community issues, not disability issues. The fact that people live in poverty and isolation and don't have control over their lives are the issues we should focus on.

People need affordable housing, but affordable housing is also a community issue, not a disability issue. We have to figure out a way for all of our citizens to have a decent place to live, and we have to build coalitions to accomplish the task.

As of 1992, over 325,000 people received services in out-of-home placements. Fourteen thousand, or 4.3%, of those people received supported living services. That means that 95.7% of people living in out-of-home placements are still controlled by somebody else. We have a long way to go. I'm optimistic, but the fact is, we have a lot of work to do. This is the hardest work I have ever done, and it may get harder before it gets any easier; but I am ready to keep doing it and I hope some of you are also.

<sup>1</sup> The five states selected on October 1, 1995, are: Georgia, Massachusetts, Missouri, New Mexico, and Texas.