

NATIONAL
HOME OF YOUR OWN
ALLIANCE

*NATIONAL HOME OF YOUR OWN ALLIANCE
1995 POLICY RETREAT
PROCEEDINGS*

APRIL 23-24, 1995

Prepared on behalf of:

*National Home of Your Own Alliance
Institute on Disability
University of New Hampshire*



July, 1995

The list of participants reflects the breadth of experience and expertise represented at this two-day roundtable. We would like to thank all the participants for their contributions to this far-reaching conversation. Jeff Strully's facilitation gave the complex and lively discussion a focus and a structure that allowed issues to emerge. David Hasbury's graphic mapping of the sessions (a section of which is reproduced on the front cover of these proceedings) provided a visual framework which helped capture people's remarkable energy and insights. Thanks to Susan Covert for recording the sessions and helping us to offer these proceedings for publication.

An event such as this could not succeed without the contributions of many people. The retreat was preceded by the first face-to-face meeting with Advisory Board members from all eight states receiving technical assistance from the Alliance. These grassroots leaders and the state steering committees who made their attendance possible provide the project with critical guidance and insight. Our project director Pat Laird and Commissioner Robert Williams of the Administration on Developmental Disabilities also attended the meeting and we would like to thank them for their attentive and reflective participation as well as their continued generous support. We also want to thank Howard Carson and Laurie Schwartz for representing the Advisory Board at the policy retreat.

As always we appreciate the willingness and vision of our colleagues in New Hampshire to support this national effort. In particular we would like to thank Don Shumway, Rich Crocker, Clair Monier, Al Robichaud, Donna Woodfin and the area agency directors.

We acknowledge the leadership and vision of Jan Nisbet, director of the Institute on Disability/UAP at the University of New Hampshire, in expanding the scope of this event to national housing finance and disability organizations. We would also like to thank Alliance coordinator Merrill Black and project assistants Rich Melanson, Kathy Bellerose and Peter McAlaster for their participation and practical assistance before, during and after the event to ensure its success and the dissemination of its proceedings.

Jay Klein
National Home of Your Own Alliance

TABLE OF CONTENTS

| | |
|--|-----------|
| Remembering Ed Roberts | i |
| Retreat Participants | ii |
| Background | iii |
| Opening Remarks | iv |
| THE PROCESS | 1 |
| 1. Support: Personal Assistance, Relationships, Home Maintenance | 2 |
| <i>Barriers/Identified needs/Opportunities, Suggestions.....</i> | 3 |
| Action Plan | 7 |
| 2. Finance | 8 |
| <i>Barriers/Identified needs/Opportunities, Suggestions.....</i> | 10 |
| Action Plan | 13 |
| 3. Options in Controlling Housing | 14 |
| <i>Barriers/Identified needs/Opportunities, Suggestions.....</i> | 15 |
| Action Plan | 17 |
| 4. Networks/Coalitions/Partnerships | 18 |
| <i>Barriers/Identified needs/Opportunities, Suggestions.....</i> | 19 |
| Action Plan | 22 |
| 5. Training and Education | 23 |
| <i>Barriers/Identified needs/Opportunities, Suggestions.....</i> | 24 |
| Action Plan | 26 |
| 6. Participation of People with Disabilities in Leadership Roles | 27 |
| <i>Barriers/Identified needs/Opportunities, Suggestions.....</i> | 28 |
| Action Plan | 30 |
| Closing | 30 |

“He said he heard the doctor tell his mother that it would be better if he died because he was going to be a vegetable. He said that if he was going to be a vegetable, then he’d be an artichoke: prickly on the outside with a tender heart.” ~ Joan Leon, *Executive Vice President, World Institute on Disability*

Remembering Ed Roberts

Activist, disability rights leader and good friend, Ed Roberts died as a result of a heart attack shortly before the Alliance policy retreat that he was scheduled to attend. Ed attended Berkeley in the sixties, inspiring a dozen other people with significant disabilities to enroll. He taught political science at Berkeley and eventually became the Director of the California Department of Rehabilitation. Ed’s advocacy efforts led the way for expanded opportunity in higher education for people with disabilities. Recipient of a MacArthur award, Ed co-founded the World Institute on Disability (WID), a public policy organization that promotes the inclusion of all people with disabilities. We dedicate the work of this Alliance retreat to his memory and to the legacy of his groundbreaking efforts.

Ed’s tenacity and resourcefulness made him a leader who helped others to see the potential within themselves. Those attending the Alliance retreat remembered Roberts’ courage, humanity, and humor:

He is an international hero, hundreds and thousands of people around the world have a ladder to climb, because he started to build it. He’s not a disabled hero, he is a hero; a real model as a man. He was someone who celebrated every minute of his life. (Judith Snow, *Centre for Integrated Education and Community*)

He transcends our movement, but it is also critical to claim him as our own; both because that is how he saw himself and because that is how we can move and build on him. His leadership will lend an example. Ed was good at curb cuts, not just in sidewalks, but in every facet of our culture. In some ways, large and small, that is what we are here to do. (Commissioner Robert Williams, *Administration on Developmental Disabilities*)

Ed Roberts was the father of Independent Living Centers. We have 400 centers, because of Ed and the people he taught. He would want us to continue the work he’s done, to keep fighting, and keep that tenacious spirit alive. (Ann Marie Hughey, *National Council of Independent Living*)

Ed had to keep working with how people perceived him. One of the things I really liked about him - was when he said, if he had to be seen as a vegetable, then he wanted to be an artichoke. I think that is because an artichoke is a very unusual vegetable and Ed was a very unusual man. (Nancy Ward, *Self Advocates Becoming Empowered*)

Retreat Participants

Betsy Anderson
Federation for Children with Special Needs

Dayna Ashley-Oehm
Nat'l Conference of State Legislatures

Mike Auberger
ADAPT/ATLANTIS

Allan Bergman
United Cerebral Palsy Associations

Merrill Black
Nat'l Home of Your Own Alliance

Val Bradley
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Howard Carson
Alliance Advisory Board Member

Susan Covert
Consultant, Institute on Disability

Elizabeth Edgar
Nat'l Association Mental Health Program Directors

Jeanne Elliott
National Action Coalition

Celia Feinstein
Institute on Disabilities, Temple

Cathy Ficker-Terrill
Ray Graham Association

Eugene Gagnon
NH State Representative

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American Network of Community Options &
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Nat'l Assoc. of State Developmental Disability
Directors

Judith Snow
Centre for Integrated Education & Community

Jeff Strully
Jay Nolan Community Services

Nancy Ward
Self Advocates Becoming Empowered

Bob Williams
Administration on Developmental Disabilities

Joe Wykowski
Community Vision, Inc.

Background

On September 1, 1993 the Institute on Disability, a University Affiliated Program at the University of New Hampshire received a five year cooperative agreement from 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.

This national center, called the National Home of Your Own Alliance, is currently working with coalitions of housing finance and disability organizations to develop pilot projects of home ownership and control in eight states. These states include: Arizona, Connecticut, Idaho, Illinois, Michigan, New Hampshire, New York and Oregon. The Alliance will work with an additional 15 states over the next three years, building coalitions of housing and disability organizations led by individuals with disabilities, their families, friends and advocates. Each state will be assisted to maximize its unique opportunities and to overcome its distinct challenges in creating home ownership and control. Our goal is to assist grassroots leadership to work with state systems to develop a critical mass of experience and practice within the lending, housing and social service industries to better serve people with disabilities.

Based at the Institute on Disability at the University of New Hampshire, the Alliance is a national technical assistance center which includes the Center for Universal Design at the University of North Carolina, United Cerebral Palsy Associations in Washington, D.C., Co-op Initiatives in Connecticut, the Institute on Disabilities at Temple University in Pennsylvania and the Human Services Research Institute in Massachusetts.

The Retreat

The Alliance sponsored a policy retreat in late April 1995 in Portsmouth, New Hampshire to bring together representatives of national housing, finance, and disability organizations supporting individuals with disabilities to own and control their homes. By bringing together a diverse group of leaders working on these issues we hoped to identify barriers and opportunities encountered in our work, share information, collaborate effectively on initiatives and influence policy. Facilitated by Jeff Strully, director of the Jay Nolan Center in Los Angeles, California, the two-day meeting brought together home owners, advocates, social service agencies, state and federal administrators and representatives from national disability, housing and finance coalitions and organizations. Thirty eight individuals attended the retreat, representing 30 organizations which share an interest in assisting individuals to own and control their homes. A complete participant list with addresses, phone and fax numbers is included in Appendix 1.

OPENING REMARKS

“Long-term care means community living and supports, not institutionalization.”

Jan Nisbet, Director,
Institute on Disability/UAP, University of New Hampshire

“We have all the more opportunity and responsibility to use what we do here to reinvigorate the American dream we call home ownership. People with disabilities for far too long have been denied the right and the opportunity to chart and control our lives and futures. This conversation is about changing that power dynamic.”

Robert Williams, Commissioner
Administration of Developmental Disabilities

“In the beginning we were unaware of the needs of home ownership for people with disabilities.... The attitudes and understanding of our staff changed with the Home of Your Own Project. We changed as human beings, and so did the bankers and mortgage officers as well. Changing vast bureaucratic systems is tough to do, but we're doing it.”

Claira Monier, Director
New Hampshire Housing Finance Authority

THE PROCESS

Framing the Issues

On the first day, retreat participants were asked to identify the issues that influence the ability of people with disabilities to own and control their homes. Each person spent time describing their organization or role in the Alliance and identifying the themes that seemed most critical. The issues which emerged from this discussion are organized around six major themes:

- Support,
- Finance,
- Options in Controlling Housing,
- Networks/Coalitions/Partnerships,
- Training and Education and,
- Participation of People with Disabilities in Leadership Roles.

From this roundtable discussion involving all participants emerged a “problem statement,” identified under each theme as a quote. For example under the theme of supports the problem statement is, “The key element in a person’s life is relationships. We don’t talk enough about the importance of relationships or work to ensure that someone is there for the person.”

Discussing Barriers and Opportunities

Day two began with participants breaking in small work groups. Each 4-5 person group spent 10-15 minutes brainstorming the opportunities and obstacles presented by each of the six themes identified in the first day. The summaries of these discussions are outlined as “Barriers/Identified Needs” and “Opportunities/Suggestions” in each of the six theme sections.

Making Plans

Finally, during the afternoon session of day two, three work groups assembled giving each participant an opportunity to work in depth on two themes. Participants were asked to develop action plans to address the barriers and opportunities identified in the morning session. Action plans follow the Barriers/Identified Needs and Opportunities/Suggestions of each theme.

What follows are the themes that emerged from the first day’s discussion, followed by the Barriers and Opportunities identified on the second day and the action plans developed on each theme.

SUPPORT: PERSONAL ASSISTANCE, RELATIONSHIPS, HOME MAINTENANCE

Problem Statement:

“The key element in a person’s life is relationships. We don’t talk enough about the importance of relationships or work to ensure that someone is there for the person.”

Judith Snow, Centre for Integrated Education and Community

Organizations providing assistance need to “stay small” to guarantee quality and personalized care. People with disabilities continue to experience tremendous isolation from the community largely due to the linkage between congregate living arrangements and supports, typically the only housing available to people with disabilities. Staff who have worked in these settings are providing assistance to people living in their own homes but may bring with them old attitudes and practices from larger congregate settings that make it difficult for the person to exercise control.

More effort can help guarantee that personal assistance is available for all those who need it. It is difficult to find competent paid personal assistance which many people require to live in and maintain their homes. Informal supports such as family, friends and neighbors are not always adequate. Home owners with disabilities may also periodically have more intensive health care needs and may require more flexible support during these periods. Increased creativity in organizing and providing personal assistance is required for services to reflect people’s preferences and gifts, and to help some people design the service package they need.

The guarantee of adequate personal assistance helps assure lenders that mortgages will be paid and homes well maintained. Lenders are concerned with risk management and property maintenance. Ownership requires an expansion of the type of support services needed to include timely paying of bills and home maintenance.

Support: Personal Assistance, Relationships, Home Maintenance

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Administering Support Dollars

- A funding stream for support must follow the person from birth through his/her life.
- Money is there, but it doesn't pay for what people need.
- If Medicaid shifts to state block grants, things could be worse. Nursing home industry and ICF/MRs have strong lobbies to protect their interests within the states.
- There is a lack of flexibility in agency practice and regulation at the federal, state and local level.
- People who have jobs and income do not qualify for financial help to pay for supports.
- If a co-owner loses their income, the mortgage can be in jeopardy.
- People may not know where to find money.
- Money doesn't flow directly to the person.

- Through the waiver, Medicaid can increasingly be a source of money for supports.
- Agencies can reallocate funds to create new options for personal assistance and other supports.
- Tax credits might allow people to pay for supports. Assistance can be provided on a sliding fee scale or by offering support subsidies.
- Existing programs are challenging rules, being more creative and flexible in providing support. Case managers are redefining their jobs.

Societal Perceptions

- There is a cultural perspective that only values work.
- People are marginalized because they need support.

- Develop a cultural definition of health that includes people with disabilities.
- Make personal assistance a viable career option.
- Assistance that comes from family, friends, neighbors and the community is more widely recognized.

Support: Personal Assistance, Relationships, Home Maintenance, con't.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Personal Assistance

- Personal assistants don't want to give up control.
- Doing taxes and the other paperwork involved in being an employer can be burdensome
- Staff/providers also fear a decrease in job opportunities.
- It is difficult to find competent workers, whether paid or volunteer. The groups we are drawing from to provide support are getting smaller and smaller.
- Labor laws can be restrictive. Laws prevent programs from paying for family members to provide personal assistance. The pay scale for live-in assistance, for instance, is in violation of wage/hour laws.
- Low pay continues to be a problem.

- Personal assistants can find new meaning in their jobs.
- We need to build coalitions among disability groups to help one another with support needs and to create opportunities for people to share/trade their skills and talents.
- National service and welfare reform could be used to create a personal assistance system.
- Locally, it may be possible to create assistance in an entrepreneurial way.
- Personal assistance can lead to increased friendships for a person who has a disability by making it possible for them to participate.

Families

- Families often have to wait too long to find out what is possible.
- Parents can feel threatened by the prospect of letting their adult children practice more choice.

- Parent support can come from those who have successfully supported their children.
- Parents can feel relieved knowing that they are learning from people who have had similar experiences.

Support: Personal Assistance, Relationships, Home Maintenance, con't.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Home Maintenance

- People are not knowledgeable about home maintenance.

- Home ownership initiatives can explore ways to provide training and counseling to first time home buyers about home maintenance.
- Utility companies can help with education about energy savers and help with bills.
- Home maintenance funds can be developed for all home buyers. Housing Finance Agencies may be willing to create these maintenance pools.
- The Alliance is working with the Social Security Administration to allow set asides in an escrow account for maintenance and to amend PASS to accommodate such funds.

Best Practices

- There are limitations inherent in written material for conveying information on providing support and building relationships.
- Information on linking people to needed supports/services needs to be better distributed.
- Providers' ingrained habits sometimes serve as a barrier.

- Training for kids on how to train a personal assistant, and mentoring on the model of Big Brother/Sister might help create a stronger base for quality service.
- A number of groups throughout the country have done innovative work around personal assistance and have valuable information to share. Expanded dissemination is needed.
- Information already exists on how to provide quality support in other materials such as WID Publications and NIDR research.

Support: Personal Assistance, Relationships, Home Maintenance, con't.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Community Involvement

- Barriers to community involvement include the isolation and loneliness that many people with disabilities experience.
- Keeping everyone involved including, extended family and neighborhoods, is difficult.
- People can become over-extended trying to provide adequate personal assistance and therefore tend not to assist people to be involved in their community.

- Community building can lead to additional assistance. Collaboration with churches, home builders, trade schools, Habitat for Humanity and Americorp offers opportunities for community participation.
- Alternative housing models (coops, mutual housing) can offer built-in assistance to its members. These arrangements also offer opportunities for meeting and developing relationships with others.
- Assistance can and is being provided in some places to inform people about social activities and community events and to help them to participate.

*Support: Personal Assistance, Relationships, Home Maintenance/
Action Plan*

| <i>Key Players</i> | <i>Action Steps</i> |
|--|--|
| National Alliance | <ul style="list-style-type: none">• Serve as a clearing house to disseminate Fannie Mae Home Owner Guide and other information• Provide more information about relationship building• Share information on best practices (i.e. innovative UAP projects)• Organize and disseminate ideas generated at this retreat• Support people with disabilities in Alliance states to have increased participation in the project |
| ADD, President's Commission on Mental Retardation, ARC's and the Consortium for Citizens with Disabilities | <ul style="list-style-type: none">• Work to insure people with disabilities are included in the national dialogue on housing• Use connections to be a force at the national level• Push a national housing agenda |
| National Action Coalition and Self Advocates Becoming Empowered (SABE) | <ul style="list-style-type: none">• Create mentoring movement where adults with disabilities connect with teens• Institute on Disability (UNH) & Partners in MA have done work in mentoring partnerships and can be a resource• ADD and OSERS can provide information about who else is working on mentoring |
| ADD & OSERS | <ul style="list-style-type: none">• Push for schools to include information and training about home ownership and personal assistance management• Put focus on relationships & personal choice by requiring providers to demonstrate they use funds to promote relationships |
| CARF & ADD | <ul style="list-style-type: none">• Part of licensing/certification/funding includes demonstration of individual choice |
| UAPs, HSRI | <ul style="list-style-type: none">• Promote training, support, and value for those providing personal assistance• Use individuals with disabilities as trainers/ provide support to them in this role |
| ADD & HCFA | <ul style="list-style-type: none">• Push for public funding to go directly to the individual |

FINANCE

Problem Statement:

"I'm tired of the term limited resources, it's limited political will that's the problem."

Michael Lehman, Institute for Community Economics

People leaving group homes and other congregate living arrangements should be allowed to take their support funds with them. Limited resources are a reality, and nearly every state has lengthy waiting lists for assistance. As Congress rearranges many federal programs, including Medicaid and HUD, the danger is that the discussion centers around how money will be saved by cutting programs and not about how people will receive the assistance they need with limited resources. Most resources are directed toward congregating and warehousing people in institutions and nursing homes.

Poverty is the common denominator for those seeking affordable housing. We need to look more closely at the cost benefit of home ownership for people receiving benefits, as resources can be reallocated in ways that make economic sense and also accommodate people's expressed preferences in assistance.

Resources available through HUD could be made more flexible to accommodate greater choice. In Colorado, the community reinvestment act was used as an incentive to involve banks in home ownership for people with disabilities. We need to learn to maximize *all* existing resources: i.e. Fannie Mae, Community Reinvestment Act, Federal Home Loan Bank forgivable loans.

There is a significant need for long-term affordability as well as dignified and equal access. As generic housing subsidies for low income people are increasingly at risk, significant tax breaks on mortgages that benefit upper income people remain protected. Resources that could be made available to make housing more affordable need to be used in a more equitable fashion. People with disabilities are "owned" by the agencies that serve them; their ability to buy a home is based upon meeting certain categorical eligibility criteria.

The group raised some other questions regarding typical sources of income people have used to finance homes of their own:

- As the Medicaid program is reorganized, will funding for personal options be deleted?
- How can housing and supports be financed for people who are not on the Medicaid waiver?
- How stable is SSI money?
- What happens to special subsidies in resale situations?

The issue of credit risk must also be addressed. A package for lenders that is easy to use and addresses their concerns would be helpful.

Finance

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Working with Others

- A person with a disability is seen as a credit risk by lenders
- Lack of understanding about specific needs of people with disabilities and different jargon prevent people from working productively together.
- At state and national levels, entities like Fannie Mae, Freddie Mac and housing finance authorities do not have input from people with disabilities.
- It is critical to build coalitions with the affordable housing community and represent home owners with disabilities as tax paying, revenue-generating citizens.
- Realtors, bankers and landlords need education about people's housing needs to help dispel myths and negative stereotypes associated with disabilities.
- People with disabilities and their advocates can have input into their states' Consolidated Plans.
- Send the Home of Your Own video and other information to housing finance authorities.
- More formal ways can be developed to connect those seeking housing with those who have it.
- Publish monthly guides on available housing, especially accessible housing
- Provide specific and continuous information to a variety of groups.

Family Involvement

- There is a lack of information available to families.
- Families have not traditionally been encouraged to participate in their adult family member's life.
- Families can use their money to help a family member buy a home.
- Families can work with the service system to plan for flexible supports.
- Information packages and training can be put together for families and distributed through parent networks.

Finance, con't.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Available Funding

- HUD may not look the same. Governmental programs are in a state of flux. We do not know how things will change.
- Mortgage underwriters typically have difficulty with nontraditional incomes and limited credit histories.
- Service providers and potential buyers are not aware of available financial resources.
- Lenders are often unwilling to consider joint tenancy and other options.

- HUD programs are currently being redesigned. We can help with the design to set a new direction more in keeping with people's preferences.
- Primary and secondary mortgage lenders are showing an interest in changing their underwriting criteria.
- Generic housing programs have information about financing that can be shared. It is important to be able to provide technical assistance to local groups about how housing finance works. Step-by-step home buyers' manual with a comprehensive list of financial resources would be valuable.
- Community Development Block grants present opportunities for specific set-asides for down payment, closing costs, rehabilitation and long term maintenance assistance.
- Many possible sources exist for down payments and financing (Fannie Mae, community loan fund, land trust, private endowments, etc.).
- State Departments of Developmental Services and Mental Health funds may provide funds for down payments.

Finance, con't.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Political Climate

- The current political climate could result in policies which cut people off completely.
- Across the board cuts will hurt people with disabilities.
- Use of Medicaid is becoming more constricted.
- Categorical groups are fighting each other.
- There is enough money, but it is allocated to the nursing home system.
- Managed care has severe limitations for people with disabilities.
- The disability community is not unified in their ideas or plans.

- The current political climate could result in policies which serve people more directly.
- People with disabilities and their advocates can lobby Congress to save programs and use electronic bulletin boards to disseminate legislative alerts.
- People with disabilities are seen as “the deserving poor.” We can use money not readily available to other low income groups.
- There is opportunity to bring anti-poverty groups together in a unified movement.
- An institution tax could be levied every time someone is moved into a nursing home.
- Insurance could be available to everyone regardless of where they live.
- As federal power shifts to the states it is increasingly important to educate key state players about housing needs for people with disabilities and share quality options.
- Proposals could be developed instituting economic incentives for universal design including not funding housing that does not include universal design and providing strong tax breaks and other incentives for its use.

Finances/Action Plan

| <i>Key Players</i> | Action Steps |
|--|---|
| National Alliance | <ul style="list-style-type: none">• Continue to work with Fannie Mae to release a product that has flexible underwriting criteria• Provide solid data to Fannie Mae on existing loans |
| National Alliance & Fannie Mae | <ul style="list-style-type: none">• Analyze and disseminate information on existing loan products from FNMA, federal Home Loan Bank• Follow through with HFAs who are interested in the Alliance |
| National Alliance, United Cerebral Palsy Associations, National Action Coalition | <ul style="list-style-type: none">• Research states with members on House Finance/Banking Committee - organize to influence them• Create party-line for constituents to use |
| Cathy Ficker-Terrill | <ul style="list-style-type: none">• Contact Kansas HUD office about pilot project with Section 8 vouchers |
| Each Alliance State | <ul style="list-style-type: none">• Help banks meet their CRA requirements with low interest loans or grants |

Options in Controlling Housing

Problem Statement:

“Beware of home ownership as a model for everyone. We’ve failed the moment we stop asking, ‘What do you want?’ “ Cathy Ludlum, Co-op Initiatives.

Housing cooperatives and community land trusts can offer people ways to work together and provide mutual supports. Home ownership is one way of having control over the place you live. We need to insure that people can exercise options, preferences and control in a variety of ways. Access to services, supports and transportation are vital considerations in helping people decide where to live.

We need to increase demands for life-span design and be realistic about what can easily be rehabbed and made accessible. Too often affordable homes are located in distressed communities, but it doesn’t have to cost more to make high quality housing accessible and universally usable.

Options for Controlling Housing

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Best Practices

- **Having a house mate means sharing control; this doesn't work for everyone.**
- **Taking on new responsibilities can be intimidating.**
- **A person with a guardian is less able to execute documents associated with control of housing (loans, leases, joint tenancy agreements).**
- **Facilitating choice for those who do not communicate in traditional ways is challenging.**
- **Lack of adequate supports can still severely limit options for individuals.**

- **Coop ownership of duplex or apartment building offers more personal space.**
- **Assistive technology is increasing opportunities for people with disabilities.**
- **In some states guardianship laws are being reformed and circles of support are replacing guardians.**
- **The National Alliance is currently researching "best practices" and will produce its results in the fall.**
- **Options which separate housing from supports have expanded choice and control.**

Training and Information

- **People do not know how to get what they want and are not aware of all their options.**
- **Human service professionals and community people do not have adequate information about individually controlled housing.**
- **Within our own civil rights movement, we need to be more in tune with people with intellectual disabilities.**
- **Neighborhood resistance can be an issue.**
- **There is lack of information about the Fair Housing Act.**
- **There is continuing prejudice against people with disabilities.**

- **Training and information about housing options (community land trusts, coops, mutual housing associations) is available.**
- **A key task is to help people build expectations about having a home and making choices. This could be accomplished by offering training to individuals on choosing the housing that makes most sense for them and on managing their own supports.**
- **There is less resistance to individual ownership than to group homes.**
- **Disability advocates are increasingly using the Fair Housing Act to educate and enforce equity in the provision of housing.**

Options for Controlling Housing, con't

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Finances/Politics

- People with disabilities typically do not have credit.
- Systems argue that there is an economy of scale in operating congregate housing. Medicaid is biased in favor of congregate settings. Congregate settings are viewed as investment opportunities.
- In most situations, the money does not follow the individual when he/she leaves an agency.
- There is a lack of adequate cash assistance for people.
- People belong to agencies. Many agencies existence is dependent on maintaining their census.

- Provide tax credits to landlords who make housing accessible.
- We need to work creatively with the housing community and consumer credit counseling to overcome credit issues.
- A key task is to collect data illustrating that when individuals control their own homes it can be financially feasible.
- Reduction of federal bureaucracy may put more money in local communities and create an environment for large system change conversion projects.

Coalitions

- We need to build partnership with grass roots community housing developers.

- An organization in Rhode Island, for example, worked with existing housing cooperatives to open up housing options.

OPTIONS FOR CONTROLLING HOUSING/ACTION PLAN

Key Players

Action Steps

Enforcement of Laws and Regulations

| | |
|--|--|
| ADD | <ul style="list-style-type: none">• Find right place in governmental structure to enforce existing accessibility laws in building and remodeling |
| National Alliance | <ul style="list-style-type: none">• Get out information about enforcing accessibility laws |
| ADD, P&As, Legal Services | <ul style="list-style-type: none">• Build case law that people cannot be refused mortgages or leases, and cannot be evicted when services fall apart or when they decide they don't want specific services• Encourage people to demand their rights |
| SABE, National Alliance, Fair Housing Councils, Disability Organizations | <ul style="list-style-type: none">• Ensure that people with disabilities have equal access to housing opportunities |

Finances

| | |
|---|---|
| National Alliance | <ul style="list-style-type: none">• Promote accessing money that doesn't link services to housing |
| ADD, CCD, ADAPT, National Alliance, others | <ul style="list-style-type: none">• Search out and pressure appropriate governmental entities to change funding structures so money follows the individual• Press for preference toward individualized funding (personal assistance, family support, vouchers) |
| Institute on Community Economics/ Michael Lehman | <ul style="list-style-type: none">• Will stay in touch with Alliance on financial issues |
| People with disabilities, their advocates, CCD, National Alliance | <ul style="list-style-type: none">• Be involved at federal and state levels in helping define how Medicaid is spent |

Training and Information

| | |
|-----------------------------------|---|
| National Alliance | <ul style="list-style-type: none">• Publish best practices of all sorts - coop housing, co-housing, how to plan and develop housing and supports |
| Self Advocates Becoming Empowered | <ul style="list-style-type: none">• Leadership training on community living, how-tos and understanding the jargon |
| ADD (other funders) | <ul style="list-style-type: none">• Don't award money until organizations have completed training and gathered up-to-date resources about personal choice and options |
| Center for Human Policy | <ul style="list-style-type: none">• Incorporate ideas into CHP products. Make it fun |

Networks/Coalitions/Partnerships

Problem Statement:

“The politics of the day seems to be divide and conquer. We can continue to play that game if we chose, or we can break out of the box.”

Robert Williams, Administration on Developmental Disabilities.

Home ownership for people with disabilities can be integrated into general state housing policies. We need to do a better job of connecting with the community-based affordable housing movement. Let's maximize, not duplicate, the efforts of others. Effective partnerships are essential to achieving home ownership. In Minnesota, the Institute on Community Integration worked with their state's ARC, Department of Developmental Services, and Housing Authority to produce a manual on person controlled housing.

It is important to help bankers and other lenders really *see* the person who wants housing. As a grass roots approach, more local partnerships need to be developed and better methods of creating a link between those who want housing with those who can provide it are needed. Local realtors have been extremely helpful in finding affordable, accessible properties. Connections can be made with the local Home Builders Associations.

The group raised other questions regarding networks, coalitions and partnerships which would assist people to own their own homes:

- how can we circumvent different low-income groups being forced to compete against one another?
- can the move to managed care, which has devastating implications for people with disabilities, be used to our advantage?
- community building is needed with different segments of the disability community.

How can families be a part of this?

- what coalitions are needed to address these concerns?

NETWORKS, COALITIONS, PARTNERSHIP

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Within Disability Movement

- We are separated by disability, we are not taught to be allies. We are caught in our own segregation - i.e. kids under 21, veterans, etc.,
- History of tension exists in evolution of MR services into a DD system.
- We are not in control of DD Councils/ Independent Living Centers.
- Limits on communication barriers and lack of transportation and funds contribute to isolation.
- While cross-disability coalitions can be used to increase mortgage availability, there is a fear that if Home of Your Own is truly cross-disability there will be fewer opportunities/ resources for people with developmental disabilities.

- We must answer the question, "Do we have a cultural identity around having a disability?"
- We can build cross-disability coalitions.
- The development of a mentoring network for adults and children with disabilities might begin to bridge some barriers. E-mail might provide a forum for kids.
- School transition plans for high school students can be written in concert with adults with disabilities.
- Anyone under 18 admitted to an institution should be provided the opportunity to have a guardian with a disability to advocate for them.

With Other Special Interests

- The disability community doesn't recognize all the players and other coalitions don't recognize the disability community as part of their network.
- The disability movement is primarily white middle class, therefore there are cultural barriers to overcome within the movement as well.

- Stronger alliances can be formed with civil rights groups, low-income advocates, multi-cultural groups, the aging (AARP) and youth builders in order to counteract the tendency toward turf protection thinking.
- In building coalitions for Home of Your Own, we can focus attention on achieving cultural diversity.

Networks, Coalitions, Partnership, con't.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

With the Housing Community

- Not knowing the key players within the sphere of housing finance is a barrier.
- We run in our own channels and don't reach out to others.
- Different groups have their own language/jargon.

- We can work with the low income housing movement to develop creative options co-housing, land trusts.
- There needs to be more collaboration with those in the housing community such as Fannie Mae, Freddy Mac et. al., Public and state Housing Authorities, Mortgage bankers, primary and secondary lenders, national and local realtors, National Home Builders Association, the National Association of Remodeling Industries, Architects, National Design Association, and community based non-profit housing developers.

Other Groups

- The group acknowledged as barriers the prejudice against people with disabilities and our own lack of patience. Becoming a credible member of a group takes time, often 2-3 years.

- Build coalitions with the private sector including making better use of personal connections for community building. One example was Ron Mace at the Center for Universal Design working with Home Depot to include universal design displays in all their stores.
 - There are opportunities to connect with community leaders and organizations such as labor unions, churches, synagogues and the League of Women Voters. Municipal, state, and national elected officials can use their networks such as National Conference State Legislators, National Governors' Association and the National Conference of Mayors.

NETWORKS, COALITIONS, PARTNERSHIP, CON'T.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Training and Information

- There is information overload. It is impossible to be aware of all that is happening.
- The question of representative leadership is an issue given that the disability movement is primarily white middle class.
- Not enough people with disabilities are in leadership roles. Some people are asked over and over again to represent the disability community.

- Synthesize and disseminate information coming from a variety of groups through the Alliance publications, I & R line and Web information server.
- People recommended exploring increased opportunities for multi-cultural training. The Peace Development Fund in Amherst, Massachusetts does training in this area.
- Develop an Alliance Newsletter to share best practices and success stories, distribute to state departments of MH/DD, housing authorities, families.

NETWORKS, COALITIONS, PARTNERSHIPS/ACTION PLAN

| <i>Key Players</i> | <i>Action Steps</i> |
|--|--|
| National Alliance | <ul style="list-style-type: none">• Define and disseminate coalition building priorities• Distribute list of key organizations: include description of organization, address, phone and fax number, and contact people• Reassign Alliance staff and contractors for month of May to network with Congress• Investigate and create plan to link people in institutions with community people who have disabilities (this should be a formal, legal relationship, but not guardianship.)• Network with organizations working on multi-cultural issues (NAACP, SNCC, the Urban League)• Work with the National League of Cities and Towns |
| United Cerebral Palsy Association | <ul style="list-style-type: none">• Identify key congressional representatives involved in housing policy |
| Disability organizations and advocates | <ul style="list-style-type: none">• Make coalition building a priority• Develop short and long term goals for working with different groups at the national, state, and local levels |

TRAINING AND EDUCATION

Problem Statement:

"We need to help people consider home ownership as a possible dream." Cathy Ficker-Terrill

We must raise people's awareness and work on building communities. The public has the notion that if you have a disability you don't deserve your own home; we need data to educate decision makers and to demonstrate that what we are doing makes sense.

The worlds of housing and of human services don't always intersect in ways that are effective. Those within the disability community need to learn more about the mechanics of affordable housing, like where to go for subsidy, alternative ownership structures and creative finance. Support staff need to learn new skills in order to assist people in selecting, purchasing and maintaining their homes. Those who are knowledgeable about affordable housing need to learn more about the needs and preferences of people with disabilities. Human services and housing each have their own complex jargon and financing mechanics. This "language barrier" is an impediment to understanding and working with one another.

Additional questions about training and education included:

- what are the mechanisms that can assist people to work effectively at the local level?
- can generic housing counseling and materials be adapted for people with disabilities?
- how can families, especially young families, learn more about the possibilities for their children?

TRAINING AND EDUCATION

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

For People with Disabilities

- Information is not in accessible formats and sometimes is outdated and discriminatory.
 - Some training fosters bad practices i.e. psychiatric and social work assessments.
 - The lack of training dollars leads to a lack of good trainers, interpreters and accessible accommodation. The information contains a lot of jargon and acronyms which are inaccessible even to the general population.
- Raise people's expectations about home ownership through teaching the basics of home ownership and maintenance using information that is easy to understand and user friendly (Fannie Mae has good materials).
 - It is important to build acceptance of disabilities.
 - Electronic communication can help in disseminating information.
 - Modify existing training resources available to low income people.
 - In the larger context, we need to work for a continuing investment in education resources for students who have disabilities.
 - We need to expand leadership training and opportunities for people to be in decision making positions.

For the Housing Community

- Neither group knows enough about people with disabilities. People don't see they have a common cause or interests.
 - For Profits understand profit, but not people's needs. Non Profits understand people's needs, but don't know as much about financing. Each specialty group has its own culture and language.
- Identify leaders to train those in Alliance network in finance, i.e. NH Housing Finance Authority.
 - Education about use of "People First" language in working with Bankers, HUD, Housing Finance Agencies, Fannie Mae, Freddie Mac, Ginnie Mae et. al.
 - Use home shows and fairs as opportunities for education. Look for opportunities to work with For Profit and Not for Profit Housing Developers.
 - Fair Housing Advocates can look at disability as well as racism.

TRAINING AND EDUCATION, CON'T.

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

For Support Services

- The bureaucratic control of budgets and programs and reliance on a medical model of services serve as barriers to people having access to the kinds of services they want.
- The status quo persists even though it is inadequate, because people are uncomfortable with change.
- There are problems with high turnover and recruitment, as well as a lack of clear expectation.
- There are currently no certification or professional requirements for personal assistants.

- Personal assistance can become a more legitimate career opportunity by:
 - creating a Personal Assistance Corps through the national service initiative.
 - using people with disabilities and their family members as trainers to provide training, support, with stipends.
 - rethinking how services interact with people and families
 - revising case managers' job descriptions to help them become personal agents.
- Training could be developed and offered in public schools for people with disabilities on hiring and managing personal assistants.

For Policy Makers

- Policy makers need to be educated more directly about the needs of typically underrepresented groups (i.e. those with environmental illness, multi-chemical sensitivity).

- Work with UAPs to develop Disabilities Studies Programs, similar to African/American Studies. Temple University currently has such a program.
- Promote expansion of *Partners in Policy Making*, in schools as a course for all students.

TRAINING AND EDUCATION/ACTION PLAN

Key Players

Action Steps

| | |
|---|--|
| National Alliance | <ul style="list-style-type: none">• Identify, adapt, and disseminate quality training materials including Fannie Mae first time home owner manual• Survey home owners in NH and other project states to determine their needs for training• Find or develop curriculum for managing personal assistance and tap into a variety of national networks to distribute education and training materials |
| Institute on Disability/ UAP at the University of New Hampshire, Institute on Disability at Temple University | <ul style="list-style-type: none">• Promote development of Disabilities Studies Programs within the UAP network• Lead effort to increase Partners in Policymaking opportunities across the country |
| Jeanne Elliott | <ul style="list-style-type: none">• Work with Denver public schools to incorporate Partners in Policymaking in the secondary curriculum |
| National Association of Directors of Developmental Disabilities Services | <ul style="list-style-type: none">• Promote changes in service culture.• Identify and disseminate information about quality training for support staff |
| Betsy Anderson and Ron Mace | <ul style="list-style-type: none">• Work with Adaptive Environment Center Networks on training and educational issues |
| Institute on Disability at Temple University | <ul style="list-style-type: none">• Talk with AmeriCorp Project about using the National Service Initiative to sponsor a Personal Assistance volunteers |
| National Association of Housing Finance Agencies, National Association of State Legislators | <ul style="list-style-type: none">• Promote increased education and training on home ownership for people with disabilities through affiliation with their national organizations• Lobby Conference of Mayors and National Governor's Conference to include home ownership for people with disabilities on their agendas |
| All retreat participants | <ul style="list-style-type: none">• Commit to include workshops on home ownership at their organization's state, regional, or national conferences• Use National Alliance as a clearinghouse for presenters and training materials• Inform Alliance about upcoming conferences so they can share this information with others• Commit to building effective community partnerships with a variety of groups (i.e. housing community, elected officials, other disability and low income groups) |

PARTICIPATION OF PEOPLE WITH DISABILITIES IN LEADERSHIP ROLES

Problem Statement:

“People outside our community are trying to design for our needs. We need to do that for ourselves.”
Jeanne Elliott, National Action Coalition

People with disabilities should be able to define their own issues versus having others declare that for them. People with disabilities need to guide all aspects of their own home ownership and be part of the coalitions that work for systems change. Each person needs to select their own home and the type of assistance they need. In terms of the work of coalition-building, people with disabilities need to be involved at every step and supported in making decisions and assuming leadership.

PARTICIPATION OF PEOPLE WITH DISABILITIES IN LEADERSHIP

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Opportunities for Leadership

- We do not do a good job of supporting participation of people who have intellectual disabilities. People need assistance in order to participate.
- Some in power do not value people's direct participation in planning. Advocacy groups sometimes fail to focus on inclusion of all.
- Groups have their own culture/language and people often don't know how to mentor. People also don't want to give up or share leadership.
- Fear, stigma, discomfort and discrimination lead to a lack of opportunities.
- There is a lack of commitment to leadership development by governmental agencies.
- There is a lack of flexibility in accepting alternative ways of participating.
- There is a lack of money for leadership development.
- Not enough people with disabilities have leadership training and experience.
- Only those who have support are asked to participate.
- There is a lack of accommodations and follow through for people with disabilities to serve on boards.

Participation of People with Disabilities in Leadership, can't

- The National Self Advocacy Movement is a valuable resource. People with disabilities have a growing political and economic power base due to improved physical accessibility, technology, advocacy, changing attitudes and mentoring
- Leadership and participation leads to personal growth, increased knowledge and better self esteem. This is our number one issue.
- We can provide leadership training across disabilities and support people to implement and share information received at trainings.
- ADD is committed to funding leadership development
- We can develop more opportunities in non-hierarchical organizations for participation and leadership.
- Self advocates are wanted everywhere
- We can facilitate participation by personalizing support to meet an individual's needs.
- There are opportunities to increase mentoring opportunities within the independent living movement for people with cognitive disabilities and broaden recruitment efforts for leadership and participation.
 - We can provide increased leadership training at regional and state levels and distribute manuals (IL, OR, MO) on how to facilitate participation by board members with disabilities.

PARTICIPATION OF PEOPLE WITH DISABILITIES IN LEADERSHIP, CON'T

BARRIERS/IDENTIFIED NEEDS

OPPORTUNITIES/SUGGESTIONS

Within National Alliance

- Housing Finance and Medicaid are “brain surgery” to understand for anyone. Adapting materials to be culturally sensitive and accommodate various reading levels is challenging.
- As people participate more in their communities they have additional expenses for transportation and personal assistance.
- It is difficult to teach people what true participation with the Alliance means.

- The Alliance will adapt RFP for third year to increase participation of people with disabilities and support gatherings within states to explain the concept of Home of Your Own.
- People with disabilities can have increased input to state consolidated planning.
- We can offer peer-to-peer support and use successful home owners as mentors for home buyers.
- There are opportunities to offer adequate support to those purchasing a home.
- We can support people with disabilities to lead the initiative in their own state and nationally.

*PARTICIPATION OF PEOPLE WITH DISABILITIES IN LEADERSHIP/
ACTION PLAN*

| <i>Key Players</i> | <i>Action Steps</i> |
|----------------------|--|
| Retreat participants | <ul style="list-style-type: none">• Reduce fear about people with disabilities in leadership positions - fear on both sides, people with disabilities and those in power• Use training/materials available through Partners in Policy Making |
| National Alliance | <ul style="list-style-type: none">• Make people's leadership a priority• States steering committee membership should be 30% people with disabilities• Redesign .. to increase participation and leadership of people with disabilities• Link with ADAPT leadership training• Develop tools to teach people specific skills: public speaking, running a meeting |

Closing

The retreat closed with all participants making a commitment to stay in touch with each other and to focus efforts this year on the action items outlined here. Jay Klein closed with thanks to Jeff Strully for his facilitation, David Hasbury for his graphics, and all participants for their thoughtful participation.

