End the Institutional Bias: No More Stolen Lives!
MiCASSA, Money Follows the Individual and More!

Testimony of the ADAPT Community
Presented by Bruce E. Darling

Good Morning. My name is Bruce Darling, and today I am testifying on behalf of the ADAPT Community and the many thousands of people with disabilities who want to have a REAL CHOICE so that they may live fulfilling and productive lives in the community.

I am the Executive Director of the Center for Disability Rights (CDR), an Independent Living Center based in Rochester, New York which provides community-based services that support people with disabilities in the community and advocates on disability issues. About four years ago, CDR began to formally transition people out of nursing homes. Since that time, our Center has helped over 100 people return to community living.

Over the last few years, I have also trained literally hundreds of people from 37 different states and the Territory of Guam on how to assist people with disabilities to return to community living from institutional settings. As I have traveled throughout the country, I have heard the same stories from people who had years of their lives stolen by a system which supports institutions over individual rights.

- People who were separated from their families,
- People who lost their homes,
- People who lost their freedom and thought their lives had ended.

People with disabilities and our allies are fighting the institutional bias, but conviction, training, and hard work are simply not enough. We need YOU to take action and establish a national Community First policy! You have the power to end the institutional bias and assure that there are no more stolen lives.

PROBLEM STATEMENT AND ITS IMPACT ON REAL PEOPLE

Our long-term care system has remained essentially unchanged since its creation nearly 40 years ago. No one would have guessed that today this system would warehouse over 1.4 million Americans in nursing facilities and 110,572 in ICFs, or Intermediate Care Facilities for the Mentally Retarded.[1]

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[1] Lakin, K.C. and Prouty, R. (2003). Medicaid Home and Community-Based Services: The First 20 Years. *Policy Research Brief.* University of Minnesota: Minneapolis, Institute on Community Integration, *14*(3). Obtained from http://ici.umn.edu/products/prb/143/

The system was built on a medical model. At the time of its creation, individuals with disabilities were considered patients who needed to be cared for. Over the years, the medical model has added costs, requiring medical staff to do tasks which could be done by an unlicensed attendant either through delegation or assignment of a health professional. In this system, health-related tasks are often done by a nurse, who charges Medicaid over $100, rather than an attendant who is billed at only $15.

The medical model fostered a system where services were made available based on diagnosis, creating fragmentation and service gaps. I worked with a woman named Lisa Cyphers. She wanted to be at home rather than a nursing home. To go home she needed support services that were provided under the state's Traumatic Brain Injury waiver, but because she had Multiple Sclerosis she was not eligible for them. Even though she had the same exact functional needs, she wasn't eligible for the services to get her home.

Over the years long term care services have become even more fragmented. Attempts at modernizing the system, including the development of new programs and a multitude of Medicaid Waiver programs, have created a disjointed mish-mash of services, which vary from state to state, and even county to county. States may have a dozen different waivers and a complicated array of services that even the most skilled social worker couldn't navigate.

Our spending in long term care clearly illustrates the institutional bias. According to 2002 Medstat data, 70% of the $82.13 billion that is spent on long term care services goes to institutional services, while only 30% funds community services and supports.[2]

The institutional bias is demonstrated on a personal level as well.

Medicaid rules allow individuals who are in nursing facilities (or deemed eligible for a nursing facility and receive services through a Medicaid Waiver) to retain income up to 300% of the Supplemental Security Income (SSI) federal benefit rate, nearly $1,700 per month for a single person. By comparison in most states, individuals who need personal care or home health care are only allowed to retain one third of that amount.

If an individual's spouse is institutionalized in a nursing home, federal rules allow them to keep at least some of their income and resources without totally impoverishing themselves. The same is not true for community-based services. As an example, we worked with Phyllis Patnode. As a 50-year-old woman, Phyllis was forced to leave her husband and home and go into a nursing home because her husband worked and she didn't want to financially devastate him and her daughters.

A fundamental problem is that Medicaid funding for long term care services is securely tied to the institutions. States must provide institutional services, like nursing home care, while community-based services are completely optional. To provide alternatives to nursing homes or ICF-MR facilities, states must apply for a Medicaid Waiver, which

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[2] www.medstat.com

means that the federal government is agreeing, on a case-by-case basis, to waive certain Medicaid requirements in order for that state to provide home and community based services. There are often no waiting lists for nursing homes. However, when states apply for a Medicaid Waiver, the federal government authorizes a certain number of "slots", which results in waiting lists for Home and Community Based Medicaid Waiver Services.

Because institutional services are mandatory, states cannot cut their funding. We are in tough fiscal times. States have no choice but to cut community based services. Even states that want to provide less expensive community-based alternatives are prevented from doing so by a federal policy that mandates institutional care.

In addition to all of this, there is one very important reason we must change this system. It isn't what people want.

According to the data from the Centers for Medicare and Medicaid Services, nearly 19% of individuals in nursing homes have expressed an interest in returning to the community.[3] This information was collected by the nursing homes themselves. From our experience, the number of people who want to live in the community is actually much higher. We have the data that shows this. According to Barriers to Independence, a study conducted by Access Living and the Center for Urban Research and Learning at Loyola University in Chicago, 64.5% of the nursing home residents that were surveyed expressed that they would prefer to live somewhere else if the opportunity were available.[4]

PERSONAL IMPACT: REAL VOICES

Last year, as part of our Stolen Lives Campaign, ADAPT began documenting the names and stories of people from nursing homes and institutions.

These stories document the voices of people institutionalized as children…

… like **Leonard Roscoe**, from **Georgia**. Leonard was put in the institution in 1972 after living in hospital the first 3 years of his life. Leonard has Osteogenesis Imperfecta (brittle bones). He was institutionalized for 35 years before he got out.

… like **Patrick King** from **Austin, Texas**. When Patrick was eight he got hit on the head in a schoolyard accident resulting in multiple disabilities. He ended up in a Texas State Mental Health Hospital and stayed there for over a decade because he had what was

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[3] MDS Active Resident Information Report: December 31, 2003, from http://www.cms.hhs.gov/states/mdsreports/res3.asp?var=Q1a&date=5.

[4] Barriers to Independence: A study of housing and personal assistance issues for people with disabilities residing in nursing homes. Access Living and the Center for Urban Research and Learning, Loyola University Chicago, June 21, 2000.

described as “bizarre behaviors”. Nobody believed Patrick could live in the community and he lost over a decade of his life because of this neglect.

These stories document the voices of people who lost their freedom during the prime of their lives…

… like **June Adams** from **Denver, Colorado**. June had two little boys when she had her stroke. She was put in a nursing home, where she was held captive for 17 years while her children grew up without her.

These stories document the voices of older persons who were forced to leave their homes…

… like **Betty Cranston** from **Lake Katrine, New York**. When Betty’s COPD worsened and she needed a ventilator, she was forced into a specialized nursing facility hundreds of miles away from her son, home, and small town. Even though she did much of her own personal care at the facility and her son wanted his mother to return home to live with him, she was forced to stay there because she couldn’t get approved for community services – or a portable ventilator.

I have included the individual stories we received at the end of this testimony. Their words are compelling. Their voices rise up and ask for just one thing: freedom.

SOLUTIONS: REAL CHOICES

It is clear that we need a new model.
No longer should community based services be the exception to the institutional rule.

Community based services must become as easy to access as institutional services.

To accomplish this, the tie between the institution and funding must be cut. Individuals must have real, meaningful and effective choices in what services they receive, where they receive services, and who provides those services.

Our nation must pass legislation which reforms the long term care system and incorporates the following principles:

- Attendant services must be available in the community, 24 hours per day, seven days per week;
- Eligibility must be based on functional need, not on diagnosis, age, or funding stream;
- Incentives are offered to encourage states to allow assignment or delegation of care tasks previously restricted to only doctors and nurses;
- Consumer control must be maximized at every step of the process, including flexible payment and management systems; and
- Attendants must earn a livable wage and benefits.

Immediate Actions

This shift will take time, but there are immediate steps you can take to end the institutional bias.

First, you must pass **Money Follows the Individual** legislation.

Under this legislation, the Federal government will fund community-based services for the first year for individuals who transition out of institutions! This legislation would provide a critical incentive to the states in providing Real Choices in long term care. This will encourage states to build their capacity to more effectively transition people back into the community.

Senator Harkin introduced the Money Follows the Person Act of 2003 (S.1394) on July 11th. Shortly after that, on July 25th, the White House distributed its own draft legislation: the New Freedom Initiative Medicaid Demonstration Act of 2003. We understand that you, Senator Grassley, are considering introducing legislation based on the administration's proposal. This more comprehensive legislation would authorize a Money Follows the Individual Demonstration program and support other initiatives to promote community-based services. Thousands of people with disabilities in nursing homes and other institutions will benefit if you fund these initiatives and give states the incentive to move people into the community. This first step, though not the complete answer to ending the institutional bias, will lay the foundation for the more comprehensive changes to the Medicaid system that must occur if nursing homes and other institutions are to become the alternative rather than the entitlement.

Whether you pass S. 1394 or the administration's proposal, it is imperative that you take action now. This legislation must be passed during this session. The CMS data I spoke about earlier shows that at least 267,000 people with disabilities want to return to the community NOW!

267,000 people are telling the nursing homes that they want to go home;
267,000 people are asking you to help them go home; and
On behalf of those 267,000 people, I am pleading with you not to make them wait one more day!

There are other steps you could take to address the institutional bias. You could create an Enhanced Federal Medicaid Matching Rate for home and community based services. By paying a larger percentage of the cost of home and community based services, you will create a strong and on-going incentive for states to promote community living.

Such a step would help the states address their budget difficulties during these difficult times and promote community living options. It would also send a clear message that our nation values the freedom of all of its citizens, including those with disabilities.

A Lasting Solution

While demonstration programs and enhanced Medicaid matches would promote community living, they still leave much work to be done. The ultimate solution to ending the institutional bias which has stolen the lives of so many thousands of seniors and people with disabilities is clear.

Pass MiCASSA!

The Medicaid Community Attendant Services and Supports Act (S. 971) gives people Real Choice in long-term care. MiCASSA provides individuals eligible for Nursing Facility Services or ICFs with the opportunity to choose Community-Based Attendant Services and Supports.

Rather than be forced into institutional placement, people would get assistance in their own homes. Such assistance would include the basic activities of daily life that most people take for granted like meal preparation, eating, toileting, bathing, grooming, shopping, managing finances, and participating in the community. MiCASSA addresses the need for assistance with health-related functions.

MiCASSA implements other necessary reforms. It would:

- provide assistance in the home and community, such as at school, work, or religious activities;
- include systems for securing back-up attendants;
- offer options for consumer control of services;
- address the inequity in financial eligibility between nursing facilities and community based services; and
- support those minor but essential expenses needed by people returning to the community, such as security deposits for housing, bedding, and kitchen supplies.

Because the money is following the individual, MiCASSA is not a new, unfunded mandate. We pay for this assistance already. MiCASSA makes the existing mandate more responsive to consumers. People who are already eligible for services will have a Real Choice.

Every major national disability organization supports MiCASSA. In fact, 92 national organizations are MiCASSA supporters. An additional 255 state or regional organizations also support the bill, as well as 306 local groups. I have included the full list at the end of my testimony. As you look through the list, you will notice that ADAPT is working with children's advocates and senior advocates. Supporting organizations represent people with all types of disabilities: people with cognitive disabilities, people with sensory disabilities, people with mental health labels and/or people with physical disabilities.

We are asking that you take action now!

Today we would not be here today had it not been for the heroic efforts of hundreds and hundreds of ADAPT members who have put their bodies on the line year after year.

On behalf of these people, I would like to thank you for this hearing.

But on their behalf, I must point out that we need more than hearings.

We need action.

Take the steps I have outlined today and pass these important pieces of legislation to FREE OUR PEOPLE!

For an institution free America,
Bruce E. Darling

ATTACHMENT 1: Organizations Supporting MiCASSA

National Organizations Supporting MiCASSA

1 ABLED! Publications: ABLED Woman Magazine
2 Ad Hoc Committee on Healthcare Reform and Disability
3 ADA Watch
4 ADAPT
5 American Association of People with Disabilities, AAPD
6 American Association on Mental Retardation
7 American Geriatrics Society
8 American Rehabilitation Counseling Association
9 Americans with Disabilities Vote
10 The Arc
11 Association for Persons in Supported Employment, APSE
12 Association Programs for Rural Independent Living, APRIL
13 Association for Protection of the Elderly
14 The Autism National Committee
15 Bazelon Center for Mental Health Law
16 Brain Injury Association
17 The Bridge
18 Center for Housing and New Community Economics, CHANCE
19 Center for Self Determination
20 Center on Human Policy
21 Christopher Reeve Paralysis Foundation
22 Concrete Change
23 Consortium of Developmental Disabilities Councils
24 Consumer Research and Advocacy
25 Democratic National Committee
26 DIMENET
27 The Disability Grapevine
28 The Disability News Service, Inc.
29 Disability Rights Action Coalition for Housing
30 The Disability Rights Center
31 Disability Rights Education and Defense Fund, DREDF
32 Disabled People's Direct Action Network of Great Britain
33 Disabled Queers In Action, DQIA
34 Eastlake Derry and Associates
35 Families USA
36 Family Voices
37 Gerstmann Syndrome Support Network
38 GnarlyBone News/Gnarly Bones Productions
39 Gray Panthers
40 HalfthePlanet.com
41 HUMAN

42 Independent Living Research Utilization, ILRU
43 Institute for Disability Access
44 Institute on Disability Culture
45 International Ventilator Users Network/Post-Polio Health International
46 Justice for All
47 Mainstream Magazine
48 The Mouth
49 National Association of the Advancement of Colored People, NAACP
50 National Association for Home Care
51 National Association of Area Agencies on Aging
52 National Association of the Deaf
53 National Association of Developmental Disabilities Councils
54 National Association of Protection and Advocacy Services, NAPAS
55 National Association for Rights Protection and Advocacy
56 National Association of State Head Injury Administrators
57 National Catholic Office for Persons with Disabilities
58 National Center for Latinas with Disabilities
59 National Citizens Coalition for Nursing Home Reform
60 National Coalition of the Chemically Injured
61 National Coalition on Self-Determination
62 National Council on the Aging
63 National Council on Independent Living
64 The National Disability Party
65 National Family Caregivers
66 National Home of Your Own Alliance
67 National Organization for Women, NOW
68 National Organization on Disability
69 National Rehabilitation Association
70 National Spinal Cord Injury Association
71 New Mobility
72 Not Dead Yet
73 Oglala Sioux Nation
74 On A Roll Talk Radio
75 Paralyzed Veterans of America, PVA
76 The Ragged Edge
77 Research and Training Center on Independent Living at the Unversity of Kansas
78 The Rural Institute, University of Montana
79 Self Advocates Becoming Empowered, SABE
80 Senior Support Network
81 Service Employees International Union, SEIU
82 Shepherd Center
83 Socialist Party USA
84 Southern Disability Law Center
85 TASH
86 United Cerebral Palsy

87 United Spinal Association
88 Universal Health Care Action Network, UHCAN!
89 US Conference of Mayors
90 Very Special Arts
91 World Association of Persons with Disabilities, WAPD
92 World Institute on Disability, WID

State/Regional Organizations Supporting MiCASSA

1 Access to Independence and Mobility, New York
2 ADA Consortium, Utah
3 Advocacy Center, Louisiana
4 Advocacy Incorporated, Texas
5 Advocates for Texans with Brain Injuries, Texas
6 Alaska Division of Vocational Rehabilitation
7 Alaska Governor's Committee on Employment and Rehabilitation of People with Disabilities
8 Alaska Transition Initiative
9 Alaska State Independent Living Council
10 Alpha-One, Maine
11 Alzheimer Society of Washington
12 The Arc of Arkansas
13 The Arc of Iowa
14 The ARC of Maryland
15 ARC of Michigan
16 ARC of Washington State
17 ARC of Wisconsin
18 Arizona Governor's Council on Developmental Disabilities
19 Arizona Governor's State Rehabilitation Advisory Council
20 Arizona Governor's Statewide Independent Living Council
21 Arkansas Independent Living Council
22 Arkansas Support Network
23 Assistive Technologies of Alaska
24 Association of Colorado Independent Living Centers
25 Association for Independent Living of Utah
26 Atlanta Alliance on Developmental Disabilities, Georgia
27 Aurora Residential Alternatives, Wisconsin
28 Autism Society of Michigan
29 Brain Injury Association of Texas
30 Brain Injury Association of Wisconsin
31 California Alliance for Inclusive Communities
32 California Coalition of United Cerebral Palsy Associations
33 California Disability Alliance
34 California State Independent Living Council
35 Campaign for Better Health Care, Illinois
36 Central New York Self Advocacy Grassroots Regional Organizing Program

37 Chemical Sensitivity Disorders Association, Maryland, Virginia, Delaware, DC, and Pennsylvania
38 CLASS CTD, Columbus Kansas
39 Client Assistance Program of Wisconsin
40 Coalition for Citizens with Disabilities, Mississippi
41 Coalition of Citizens with Disabilities in Illinois
42 Coalition of Montanans Concerned with Disabilities
43 Coalition of Texans with Disabilities
44 Coalition on Disabilities Education (C.O.D.E.) Georgia
45 Colorado Cross-Disability Coalition Colorado Democrats
46 Colorado Developmental Disabilities Planning Council
47 Colorado Governor's Council for People with Disabilities
48 Colorado Nurses' Association
49 Colorado State Independent Living Council
50 Commonwealth Coalition for Community, Virginia
51 Comprehensive Advocacy, Idaho
52 Connecticut Coalition of Citizens with Disabilities
53 Connecticut Council on Developmental Disabilities
54 Connecticut Legal Rights Project
55 Connecticut Statewide Independent Living Council
56 Council for Disability Rights, Illinois
57 Delaware Maryland Paralyzed Veterans Association
58 Delaware Statewide Independent Living Council
59 Demanding Equal Access for All (D.E.A.F.) Georgia
60 Disabilities Law Project, Pennsylvania
61 Disability Law Center, Massachusetts
62 Disability Law Center, Utah
63 Disability Law Center of Alaska
64 Disability Policy Consortium, Texas
65 Disability Resource Association, Missouri
66 disAbility Resources of Southwest Washington
67 Disability Rights, Hawaii
68 Disability Services of the Southwest, Texas
69 Dykes, Disabilities and Stuff Quarterly
70 Easter Seals Delaware & Maryland's Eastern Shore
71 Environmental Illness Association of Hawaii
72 Equip for Equality, Illinois
73 Families Helping Families, Louisiana
74 Federation of Families for Children's Mental Health, Georgia
75 Florida Independent Living Council
76 Florida Spinal Cord Injury Research Center
77 Georgia Advocacy Office
78 Georgia Developmental Disabilities Council
79 Georgia State Independent Living Council
80 Governor's Commission on Disability in New Hampshire
81 Governor's Committee on Concerns of the Handicapped, New Mexico

82 Governor's Committee on Disabilities Issues and Employment, Washington
83 Governor's Council on Disabilities and Special Education, Alaska
84 Georgia Parent Support Network
85 Granite State Independent Living Foundation, New Hampshire
86 Great Lakes ADA, Illinois, Indiana, Michigan, Minnesota, Ohio & Wisconsin
87 Hawaii Statewide Independent Living Council
88 The Howell Group, Michigan
89 Idaho State Independent Living Council
90 Illinois Network of Centers for Independent Living
91 Illinois Rehabilitation Council
92 Illinois State Council of Senior Citizens
93 Illinois Valley Center for Independent Living
94 Iowa Creative Employment Options
95 Iowa Human Rights Commission - Division of Persons with Disabilities
96 Iowa Statewide Independent Living Council
97 Iowans with Disabilities Exercising Advocacy Skills
98 Indiana Institute on Disability and Community
99 Institute on Disability, New Hampshire
100 Irene Ward and Associates, Ohio
101 Jay Nolan Community Services, California
102 Kansas Association of Centers for Independent Living
103 Kansas Association of the Deaf
104 Kansas Commission on Disability Concerns
105 Kansas Council on Developmental Disabilities
106 Kansas Disability Rights Action Coalition for Housing
107 Kansas Nurses Association
108 Kansas State Independent Living Council
109 Kansas State Chapter WAPD
110 Kansas TASH
111 Kentucky Developmental Disabilities Council
112 Kentucky Statewide Independent Living Council
113 League of Human Dignity, Nebreska/Iowa
114 Legislative Coalition for People with Disabilities
115 Let's Get Together, Georgia
116 LIFTT, Billings Montana
117 Lupus Foundation of Colorado
118 Maine Disabilities Coalition
119 Maryland Association of Community Services
120 Maryland Developmental Disabilities Council
121 Maryland Disabilities Forum
122 Maryland Statewide Independent Living Council
123 Massachusetts Arc
124 Massachusetts Office on Disability
125 Massachusetts Statewide Independent Living Council
126 Massachusetts Statewide Personal Assistance Coalition

127 Mental Health Association in Texas
128 Mental Patients Liberation Alliance of New York State
129 Michigan Association of Centers for Independent Living
130 Michigan Developmental Disabilities Council
131 Michigan Disability Rights Center
132 Michigan Protection and Advocacy Service
133 Minnesota Association of Centers for Independent Living
134 Minnesota Governor's Council on Developmental Disability
135 Minnesota State Independent Living Council
136 Missouri Governor's Council on Disability
137 Missouri Head Injury Advisory Council
138 Missouri Planning Council for Developmental Disabilities
139 Missouri Statewide Independent Living Council
140 Monday Morning Project - New Jersey
141 Montana Advocacy Program
142 Montana Independent Living Project
143 National Association of Social Workers, Texas Chapter
144 National Multiple Sclerosis Society - Oklahoma Chapter
145 National Multiple Sclerosis Society - Wisconsin Chapter
146 Nebraska Advocacy Services
147 New England Health Care Employees Union - District 1199
148 New Jersey Developmental Disabilities Council
149 New Jersey MiCASSA Advocacy Coalition
150 New Jersey Statewide Independent Living Council
151 New Hampshire Developmental Disabilities Council
152 New Hampshire Statewide Independent Living Council
153 New Mexico Developmental Disabilities Planning Council
154 New Mexico Legislative Health and Human Services Committee
155 New Mexico State Agency on Aging
156 New Mexico Statewide Independent Living Council
157 New York State Developmental Disabilities Planning Council
158 New York State Independent Living Council, Inc.
159 New York State Institute on Disability
160 NHHomeless@egroups.com, New Hampshire
161 North Carolina Statewide Independent Living Council
162 The Oaks Group, California
163 Office of Handicapped Concerns, Oklahoma
164 Ohio Association of Centers for Independent Living
165 Ohio Developmental Disabilities Council
166 Ohio Disability Action Coalition
167 Ohio Personal Assistance for Independent Living, OPAIL
168 Ohio Personal Assistance Services Coalition
169 Ohio Statewide Independent Living Council
170 Oklahoma Conference of Churches Impact Committee
171 Oklahoma Parent Network
172 Oklahoma Statewide Independent Living Council

173 Oklahomans for Independent Living
174 Oklahomans for Reasonable Health Care
175 Older Adult Services Providers Consortium, Wisconsin
176 Options IRCIL, Minnesota and North Dakota
177 Oregon Developmental Disabilities Coalition
178 Oregon Disabilities Commission
179 Oregon State Independent Living Council
180 Osteogenesis Imperfecta Council of Georgia
181 Out in the Valley, Oklahoma
182 Paralyzed Veterans Association of Florida
183 Paralyzed Veterans of America, PVA, Delaware - Maryland Chapter
184 Paralyzed Veterans of America, PVA, Zia Chapter, New Mexico
185 Parents Education Project of Wisconsin
186 Parents, Let's Unite for Kids, PLUK, Montana
187 PEAK Parent Center, Colorado
188 Pennsylvania Action Coalition for Disability Rights in Housing, PAC
189 Pennsylvania Association of Area Agencies on Aging
190 Pennsylvania Coalition of Citizens with Disabilities, PCCD
191 Pennsylvania Council of the Blind
192 Pennsylvania Council on Independent Living
193 Pennsylvania Developmental Disabilities Council
194 Pennsylvania Statewide Independent Living Council
195 People First of California
196 People First of Georgia
197 People First of Wisconsin
198 Project PAS-Port for Change of Washington
199 Rammler & Wood, LLP, Connecticut
200 Rehabilitation for Wisconsin
201 Roosevelt Warm Springs Institute for Rehabilitation
202 Self-Advocacy Association of New York State
203 Self-Advocacy Network of Michigan
204 South Carolina Independent Living Council
205 South Carolina State Chapter WAPD
206 South Dakota Coalition of Citizens with Disabilities
207 Speaking for Ourselves, Colorado
208 Speaking for Ourselves, Pennsylvania
209 Special Education Associates, SEA, Missouri
210 State Council for Persons with Developmental Disabilities, Delaware
211 State Independent Living Council of New Hampshire
212 State Independent Living Council of Wisconsin
213 State Rehabilitation Planning and Advisory Council of Wisconsin
214 Statewide Independent Living Council of Illinois
215 Tennessee Association for Disability Rights
216 Tennessee Developmental Disabilities Council
217 Tennessee Disability Coalition
218 Tennessee Network for Community Economic Development

219 Texas Advocates
220 Texas Advocates Supporting Kids with Disabilities
221 Texas Association of Centers for Independent Living
222 Texas Civil Rights Project
223 Texas Health and Human Services Commission
224 Texas Mental Health Consumers
225 Texas Nurses Association
226 Texas Paralyzed Veterans of America
227 Texas Planning Council for Developmental Disabilities
228 Texas Rehabilitation Commission
229 Texas State Independent Living Council
230 Texas State Chapter WAPD
231 United Cerebral Palsy of Pennsylvania
232 United Cerebral Palsy of Texas
233 United Cerebral Palsy of Wisconsin
234 University Affiliated Program, University of Texas
235 University of Delaware Disabilities Studies Program
236 Utah State Democratic Committee
237 Utah Statewide Independent Living Council
238 Vermont Center for Independent Living
239 Vermont Coalition for Disability Rights
240 Virginia Association of Persons in Supported Employment
241 Virginia Statewide Independent Living Council
242 Virginia TASH
243 Washington Coalition of Citizens with Disabilities
244 Washington Protection and Advocacy System
245 Washington State Independent Living Council
246 West Virginia Statewide Independent Living Council
247 Wisconsin Coalition for Advocacy
248 Wisconsin Coalition of Independent Living Centers
249 Wisconsin Council on Developmental Disabilities
250 Wisconsin Council on Physical Disabilities
251 Wisconsin Governor's Committee for People with Disabilities
252 Wisconsin Nurses Association
253 Wisconsin Rehabilitation Association
254 Wisconsin State Independent Living Council
255 Wyoming Statewide Independent Living Council

Local Organizations Supporting MiCASSA

1 504 Democratic Club, New York New York
2 ABIL, A Bridge to Independent Living, Phoenix Arizona
3 The Ability Center of Greater Toledo
4 Abilities In Motion, Reading Pennsylvania
5 Ability Resources, Tulsa Oklahoma
6 ABLE - CIL, Odessa Texas

7 Absolute Care Enterprise Inc., New Orleans Louisiana
8 Access II Independent Living Center, Gallatin Missouri
9 Access Center for Independent Living, Dayton Ohio
10 Access Center for Independent Living, Gainesville Georgia
11 Access Living, Chicago Illinois
12 Access Resorts, Hilton Head South Carolina
13 Access to the Arts, Louisville Kentucky
14 Access to Independence, Madision Wisconsin
15 Access to Independence of Courtland County, Cortland New York
16 Accessible Construction, Cary Illinois
17 Action for a Better Community, Rochester New York
18 Active Re-Entry, Price Utah
19 Advocating Change Together, St Paul Minnesota
20 Aging & Disability Coalition of Metro Kansas City, Independence Missouri
21 Alameda County Developmental Disabilities Planning and Advisory Council, Oakland California
22 Alliance for the Disabled in Action, Edison New Jersey
23 American Legion - Post 400, Topeka Kansas
24 Americans Demanding Access of NY State, Binghamton New York
25 Ann Arbor Center for Independent Living, Michigan
26 Anthracite Region Center for Independent Living, Hazleton Pennsylvania
27 Arc Cobb, Cobb County Georgia
28 The ARC of Detroit
29 The Arc of Lincoln/Lancaster County, Lincoln Nebraska
30 ARC of Milwaukee, Wisconsin
31 Area Agency on Aging, Cameron, Elk and McKean Counties, Pennsylvania
32 Area Agency on Aging, Price Utah
33 Area Agency on Aging Office of Human Services, Ridgeway Pennsylvania
34 ARISE Child and Family Services, Syracuse New York
35 Arkansas Support Network, Bentonville Arkansas
36 Association for Community Advocacy
37 Atlantis Community, Denver Colorado
38 Aurora Community Services, Menamonie Wisconsin
39 Austin Resource Center for Independent Living, Austin Texas
40 Austin Mayor's Committee for People with Disabilities, Austin Texas
41 Bainbridge Advocacy Individual Network, Bainbridge Georgia
42 Baltimoreans Against disAbility Discrimination, B.A.d.D., Baltimore Maryland
43 Birmingham Independent Living Center, Alabama
44 Blue Panthers
45 Blue Ridge Independent Living Center, Roanoke Virginia
46 Blue Water Center for Independent Living, Port Huron Michigan
47 Bootheel Area Independent Living Services, BAILS, Kennett Missouri
48 Boston Center for Independent Living, Massachusetts
49 Brain Injury Family Assistance Center, Atlanta Georgia
50 Brain Injury Services, Fairfax Virginia

51 Brazoria County Center for Independent Living, Angleton Texas
52 Bronx Independent Living Services, Bronx New York
53 Brooklyn Center for Independence, Brooklyn New York
54 Bucks County Area Agency on Aging, Pennsylvania
55 Buffalo River Services, Waynesboro Tennessee
56 Calvert County Commission for Individuals with Disabilities, Maryland
57 Camden City Independent Living Center, Camden New Jersey
58 Cape Organization for the Rights of the Disabled, CORD, Hyannis Massachusetts
59 Capital District Center for Independence, Albany and Schenectady New York
60 C.C.E., Chicago Illinois
61 Center for Advocates for the Rights and Interests of the Elderly, CARIE, Philadelphia Penn.
62 Center for Disability Rights, Rochester New York
63 Center for Independence, Grand Junction Colorado
64 Center for Independence of the Disabled, Belmont California
65 Center for Independent Living for Western Wisconsin, Menomonie Wisconsin
66 Center for Independent Living of Broward, Tamarac Florida
67 Center for Independent Living of Central Pennsylvania, Camp Hill Pennsylvania
68 Center for Independent Living of Mid-Michigan, Midland
69 Center for Independent Living of Middle Tennessee, Nashville
70 Center for Independent Living of North Central Pennsylvania, Williamsport Pennsylvania
71 Center for Independent Living of Northeastern Minnesota, Hibbing Minnesota
72 Center for Independent Living Options, Cincinnati Ohio
73 Center for Independent Living of South Central Pennsylvania, Altoona Pennaylvania
74 Center for Independent Living of South Jersey, Westville, New Jersey
75 Center for Independent Living of Southwest Kansas, Garden City Kansas
76 Center for Independent Living of South Valley, Visalia California
77 Center for Living and Working, Inc., Worcester Massachusetts
78 Center for People with Disabilities, Boulder Colorado
79 Central Texas Coalition on Aging and Developmental Disabilities, Central Texas
80 Central Texas Rehabilitation Association, Central Texas
81 Citizens for Independence and Access, York Pennsylvania
82 City of Chicago
83 Coalition for Independence, Kansas City Kansas
84 Coastal Community Advocates, Aberdeen Washices for Independence, Erie Pennsylvania
85 Community Service Options, Chicago Illinois
86 Concerned Citizens with Disabilities, Logan Utah

87 Connections for Independent Living, Greeley Colorado
88 Consumer Connection, Philadelphia Pennsylvania
89 CORD, Spokane Washington
90 Council for Disability Rigcson Arizona
91 Disability Action Center - NW Inc., Moscow Idaho
92 Disability Center for Independent Living, Denver Colorado
93 Disability Connections, Middle Georgia Center for Independent Living,
94 Macon Georgia
95 The Disability Institute, Hopkins Minnesota
96 disAbility LINK, Decatur Georgia
97 Disabilities Network of Eastern Connecticut, North Franklyn
98 Disabilities Network of NYC, New York New York
99 The Disability Network, Flint Michigan
100 Disability Resource Agency for Independent Living, Modesto, Stockton and Sonona California
101 Disability Resource Center, North Charleston South Carolina
102 Disability Resource Center, Knoxville Tennessee
103 Disability Resource Center of Fairfield County, Stratford Connecticut
104 disAbility Resource Center, Everett Washington
105 disAbility Resource Center of the Rappahannock Area, Fredricksburg Virginia
106 Disability Rights Enforcement, Education, Services; San Rafael California
107 Disabled Citizens Alliance for Independence, Virburnum Missouri
108 Disabled in Action, DIA, of Greater Syracuse New York
109 Disabled in Action, DIA, of Metro New York
110 Disabled in Action, DIA, of Philadelphia Pennsylvania
111 Disabled Resource Services, Fort Collins & Loveland Colorado
112 Disabled Rights Action Center, Salt Lake City Utah
113 The Disabled Womyn's Education Project, Madison Wisconsin
114 East Bay Innovations, Oakland California
115 East Tennessee Technology Access Center, Knoxville Tennessee
116 Easter Seals South Eastern Wisconsin, Milwaukee
117 Employment Resources, Madison Wisconsin
118 Endependence Center, Norfolk Virginia
119 Environmental Illness Association of Hawaii, Waikiki
120 Evert Conner Rights and Resources Center for Independent Living, Iowa City IA
121 Everybody Counts, Merrillville Indiana
122 Families Helping Families, Monroe Louisiana
123 Family Empowerment Council, Inc., Middletown New York
124 Finger Lakes Independence Center, Ithaca New York
125 The Freedom Center, Frederick Maryland
126 Freedom Center for Independent Living, Middletown Delaware
127 Freedom Valley Disability Center, Newton Square Pennsylvania
128 Gaston Residential Services, Inc, Gastonia North Carolina
129 GMSA Management Group, Austin Texas

130 Grandmothers, Aunts, Mothers, Sisters and Supports, Witchita Kansas
131 Great Lakes PAS PAC, Detroit Michigan
132 Greater Austin Texas Paralyzed Veterans Association, Austin Texas
133 Greater Boston Arc, Boston Massachusetts
134 Greater Rochester Spina Bifida Association, Hilton New York
135 Hamilton County Early Intervention Collaborative, Cincinnati Ohio
136 Head Injury Support Group, Hays Kansas
137 Headlines: Brain Injury Support Group, Rockford Illinois
138 Health and Medicine Policy Research Group, Chicago Illinois
139 Houston Area Women's Center, Texas
140 Houston Center for Independent Living, Texas
141 Humbolt Community Access and Resources, Eureka California
142 Huntington West Virginia Grassroots Advocacy Project
143 Hutchinson Resource Center for Independent Living, Kansas
144 Illinois Iowa Center for Independent Living, Rock Island Illinois
145 IMPACT, Alton Illinois
146 Inclusion Daily Express, Spangle Washington
147 The Inclusion Network, Cincinnati, Ohio
148 Independence Inc. Lawrence Kansas
149 Independence Inc Center for Independent Living, Minot North Dakota
150 Independence First, Milwaukee Wisconsin
151 Independence Now, Riverdale Maryland
152 Independence Unlimited, Rocky Hill Connecticut
153 Independent Lifestyles, St Cloud Minnesota
154 Independent Living Center of North Central Ohio, Mansfield Ohio
155 Independent Living Center of North Shore & Cape Ann, Salem Massachusetts
156 Independent Living Resource, Fairfield California
157 Independent Living Resource Center, Albuquerque New Mexico
158 Independent Living Resource Center, Jefferson City Missouri
159 Independent Living Resource Center, San Francisco California
160 Independent Living Resources, Portland Oregon
161 Independent Living Resources, Roswell New Mexico
162 Independent Resources, Inc., Wilmington, Delaware
163 Indianapolis Resource Center for Independent Living, Indiana
164 Innovative Solutions Inc., Louisville Kentucky
165 Interfaith Specialty Services, Philadelphia Pennsylvania
166 Iowans with Disabilities Exercising Advocacy Skills, Iowa City Iowa
167 JAM Specialists, Inc. Cape Cod Massachusetts
168 Jefferson County Association for Retarded Citizens, Mapaville Missouri
169 Justice For All Social Services, New York New York
170 Kalamazoo Handicappers United, Michigan
171 Kenai Peninsula Independent Living Center, Homer Alaska
172 Lakretz Creative Support Services, Copiague New York
173 Law Offices of Mark Partin, Middlefield Connecticut
174 Lawrence County Comm on Disability, New Castle Pennsylvania

175 League for the Blind and Disabled, Fort Wayne Indiana
176 League of Women Voters of Rochester Metro Area, Rochester New York
177 LEAP Center for Independent Living, Lorain County Ohio
178 Lehigh Valley Center for Independent Living, Allentown Pennsylvania
179 Leon Advocacy and Resource Center, Tallahassee Florida
180 Liberty Resources, Inc. Philadelphia Pennsylvania
181 LIFE, Inc. Pocatello Idaho
182 LIFE, Inc. Savannah Georgia
183 LIFE Center for Independent Living, Bloomington Illinois
184 Life and Independence for Today, St. Mary's Pennsylvania
185 LINK Inc., Hays Kansas
186 Living Independence for Everyone of Central Mississippi
187 Living Independence for Everyone of North Mississippi
188 Living Independence for Everyone of South Mississippi
189 Living Independently for Everyone, Farmington Missouri
190 Living Independently for Today and Tomorrow, LIFTT, Billings Montana
191 Long Island Advocacy Center, New Hyde Park New York
192 Lorain County Coalition of Citizens with Disabilities, Lorain County Ohio
193 Lupus Foundation of Philadelphia Pennsylvania
194 Mainstream Supported Living Services, Soquel California
195 Marin Center for Independent Living, San Rafael California
196 Massena Independent Living Center, Massena New York
197 MCIL Resources for Independent Living, Baltimore Maryland
198 Memphis Center for Independent Living, Tennessee
199 Mental Health Association of Rochester & Monroe County, Rochester New York
200 Mental Health Association of Southern Tier, Binghamton New York
201 Metro Justice of Rochester, Rochester New York
202 Metro Seniors in Action, Chicago Illinois
203 Metropolitan Center for Independent Living, St. Paul Minnesota
204 Metrowest Independent Living Center, Framingham Massachusetts
205 Midland Empire Resources for Independent Living, MERIL, St. Joseph Missouri
206 Mid-Ohio Board for an Independent Living Environment, MOBILE, Columbus
207 Montana Independent Living Project, Helena Montana
208 Montgomery County Commission on People with Disabilities, Rockville Maryland
209 Mountain State Centers for Independent Living, Huntington West Virginia
210 Mountain Valley Regional Center, Stockton, Modesto and San Andreas California
211 Multnomah County Disability Services Advisory Council, Portland Oregon
212 Mycare Home Medical Supplies, Niles Illinois
213 National Multiple Sclerosis Society Greater Delaware Valley Chapter
214 New Horizons Independent Living Center, Monroe Louisiana
215 Niagara Frontier Center for Independent Living, Niagara Falls New York

216 North Country Center for Independence, Plattsburgh New York
217 North Country Independent Living, Ashland and Superior Wisconsin
218 North East Pennsylvania Center for Independent Living, Scranton Pennsylvania
219 North Shore Arc, Massachusetts
220 Northeast Independent Living Program, Lawrence Massachusetts
221 Northern Regional Center for Independent Living, Watertown New York
222 Northern West Virginia Center for Independent Living, Morgantown West Virginia
223 Northwestern Independent Living Center for Independent Living, Rock Falls
224 Illinois
225 Office for Persons with Disabilities, Bridgeport Connecticut
226 Options Center for Independent Living, Bourbannais Illinois
227 Options for Independence, Logan Utah
228 Options for Independent Living, Green Bay Wisconsin
229 Panhandle Independent Living Center, Amarillo Texas
230 Parents as Case Managers, Houston Texas
231 Pathways for the Future, Sylva North Carolina
232 Paraquad, Inc. St. Louis Missouri
233 Partnership for Choice, Pittsburgh Pennsylvania
234 People of Livonia Addressing Issues of Diversity, PLAID, Livonia Michigan
235 Personal Assistance Services Program, Mellville New Jersey
236 P-FLAG, Rochester New York
237 Pierce County Department of Human Services, Ellsworth Wisconsin
238 Placer Independence Resource Services, Auburn California
239 Planning for Elders in the Central City, San Francisco California
240 Professional Home Health Services, Hays Kansas
241 Progress Center for Independent Living, Forest Park Illinois
242 Progressive Center for Independent Living, Ewing New Jersey
243 Progressive Independence, Norman Oklahoma
244 Public Interest Law Office of Rochester, New York
245 Queens Independent Living Center, New York
246 RAMP Center for Independent Living, Rockford Illinois
247 Ranch Community Services, Menomonee Wisconsin
248 REACH Resource Centers on Independent Living, Dallas, Ft Worth & Denton TX
249 Red Rock Center for Independence, St. George Utah
250 Resource Center for Accessible Living, Kingston New York
251 Resouce Center for Independent Living, Osage New York
252 Resouce Center for Independent Living, Utica New York
253 Resouces for Independence, Cumberland Maryland
254 Resources for Independent Living, Baton Rouge Louisiana
255 Resources for Independent Living, New Orleans Louisiana
256 Resources for Independent Living, Sacramento California

257 Restructuring for Inclusive School Environments, Memphis Tennessee
258 Rights for Equality and Dignity of the Disabled, Worcester Massachusetts
259 Rochester Center for Independent Living, Rochester New York
260 Rochester Chapter of the National Spinal Cord Injury Association, New York
261 Rockland City Commission on Human Rights, New City New York
262 Rocky Mountain MS Center King Adult Day Enrichment Program, Denver Colorado
263 Rolling Start, San Bernadino, California
264 Ron Mace Center for Disability Community Development, Raleigh North Carolina
265 Rural Advocates for Independent Living, RAIL, Kirksville Missouri
266 San Antonio Independent Living Services, San Antonio Texas
267 San Juan Center for Independence, Aztec New Mexico
268 Saratoga County Options for Independent Living, Saratoga Springs New York
269 Savannah-Chatham County Fair Housing Council, Savannah Georgia
270 Self Help for Hard of Hearing People, Western Kansas Group, Hays Kansas
271 SETLIFE, Beaumont Texas
272 Services for Independent Living, Cleveland Ohio
273 Silicon Valley Independent Living Center, Gilroy California
274 Society for Equal Access, Dover Ohio
275 So-Lo Center for Independent Living, Vallejo California
276 Sources, Fayetteville Arkansas
277 South Central Iowa Center for Independent Living, Oskaloosa Iowa
278 South East Kansas Independent Living, Parson
279 Southern Indiana Center for Independent Living, Bedford Indiana
280 Southern Maryland Center for L.I.F.E.
281 Southern Maryland Independent Living Inc. Mechanicsville Maryland
282 Southern Minnesota Independent Living Enterprises & Services, Mankato, Truman, New Ulm
283 Southern Tier Independence Center, Binghamton New York
284 Southwest Center for Independence, Durango Colorado
285 Southwest Louisiana Independence Center, Lake Charles Louisiana
286 Southwestern Center for Independent Living, Marshall Minnesota
287 Southwestern Independent Living Center, Jamestown New York
288 Soyland Access to Independent Living, Decatur Illinois
289 Spa Area Independent Living Services, Hot Springs Arkansas
290 Spinal Cord Injury Outreach Network, Largo Florida
291 Springfield Center for Independent Living, Springfield Illinois
292 St. Clare Management, Milwaukee Wisconsin
293 St. Francis Catholic Worker Community, Columbia Missouri
294 St. Louis Civil Rights Enforcement Commission, St. Louis Missouri
295 Staten Island Center for Independent Living, Staten Island New York
296 Staten Island Independent Living Association, Staten Island New York

297 Stavros Independent Living Cety Center for Independent Living, Rolla Missouri
298 Tri-County Independent Living Center, Akron Ohio
299 Tri-County Patriots for Independent Living, TRIPIL, Washington Pennsylvania
300 United Cerebral Palsy of Central California, Fresno California
301 United Cerebral Palsy of G, Missouri
302 West Coast Florida Multiple Chemical Sensitivities & Chemical Injury
303 Support Group, Bradenton
304 Westchester Disabled on the Move, Yonkers New York
305 Western Alliance, Asheville North Carolina
306 Western Kansas Association on Concerns of the Disabled, Hays KS

ATTACHMENT 2: ADAPT's Principles for Reforming Long Term Care

ADAPT believes the following principles should be incorporated as minimum standards in any national attendant services program passed by Congress and attendant programs run by the states:

1. Maximum control of the consumer to select, manage and control their attendant services.
2. Attendant services must be community-based, in other words non-institutional.
3. Eligibility based on functional need not medical diagnosis, disability and/or age.
4. Services must be available in-home and other locations.
5. Attendant services must be available 24 hours a day, 7 days a week.
6. Back up and emergency attendant services must be available.
7. Program must allow for co-pay and cost sharing for people with higher incomes.
8. Delivery of service must include vouchers, direct cash payment, individual provider model, as well as consumer directed agency model.
9. Health related tasks can be delegated to or done by unlicensed personal attendants.
10. Voluntary training should be available for consumers.
11. Attendants should receive a livable wage and benefits.
12. Attendant services should be based on an agreed upon individual service plan.

ATTACHMENT 3: Consumer Direction in Long Term Care

ADAPT Definition of Consumer Direction

As it relates to program design for attendant services, consumer direction means the right of the consumer to select, manage and dismiss an attendant.

The consumer has this right regardless of who serves as the employer of record, and whether or not that individual needs assistance directing his or her services.

This includes but not limited to delivery systems that use:

- Vouchers
- Direct cash
- Fiscal intermediaries
- Agencies that allow choice (Agencies with Choice)

Components of Agency-Delivered Consumer Directed Services

1. Maximum control by the consumer to select, manage and dismiss the attendant, regardless of who is the employer of record.
2. Flexibility of services. After number of hours are assessed, the consumer has the responsibility to determine when and how these services are delivered.
3. Services must be community-based, in other words non-institutional.
4. Services are available based on functional and health related needs, regardless of disability and/or age.
5. Services are as non medical as possible and allow for unlicensed people to perform health related tasks through delegation or assignment.
6. Agency can provide a pool of attendants for the consumer to select.
7. System has a back up and emergency requirement that is designed by the consumer and/or the agenc.
8. Services are provided where the consumer needs them (including home, work, school, church or other locations).
9. Services must be available 24 hours a day, 7 days a week.
10. The agency can be the fiscal agent for employment responsibilities, or these responsibilities can be done by the consumer.
11. Voluntary training is available on attendant management and employment responsibilities.
12. Program must allow for co-pay\cost sharing for people with higher incomes.

ATTACHMENT 4: Summary of MiCASSA

MiCASSA provides direct services to the Consumer:

1) MiCASSA provides community-based attendant services and supports including assistance with:
   • activities of daily living (eating, toileting, grooming, dressing, bathing, transferring),
   • instrumental activities of daily living (meal planning and preparation, managing finances, shopping, household chores, communications, participating in the community),
   • health-related functions.
2) MiCASSA includes hands-on assistance, supervision and/or cueing, as well as skills development to learn, keep and enhance skills to accomplish such activities more independently
3) MiCASSA provides community-based attendant services and supports that are:
   - based on functional need, rather than diagnosis or age,
   - provided in home or community settings - school, work, recreation or religious facility,
   - selected, managed and controlled by the consumer of the services,
   - supplemented with backup and emergency attendant services,
   - furnished according to a service plan agreed to by the consumer including voluntary training on selecting, managing and dismissing attendants
4) MiCASSA requires services and supports be provided in the most integrated setting appropriate to the needs of the individual.
5) MiCASSA provides for quality assurance programs which promote consumer control and satisfaction.
6) MiCASSA includes a maintenance of effort requirement so that states cannot diminish more enriched programs already being provided.

MiCASSA offers flexible management, delivery and payment options:

7) MiCASSA allows consumers to choose among various service delivery models including vouchers, direct cash payments, fiscal agents and agency providers. All of these models are required to be consumer controlled.
8) For consumers who are not able to direct their own care independently, MiCASSA allows an "individual's representative" to be authorized by the consumer to assist in managing these services and supports. A representative might be a friend, family member, guardian, or advocate.
9) MiCASSA allows health-related functions or tasks to be assigned to, delegated to, or performed by unlicensed personal attendants in accordance with state laws.
10) MiCASSA also covers individual transition costs from a nursing facility or ICF-MR to a home setting, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.
11) MiCASSA serves individuals with incomes above the current institutional income limitation if a state chooses to waive this limitation to enhance the potential for employment.

MiCASSA provides financial incentives for states:

12) MiCASSA allows an enhanced Federal match (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs.
13) Between 2003 and 2007, after which the services become permanent, MiCASSA provides enhanced matches (additional 10% for each category) for states which:
    - begin planning activities for changing their long term care systems, and/or
    - include Community-based Attendant Services and Supports in their Medicaid State Plan.

MiCASSA encourages systems change:

14) MiCASSA provides funding for grants for Systems Change Initiatives to help the states transition from current institutionally dominated service systems to systems more focused on community based services and supports, guided by a Consumer Task Force.
15) MiCASSA calls for national five to ten year demonstration project in five states to enhance coordination of services for non-elderly individuals dually eligible for Medicaid and Medicare.

ATTACHMENT 5: Effectiveness of Rider 37
The Texas Money Follows the Person Policy

While we have not seen Money Follows the Person implemented on a national level, several states have been effective in establishing the policies and infrastructure needed to allow the money to follow their citizens into community living. The efforts in Texas to develop a money follows the person policy led the Texas legislature to pass a budget rider, Rider 37. In a review of Texas's Rider 37 conducted by the Independent Living Research Utilization (ILRU), the ILRU found that:

"There was unanimous agreement among interview participants and the study team that Rider 37 and its implementation were successful for a number of reasons. Five of the major reasons include:

1. Movement of 2,022 people. The greatest success is the fact that 2,022 people of all ages, including some with significant support needs, moved out of nursing facilities from September 1, 2001 through August 31, 2003. As a result, these individuals have much greater opportunities for choice, independence, and community life.

2. Increased awareness. The implementation of Rider 37 has raised awareness within the legislature and among people with disabilities and their families about the possibilities of community living.

3. Learning experience. The collective experience of implementing the transitions from nursing facilities--by people with disabilities, family members, advocates, DHS staff, relocation specialists, and others--promoted the realization that "it really can be done," and generated a deeper understanding about the types and amount of work required to make it happen.

4. Increased collaboration. Efforts to implement Rider 37 promoted new or increased collaboration among various stakeholders, who felt that the collaboration, alone, represented one of the major successes of Rider 37.

5. Cost savings. Participants in the study assumed that Rider 37 resulted in a considerable cost savings. DHS has reported that in State Fiscal Year 2002, the Community Based Alternative (CBA) Waiver served an average of 443 people per month who entered the program via Rider 37. During this time, Texas spent an average of $1188.70 per month for these individuals, compared to an average monthly nursing facility cost per person of $2373.66. In Fiscal Year 2003, Texas served an average of 1513 CBA individuals per month who entered the program using Rider 37 at an average monthly cost of $1256.721, compared to a monthly average Nursing Facility cost of $2375.49."

ATTACHMENT 6: MDS Data on Discharge Potential

MDS Active Resident Information Report: December 31, 2003			
Q1a: Discharge Potential and Overall Status			
Resident Expresses/Indicates Preference to Return to the Community			
State	**No**	**Yes**	**State Total**
Alabama	85.90%	14.10%	22,991
Alaska	74.10%	25.90%	607
Arizona	74.60%	25.40%	12,342
Arkansas	84.30%	15.70%	17,937
California	78.20%	21.80%	103,291
Colorado	79.00%	21.00%	15,806
Connecticut	80.40%	19.60%	27,352
Delaware	79.40%	20.60%	3,821
District of Columbia	82.90%	17.10%	2,747
Florida	76.60%	23.40%	69,943
Georgia	86.00%	14.00%	35,327
Hawaii	85.40%	14.60%	3,682
Idaho	75.00%	25.00%	4,570
Illinois	80.60%	19.40%	77,228
Indiana	82.70%	17.30%	39,659
Iowa	82.80%	17.20%	26,835
Kansas	83.40%	16.60%	20,381
Kentucky	83.20%	16.80%	22,088
Louisiana	89.50%	10.50%	28,087
Maine	79.10%	20.90%	6,698
Maryland	77.90%	22.10%	24,664
Massachusetts	82.10%	17.90%	44,393
Michigan	76.90%	23.10%	41,062
Minnesota	80.80%	19.20%	34,515
Mississippi	90.00%	10.00%	15,598
Missouri	80.10%	19.90%	37,301
Montana	78.60%	21.40%	5,565
Nebraska	81.40%	18.60%	13,057
Nevada	78.00%	22.00%	4,091
New Hampshire	84.20%	15.80%	6,957
New Jersey	80.90%	19.10%	43,190
New Mexico	77.30%	22.70%	6,265
New York	81.80%	18.20%	111,244
North Carolina	82.10%	17.90%	37,451
North Dakota	85.70%	14.30%	6,028
Ohio	78.30%	21.70%	76,541
Oklahoma	84.40%	15.60%	20,684
Oregon	73.30%	26.70%	8,165
Pennsylvania	83.60%	16.40%	77,846
Puerto Rico	44.40%	55.60%	169

Rhode Island	83.20%	16.80%	8,345
South Carolina	83.20%	16.80%	15,981
South Dakota	84.90%	15.10%	6,652
Tennessee	81.00%	19.00%	32,697
Texas	84.50%	15.50%	88,072
U.S. Virgin Islands	70.00%	*	30
Utah	70.00%	30.00%	5,187
Vermont	79.30%	20.70%	3,208
Virginia	78.90%	21.10%	27,444
Washington	74.70%	25.30%	19,410
West Virginia	78.60%	21.40%	10,129
Wisconsin	80.10%	19.90%	35,134
Wyoming	78.00%	22.00%	2,415
NATIONAL TOTAL	81.10%	18.90%	1,410,882

ATTACHMENT 7: Long Term Care Spending by State
Comparison of Institutional and Community Spending

2002 Long Term Care Expenditures by State

	Institutional	%age	**Community**	**Percentage**
AL	$753,386,069	77.00%	$225,195,368	23.00%
AK	$87,224,259	43.90%	$111,593,160	56.10%
AZ	$18,767,801	84.00%	$3,573,553	16.00%
AR	$526,198,840	74.70%	$177,904,393	25.30%
CA	$3,406,273,915	64.40%	$1,886,784,547	35.60%
CO	$410,738,443	48.60%	$435,189,857	51.40%
CT	$1,239,787,432	65.40%	$654,910,254	34.60%
DE	$155,632,375	73.00%	$57,640,633	27.00%
DC	$260,487,903	92.40%	$21,365,476	7.60%
FL	$2,186,242,530	74.30%	$755,303,767	25.70%
GA	$946,351,188	74.50%	$323,535,029	25.50%
HI	$177,993,887	73.30%	$64,848,069	26.70%
ID	$177,427,142	64.00%	$99,739,643	36.00%
IL	$2,235,201,332	81.80%	$497,310,644	18.20%
IN	$1,211,606,096	83.70%	$235,584,539	16.30%
IA	$913,059,994	80.90%	$215,312,623	19.10%
KS	$582,425,417	61.00%	$372,021,441	39.00%
KY	$713,041,753	71.60%	$283,188,173	28.40%
LA	$1,686,790,945	90.20%	$184,271,878	9.80%
ME	$246,482,636	56.20%	$192,331,124	43.80%
MD	$816,510,398	71.20%	$330,382,992	28.80%
MA	$1,617,650,360	64.80%	$878,485,328	35.20%
MI	$1,809,960,555	75.70%	$579,520,543	24.30%
MN	$1,101,344,752	51.10%	$1,054,761,777	48.90%
MS	$626,760,332	87.40%	$90,719,371	12.60%
MO	$1,425,612,251	72.90%	$528,821,781	27.10%
MT	$155,403,321	62.70%	$92,535,111	37.30%
NE	$439,202,235	69.60%	$191,556,715	30.40%
NV	$137,823,149	73.40%	$49,870,146	26.60%
NH	$304,374,773	65.40%	$160,759,154	34.60%
NJ	$2,758,913,933	80.10%	$683,492,314	19.90%
NM	$187,765,214	38.20%	$303,558,884	61.80%
NY	$9,077,231,956	62.80%	$5,367,977,066	37.20%
NC	$1,306,504,101	60.60%	$847,721,805	39.40%
ND	$229,159,313	80.60%	$55,236,925	19.40%
OH	$3,431,656,290	83.50%	$677,658,057	16.50%
OK	$562,306,180	63.80%	$319,465,385	36.20%
OR	$207,993,750	27.10%	$560,712,555	72.90%
PA	$4,502,350,838	81.20%	$1,039,509,121	18.80%
RI	$269,302,754	59.30%	$184,484,158	40.70%
SC	$565,146,822	65.40%	$299,228,043	34.60%
SD	$190,167,009	73.20%	$69,487,425	26.80%

TN	$1,197,393,742	84.40%	$220,869,173	15.60%
TX	$2,582,158,096	70.40%	$1,083,152,546	29.60%
UT	$150,602,607	58.20%	$108,312,811	41.80%
VT	$93,814,492	44.20%	$118,341,454	55.80%
VA	$914,526,111	73.10%	$335,704,635	26.90%
WA	$839,356,363	52.70%	$753,493,288	47.30%
WV	$358,783,151	62.10%	$219,017,679	37.90%
WI	$1,544,148,990	70.40%	$649,175,975	29.60%
WY	$65,901,189	49.20%	$68,026,194	50.80%
Total	$57,404,944,984	69.90%	$24,719,642,582	30.10%

ATTACHMENT 7: Long Term Care Spending by State
Comparison of Institutional and Community Spending

June Adams
Denver, Colorado
17 years

I had two little boys when I had a stroke. My husband became my guardian and put me in a nursing home, where I was held captive for 17 years as my children grew up. I was able to get rid of the guardianship and move into my own apartment where I can live.

Judy Anderson
Denver, Colorado
7 years

It was terrible, and they took advantage of me. It is more peaceful in my home.

Nancy Anderson
Denver, Colorado
10 years

I was in the military at age 21. I developed a brain tumor. They put me in a nursing home for 10 years. I sued the nursing home for abuse. I won and bought my own house. I have been free for the last 28 years.

Adren Ward Ange
Norfolk, Viginia

I'm fed up with all the shit at the Transitional Care Hospital where I live. They never let me go out by myself. Can't have loud music. Can't have no privacy. Notice the word "transitional." Under Medicaid's defintion, if you look up the word "transitional", it must say "ten years" or more because I've been here for 14 years and am on the DD Waiver Medicaid wait list until Moby Dick was a minnow. I'd rather be sitting on the beach, watching the beautiful people. I'd rather be living in my own apartment, going fishing, and working.

Anthony

Intro:Anthony

This is a third person account of a man who has repeatedly refused and spat upon the current service options offered to him. His story epitomizes the struggle we have with the concept of personal freedom and choice. Anthony is not a man who many would call honorable. His teasing and joking belies the fact that his circumstances are largely of his own making and he does not accept the consequences of his actions with adult logic. Rather, he flies into a rage, and threatens to "run you over" as he flings hurtful words at the bearer of unfair news. He has little self-control and no interest in developing any. People prefer not to be around him, if only from a sanitation level.

Yet, how we treat Anthony defines who we are. We have an uncomfortable kinship with this man who acts before thinking, who can only see the next moment instead of the larger picture. We don't understand how someone who complains about not being able to take more than one shower a week would choose to live in Pioneer Park, where he may not have a shower for months.

Kay Fox from SLCAP first met Anthony while part of a community effort to secure SSI for homeless and disabled individuals. Since that time, according to Kay, Anthony was in a car accident, which made him a wheelchair user. As Anthony grows weaker from AIDS related problems, his anger isn't so dramatic.

He is happy to see people, but then verbal harassment begins. We can do better. We can treat people with more respect and common courtesy than he was treated. We can be better. Perhaps we can begin by providing services for individuals, not institutions. Why couldn't Anthony have someone help him with personal needs such as personal hygiene and taking medication where he is?

Anthony's quality of life would be better for it. Anthony's search for respect may have been broader had he been able to take a simple shower on his terms. If he were cleaner, more people may have interacted with him. He may have even discovered that respect is a two way street.

Not all news is bleak – the Utah Department of health staff are aware that there are people in nursing homes or on the street who have behavior problems the state doesn't have resources to address. They are applying for funding to study how best to assist this population.

Anthony's Story:
Anthony Wadell has burned more bridges than most people have occasion to build, according to Sheryl Dobson, CHAMP worker. In the two years she has worked with Anthony, virtually every nursing home in the Valley has offered Anthony shelter that he has eventually walked away from. After Anthony has left against medical advice, the nursing homes rarely want him back.

He violates rules at shelters, or at the hotels that offer temporary shelter to people on the street. He is not on good terms with the food pantries, and the Utah AIDS Foundation can only allow him minimal services.

“Anthony is verbally abusive to just about everyone. He has trashed and destroyed furniture and other property in most of the p0laces he has stayed,” said Dobson.

The staff and volunteers involved with the ”Our Homes, Not Nursing Homes” project at the Disabled Rights Action Committee (DRAC) echoes Dobson’s assessment.

“Not many organizations will offer services to Anthony anymore. His behavior jeopardizes their relationship with other service providers and makes it harder to get services for other people.” A DRAC volunteer explains.

Dobson, however, recognizes both Anthony’s vulnerability and strength. “If he were anyone else, Anthony would have been dead a long time ago, “ said Dobson. “I like Anthony, and he likes me because I am straight with him. While he plays up his delusions to others; he and I have real conversations and I find him to be a very personable man.”

“The man is incredibly resilient,” agreed Jerry Costley, supervisor of the Our Homes, Not Nursing Homes project, “and people seem to respect this trait.”

Indeed, in the past, some agencies have gone out of their way to accommodate Anthony because they see this strength of will. Repeatedly over the years, a multi-discipline team consisting of representatives from different organizations has worked with Anthony to provide a service plan to meet his needs, only to have Anthony sabotage the plan. But, can we just turn away?

“Everyone needs somewhere they can go, someplace where they are not stopped at the front door. Ironically, DRAC and CHAMP can do this because as advocacy organizations, we have no services to provide. We don’t have living spaces that can be trashed, counselors with egos to bruise or food to complain about,” said Dobson.

DRAC works on long-term goals for equal access, while advocacy is invaluable to the disability community, when your clothes are deteriorating under layers of filth, the last time you ate was the day before last and you are battling AIDS related pneumonia, political advocacy on your behalf seems a little too abstract.

Looking through the case files at DRAC, Lori Brock realized that DRAC also spends a lot of time trying to repair burned bridges between service providers and Anthony.

“People at DRAC take the time to listen and because we do not provide expensive services that may be trashed and mutilated, we are able to listen without bias, I realized.”

Sometimes advocating for Anthony means getting him not to reject the few services being offered.

“It is so ironic to be part of an organization that tries so hard to find community options for people in nursing homes to actually encourage someone to stay in a nursing home!” Brock laughs ash she remembers how DRAC members tried to find Anthony temporary housing in a nursing home so he could be out of the cold and confusion during the Olympics.

At first, DRAC’s willingness to look at nursing homes as an even a temporary option seems to go against the philosophy of the Our Homes Not Nursing Homes Project, but as Costley explains, “Although we believe vehemently in necessity of providing services to people in community settings rather than in isolated and segregated settings like nursing homes; we also believe that people need to be informed of all the current options available.”

Anthony, however, doesn’t wait for any options. When the restrictions and regulations of a shelter or nursing home program anger and frustrate him; he leaves.

When the weather is warm Anthony’s home is Pioneer Part. “He knows where he can get the things he needs and wants,” said Crock, who first met Anthony when he grudgingly accepted nursing home services during the Olympics.

“He has people who will provide him with his favorite soda, other people who replace his clothes periodically and still other people who will replace a stolen sleeping bag from time to time. Every time I see him, he looks thinner and sicker than the last time I saw him,” said Brock.

“The Our Homes, Not Nursing Homes Project at DRAC is all about people making their own choices and having power over their own lives. Anthony is actually a teacher. He teaches us that people’s choices may not be the ones we want or wish for them but their own choices make them uniquely who they are. Whether Anthony is sheltered from the cold in a nursing home or homeless in Pioneer Park, he is in charge. And he wouldn’t want it any other way,” said Costley.

Jeff Arrison
Corning, New York

His “way of life” was progressing. Jeff Arrison was born September 24, 1959. H went through high school, land was preparing for college when he had a single car accident in 1980. This resulted in him becoming a quadriplegic. From age 20 onward Jeff would pretty much be in Medicaid institutions.

He had been planning the arrest of his life of completing his education, a job, marriage, and children. Medicaid institutionalization would end this plan. Although he made over one dozen serious attempts he never was able to “break free” from Medicaid’s grip. Even when his counselor said to him “we will get you out of that nursing home”, he remained there.

Jeff did know for positive that he was capable of managing an apartment because for a while he had an apartment of his own from 1981-1984. Due to the fact that Social Security and Medicaid and the state of Massachusetts did not live up to their word about available community services, he returned to institutionalization and was never able to ‘escape” again.

Right now Jeff is institutionalized in Founder’s Pavilion Nursing Home, a very inappropriate place for him, but the only place available in his hometown of Corning, N. Y. He “rots” there with little hope of returning to society.

His day begins at approximately 10:30 (he says any nursing home is pleasant when you are asleep, so he tries to sleep as much as possible.) After getting morning “hygiene” he exists by having lunch (he worked in kitchens before his accident so he knows what kitchens are capable of, this kitchen doesn’t even try). Adequate nutrition is maintained by “junk food”. After lunch he gets through the afternoon by watching boring television, napping, etc. Keeping him appropriately entertained would be impossible if it were not for his relations pooling their efforts and purchasing him a computer to keep him busy (when he asked the state to help him finance the computer they said “No”). Then another meal of inadequate dinner is served. Followed by doing the days business (like correspondence) and more television. This is followed by his evening ‘hygiene” at approximately 10:30. Then at approximately 1:30 A.M. he goes back to sleep.

He has had to endure such things as broken and dislocated bones, inadequate doctors care, physical “forcing,” unpleasant social care, medications that is prescribed or requested being often more than one-hour late without immediate correction. After many years of non action about “problems” he has come to the conclusion that Medicaid institutions “just don’t care.”

Michael Barczak
Jackson, Mississippi
5 ½ years

For several months during the mid seventies there was some talk about me leaving my parents home. After some lengthy discussions I thought the talk had subsided. One day I was sitting eating lunch and to my complete surprise this strange woman walked into the house. My mother proceeded to tell her that I could no longer live with them because of illness in the family. I knew my parents had been ill but I had no idea things were that bad.

This strange woman began looking for a place for me to live. I told her about a care home that I had heard about. She contacted them and they had a bed open so I moved in with them. I didn't know anything about the system. It was a hard time for me. I pretty much went along with whatever the powers that be told to me. To my knowledge there wasn't any handbook and if there was I didn't have access to it. Things went reasonably well for the first three or four months, but when my father stopped making regular visits things changed considerably. In general, the staff started to treat me like a five year old and this was unacceptable to me as a young man in my mid-thirties. The staff had very little understanding that as a person with Cerebral Palsy it often takes long to complete tasks and they began to complain.

I received an eviction notice and my search for a new home began again. A social worker that was put in charge of my case didn't like me because I would often speak my mind. I've always been a natural problem solver and I often had my own connections and would attempt to solve my own problems. This was an alien concept that someone could actually advocate for themselves and control their own destiny after a short unsuccessful search the social worker and the owner of my current home recommended that I be placed in a nursing home.

Being in a nursing home was a completely different experience. The atmosphere was dark and filled with hopelessness. I tried to make friends with the other residents but when the mindset of your potential friends dwells on dying it is a hard thing to accomplish. Most of the real relationships I had were with the staff members. One of the only positive activities that helped me to maintain my sanity was that I was able to go town a couple of times a month. After four and a half years of that there was an annual state inspection at the facility I was housed in conducted by the health department. To my complete surprise they told me I couldn't stay there any longer because I did too many things for myself. This was my beginning in the Independent Living Movement. In the beginning my shocked. Parents tried to block my becoming independent. They even went as far as to threaten legal action against the nursing home. In the end they couldn't stop my drive to become independent.

The caseworker I had told everyone at that time I wouldn't make it on my own. Well my friends that statement was made some fourteen years ago and I'm still living independently in my own apartment. Independent Living is a challenge, a series of problem solving steps that with some work can be done. My message is that people with disabilities need to be prepared for Independent Living as early as possible. Much earlier than myself the earlier people get started the more opportunity they will have to meet their goals.

Paula Barton
Rochester, New York

My name is Paula Barton. I am a 28 year old, disabled female. After going to emergency with chest pain, I was sent to a nursing home. They told me I could not return to my apartment because I could not get any Nurses Aide service to get me in and out of bed. I was there for four months.

During my stay in the nursing home, the experience was not good. Here are some of the reasons why. The hospital was not geared for a young person. I could not move freely and I had to be signed out by a person who was not in a nursing home. I had no independence.

I did have one good experience. The social worker was a young woman. She understood what I was going through. She started a month after I arrived there. Together we found an agency that would give me aide service. I am now home after 4 months. I have 20 hours of aide service and I'm doing very, very well.

Barrie Berliner
Gloversville, New York
1 Year

I, Barrie Berliner, was in a nursing home because I fell off a balcony and the nursing home was not a place for me to spend the rest of my life. With financial supports funded by the Department of Health, I moved into a house with a few housemates where the care is great. I have my own room with my own things, help to cook my own meals and I have all my workout equipment in the living room and it is basically my own home.

At the nursing home, I had room assigned to me and there were elderly people there and it was very regimented. Being a spontaneous person, I couldn't go out with my friends. It was very strict, there were strict rules and I hated it there. I felt almost dead. It was because of the Physical Therapy at Lexington, I can walk by myself and before, I couldn't walk by myself, I couldn't transfer. I needed a lot of help. Now I need no help. I am so independent. I couldn't even take a shower before. Now, I can take a shower by myself and I can take a shower everyday. Lexington Center has done wonders for me. They've done so much. There is personal help. Instead of being fed, they taught me how to feed myself, which in the long run, made me feel great. Nobody wants to be fed for the rest of their life. Independence is great.

I am a true testimony of what not living in a nursing home can do for you. Do they want to be waited on or do they want a free independent life? A choice of freedom. This is America.

I am also available as a public speaker to support this, because I have such strong feelings toward this.

Joe Bonomo
Rochester, New York

Christmas time is always one of my favorite times of the year. It's when people spend time with their families, friends and loved ones. It is also the time I'm reminded of how wonderful my life is; it's when I became a free man.

I was born with a disability, Osteogenesis Imperfecta (OI), brittle bone disease. Shortly after I was born, I was imprisoned at the Newark State School, where I was incorrectly diagnosed with being mentally retarded as well as having OI.

This institution was hardly a school at all; it was a horrible place, a place where I was mentally, physically and sexually abused for fifteen years of my life. I was never offered anything that would resemble a class in Mathematics, English or Reading. Instead, everything I learned I picked up from watching television. Staff would sedate me with drugs and then I would be forced to sit in a room covered in urine and feces by the other unattended people who were imprisoned with me and left to watch television.

When I was fifteen I was reevaluated. The institution's doctor was shocked to learn that I could tell time. He realized that in fact I was not mentally retarded I was incorrectly diagnosed. He befriended me and encouraged me to enter the Helen Hayes Rehab Hospital.

It was at the Rehab Hospital that I was able to take classes and start to assemble something which reflected a "normal" life. In two years I was able to complete all the required course work for grades 1 through 8. It was here that I realized that my life was nothing like I wanted it to be.

At the age of eighteen I was forced to leave Helen Hayes Rehab Hospital because I was too old to receive services there. I was then transferred to Monroe Community Hospital. I was in an institution once again and one thing remained the same - I still felt like a prisoner. I was again put on drugs, sedated and attended by nurses and doctors that didn't seem to care about me or anyone else there.

After four months of intolerable living conditions I decided that I wanted to be *needed*. I wanted to be *free*. Through the help of a staff member, whose daughter I befriended in the hospital, we escaped late on Christmas Eve, 1977.

I moved into my first apartment with my friend with whom I escaped. We supported ourselves by using the money that was to be spent on us in the institution. When we informed the state that we had moved, no one checked to see where we moved, they just changed the address on our checks. **I was free!**

Over the next few years, I attended Jefferson High School, graduated, moved into my own apartment, and with the help and guidance of a counselor at VESID, I enrolled in BOCES and learned the skills needed to work in electronics.
In 1982 I was offered a job with Kodak and met my wife Debbie who has Cerebral Palsy. Today, we live in a home we own and everyday we continue the fight to keep our freedom. In February of 2002, I suffered three strokes which diminished my physical

abilities, but not my intelligence or desire for freedom. Several doctors said I should go back to the nursing homes, but I refused. With the help of my family, friends and aides paid for through Medicaid's personal care option, I returned home from the hospital just before Christmas of 2002. Almost exactly 25 years after first escaping to freedom I had again fought for and won my freedom.

According to Minimum Data Set numbers, collected by New York's Department of Health, nearly 20,000 of New York's nursing home residents would rather live in the community. Though the only crime they have committed is having a disability, these people are prisoners. Every time I hear about someone imprisoned in a nursing home I feel nothing but pity for him or her because I have lived that life, and I know how much better life is in the community. I can't fathom anyone wanting to live in a nursing home or any institution.

In the November 23rd New York Times magazine, Harriet Johnson wrote "In the gulag (institutions) you have no power. The gulag swallows your money, separates you from your friends, makes you fearful, robs you of your capacity to say-or even know-what you want." I couldn't agree with this more. More recently, the New York times reported that according to NYSDOH, the percentage of nursing home residents who are under the age of 65 is climbing! Now, 12.5 % of nursing home residents are under the age of 65.

There are options that could help these many young people and seniors with disabilities live in the community like me. In Congress right now, there is a bill, the Medicaid Community-based Attendant Services And Supports Act of 2003, also known as MiCASSA. MiCASSA would shift the bias of funding away from nursing homes and into community support services. Money that is spent on institutions would be redirected to individuals and allow them to make the choice to live their lives in their own homes. MiCASSA would help people escape from nursing homes and institution and give them the choice, the freedom, to live just like the rest of us.

So this Christmas, I will celebrate with my family, friends, and loved ones, not only a holiday, but the anniversary of my freedom. I can truly say that it's a wonderful life. With MiCASSA, many thousands of New Yorkers will have this same opportunity.

Marie Brawn
Eastern, Kentucky
20 Years

I was born in Eastern Kentucky in 1953. I have Cerebral Palsy. It affects my limbs and speech. I was institutionalized from age 2 until 27. I will tell you of things that happened to me during this time. I was drugged so I wouldn't talk about what I heard or saw. I saw physical abuse. People were being hit. I went to school wearing dirty clothes. I had to wait a long time for help to the bathroom. I had very little privacy, even when talking on the phone or to my priest.

Some of the aides would make fun of me.

Things are now changed for me. I have been out for 23 years because my second husband got me out after a big fight. He died in 1994 from a heart attack. Then with the assistance of personal attendants, I learned to live on my own. I have a part time job working for the Salvation Army collecting money. I have a pet cat named Shadow. As a child in an institution, I could never have a pet.

I hope that Congress will pass MICASSA. I know a lot of people in institutions who Want and need to get out. It would cost the government less to keep us in the community. I am glad to be out and to have more freedom. I can be my own boss.

Kurt Breslaw
Boulder, Colorado
15 Years

You don't live in a nursing home; you only exist in a nursing home. I love living in my own house. I get better care in my own home then I ever did in the nursing home.

Brian
Utah

Introduction: Brian
If Brian's family had received community support services such as respite care and home health assistance, it is possible that Brian never would have gone to a nursing home. Furthermore, since Brian was already deeply rooted in his family and community, it is more than likely that with only a little instruction on the need for structure Brian would have gone on to be a very productive and influential person within that microcosm of society. As it was, Brian spent years of his life waiting for the next meal, the possibility of a recreational activity, or bedtime.

Brian watches as others were able to access specific waivers to get the funding they needed to move out of the nursing homes. Brian followed suit but was continually frustrated in his efforts to move out into the community, because he didn't meet the specific requirements of the existing waivers.

Finally out of the nursing home and receiving services from Flexcare (a pilot program that accesses funding for people who don't fit into any of the waiver programs) Brian has moved into an assisted living program. He reports that he is happier and more energetic. He is also looking for volunteer opportunities that will let him contribute to the community.

Brian's Story

I want to tell my story because I want others to know how frustrating it is to want to be a part of the community when you live in a segregated setting such as a nursing home.

When I was nine years old I was diagnosed with an inoperative brain tumor and while it didn't kill me, both the tumor and the exploratory surgery I underwent at that time caused some brain damage. My father died when I was ten and it was a difficult time for my family. One of my early experiences living in a nursing home happened when my brother and his wife could not longer take care of me. My legs were swollen and so big that I couldn't move around.

That first night, I felt totally devastated because I couldn't live with my family anymore. I felt useless like there wasn't anything I could do for them and I felt like it was my fault. Instead of being with my family all the time and being part of its on going story, when I was in the nursing home I saw most of my family only on occasion. This made me very lonely.

This first experience happened over twenty years and it was really the only option for me and my family at the time. Now we could have thought about community services such as personal assistance and respite care—provided we could access the funding for these services. The availability of services could have allowed me to participate in family and community life and get the care I needed at the same time. (And these services would have cost much less than living in a nursing home.)

I've been out in the community living on my own several times but I always had to go back because without the services I needed to help me maintain a structure, I tended to gain a lock of weight and my skin would break down. That meant that I couldn't move around very much, which would cause my skin to break down even more. Every time I went back to the nursing home, I tasted failure. It was like I had my chance but now I was back to square one. I blamed myself. I didn't want to be in the nursing home but I couldn't get the specific services I needed to be successful on my own. Now I realize that services (similar to what I now receive in the assisted living program that I now participate in) including: cooking instruction, personal assistance, accessible housing and transportation, would have opened so many doors. I could have found (and gone to) work—even volunteer work would have kept me interested and connected to the community. I could have also been more involved with my church. I could have given more to the community. So often I felt like all I could do was take but with the right services, I could have given more.

Now I want to help make sure services like: scheduling and planning assistance, transportation, physical therapy, and diet and medication reminders are not only available to me but to the younger people who want to both live in and give to the community.

The nursing home alleviated the problems that my family and friends had taking care of me. But in the nursing home, I very often didn't have control over what I did or when I did it. I had to schedule a shower and was lucky if I could have one three times a week. Now, in the assisted living program, I take my own showers everyday if I want to. In the nursing home, I had a limited choice in what I ate. In assisted living, I have my own refrigerator and microwave in my room, so if I don't like what they are serving, then I can have my own food. I guess the most important thing that is happening now that I'm not in a nursing home is the availability of natural opportunities I have developed and practice more skills on my own. In the nursing home, there is an encouraged and forced dependence.

A typical day in the nursing home began when I woke up at 6:00 am. I got ready for the day and went downstairs to the dining room. There were usually two, sometimes three others down there and we would play cards until breakfast time. We waiting, breakfast would come, and we would have our breakfast.

After breakfast, I went to my room. That was about 9:00 am. A lot of the time I sat and watched TV. I waited to see if there would be an activity to go to. Sometimes the staff would run bingo or something. If that was the case, I would go the activity, and then come back and sit around.

At 10:30 am, there would be a coffee break, but I don't drink coffee, so I would have hot chocolate. Sometimes immediately following the coffee break, there would be another activity, which I usually went to. Then it was time for lunch. I would go down to lunch early to play cards again. We ate lunch and I went upstairs and I just sat around because there wouldn't be anything to do. Sometimes I took a nap. Around mid-afternoon, they might have some kind of activity.

Once in a while, they would have some kind of entertainment after dinner but not very often. After dinner, we just went to out rooms and waited until it was time to go to bed.

People normally have at least one roommate in a nursing home. Sharing a room with someone was intrusive because of a lot of things. I had to take into consideration things like having the TV on, or the radio, or the light on. Even how late I stayed up or when I went to bed depended on a shared understanding with my roommate. I had many arguments with my roommate because I might not agree with him on something. It's worse if you have separate TV's because one is watching one and one watching another. I had to keep my TV loud enough to hear it and quiet enough for my roommate. To top it off, my roommate was in the bathroom constantly! I had to watch and take advantage of the times he would vacate the throne in order to relieve myself!

I did meet a dear friend in the nursing home and I missed seeing her everyday. I think the world of her. The main reason I think so highly of her is that she is one who will stand her own ground for herself. She will say what she feels and ever since I have met her I have really, really looked up to her for that. I didn't used to be that way. My mother even likes her. My friend always tells me to make sure that I tell my mother I love her. This friend has and will always have a very, very special spot in my heart. My relationship with her is one of the very few positive things about my experience the nursing home where I lived.

Now that I am in an assisted living place I feel happier now because the environment feels happier to me. Family members who come to visit say they notice a difference. They all say, “This is so much better than the nursing home.” There is more energy in the air and more of an assumption that you will find things to do, even though there are not as many planned activities. The staff assumes that you have interests and hobbies of your won that you will pursue.

My room feels more like an apartment. It is my own room. I don’t share it with anyone, unless I invite someone to be there. I have my own shower, refrigerator, microwave and I could have a pet if I wanted to.

I think almost everyone would want to live as independently as possible but the funding is not set up make it easy to get services in the community. In order to get the money that was used to pay the nursing home to pay for the assisted living place I am in now, I needed to fit into a category so I could qualify for a waiver that would channel my funding. The trouble was that I didn’t fit. The Personal Assistance Waiver requires that you have the loss of function in at least two legs needed to perform daily living activities. With me, sometimes this is true but sometimes it’s not. (Sometimes I walk quite well but a lot of the time I really can’t.) The Traumatic Brain Injury Waiver requires that the brain injury be traumatic and caused by some sort of accident. My brain injury wasn’t caused by a traumatic event so I don’t qualify for the TBI Waiver. I do get funding from Flexcare, a pilot program that helps people who are hard to fit into other waiver programs transfer funds from nursing homes to community based services. But there are so many people who could live successfully in the community and do it a lot cheaper than they would in a nursing home and not enough programs like Flexcare to help transfer the funds. Right now, people are entitled to nursing home care and not community services. This is what needs to change. It needs to change because not only is it cheaper to provide services in the community, but it lets people be part of the community, but it lets people be part of the community. I not only receive services in the community, but it lets people be part of the community. I not only receive services in the community but I shop, attend church and I am thinking about volunteering for a youth organizatrion. And this makes me a contributor as well as a consumer. And isn’t
That what the community needs.

James Burke
Erie, Pennsylvania
1 Year

I was brain injured in 1993 and then spent the worst year of my entire life at Anchor Inane in Erie Pa. From May of 96 to May of 97. I witnessed and had atrocities done to myself by staff. Now I thankfully live on my own. How short is a short summary because I have a lot to say. The owner Sherry hill has a lot of friends in high places and my three page complaint sent throughout law offices and state agencies went unanswered.

Donna Caudill

Thank heaven I didn't have to stay too long in a Nursing home. It was a big waiting game. If they didn't come on time when you called, they didn't mind fussing at you when you had an accident. If it was treatment day, in my case, the treatment was to keep down the odor when they did not come in time to take me to the bathroom.

I thought I'd better myself by going to a state institution, developmental disability home. However, I didn't. The things they showed me and promised me were a joke. They said I'd receive occupational and physical therapy. I didn't. Thank God I'm out and in my own home.

Thanks to supported living, I'm out on my own. I can tell people what I want them to do for me. I can go out every day if I choose.

Would you please support MICASSA so other people can do what I am already doing.

Maureen Charley
Gallup, New Mexico
9 Years

Maureen Charley moved off the Navajo Reservation into a group home in Gallup in 1985. She lived in the group home until it closed in 1994. She then moved into her own Apartment.

The past 10 years she has been working at The Thunderbird jewelry Supply Store in Gallup. She lives with her boyfriend and her baby boy.

Barbara Coppens
Cherry Hill, New Jersey
15 years

I lived at Vineland State School for 15 years. I went there when I was five years old. When I was a teenager they let me go to public high school so I got my high school diploma. When I was 20 years old I was moved to a group home. I knew that I wanted to live in my own place. I have a real job, learn new things, and can be on my own. So I learned everything at the group home. I found a job as a janitor on my own, and then moved into my first apartment with my friend Josephine.

Josephine and I just moved into a brand new apartment. I am no longer a client. I travel all over the state by public transit working for self-advocacy. I have a state job helping people with developmental disabilities understand their health insurance rights. I keep busy serving on boards, committees. Life changed for the better the day I walked out of the institution. I had a dream. I am living my dream come true. I like to tell people to have a dream and believe in your self, matter what.

Kit Cromwell
Ann Arbor, MI

I was in a nursing home for seven months. I was treated with extreme cruelty. I was told, more than once, that I would have to choose between lunch or dinner, they didn't have time to feed me both. They rarely washed me. I was sexually abused by the physical therapist. One night my ventilator came loose and the respiratory therapist stood there with her arms crossed in front of her and asked "So, do you want me to hook you back up?" By the time I was transferred to a hospital , I was like a wild animal. They had to sedate me. I had become so accustomed to fighting for any scrap I got. I was treated with valium for quite a while.

While nursing homes instill powerlessness living independently germinates empowerment. Living on your own and having the freedom to hire and fire is liberating. Now, is my life always easy-no. There are tremendous challenges in living on my own. But I wouldn't give up on it for anything.

It's been ten years since my stay in the nursing home and I have come a long way. Family Independent Agency pays for my care attendants now. I work as a disability advocate for the Center for Independent Living and the Alliance for the Mentally, Ill. I have good friends, a handsome and supportive finance and three cats! I am a happy and productive member of society.

We need supportive independent living options-not nursing homes!

Robert Cutler
Arlington, Massachusetts

I am going to say enough with institutions. There is not one illness or deformity which should be given as an excuse to be discarded away from society.

I, Robert Cutler, am 46 years old. I am autistic. My life has been hell because nobody truly understands autism. I live a life hunting to survive. I enjoy the opportunity to choose who helps me. This was not always the case.

I lived for five years at the Fernald State School. I call it in the Fernald Penitentiary. I felt like a criminal the first day I was in Fernald. My crime was no one really understood autism, allergies and sadness in my heart.

Fernald was worse than prison. The food was garbage. My daily life was military like. I lost the right to be human when I entered Fernald. It was a horrible experience. I was beaten.

Suicide was a thought I had while in Fernald. I was asked to act like a seal, being fed food to do nonsense jobs because I was different. If I was good, I was given food. If I was bad, I was restrained. I was beaten, locked in dark rooms. Not because I was bad but because no one took the time to understand me. The screams through my stay were screams for freedom. A staff person loved to beat and hurt me almost every night and no one hear my screams. I hated this but I had no voice.

They tried to destroy my will but I hung onto my sanity. But I still have nightmares and they are even worse than the flashbacks. I live a life hunting to survive. A survivor is a person who even though he was physically and mentally beaten, refused to give up the hope that someday I would be free. Yes, I am a survivor.

I want to type about the freedoms I now have but didn't have at Fernald. I have the right to vote. I have the right to walk when I want to, not when they want me to. I can choose to have a sick day, a vacation wherever I want to go. I don't need staff staring at me while I use the bathroom.

I feel there needs to be more money vested in people who suffer from PTSD because of being sent to institutions because they were different and society wanted not to help us but to hide us.

Why do states take away our rights to determine our life's pathways when they put us away in institutions instead of homes? I think this is wrong! We need services in the public eye, instead of hiding us away from society.

Too long have many suffered away from the community. No amount of money can recreate a community on institutional grounds. I find it offensive when I hear of MIA/POW flags at institutions. Don't they realize that those people in institutions are held captive and can't roam communities like American citizens do. Is our nation creating institutions to discard us as waste, garbage, or is this country willing to admit they made a mistake?

Freedom will prevail.

Dan
Logan, Utah

Introduction:
"When I first met Dan in the spring of 2000" said Kay Fox "it was at a living wage coalition meeting. I mentioned a new project that Salt Lake Community Action Program and DRAC were co-sponsoring to assist nursing home occupants to live in the community. I couldn't have been more surprised when after the meeting Dan said he had

lived in a nursing home, but had escaped. What first stood out as I listened to his story of survival was that no one ever talked to Dan about any services and options to live in the community. As a result, when he left the nursing home he had open wounds in his side. Dan risked infection and death by leaving. Later when I talked to my colleague, Jerry Costley, about the risk Dan took when he left the nursing home against doctor's advice, Jerry said that Dan exemplifies "how life in an institution can be so restrictive and degrading that the only alternative he had was his van." He had no money, no home, but in his flight from the oppression and segregation he experienced, Dan found dignity and self respect."

Dan has been one of the Our Homes project's most active volunteers. As a peer advocate, Dan is a role model of independent living. If a nursing home occupant complains about the amount of paperwork necessary to apply for housing subsidies, utility assistance, food stamps and housing applications, Dan can laugh and explain that its better than living in a van. In addition to the Our Homes project, Dan has volunteered to work for change in Medicaid policies and funds.

He has participated in protests and marches, press conferences, policy meetings and at the Utah Legislature on issues that impact health and quality of life. He works to assure that others at risk of or who are in nursing homes are told of their rights and the resources available. For those of us who Dan volunteers with, this self-described "troublemaker's" mischievous smile makes a hard issue more fun.

Dan's Story:
I was born in Logan, Utah and graduated from Utah State University in 1972. After graduation, I migrated to northern California where I started a custodial service business. In 1996, I moved to Wyoming. On the way, I visited my sister in Salt Lake City. I became ill while there and my sister took me to the emergency room. I had bleeding ulcers and went into a coma from the loss of blood. The doctors performed a radical surgery, removing one third of my stomach and four inches of intestines and bowel.

Amazingly, after the surgery, I felt fine. But because I had no insurance, they tried to rush my recovery and gave me solid food before I should have been eating it. I had massive hemorrhaging. My kidneys and liver were also failing. I became delirious and I thought I was being kidnapped and tortured. I was sent to the University of Utah Trauma Center and from there to a nursing home.

I stayed at the nursing home for a year. At first, I was very weak. I curled in a fetal position and slept and slept. They thought I was going to die but I slowly gained strength and decided to live. I became more and more aware of what was going on in the nursing home.

The treatment at that nursing home was dehumanizing. Nursing home administrators wanted everyone to be docile. They frowned upon individuality. People were herded like cattle. They didn't treat my needs or wishes seriously. When I asked for information, I was branded a troublemaker. So, I accepted that role.

There was a lot of theft in the nursing home. A contributing factor of this theft may have been that the people who worked there were at the bottom of the labor market and not paid enough. People who value their jobs would not steal. When I reported theft from my closet, I asked for a lock. I was told that to get a lock I had to submit a work order and go through the procedure. I did. Still, I did not get the lock. This was part of the established communication pattern: I asked, they said go through the proper channels, I would, they ignored me.

Diet restrictions likewise were ignored. Diet was very important for me because of my medical history, surgery and the liver damage. I was not supposed to eat those things they served. But, everyone was fed the same thing. I talked to the nutritionist and administrators. They would not make changes. Fortunately, I had some money, so I started to go out and eat nutritious meals. But that made me a troublemaker and I could not afford to go out and eat every time.

As soon as I could, I started walking. There was no rehabilitation for me at the facility. Because I had hepatitis C, they said that I was dangerous and they could not provide rehabilitation. I used to be athletic when I was young, so I knew what I should do. I did my rehabilitation myself.

Medication was another problem. I talked with my doctor at the University Hospital and he told me not to take some of the medication that they wanted me to take at the nursing home. So, troublemaker that I am, I didn't take them. They put on my record that I was non-compliant.

One of those medications was a depression medicine. I watched what happened to other people who took the medication. Every morning, they'd go down and stand in a line to take medication. By the time breakfast was over, the drug kicked in. It took their spirit away and they became automatons. Everyone was depressed there. In that situation, being depressed was normal.

Life is an expression of identify. You need to express your individuality, make independent choices about your life, be creative. If you take that away, you might as well be dead. I watched people come in the nursing home fine. But they deteriorated rapidly. In three months, they didn't know who they were. They were dead in a year. Being treated like a none-person will erode you.

Another thing that infuriated me was that they were making a profit on the residents. Once, a guy's feet became purple. So two aides and I tried to get socks to protect his feet. We worked hard but it took two weeks to get a pair of socks. It was a for-profit agency. It made me angry that the owner made a profit and could not afford a pair of socks immediately for a patient.

I saw feces on the floor one night. In the morning the feces were still there. They left it all night. The nursing home makes money, but cannot afford to have a night cleaner. An attendant was joking that he had to put on rubber boots to come to work. I said that I hoped they lived long enough land got sick enough to experience this. Residents were injured because the staff was not trained well enough to assist them. I don't think those incidents were ever reported.

Residents had to stand in line for everything. We had to stand in line to get permission to go for a walk. By the time we got it, we were tired and our time was up anyway. So I left and went for a walk. I needed to go out and see flowers, go to the park, and meditate. I was trying to live. Of course, I got a non-compliance recorded for that.

At first, the staff chased me when I went across the street to get a cup of coffee. Eventually they gave up and marked me as non-compliant. They tried to force me into the role of docile patient, but I wasn't playing.

While I was there, the nursing home got a new CDO. Her goal was to have 100% occupancy rate, and tighter control of the residents. By that time, I had a refrigerator in my room for my special diet. She took the privilege away from me. I already felt that my self-respect was deteriorating by staying in the nursing home. And I knew that with the new management, it would only get worse.

"I won't let you kill me" I told them. I had my van, so I put in as much as I could carry. An aide even helped me load things. They understood that they could not stop me. They made me sign a paper and I left.

I had no place to live, so I lived in the van. It was hard. But it made me stronger, more able. At that time, I still had a hole in the side of my body and it was draining. But I could not take more dehumanization and de-self-actualization in that nursing home. I studied herbs and took care of myself.

After awhile, I got involved in the National Health Insurance Campaign and Living Wage Campaign. I met members of the Disabled Rights Action Committee and I got involved with their activities too. I purchased a property in Northern California and left Salt Lake. I dreamed of living with nature, independently, growing my own vegetables. But I also realized that I wanted to do more with my life than just live in a beautiful place. So I came back.

Since I got back, things have been working better. I got a place here that is better than I ever dreamed I'd find. It's close to Salt Lake. I can even have animals. I have a goat and chickens. I have the best of both worlds, living in a city and the country.

I believe that people were born to fulfill the purpose of universe, becoming who we are. I feel more and more that my life has purpose and meaning. My involvement with DRAC is a part of the process of becoming. I am living a far more rewarding and fulfilling life.

I am happy the way things are for me right now. I will never stop working to reform this system.

Adelaide Daskam
Elizabeth, New York
5 Years

When I was a teenager I was taken from my family and put in Totowa State School for Girls, now called North Jersey Developmental Center. I have three brothers and two sisters and my mother was sick. They said I was retarded so they put me away. I was badly treated, beat up by the staff, and other girls. They accused and punished me for things I didn't do. I was there for five years.

I say that getting out and living in the community is 100% good. I have made friends. I am happy to be free. I learned to be independent. I got to take care of my mom when she was sick and dying. Last year I went to my family reunion. It was great. I became a self-advocate to help others. I help other people get out of institutions. I tell them they will do new things, make new friends and have more control over their lives out where it is free. I am happy. I have my apartment. I have my job. I have my cat. I have my boyfriend.

If I could talk to President Bush I would say to him~ "Free my brothers and sisters."

Sheila Dean
Denver, Colorado
2 Years

I was 28 years old in a nursing home, and had a seven year old son. I got out when I was 30, and I wouldn't trade my freedom for anything!

Darrin Decker
Murfreesboro, Tennessee
4 Years

My name is Darrin Decker. I live in a nursing home to get the services I require because I cannot get the services that I need outside of the nursing home. I need these services because I have had cerebral palsy since birth. I have to have help to ear and bathe and toilet. I am around older people all day long. And it is not much of a life for a 36 year old man. And to get out of this nursing home they want me to be declared mentally retarded. I am not mentally retarded. There is only money for in home services for certain types of disabilities in the State of Tennessee. I lived at home until I was 32 years old. I lived with different family members and they cared for me. I felt like a burden on my family because they were having to do everything for me. So I wound up in the nursing home. It was my only option. I have been there four years and it is really hard to be in that type of situation. I hope to one day very soon to be able to get out of a nursing home and have a normal life. I would like to work, be able to come and go as I want to, and have a real life.

Jay Dickens
Gallup, New Mexico
43 Years

Jay Dickens lived in Gallup with his family until he was court ordered into a state institution for the mentally retarded at the age of 11. He lived in two different state institutions for a total of 29 years. Then moved back to Gallup and into group homes for the next 14 years. For the past 9 years Jay has lived in a two-bedroom apartment he shares with a roommate. He pays for his own living expenses. Jay has been employed in the community for the past four years.

When jay was moved back to Gallup his contact with his mother was limited as she was living in a nursing home and had Alzheimer's. Three years ago Jay attended the funeral of his mother, and was reunited with his mother's best friend and her adult daughter who is the same age as Jay. Jay remembered them and was thrilled to see them. The daughter was Jay's playmate during the first 11 years of his life. He had lost contact with them because of being institutionalized. Jay is now supported in maintaining close contact with them.

Jay had been conditioned to be compliant as a result of being institutionalized for so many years. It has taken him years to break free to where he can now make his own choices and he can say "no" to staff, land have his wishes respected.

Jay likes making his own decisions, and living and working like anyone else in the Gallup community.

Ella Dil
Gallup, New Mexico
33 Years

I went to Los Lunas institution, then to Ft. Stanton institution, then to Santa Rosa group home, then to the MASH group home in Gallup.

I never came home for Christmas or Thanksgiving. I was sad and very scared living in these places. I wanted to be with my family growing up, not in institutions.

I have had my own apartment for years. I live by myself. I pay my own rent and pay for my food, and everything else I want. I work at Subway. I have worked there for many years. Now, I visit with my family on Christmas, Thanksgiving and when I want to on weekends.

Paul Dorenkamp
Chesterfield, Missouri
2 ½ Years

I have been living with MS for over ten years. I'm unable to walk and care for myself. When my care became too burdensome for my wife to care for me, I was placed in this nursing home. Since I arrived at this place, I've been sexually and physically abused. My needs and wants are ignored and neglected on a daily basis. I want to go home and live with my family. I want to watch my children grow up, because of the current Medicaid policies. I'm trapped and imprisoned in this nursing home.

PLEASE support the MICASSA legislation that will reform the long-term care system so no other person has to be unnecessarily institutionalized and have to go through what I am going through now and I can go home to be with my family.

Curtis Dudley
Macon, Georgia
4 Years

Since being out of the nursing home my health has improved. I was ill most of the time I was in the nursing home. I went to the nursing home after I had become ill and was not able to take care of myself at the time. I lost everything as a result. I feel I am taking better care of myself since moving out of the nursing home.

Mikel Elmore
Washington, D.C.
5 Years

In December 2001 at age 47, Mikel Elmore was released from a nursing home in Washington, DC where he had lived for 5 years following a hit and run accident that left him paralyzed and in need of wheelchair accessible housing and Medicaid attendant care services. H now lives with his wife in an accessible public housing apartment close to the wharf where he goes fishing every day. He currently attends a computer instruction course and intends to become a technician.

Mikel is an active member of Capital Area ADAPT and he was a named plaintiff in Young et al v. District of Columbia Housing Authority (DCHA), a class action lawsuit seeking compliance with Section 504 of the 1973 Rehabilitation Act. The case resulted in a federal court order requiring the renovation or construction of 565 fully wheelchair accessible public housing units, among other mandates.

Todd Emmoms
Mapleshade, NJ

Hi! I’m Todd Leroy Emmons. When I was thirteen years old I went to live in New Lisbon, NJ When I was fifteen years old I went to Edward R. Johnstone Training and Research Center. I helped take care of the blind boys. I left Johnstone on June 16, 1976. Johnstone closed for good in 1991.

Since I have been living in the community I got my high school diploma. I am very active in my church, Special Olympics, self advocacy, and I have a good job at the mall.

Thank you very much for listening to me.

Michael Engro
Philadelphia, PA
6 Years

They took my independence. Now I have a life, eat what I want, when I want. I have privacy.

Vircy Evans
Jacksonville, Florida
21 years

Perhaps you will help me get this idea across to the multiple numbers of disabled folks that do not have to have total nursing care. I was one. I only needed “custodial” care for a few years eventually becoming well enough that I did not need to cost Medicaid the unnecessary” expense of a nursing home. Tell me why should the taxpayer’s have to pay for ME to live in a nursing home when it would be cheaper living independently? I was thirty-eight when I became partially and permanently disabled. I had to go live in a Nursing Home because I had no where else to go. I lost my job because I had to use a wheelchair and I could not afford to hire someone to just stay with me. Can you imagine having to take orders from the people that YOU use to give orders to? Can you imagine having to share your little space with a roommate when you have been used to doing your own thing in your own space. For twenty-one years, I cost “taxpayer’s such as yourself the burden of paying for my upkeep”, in a nursing home. This cost Medicaid from $350.00 to $400.00 a day in addition to my SSDI of $865.00. Now, all I pay is $235.00 plus my groceries and medicines.

Sybil Feldman
Boston, Massachusetts

“I live on my own, I go out on my own, I go anywhere I want, and I live dangerously.”

My name is Sybil Feldman and I am writing this to speak out about support services in the community for persons who are developmentally disabled and physically disabled.

I was born with Cerebral Palsy (CP) on October 1st, 1940 in the Boston Lying Inn Hospital, Boston, MA. I had one sister who was four years older, and lived with my parents in Malden, MA. When I was one year old at the time of the famous Coconut Grove fire in Boston. I was very sick and had a high fever of 105 which worsened my CP. At this time my parents were unable to find a doctor to care for me because of this unfortunate dire disaster. Because of this I think my CP became more severe. I have had muscle spasms since. Although they call these spasms “seizures” they are not technically not seizures because I do not black out.

At the age of five and a half I had an operation on the heel cords of both feet to help me walk better. It was successful. But I also recall a conversation between my specialist and my parents. The reason I remember this is because the specialist advised my parents to put me away and for get about me. As a result of this, I went to Pine Harbor, Rhode Island and attended Miss Gilmore’s School until I was nine. I learned to dress myself and walk better there.

I returned home for a year and a half and enrolled in the Industrial School now known as the Cotting School which was in Boston (now in Lexington). There I received a first grade education at age 10. By this time, 1950, I attended the Kennedy School; after staying for afive years I received the equivalent of a third grade education.

I had tried to get into the Canton State School but I couldn’t pass the test. On March 30, 1955 I was admitted to the Walter E. Fernald State School in Massachusetts. I was fifteen and a half. Some of my experiences at this school were:

When experiencing muscle spasms they immediately tied me to my bed.
They would also leave me on the floor tied up for hours.

There were a lot of nurses that I didn’t like because they’d yell at me, and tell the doctor that I was “putting on” a spasm when I was not. I can only remember one doctor believing me.

Also because of being tied and not believed, I often developed bruises all over my body. During this period my mother and father died.

On August 22, 1969 I was moved to a better and newer building at this school. Although the staff were not better I was encouraged to become more independent yet. I received no formal schooling whatsoever during my years at this school. I remained at the third grad level; and almost all of this I lost.

After living at the Fernald State School for 21 years, 4 months, and two weeks I went to a community residence named Stott House located in Needham Mass. It was now July of 1976, and I was 36 years old. It was avery big move after living all that time at the state school. They did not have my records. I had a series of long spasms and after two weeks they had to bring me back to Fernard. But this was only for two weeks and then I returned to Stott House.

I had independence at Stott House for six years, but they were for the most part not nice to me. They did not always know what they were doing. However despite this I was able to move to bigger and better things.

Although my father was never able to see me out on my own, I think he would have liked to. On May 18, 1982 I began the transitional living program through the Boston Center for Independent Living (BCIL). I moved into my own apartment, in Brookline; my very first.

Now I am going back for my GED after living through the (BCIL) for fourteen years on my own. During this time I have worked in various places: I have volunteered at the Brigham and Womens hospital transporting lab work and paper work from one department to another. I was trained in 1989 as an "Access Monitor" to access accessibility in public buildings. I have worked at a workshop in Lynn for Independent Living, and was paid $9/hr, but it was for "doing nothing". This lasted six months. The last time I had a paying job was in 1990.

I want to learn to read instead with the help of a volunteer, but I have been waiting for a volunteer since I moved here. I am not waiting around. Over these years I developed my own motto "I live on my own, I go out on my own, I go anywhere I want, and I live dangerously."

In 1990 I was at the State House in a protest demonstration. I met Bill Henny who invited me to go on a Civil Disobedience protest in Baltimore for the rights of disabled people and those in nursing homes. So I joined ADAPT (American Disabled People for Attendant programs Today). We want disabled people in nursing homes to be able to get out and live independently like anybody else. This was my first action of civil disobedience.

The second one I went to was in Orlando, Florida. I took my electric wheelchair. During this action I was arrested for trespassing. Next to the Disabled Persons Commission we shut down the street so that no one could drive a car through. Our point was to say disabled people can be independent without being in nursing homes; we want care at home, not in nursing homes at all. There were 75 of us arrested; blind, in wheelchairs, with canes, and walkers. The police did not know what to do with us. I spent two nights in jail. This meant that I did not get my medicine. The police had to call my doctor. Every time I laid down I had spasms. They let us go and I was fined but the organization ADAPT paid and also my cousin helped. CORD (Cape Organization for the Rights of the Disabled) pays half my transportation.

I have been to Washington DC three times to Civil Disobedience actions. I was arrested once there and dealt with similarly. I have been to Chicago once; Las Vegas once; and Atlanta after the Olympics. In November last year (96) I joined 30 other ADAPT members and met with House Speaker newt Gingrich. Because of the pressure we put on him, he pledged in writing "to pass a bill which will create choices so people with disabilities can get attendant services instead of being forced into nursing home care." This June I am going back to Washington, DC.

I have paid for my independence with my life and every ounce of my strength, and I am determined to not lose any freedoms I have gained.

Robert Fesel
Robbinsville, New Jersey
11 years

I am a man with Cerebral Palsy. In my life I have lived in a boarding home, a developmental center, and three group homes. I have been restrained, starved, burnt with cigarettes, and abandoned for dead.

I use a wheelchair and I communicate via an electronic language board called a Liberator. Technology has changed my life. I now live in a condominium and work with preschoolers. I work as a volunteer to help other people move out of developmental centers.

I have my freedom.

I ask you if one of your daughters had a disability would you put her in an institution. PLEASE, PLEASE help us get people out of institutions and help get institutions out of our great nation.

Carolyn Finnell
Denver, Colorado
5 years

It was hard getting out, but I knew that the older I was, it would be. I never regretted getting out. It has been over 27 years.

Barney Franklin
Idaho

"It was suggested...that I write to you regarding my experiences with a forced nursing home confinement, the type of Personal Care Services (PCS) (in my situation, this involved a Personal Care Attendant (PCA), which is usually a Certified Nurse's Aide (CNA)), not of my chosen, and Medicaid ineligibility. Perhaps they will shed a favorable light toward your accepting the recommendations as presented in the "Report of: The Governor's Medicaid Reform Advisory Council -- December 1996." Perhaps, also, it will manifest a better understanding of the constant struggle my wife, Edna, and I have in retaining and maintaining our independence and self-assertiveness, our strive and drive for self-integrity and dignity, and our life-long fight for the right of self-worth and self-decision-making -- these are some of the inherent qualities which constitute the well-deserved but little recognized and seldom-bestowed Red Badge of Courage worn so proudly by the far too few of the mainstream disabled!

"Edna and I will be celebrating our 27th wedding anniversary on June 27th. We both have cerebral palsy of the worst type: athetosis. Our ages are that of young seniors, but our minds and hearts are that of the young and the bold. The only source of income we have is my disability pension from Civil Service, not SSI as many people think -- I had worked as a computer programmer/analyst in the Federal Government for seven years (1970 - 1977).

And to add to our pride, we are buying, with no government assistance, a house in which we had resided since 1979 at the address shown in the letterhead above.

"(Athetosis: The most puzzling of all cerebral palsied conditions – AND the most prone for many, both professionals and the lay alike, to wrongfully associate with mental retardation!

"Range of Disability: The most varied imaginable, from the triflest of quiver to the tremblest of quake a human body can involuntarily emit – AND the most apt for the haughty to voluntarily interdict!)

"My disability is far greater than that of Edna's. I am wheelchaired; she is quite ambulatory. My speech is heavily slurred and slow but intelligible when attentively listen to; hers, although impaired, is quite understandable in most instances. My manual dexterity only allows me limited use of my left hand, e.g., holding a pencil to enable me to keystroke the computer keyboard; she is able to drive our golf cart around town, grocery shop, and provides and cares for both herself and me with the best homelife for which I can ask. Despite my apparent physical limitations, however, I am able and mobile enough to go through a day or so alone should Edna finds it necessary to be out of the house for that long. She would arrange certain items to make it easier for me to manage myself. And at present, I have arranged with a local private PCA provider for a CNA to come once a month for about an hour (at $15 per plus transportation, that's all I can afford) to tend to my needs which are very difficult, if not impossible, for Edna to handle.

"The current amount of my monthly income ($1,079 gross) makes me ineligible for the Medicaid program; yet, it is not really and nearly enough to pay for the type of products and/or services from which we would benefit. This puts us "in between the cracks," a somewhat comfortable and uncomfortable predicament to be in. We are covered by standard Blue Cross under the Federal Employees Health Benefit plan, of which I pay $108 a month. I find this more or less adequate, for it pays much of our medical bills. It does not provide coverage for a PCA/CNA, however.

"In late summer of 1994, Edna had to go into the hospital for an operation. However, I started asking around two or three months before this about getting a PCA/CNA to come in to help me just in case she becomes incapacitated or something of that sort, unaware then of what was to happened. I wanted to set up a support system for myself. (A premonition or foresight!?) I tried several agencies serving the disabled and the elderly for assistance, but they couldn't or wouldn't offer any. They just gave me the all-too-common bureaucratic mumbo jumbo. When I did found out a few days before hand that she was going in, I really worked frantically trying to arrange something until she was home, up and going again. Still, I didn't get anything positive. Three basic excuses stood out as to why I was virtually denied help: 1/ Boise would be the place to live if I wanted the services requested; 2/ the surprise and dismay that I wasn't receiving SSI and subsequently was not under the Medicaid program; and 3/ the ever popular "It takes time" cliché -- they still do!

"On the day she went into the hospital and was operated on, I was told by someone from an agency on aging here that help was on the way for me. With a slight sigh of relief, I got a friend to take me to see Edna. She was just coming out of the anesthesia when I got there. I stayed a couple hours, then came back home with the assurance that the prognosis on her condition would be positive. Then my rights to decide for and do myself were suspended for the next two or three weeks.

"Around 3 o'clock that same day the senior citizens van pulled up into our driveway. The driver came to the door and asked for person from the agency on aging. Puzzled at first, I told him that she wasn't here yet. After saying that, she came by. She then came in and told me how sorry she was that she was unable to find someone to help me, that there were concerns about me being home alone, that the house might burn down and, because of this, arrangements had been made for me to stay at a local nursing home until Edna was released from the hospital, hence the reason for the van. So, very reluctantly, I went upon the stipulation that I come home when Edna does; and that a PCA/CNA come for about an hour a day, primarily to get me out of bed in the morning and to help me back in at night until she's back on her feet again.

"(The argument here was that I had agreed with this woman's line of logic. However, since I was not given a choice of alternatives, my contention is that I had been forced into the nursing home out of ignorance to my civil rights.)

"This was on a Tuesday. Edna came home that Friday while I was going bananas trying to secure my freedom. The social worker at the nursing home first told me on that same day that the woman at the agency on aging was looking around for a PCA/CNA for me. But on the following Monday she said that she, the social worker herself, had assumed that responsibility.

Exhausted and tired from lack of sleep due the sickness of the man with whom I shared the room, disgusted and disgruntled with having my humanity retarded, agonized and aggravated by being unnecessarily separated from my wife, and issuing a threat of legal action should I be constrained another day, I finally came home that Thursday, 10 days after being incarcerated.

"(I was told that my stay at the nursing home had been paid out of a Medicaid emergency fund.)

"The kind of outside help I really needed when I got home was basically for someone to help me to get in and out of bed. (If I had a ceiling-to-floor grab pole beside our bed, I could do it myself, thus eliminating the need for this kind of help. This was one of the items I told an agency serving the disabled about several months prior, but nothing was done.) So arrangements were made by the nursing home with a local church to have a volunteer to come in, starting that Thursday night, to help me the way I had requested it. A man came at my designated time of 10pm and 8am, help me the way I wanted, and then left. This continued until a CNA was selected and started coming Monday morning.

"When she did, she first got me up and then tried to transform our home into a nursing home environment, as she was from one of the other local nursing homes. Her schedule was from 9 to 11 in the morning and 7 to 8 at night -- this peeved me and Edna very much, as we don't go to bed that early. And to make matters worse, much of her time was spent in idleness because I refused to do some of the things she had on her nursing home agenda. It was disrupting our lifestyle. Something had to be and ultimately was done.

"(The money for the CNA was obtained through a grant from one of Idaho's largest utility suppliers, I was informed by the woman from the agency on aging. The amount was enough to cover five weeks of service, seven days a week, three hours a day. However, it was not used and was returned due to the following.)

"The woman from the agency on aging came by that Tuesday evening to see how things were going. I told her about my dislike of the 7 to 8pm time slot for going to bed. Since the CNA was already present, a compromise bedtime was more or less agreed upon: between 8 and 9pm. However, I kept insisting and pressing for the grab pole aforementioned herewith and of which she knew about, to be placed in the bedroom. It paid off because she, to my surprise, the woman came again Thursday evening with a friend of hers to install such a pole they bought and brought along. I then practiced getting in and out of my wheelchair onto the bed and back until I felt comfortable with it.

"As for the CNA, she came Friday but not Saturday nor Sunday. If it wasn't for the grab pole, it would have been extremely difficult for Edna to help me to get in and out of bed, for as she was well on the way to recuperating from her operation, she was still quite weak yet. So, when she, the CNA, arrived Monday morning, we asked her what happened. She said another CAN was to have taken her place that weekend, but offer no reason for the no-show. Then, with Edna's approval, I terminated her position here.

"I had taken a lot of heat for doing this. I have been accused of not understanding, not appreciating the kind of help people have given me under the handicap of limited resources. And, in a mega-subtle manner, I'm being told by some ,that the amount of freedom and rights a disabled person has is proportionate to the degree of his/her abilities. Many of my peers even with far less physical limitations than mine have experienced this type of imposed criteria for "mainstream acceptance." But the fact remains, I did not get the assistance I requested in establishing a support system for myself in case something should happened to my wife. And because of my ineligibility for Medicaid at a critical time, I was committed to the cold confounds of a nursing home instead of continuing to enjoy the comforts of my own home with a PCA of my choice and direction while Edna was in the hospital.

"Several times since that horrible happening, a few people from local and state health agencies, including Health & Welfare, tried to get me eligible for Medicaid but couldn't because the amount of my monthly income is slightly above the maximum limitation of that program. The only way, which I could become eligible would be under the Miller Trust. But because of its two main requirements, I cannot in good conscience participate in it:
1. The relinquishing of everything above $863 of my income a month to a trust fund; and
2. and the requirement that I have a CNA for a minimum of 16 hours per week. First and foremost, my income is direct deposited into a joint checking account under my name and that of my wife's. It is to remain under our sole control. And, I do not need a CNA for 16 hours a week. If a minimum is required, I would put it two to four hours per month barring any emergencies. That's the maximum number of hours I would like to have for the PCA/CNA who presently comes, but I can't afford it.

"It is my sincere and utmost hope that this letter be given serious consideration when weighed with the Medicaid reforms as discuss in the Governor's Report. Also, clear and precise thoughts must be given to any alleviation or waiver of regulations, which would have beneficial effects on the disabled's goal of independence with respect and honor. Thank you for your patience, courtesy and understanding..."

And this is an excerpt from an email, which I sent the executive director of the State Independent Living Council.

"...That was the second time I was incarcerated in a nursing home, the first being Christmas Eve 1990. Edna was forced to join me a few days later. It then was used as a totally miscalculated ploy by CO-AD (Idaho's P&A system for the disabled), particularly by then executive director B....M...., to get us PCS and Medicaid, something we didn't want nor need at the time. We were threatened by him that if we try to leave the nursing home sooner than the "required month's stay" in order to quality for these services, he would have us judged as "mentally incompetent" to make us stay. Along with this, nobody from the outside would help us because "...the state knows what it's doing..." And so, we had to, in the absence of due process, stay until our release late January of '91.

"Why were we committed? It was by the strict temperance and irrationality of a so-called friend of ours who was able to convinced a doctor, a social worker and God knows who else that our house was a fire trap and that our lives were in danger. All I did was to asked her to get Edna a Christmas present for me. Instead, she walked into our house, saw that we celebrating the holidays in our own way and decided to take over. Quite literally, I was shackled and gagged in such a way that no matter what I had said or did, we were, according to M.... of CO-AD, "...under house arrest by the state for being cerebral palsied!"

"All in all, it was the most dehumanized experience we have ever had. A short time after coming back home, we were informed by Health & Welfare that our "application" for PCS and Medicaid was denied because of the amount of my income. (Some people still don't understand that.) And even though most people wouldn't denied that we had a pretty solid legal case against those who had anything to do with our imprisonment, I think B.... S...., State Rep. from Nampa, summed it up best the prejudicial ignorance of those who are empowered to help in these types of situations, including himself: "I understand what you're saying, but who else will?" This was in reference to my speech impairment. Are there any defense mechanisms here to prevent these shinanigans from happening?..."

(I have tried and tried to seek legal council here in Idaho regarding the first incarceration but to no avail, including the Idaho Chapter of the ACLU. They claimed that since my case didn't involved the First Amendment. How can that be when we were prohibited from speaking in our defense. Since the statutes of limitation have long expired for this type of case, we can't do anything about the criminality and, the cruelity, both physically and psychologically, my wife and I were force to endured. My question then is, isn't there a national defense fund setup to defray the legal costs of those disables who are entrapped in similar situations?)

I sincerely hope I can be of help to the cause of ADAPT in whatever capacity and capability of which I am able to fulfill.

Eddie Lee Freeman
Milledgeville, Georgia

Since I have been out of the nursing home, I have been able to purchase a new electric wheelchair. Have a ramp built to meet my needs. When I was in the nursing home I was not able to spend a lot of time with my family because the nursing home had restrictions on how long I was able to stay away from the nursing home. I was also not able to purchase a wheelchair to meet my needs while I was in the nursing home but was able to do so since being out of the nursing home. I am able to spend more time with my family and do the things I want to do without restrictions.

Marlene Fulton
Hammonton, New Jersey

21 years

I lived at three institutions, When North Princeton Developmental Center closed in 1998 I moved into an apartment but I didn't like living alone so now I share a home with two housemates. It was hard adjusting to the community. I went through a lot of changes. They had misdiagnosed me in the institutions. I got help learning how to cook and houseclean when I moved into the house with Robert and Chris. Now I cook for all of us. Right now I am learning how to manage my own medication. I have a lot of medicine to take. I do volunteer work. I have made friends and I go to church, which is something I couldn't do in the institutions. I have freedom. I can go where I please. In an institution they keep you locked up.

The institution was not good for me. There were mean people there. You feel like a prisoner.

I say to President Bush – "No one should have to live in an institution. Everyone deserves a chance to live in the community. All the institutions should be closed."

Roberta Gallant
New Hampshire

My name is Roberta and I am a 51 year old "child left behind." The state-and-federal education service-delivery systems ought to be reformed soon. They contain gaps. For example, many other adult citizens and I lack some basic math, reading, and writing skills. While they and I were children living at the Laconia State School and Training Center (the residential placement), New Hampshire deprived them and me of opportunities to receive proper elementary-and-secondary grade school academic services. The Laconia State School and Training Center itself also never offered private tutoring which we needed.

On April 12, 1978, residents' parents filed a class action lawsuit against the Laconia State School and Training Center and the state of New Hampshire to correct problems at Laconia State School. However, the settlement left no entitlement-funding resources available for us uneducated and undereducated adults to finish school as full-time students.

New Hampshire still owes those people and me appropriate math, reading, and writing education because the state stole it from us. A few other persons and I had to hire personal tutors to recoup some of that missing instruction. This cost Lakes Region Community Services Council and Community Bridges too much money and has been unfair.

The New Hampshire **House Bill 914** and the **public Law 94-142** are guilty about age discrimination! **RSA 186-C:7** of the Special Education Laws for New Hampshire and part B of the Individuals with Disabilities Education Act protect children's educational

rights but do not apply to people currently age 21 and over. Regarding age, every citizen should now be entitled to an elementary-and-secondary grade school education.
The state-and-federal legislatures must remove the age restrictions from **House Bill 914** and **Public Law 94-142**, allowing everyone the opportunity to earn a diploma or its equivalency. By eliminating such ridiculous restrictions, we will finally be able to obtain the education the state initially denied us during our childhoods spent at the former Laconia State School and Training Center. Therefore, elementary-and-secondary grade school instructions are very important to adults - not only children. I encourage the state-and-federal representatives and senators to expand **House Bill 914** and **Public 94-142** to adults, so that they have the same educational rights, as children with and without disabilities do so today.

Gary
Utah

Gary's life underwent a dramatic change after a drug overdose that resulted in a traumatic brain injury. As a young man he was involved in an armed robbery for which he was convicted and sent to a prison for 18 months. He was a promising boxer, but illicit drug use halted his career. The brain injury has affected Gary's mobility (he now uses a wheelchair to get around), his coordination, speech and his short-term memory. Other changes are less tangible. Gary has a lot of time to thin. He has undergone a religious conversion to Islam, has deliberately and purposefully chosen role models to emulate, and has nurtured a fire within him that longs to spark and ignite other spirits. Gary feels he must help young people learn from his life and wants to share his story at every opportunity.

Gary is #28 on a static Traumatic Brain Injury Waiver. He's been #28 for three years. Because of his particular difficulties, especially his problems with short-term memory, Gary needs a more supervised and structured place in the community. Right now, while Gary is tucked away in a nursing home, both Gary and the community are suffering form his exclusion in its daily life.

Gary lives in a kind of twilight zone between two states. Nevada funds a private nursing home in Utah. Out of sight, out of mind: Nevada officials don't visit the nursing home to review his case, Utah officials never see Gary's name on any of their lists as they survey the nursing homes. Is Gary getting adequate services? Has anyone considered whether he can live in the community? Does he even have the federally mandated discharge plan? No one knows because Gary doesn't quite exist as a Nevada resident and he doesn't quite exist as a Utah Resident. It seems a sad commentary on this society that Gary was sentenced and served 18 months in jail for armed robbery and 10 years in a nursing home for having a brain injury.

Gary's Story:
I like women, the Utah Jazz and talking with kids. I have two kids of my own. A boy about 22 years old and a girl about 18 years old. I didn't really get a chance to tell them

when they were younger how good life is and how terrible it would be to mess up their lives with drugs. Fortunately, their Mamas did that for me. My kids are really good kids and they are doing well. I'm proud of them. But I need to tell other kids. If I could, I would tell them to stay away from drugs, that drugs, will take everything away from you. I would also tell them to learn all they can.

I was doing real good as a boxer until drugs messed my world up. I was boxing in Las Vegas and doing drugs. I thought I was having a good time. Now, when I look back at that time, I can't imagine what I thought was good about it. I was young and didn't know what I was doing.

One day I used drugs with a friend, and the next thing I knew I woke up in a hospital. I don't know how long I was unconscious or how long I was in the hospital. The doctors told me that the drugs went to my brain. I could not walk, so I was discharged to a nursing home in Vegas.

Nevada was OK. People there treated you like a friend. The nursing home there had professional physical therapists. They worked with me. One day, Nevada's Medicaid sent met to a nursing home in Salt Lake City. They sent many of us here. It was not my choice.

I've liked in the nursing home in Salt Lake City for 10 years. In many ways it is worse than a prison. They treat you like a number, not a person. Nevada's physical therapists were good. They were real physical therapists. Here, in the nursing home I am in, they don't have real therapists. They have people there who have that job title but they don't know what to do. I am not getting muscle exercises at all.

It's really like a prison. The staff should be helping us to find housing in the community. But they don't because we are their paychecks. It's just a job for them, so they don't care. And they don't stay very long. We had three different administrators in two years. But, they make us stay.

In the nursing home, they control my life. I can't go to bed when I want to. They decide when I go to bed. I can't have food in my room. Once, I wanted to go out but they didn't let me go out. They said that it was my punishment because I had bad behavior that day but they didn't explain what I had done.

Once, I invited Governor Leavitt to visit our nursing home. He should know what it is like to live in here.

The only good thing that happens is having visitors from organizations like the Disabled Rights Action Committee (DRAC). I joked with my first visitor from DRAC, "Are you my parole officer? They told me about getting out of the nursing home. Another visitor from DRAC, who uses a wheelchair like I do and also has severe cerebral palsy, so she can't do a lot of the things that I can, has shown me there's another life. She showed me her apartment and explained the modifications and services she gets so she can live there.

The people from DRAC look after you. They show me there is life outside. I know my life is more than a nursing home. Now I want to be going out and doing different things. That gives me hope. They also show me respect, so I can trust them. The nursing home staff treats me like a number. But if other people outside care about you, the nursing home staff begins to show you some respect. They know that if they treat you wrong somebody will stick up for you.

In the nursing home, I also learned that no one will respect you if you don't respect yourself. We need some people who work here because they love what they do. I pray sometimes, not so much about me, but for people like the people at DRAC or the nursing home staff who are decent people, that they'll be rewarded in real life for what they do and who they are.

I know someone who lived in the nursing home with me who got out. So I know it can be done. With the support of his family and hard work, he got out and now he has his own place. That was a good lesson for me. Thing can be better. I want to get out of here and be a good lesson for someone else in the nursing home. I want to prove not only to other people but also to myself that I'm not a loser.

The trouble is when you get out of the nursing home you need funding to get the services you need in the community. There are programs and waivers that let the nursing home funding go with you when you leave. That way you can pay for the help you need. I am #28 on The Traumatic Brain Injury Waiver at this time. I have been #28 for years. I'm tired of being a number. I'm a person, not a number.

When I get out of the nursing home, I want to go back to school to get a GED. The nursing home gives me no chance to get an education. It is understaffed. I have no change to study in there. You need to get education to learn right from wrong.

When I get out of the nursing home. I'll get my life together. I want to be a good father. My boy did not have me while he was growing up. My ex-wife did a great job. My young man is in college becoming an architect. My ex-wife did good by my boy. I can't say nothing bad about my ex-wife. Allah blessed me. She went the whole nine yards. She told my sister that she always cares about me. My girl calls me too. She is becoming a receptionist. Family is important.

I want to be a counselor. I want to work with kids and teach them about drugs, gangs, and safe sex. I want to teach them if you do the right thing, you don't have to worry. I want to teach them that education is important.

When I am out of the nursing home, I will see the People of Islam on a regular basis. Malcolm X opened lots of doors. He taught that you have to respect women like queens. He taught that just praying gets you nowhere. You need to put action in your prayer. If you want to get out of the nursing home, you need action. I learned in the nursing home that I have no one to rely on but Allah. Allah blessed me when I met people like those at DRAC.

I pray 5 times a day – in the morning, afternoon, evening, late at night, land before going to bed. I can keep on because Allah gave me the strength to carry on.

There's so much more I'd like to say. But there's even more that I want to do. I need to put my thought into action. I hope my story can make life better for someone else.

Nathaniel Gates
Rochester, New York
3 years

My name is Nathaniel Gates and I have Multiple Sclerosis. In 1999 while living independently, in Rochester, New York, I found out I needed spinal surgery. After my operation, I was sent to Monroe Community Hospital for rehabilitation. Following my rehab, I waited to return home. I was then told I could not live on my own because I couldn't walk. They told me I was unable to get aides to take care of me through a traditional Home Health Care Agency. For this reason I ended up staying at Monroe Community Hospital for the next 3 years. Living at the hospital was a big disappointment. It was very depressing and I felt the whole world was passing me by.

The Center for Disability Rights has helped me to get an apartment. I have hired my own aides and live independently. I'm happier now and I'm own boss again. It's like being on top of the world.

Ray Gerke
Perry, Iowa
6 years

It was scary and didn't know what to expect from the other individuals that were residing there and the staff.

However, I learned quickly that the way to service there was to lie, cheat, steal. Be destructive so that I could get the attention of the staff.

After leaving that living enviroment it took me several years to change the inappropriate behaviors that I learned there. I mostly learned this by myself with some support from friends.

I am presently and have been working for (32) thirty-two years-the past (27) twenty seven of these years with my present employer.

Karen Greeban
Austin, Texas
12 years

I am disabled, I have cerebral palsy. I lived in a nursing home for 12 years, but now have been living in my own home, with attendant services, for 10 years.

I would never go back. I sympathize with the parents or kinfolks but on the other hand they don't look at it that it could be better for their loved one, and they could still be taken care of in the community. My parents were against me moving out of the nursing home, because they felt like that I was better off where I was. They said that I could not make it, that I would be right back where I was in a couple weeks, and here I am going on 11 years on my own. They said, "you can't feed yourself, go to the bathroom, go grocery shopping." I realize I can't do these things, but with attendant care I am making it like anybody else in the community. So I feel like the parents should wake up and realize it can be better. We just have to give it a chance.

When you're in a State School or other institution it's hell because your life is not your own. You are under constant supervision. I don't care how old or young you are they treat you like you don't have a lick of sense. They speak for you. You don't get no respect. You got to go to bed when they say go to bed. You got to eat when they say eat -- or you go hungry. If you get hungry after supper and you want a snack, they say "sorry kitchen's closed." Then you got to go hungry until the next morning. An older person may not eat at all and then after a while they get hungry. Sometimes they do go around after the last meal and offer you juice or a cookie but some people need more than that.

People that have to eat pureed food, I've seen their food that looked like water, it was ice cold. And when the state people would come and you would tell them about the food, they would always take up for the dietitian and say that's the way its supposed to be. Or they would make it better as long as they stayed. Then they go and the nursing home would get a high rating. And then they would go right back to the way it was before.

People laying in their own urine. You would go down the hall and you would see the bed patients half covered. You go up to them and feel on their leg or arm and they would be cold and wet and you would go and tell a nurse they need to be changed and they would say it's not time to change them yet. They changed on the two hour shift so they might not go back for hours to change that person. To me that's a hell hole.

At night you would hear people screaming harder, crying from pain. I know they can't give an overdose of medication, but they would be so ugly to that person, let them holler all night long with pain. They would close the door so they would not hear the noise, but being in an institution you can still hear the noise.

In a person who normally don't need medication, if you would get upset about something the first thing they would do is throw a damn valium down your throat so you would be quiet. What it all boils down to is they just don't give a damn about a person's personal life. They just want the money that's all they care about.

Every time all they talk about is people being let go from jobs if [State] Schools are closed. Like at the [legislative] hearings they were talking about a lot of people loosing jobs. It's funny when people are talking about rights the first thing that comes up is the employees, which I know is very important. Everybody needs a job.

This would eliminate jobs but on the other hand they could work in the same field only they would be working in the community instead of the warehouse (that's what I call an institution – a warehouse). If we would get enough money in the community people could get paid the same amount as they would in an institution. If we get people out in the community then we could give them more quality care, because you would be working for only one or two people and you could give them more quality care than you could give them in an institution.

I agree that some people won't be able to live all by themselves but people who can't live on their own, I think they have the right to live in community as anyone else.

That stuff about people being too disabled -- just because you are disabled don't mean you have to be hospitalized for the rest of your life! You're not sick, your body just don't perform like you'd like it to. And me and a lot of my friends, have proved that already. We can live on our own.

Now that I'm living on my own I can do what I want and don't have to answer to anybody. I can come and go as I please and I have control over my life. (If

I make a mistake so what? I like making mistakes. You learn from them.) I feel like a person not like a number or a puppy dog. In an institution somebody pats you on the head and says, "oh you poor thing you're in here and we got control over you life." They may not say it in so many words but you can feel what they're thinking. I have a better feeling about myself because I'm making it on my own. I use attendant services and it's not always easy, but at the same time you have control of who you want and who you don't want.

Like everything else you have to give and take, but that's everywhere; that's part of life.

To sum it all up, all institutions should be closed so we can get on with more productive and happier lives. They say it's cheaper to live in an institution ... that's not so. There are costs besides dollars. It's not dollars its people's lives."

Arthur Gutierrez
Gallup, New Mexico
8 years

I am Arthur Gutierrez.

I lived with my family when I was a child. When I was 10 years old I was taken to Los Lunas (Institution). I was scared, crying. They let me out when I was 18. I went back to live with my mother and father in Gallup. I moved out on my own when I was 22.

I'm handicapped. My brothers and sisters don't want much to do with me.

I live on my own, pay my own rent and bills, get my food, everything on my own.

Robert Habas
Savannah, Georgia
9 years

Nine years of my life were wasted or at least not lived to their fullest or happiest because of my being forced to live in a nursing home. The care, staff, and attitudes, there were terrible. This home taught me a lot about bad side of the human spirit as the people caring for our elderly and the disabled were in many ways abusive. For example, employees were drinking and smoking drugs on a regular basis. Another rather horrid story involved two staff member stealing a gold tooth from one of the resident who had died in his room. In many ways abuse was pervasive and hard to describe, but it certainly was constant.

Since I left this home where I was constantly told I CAN'T or WON'T be able to live on my own, or do anything, I completed my college education. I purchased an accessible van, which I drive daily. I also work for an Independent Living Center. My health, life and my general well-being is 1000% better (yes, that is one thousand percent better).

I support the MiCASSA legislation that will reform the long-term care system so no other person has to be unnecessarily institutionalized and have to go through what I went through.

Bobby Hartwell
Denver, Colorado
26 years

I was put in a nursing home when I was one year old. Wade Blank got me out when I was 27 years old. I have lived in my own apartment for the last 26 years.

John Hays
Parsons, Kansas

Let me introduce myself. I am John Hays. I was just a little kid when I was first sent to an institution. I was so young, I don't remember what year it was or how long I was stuck there. I was in several different institutions, Osawatomie State Hospital, KNI in Topeka and Parson State Hospital.

I finally got an opportunity to live in the community about 10 years ago. I have had lots of good and bad times. It is not always an easy world to live in, but I'm making it. I have gone without any formal supports for over 3 years. I know that I will ace many more challenges, but I will gladly face them, rather than ever spend another day in an institution.

Katy Hoffman
Denver, Colorado

I felt bad. I didn't want to be there. I cried all the time. I feel independent beong on my own.

Rick James
Denver, Colorado
5 years

It was fucking hell, and it is better in my own home.

Patrice Jetter
Montclair, New Jersey

Sometimes the staff would steal our personal property; especially clothes and shoes. My brand new outfit my Mom bought me for Easter and some brand new underwear (still had the tags on) were stolen by staff members.

The staff member who stole not only wore it to work the next day, but helped me look for it when it turned up missing.

She denied stealing it, despite it had my name in the collar.

I told my family not to bring me anymore brand new clothes. From that day on, I wore all "County clothes" to deter stealing. It didn't hurt as much if they stole the donated clothes as much as the clothes my family paid for.

Another one of my most memorable moments was when I finally got a holiday pass to go home for Christmas. I was so happy because I hadn't been home for almost a year.

One of the staff deliberately started a fight with me so I couldn't go home. (This happened quite regular, especially with the patients who get upset easily-like me).

He came in the TV room and began shouting profanities and the usual, “Go ahead, hit me!… I want you to”. I got up to leave the TV room and he hit me from behind.

Four other staff members immediately jumped on me so fast I couldn’t react. The head nurse was told that I started the fight, and she believed the staff, not me.

I was put in seclusion and lost my holiday pass.

Not only did the staff find the whole thing amusing, the same staff member who started the altercation ended up being my one-on-one on Christmas Day.

To this day I will never understand why the staff would find this sot of thing as a form of entertainment, staff sympathizers are either fired or reassigned to other hospitals, or why staff members continue to defend each other when you can have as many as 10 or more witnesses to on incident and will outright deny seeing anything,

Today I am living independently in the community with supports. I work as a school crossing guard in Montclair, NJ and in the fabric department at the Rag shop in West Orange. I also volunteer with special education students and active member of DIAL Inc. for Independent Living. Even though now I’m out of the institution, I still have fear of being sent back there sometimes and still have occasional nightmares.

I worry about some of my friends who are still there and wonder if they’re okay, or still alive, or still being mistreated.

One of my good friends died as a result of an alleged beating by staff (they told his family he fell). He had black and blue marks all over his body that indicated to his family he took a beating, but nobody is speaking for him.

I need to go to Washington to testify because I don’t want anyone else to suffer the way me and my friends have. That could be your home tomorrow.

I must do this—for myself and for my friends who cannot speak for themselves. Maybe I can have some closure and try to save some of my friends as well. Thank you for this opportunity.

Charles Jurek
San Antonio, Texas

My name is Charles Jurek. I am sixty-four years old. I have cerebral palsy. I spent thirty-five years of my life in the State School because no one could understand my speech and no one believed in me. For the last ten years I have been living with two roommates in my own apartment. I work at Burger King, I volunteer in the community, and I spend weekends with my adopted family.

Janet Kelly
Oneonta, New York
11 ½ years and counting

Hello, my name is Janet Kelly. On 8/3/91, I was involved in a motor vehicle accident in which I was hit by a drunk driver; rendering me a quadrapalegic at C4/5. After rehab at Rusk Institute NYC, I was told by the social worker that I never ever could be alone, and had to be in a nursing home. I was 38 years old, my children were age 10 and 12.

My children went to live with their Father, I had been their sole caregiver under joint custody agreement in my divorce 2 months prior. Life with a new stepmother, and separation from me (their natural mother) was a great source of trauma for both the children and me. I was reduced from being a fully involved parent in my community to a "visitor", as in jail. What was my crime? I felt like I was dropped down a well with no one to hear my cries! No one should have to be treated like that. Ever.

What I missed: birthdays, school events, my children's daily lives, religious celebrations, graduations. To date I have missed half my children's lives and important milestones. I was, and still am, segregated from my children and community. I still am in a nursing home.

What I got in a nursing home: being treated like a permanent patient, loss of privacy/dignity, homesickness, depression, having people die at my bedside time and time again (semi-private rooms), a feeling of homelessness. Despair at being locked in while everyone else seemed to be enjoying a normal life.

This year, 2003, I will be 50. I feel like the way I'll get out is in a hearse. If I can earn a B.S. in Psychology from the nearby State University, why can't I live outside nursing home walls? I am told again and again that I need "care", can't be alone, can't get nurse's aides help or the hours I require. My family says this, the nursing home says this.

This is my story. This is how it is, and I want someone to listen to me. If I could, I'd testify before congress to make my story heard so others won't suffer like I still do.

Joanne Kenworthy
Philadelphia, Pennsylvania
14 years

My independence was stolen from me and I had to live by the rules. They took all of my money and only gave me $30. a month and you had to buy clothes with this money. The people that take care of you call you every name in the book and you can't prove that they did. You don't get any respect and you are nothing but a vegetable.

Bernard King
Mapleshade, New Jersey
20 years

In 1963 I was put away at the New Lisbon State School for Boys. My mother didn't want to send me there but I had Cerebral Palsy and a lot of brothers and sisters and she didn't have a choice. But she came to visit me almost every Sunday. I saw a lot of abuse, sexual and physical. The staff used to get the stronger boys to beat up on the weaker ones. It happened to me. If you didn't do what they said there were consequences.

When I got out I lived in a group home but now I live in my own apartment. I wish my mother could see me. I make my own decisions and the support staff is better than in the institution. I work, I like to play botchy, and I am very active in the self-advocacy movement in New Jersey. I go back to institutions including the State School (now New Lisbon Developmental Center), to help people get out. I wish someone could have helped me when I was getting out. That's why I do it. I will do it as long as I am needed.

I want to tell President Bush that <u>all people</u> with disabilities need to be in the outside world. No one really knows how institutions really are, only the people who live there. If a person needs help it can come to the person in the community.

Jim King
Boulder, Colorado
1 year

People should not have to put up with that shit.

John Kover
Barrington, New Jersey
40 years

I was 16 years old when I was sent with my mother to love at the Village for Epileptics near Princeton. My mother and I had seizures and my father was told to put us there. She and I lived in different parts of the village but we would meet at the bridge near the barn (my job was to milk the cows) almost every day and I saw her at dances, on visitor's days, and the such. My mother got a job as a live-in maid with one of the staff and I didn't see much of her. Then she died.

I left in the late 1970's. I can't remember exactly when. My dream was to get my high school diploma, get a good job and see America. I did all those things and then some. I retired from my job as a janitor when I became 84 years old. I have seen the Pacific Ocean, traveled to Florida, Rhode Island, Virginia, just to name a few and have been to Washington, D.C. several times to testify on behalf of people with disabilities. I'll be going to Washington, D.C. in May for MiCASSA.

I want to tell President Bush to sign a law to close all Institutions. That's my dream now.

John Lagamarsino
Macon, Georgia
3 years

I have been to Disability Connections and have been able to ride the local paratransit system since getting out of the nursing home. I feel that I am able to do whatever I choose to do with my life since moving out of the nursing home.

Herb Larkins
Philadelphia, Pennsylvania
5 years

I was robbed of my freedom to come and go as I pleased. They took away my dreams and independence and what I was capable of doing. I was robbed of my privacy and my ability to have company when I wanted it. They took away my right to speak up for myself and to speak my mind.

Roger Manuelito
Gallup, New Mexico
21 years

I am Roger Manuelito. I am Navajo.

I was born in my family's Hogan in Naschitti (New Mexico). I lived on the Navajo reservation. I lived with my mother, father, brothers and sisters. I helped with herding sheep. I was 8 years old when I was taken away from my family, my home. They put me in institutions. I was in lots of institutions, they moved me around a lot

I was scared and missing my family. It felt like being in prison. I wanted to go back home to my family. I cried a lot.

I got out, finally, in 1981 and moved to a group home in Gallup, New Mexico.

After a few more years, I got a real job. I got my own apartment. I have lived by myself in my own apartment for several years. I pay my own rent and other bills. My sister visits me at my apartment. I visit my sisters and brothers at their homes when I want to.

I work at the McKinley County Humane Society and the Cedars Hill Animal Clinic. I've been working there for 9 years. I just got another job with Pep Boys. I quit the Humane

Society. I still work at Cedars Hills Animal Clinic. I make extra money at the mall. At night time I go to several stores and take out their trash and they pay me money.

I don't want any more institutions. I get scared if I think I might be sent back. I helped start People First of Gallup last year. I go to Albuquerque to help with People First of New Mexico. It is new. I go to Sante Fe on Freedom Day to talk to people who make the laws. I go to conferences and learn about self-advocacy. I speak up for myself and others.

Frank McColm
Denver, Colorado
43 years

My father put me in the home when I was 14 years old. I was in for 43 years. Wade Blank helped me move out 23 years ago.

Veronica McSherry
Worchester, MA
5 years

My life was theirs.

Being in a nursing home was very controlling/suffocating. Having little freedom and rights. Also there was a limit on time spent out. Days were fine but taking to many nights out would result in loss of residency or your personal belongings being moved to another room with things missing. The residents could get violent ex. One time while in my wheelchair I was tipped over backwards. The staff could be careless as well being understaffed they moved to fast and I ended up on the floor, and the time for Mother Nature doesn't come when they do.

My life on my own has given me full rights and my dignity as a human being – My Freedom – as Americans should have – No Matter the Person or Disability. It took courage to get here some 20 years now. I had to fight for my right and freedom – Literally – having been arrested and I continue to be as active as possible still. It's who we are inside. Today I am able to have my own apartment, go where I chose, stay out as late as I want and Mother Nature Knows. Hello My Name is Veronica McSherry

Josephine Messina
Cherry Hill, New Jersey
15 years

When I was a very little girl I was put in Vineland State School because my mother was sick and they said I was retarded. When I was 12 years old I went home to live with my mother and I went to public school. But my mother was too sick to take care of me so I was sent to Edward R. Johnstone Research and Training Center when I was 14 years old. I lived there for five years. Then they put me in a boarding home. They beat me there so I ran away. When they found me they sent me to a group home. It was the best place I had ever lived. I was glad to be there. I met my best friend Barbara there. I learned how to take care of myself, how to keep house, cook, shop. It was the first time I had freedom.

Barbara and I have been roommates for years. We just moved into a new apartment. I have a job. Barbara and I have been very active in self-advocacy. We like to travel. We went to the TASH conference in Boston in December. We are helping to start a NJ TASH.

People should not live in institutions. People should have a choice where they want to live. Anybody with a disability can live out in the community if they get the help they need. Listen to us.

Marjorie
Utah

Introduction:
Marjorie doesn't quite remember how long she has been living in the nursing home; one day creeps into the next. An immediate Care Facility for people with Mental Retardation (CF-MR) would likely have been a more appropriate placement for her than a nursing home.

If Marjorie had been placed in an ICF-MR, she would have been out of the facility and living in the community under the Portability Waiver three years ago. Now due to bureaucratic mishaps, this option is not available at the present time. The nursing home cites her diagnosis of mental retardation as the most significant barrier that is preventing her from achieving her dream of living in her own apartment. The state has also determined that she qualifies for developmental disability funding for persons with mental retardation and related disabilities; she is just 71 on the waiting list. Marjorie falls through the cracks with other funding possibilities. For example, she doesn't qualify for the Personal Assistance Waiver because she needs help hiring and firing her attendants.

She has also been a casualty of medical professionals who not only have little understanding of the community services available but because they are paid by the nursing home industry, have a vested interest in keeping people in the nursing homes. If it weren't for such a medical professional who denied her access to community services "for her own protection," Marjorie would be receiving community services now through the Utah Flexcare program.

Finally, because of the institutional bias in funding, community services are often unable to accommodate all the people who need services. There are also individual needs that can't currently be met by our community services. If people were entitled to needed services instead of a bed in a nursing home, perhaps Marjorie would not be faced with the potentially terrible choice of moving into the community and leaving her husband or staying in the nursing home with her husband because there are not adequate community services for him. Marjorie's story was written before her recent marriage.

Marjorie's Story:
I have cerebral palsy. I was living in Ala Chapell condominium. The man up above me turned his bathtub on and forgot to turn it off and water leaked down through the ceiling in the kitchen and on the carpet. As a result, I was moved into a nursing home and nobody told me why.

In my room at the nursing home, the space between my bed and my roommate's dresser is narrow that it is hard to use my motorized wheelchair. It is too difficult to back out or turn around. The telephone cord gets tangled when I move the over-bed table for me to go in or out.

When my boyfriend and I want to get together and talk, there is no place to go and be alone. We both want to move out of the facility and get married. To get out of the nursing home and have some happiness. I believe we have the right to some happiness.

I'm really getting tired of all the things I have to deal with such as: Nursing home people bossing me around; the other patients telling me what to do; always being asked if I want to go to an activity but when I say no they try to coax me into going. I like bingo and when someone comes to play the accordion or sing but other stuff I don't like. I've got my own life to live.

I don't understand why I can't live in an apartment instead of a nursing home. First, the staff at the nursing home told me I couldn't live in my own place because I liked to sleep during the day. Well, life here is boring. Why do I want to stay awake during the day, when I can get together with my friends in the evening after they get off of work? Then the staff told me I couldn't leave because I couldn't manage my medications. So I learned how, and the doctor still wouldn't let me leave. Then they told me I would not be able to manage my attendants. I can do that. I could tell them what I needed them to do when they came over. I would want help checking their backgrounds and things before I hired them and I don't like to fire people. But, I can tell them what to do.

I'm also worried because my boyfriend and I want to get married but he is going to have a much harder time getting out of the nursing home than I will. The nursing home will let us share a room after we are married but it will be so crowded that it won't be much of a home.

Now they tell me that I might be able to leave the nursing home without my husband. They say he can come visit me anytime but that he has to live in the nursing home. Would you want to start a life together like that?

Floyd Nelson
Gallup, New Mexico
16 years

I lived in institutions and group homes. I didn't like it. I had lots of problems living in institutions. Staff told me what to do.

I live on my own now, in my own apartment. I do what I want to do. No one tells me what to do now.

Preston Nelson
Gallup, New Mexico
16 years

I am Preston Nelson. I grew up on the Navajo Reservation. When I was a kid I was sent off to live in an institution. When I got out of there I had to live in group homes. I did not like living there. I was told what to do. I couldn't go out in Gallup without a staff saying I could.

Today I live on my own. I do what I want to do now. I don't have to ask permission.

I live alone in my apartment. I pay the rent, gas and cable and phone bills with my money. I work at Pizza Hut. I worked at a truck stop before Pizza Hut. I'm happy being my own boss.

Greg Nix
Boulder, Colorado
5 years

No hope, no privacy, no self accomplishments. Feel like I'm not living, just existing. At least one congressman or senator ought to visit one nursing home in their state and do the math to determine how much it costs for a person to live in the community versus how much it would be to live in a nursing home. In here, you are a number, and you feel like a number. They say they can provide anything you need, but that's not so. There is good and bad living in a nursing home or living outside. Outside the nursing home you have freedom and I will take the bad things about living outside the nursing home any day to have that. Give me 20% of what they give the nursing home and I can live outside the nursing home like a king.

Lahoma Osment

Denver, Colorado
11 years

I was 24 years old when they first got me (the state). I ran away 'cause they didn't take care of me.

Lisa Owen
Augusta, Georgia
2 years, 4 months

It was boring, you had no life, people told you what time to go to bed, what time to get up. You couldn't go outside the facility at all for recreational activity. It was no life and I Had to use the Protection and Advocacy office (Georgia Advocacy Office) to help me get out. Now I'm in charge of my life and house. I'm going to be going to work and be successfully employed. Soon I hope to be in my apartment and not just the personal care home. I can do anything I want to.

Edward Palermo
Robbinsville, New Kersey
19 years

I was sent to live at Edward R. Johnstone Training and Research Center because I use a wheelchair and I am blind. My mother didn't know what it was like in an institution. When the state announced they were going to close Johnstone I wrote to the governor and told him to keep it open because I didn't know what it was going to be like to live and on the outside and I was scared. So were my friends. My mother had died and a lot of the staff told us scary things about the community. But they closed Johnstone and now I am glad.

In the institution you couldn't say how you felt about things, you had to do what you were told, you couldn't speak up. I had friends who were handcuffed and locked up for doing those things in the institution.

Now I live in my own condo with my housemate. I have good support people to help me. I work at a copy center and I travel. I love to travel and visit new places. I make my own decisions, I vote, I worship. In 2001 I testified in Washington DC at the New Freedom Initiative Hearings and this past January I testified at our State House against restraints and aversive treatment for institutionalized children and adults. I would never put a member of my family in an institution. I will never go back.

Gerald Pemberton
Universal City, TX

A few years ago, a man died in a car wreck. He grew up a Christian, but somewhere along the way he fell down. The best thing in his life was that slap on the head that God used as a wake up call.

I spent five months in a coma, and then another year in the VA hospital. When I first woke up my world was just a spot on the ceiling. I couldn't speak nor walk and my short term memory was gone. Over the next year, they taught me to speak again. I spent the next few years in and out of hospitals and nursing homes for a total of eight years.

One day while I was in my wheelchair, I met a lady who worked as a relocation specialist for an agency which assists people to transition from nursing homes to the community. The agency's name is MOVE which is located in Salado, Texas. I spoke with her about me moving out of the nursing home into my own place, but I wanted to live near my family in San Antonio. She contacted an agency called the San Antonio Independent Living Services (SAILS). SAILS worked in conjunction with the Department of Human Services to assist me in making my dream come true. With everything in place, and a lot of hard work on everyone's part on December 9, 2002, I was driven to the bus station and started my life in my own apartment in San Antonio.

To assist me with my personal needs, I have a provider who comes in about 20 hours a week. She is a vital part of my success, she assists me with such things as washing my clothes, cooking my meals and other tasks that most people take for granted. I pretty much do things on my own. I have two sisters and their husbands, and one brother and his wife who live in this area who also are a big help.

What prompted me to write this article was one day I was sitting out front, smiling and waving at the cars passing by and I realized that in all my life this is the best I've ever felt about myself and my life.

Before the wreck, I was married and had my own business. I lost everything, and now I have regained my spirit and life. What a wonderful thing.

Francis "Tubby" Peyrouse
Denver, Colorado
35 years

They treated me bad, and I had five televisions stolen from me. I was really happy when Wade got me out. I'm more happy in the community.

Samuel Ray Price
Gallup, New Mexico
20 years

I lived with my Grandparents when I was a child. I lived in Smith Lake, on the Navajo Reservation.

I was taken away from my family and put in a group home. I lived in two group homes.

I was treated like an animal. They (the staff) bossed me around. Always telling me what to do. If I didn't do it I punished, I was told O couldn't go places with everyone else. They (the staff) got pissed off at me.

Three years ago I got out. They didn't want me to go. I wanted out and to be in Gallup. I live in my own apartment now. I pay for my own bills. Nobody tells me what to do. I can do it on my own.

I am President of People First of Gallup. I can go anywhere I want to.

That's it.

Peter
Utah

Introduction
Peter's experience with the nursing home industry is in one way unusual and in another poignantly illustrated that even a "good" nursing home is still a segregated, warehouse environment and not a place where many people would choose to call home. Peter's first experience in a nursing home is painfully familiar to most people who have spent time in one of these institutions. The second experience shows what happens when the staff recognizes a resident as a person.

Peter's Story:
I went into my first nursing home about twenty-five years ago. As a young man of twenty with psychiatric problems, I didn't have the skills to live on my own. I had problems with my family and more problems managing all the medications I was taking for my psychiatric disorder. Without a job, I took to hanging and loitering around the county building. Finally, a social worker told me to go to a nursing home. Back then there were no group homes or home care services. No one came to your door to help you out. There were no one to tell you about independent living. If you couldn't take care of yourself, you went to a nursing home.

Growing up with a dad who was an engineer, we traveled around the country. We lived in many places. When I was a kid, I was identified as having a learning disability. At the beginning of 6th grade, I was diagnosed with ADHD and was put on lots of medications. In the 7th grade I was hospitalized for the first time and by the 8th grade I had numerous hospitalizations. These hospitalizations continued through high school and contributed to my lack of independent living skills. These hospitalizations disrupted an already stressful and dysfunctional family life.

Living in the nursing home was a bad experience. The nursing home staff told me when to get up, when to go to the bathroom, when to eat, when to take a nap, and when to go to bed. There was very little independence. There was a strong smell of urine. It was not a place to live. You don't have a life there.

Another very frustrating thing was that one aide would tell me one thing, another aide would tell me something else and the nursing supervisor would overrule everything. I never knew what to do.

I was accused of starting fires and all kinds of things. I don't know how this could be true because I couldn't really function physically. I was on so many medications that I was in bed all the time. I was never in trouble with the law and I don't think I would ever do such a thing.

One morning in November 1979, I went to see people at the Mental Health Department and was told that I could not go back to the nursing home. At the time, they didn't explain why; but later, I found out that the nursing home did not have Medicaid's prior approval. I slept on the floor of the Rescue Mission that night.

Not only was I kicked out of the nursing home, but I was also kicked off of SSI, main source of income. In order to survive, I joined the Navy. Boot camp was very hard and many people couldn't cut it. But I wanted to succeed. I graduated from boot camp but I was later discharged because I couldn't meet the physical requirements.

After getting out of the Navy, I got an apartment and got a job as an orderly in a nursing home in Salt Lake. But I had to quit because the job pressure was too much. I went to Mental Health and I got medicine and they helped me apply for welfare, medical assistance and food stamps.

I traveled around on freight trains in Colorado and Idaho. The Mental Health Department in Colorado got me a bed at the Salvation Army and I also spent some time in a group home.

One day I called my sister from Denver. I was sleeping on a floor in front of a bank on newspapers at that time. She sent me a bus ticket to come back to Salt Lake.

Back home, my social worker once again told me to "take advantage of the system" and check into a nursing home to get my weight stabilized and help once again with mental health issues. I was not eating right and had lost a great deal of weight. The social worker referred me to a nursing home. As it happens, I knew a nurse who was a coordinator in the nursing home. As it happens, I knew a nurse who was a coordinator in the nursing home since I was fourteen and this nursing home treated me like a person.

As part of my treatment plan, I had to attend Mental Health group sessions and day programs, which was fine with me. The nursing home staff made sure that I went to

Mental Health. While I was there, I joined a group – a kind of a social club. This club provided me with several work and social experiences.

When I got my weight stabilized, I left the nursing home. This was a good nursing home. I visit nursing homes now, so I know that a good nursing home is one in a million. This nursing home does not exist anymore because it was sold to a different company. And even though this nursing home was a good nursing home, it doesn't begin to compare to living independently in the community.

I am also able to make real contributions to the community. One project that I am particularly proud of being part of is an apartment project for people who need mental health services. When I saw a need for this kind of housing, I contacted an administrator at Mental Health and together, we started an apartment project managed by Mental Health. I was there in the project for thirteen years.

A few years ago, I was diagnosed with manic depression. I had been misdiagnosed and had been taking the wrong medications until then. Now with the right medications, I'm doing fine. I have continued with day treatment. I met my current girlfriend five years ago. Our biggest focus is on taking care of ourselves and each other. If I have problems with driving, she drives. When she gets tired, I drive. We share. When we clean our apartment, she cleans one room and I clean another room. Then we sit down and take a break.

We're also members of the Disabled Rights Action Committee (DRAC). We are very proud to be members. I belong to other organizations and advocacy groups. But there's no advocacy group like DRAC. I am just sold on DRAC. We get things done rather than sitting back and waiting for the change of government to happen. Sometimes things move fast, sometimes slow.

But at least we have an organization of disabled people. It is not run by social workers. It is run by us, people with disabilities. When we mess up, we mess up. But we usually correct the mess very quickly.

Nancy Qual
Austin, Minnesota

My name is Nancy Qual. I was born in Thief River Falls, Minnesota to wonderful, wonderful parents, Alice and Bob. I started out in grade school in special education. I went on to middle school before it burned down, they had to add on. I spent one extra year at Ellis School in Austin. Then I was institutionalized at Fairbault State Hospital. I have come a long way when I was discharged. I am real happy about that. I encourage everybody to do the same. It is a wonderful things. Don't give up, keep going! After I was discharged from the State Hospital I lived in Cedar Valley residence. From there I got my own apartment and started working at Cedar Valley residence. From there I got my own apartment and started working at Cedar Valley Rehab workshop. I now am on community based with Cedar Valley Services doing janitorial work. I would like to earn myself a competitive job in the future. In the late 80's my dad opened up an Arc for everybody's benefit. What a wonderful dad. I would like all counties to get Arc's and People First groups started.

Katie Ranck
Minneapolis, Minnesota

My name is Katie Ranck. I was in a wheelchair in the past and as I got older I went into alcoholism and drugs. I landed in a state regional hospital and I went through a treatment program. I was told that if I had passed away there, I would have been buried as a number. I am now a member of ACT, and I'm on the Board. I am one that does not want to see a number on a persons grave; whether or not they have a disability they should all be treated as human beings and buried with dignity.

I would like to see the communities and all races be treated with respect. There should be no discrimination in this world. We have a voice in this community, all of us, and every voice should be heard. Together we work as a team and team works towards success.

James Riddle
Cheyenne, Wyoming
30 years

They put me in Lander State Training School 1961-1976. I worked my butt off. After all that work I did up Lander and her now I am at a retirement home. This home better that Lander State Bug House. I took care of kids and helped people at kitchen up Lander. But don't have to do that here.

There was hard floors like in kitchen. Is not good for my feet. In '67 I walked to work when it was 29 below. I am a tough guy! When first went in Lander, I worked 7 day week. Bug House that what I call it.

In '75 I went home. I said, "Now! No more Lander. You know what? Lander State School, it is no good!"

They used say dumb guy Jim don't got any sense. I have my own mind. I have. I can tell they think I have not.

1976-2001 I was at Magic City, Cheyenne Wyoming. I lived in group homes. I moved into an apartment July 1989. 10 years lived by myself. No roommates. Nobody there to bug me. I went to bed when I wanted to and got up 5:30 in the morning. They had TV up Lander but not my own TV, When I had my apartment, I bought my own TV.

More than 3 years ago I was on my deathbed. Heart trouble. I moved into old folks home. This better than group home. I need be with other people. If I was in a group home, they would have to make too many changes. I am better off here. I don't have much choice. 2001-2002 I was People First of Cheyenne President. I am Past President now. I still go every month. My friend takes me. Nursing home won't take me in their van since meeting is on Sunday afternoon. They use to but say can't anymore.

I am 67 years and holding. 1961 I went to Lander. If I could talk I could right all things. If I could talk I just about have Lander closed. I could tell George Bush about Lander. Don't think I wouldn't tell Bush. If I could talk.

Willie Robinson
Memphis, Tennesee
5 years

Everything here (on my own) is perfect, well, not technically perfect, but such a vast improvement it seems perfect.

Linda Romanelli
Midland, Michigan

During March 2002 I went into the nursing home for rehabilitation due to a complicated hip replacement. I was allowed only 10% body weight on my leg, and also had a brace that fit around my waist and down my leg to help keep it stable. During my stay there I received insufficient physical therapy from the rehab staff or from the nursing home staff. I got so frustrated and discouraged that I decided I was leaving. That is when they showed an interest in helping me after I told them I was leaving in a few days. Then they couldn't do enough. I did what therapy that I could do on my own so that the doctor would approve my release. I had not walked in two years and was given a faulty wheelchair that had no brakes and the left leg didn't lock, when I complained about it! I was punished by having the wheelchair taken away. I talked to A supervisor and she agreed that I could use the wheel chair to go to the dining room and then use my walker to walk back, the few times a nurse or an aide would walk with me. There were times I had to walk by myself, from my room to the dining room was approximately 2 hallways long. Too long to walk alone. At bedtime when it came to getting me up or down I had to remind these people how to handle my leg so to keep them from doing harm. At one point

I was given the wrong medicine and if I hadn't noticed I would have taken something that could have done considerable harm to me, the nurse laughed it off and said it happens. The depression I and the others suffered is heartbreaking, depression is a terrible thing. I pray no one who reads this has to go through it.

Leonard Roscoe
Atlanta, Georgia

25 years

I was put in the institution in 1972 after living in hospital my first 3 years. I have Osteogenesis Imperfecta (brittle bones). It was assumed I would be retarded. My mother was tricked by the state into institutionalizing me. I was here 35 years. I had unnecessary Pneumonias and breaks from the environment. Now that I'm out I have a life. I come and go like everyone else.

Dorothy Ruffin
Philadelphia, Pennsylvania
3 years

When I was in the Philadelphia Nursing Home they use to get me up at dark time they said because I was easy to do so they were getting me out the way for the next shift.

Bonnie Schuller
Vineland, New Jersey
38 years

There are seven developmental centers still open in New Jersey. In my lifetime I have lived in five of those seven institutions. I was institutionalized when I was 2 years old. My mother couldn't take care of me and they said I was retarded. I was sexually abused when I was a little girl in the developmental center. I know they abuse and kill people in institutions and the food is terrible. I have been put in straight jackets and tied down. While I was in North Jersey Developmental Center I found out about self-advocacy. Steve Gold and Tim Cook came and helped me and some other women get out and move into a group home but they sent me back because I had behaviors.

I finally got out of Vineland Developmental Center in 1999. I now live in a supervised apartment. I have my privacy, I can watch TV when I want, and buy my own food. I am a member of a group of self-advocated that help other people get out of institutions. Self-advocacy helped me to understand that I have rights and I want to help other people living in institutions understand that they have rights!

Dorothy Shatzky
Cortland, New York
5 years

What I Miss about Life by Being in a Nursing Home…

Having a place where I'd have room to keep things that I have had in the past like pictures and personal things. I miss my personal privacy, particularly having to share a room with somebody else. Not being able to go out as often as I'd like is something else I miss.

What I Want to do Outside a Nursing Home…

I prefer to have my own choice of food, not having a huge meal at lunchtime and a small one at dinner and I'd like some diet food and real eggs instead of egg products. I'd also be able to have my own schedule for doing things instead of having to depend on the schedule established by the nursing home.

Irma Shirley
Gallup, New Mexico
35 years

I am Irma Shirley. I live in my own apartment and pay the rent and bills. As a child I was taken from my home to live in an institution. For 35 years I lived in institutions and group homes.

I have worked the past several years at day care centers for little children. I am paid just like everyone else. I am happy where I live and work. I am looking for a house to rent where I can have my own dog. I make my own choices for my life.

John Sime
Minnetonka, Minnesota

My name is John Sime. I have worked in Faribault, Owatonna, and Cambridge. I have done janitor work, cashier work, restaurant work. I have received awards for helping people in wheelchairs, choir singing. Our father was an alcoholic. I went to the workshop today to learn how it affects our family, friends and jobs. It has a big effect on all! I think my two sisters, even though they are both married now, have taught me to respect other people and get along with everybody. That has changed my life completely. Right now I am involved with an empowerment group on Tuesday nights. It is an interesting class. I'm learning different things that I didn't know. I've been in self-advocacy help empowerment group for about four years, I've had three or four instructors, they have been a big help. I work in the community Monday and Tuesday at Maple Grover, Minnesota at a packaging plant. We do a lot of sorting for many different companies. Wednesday and Thursday I work at Opportunity Partners at Minnetonka, Minnesota, which we do all different kinds of work. I'm trying to get along with all the instructors in class. I'm trying to meet new friends each day. On Friday, they have a senior option class, which we go to different places. My new instructor is Beth, she has also been a big help to me and the rest of the group. We all like her!

Bobby Simpson

Denver, Colorado
11 years

It was terrible and the food was awful and I was treated bad. I am glad I have my own home.

Paul Smith
Minneapolis, Minnesota
13 years

My name is Paul Smith. One of the things I had a time with is at the State Hospital. With all the assaults. I was at the State Hospital down in St. Peter. One time I got upset and one other person didn't know what the reason I was getting upset. I tapped him on the shoulder and he ended up flipping me on the floor which was damaging to both of my knees. That kind of thing would happen a lot. I lived there for 13 years. Now I live in a Mains'l home. I live alone and basically do everything on my own. It's a big direct turnaround when you move out of the State Hospital and into the community. You have to start dealing with reality and that's a hard thing to learn. I do not have a job now, but would like to have one. I would like to do anything that would bring me money.

Genell Stopp

I moved to a nursing home a few months before my 19th birthday. My mother could no longer take care of me. I have a form of Muscular Dystrophy that is not as progressive as some although I have never walked. At the time of my stay in the nursing home, I only needed help getting on and off the commode, bathing, and getting in and out of bed. I was able otherwise to care for myself. This cost the state $1700 per month for a 12 by 12 room. This room I shared with 80 and 90 year old people. And I might add, 3 unbalanced meals and no snacks.

When I moved to my own apartment, it cost $ 800 per month for the state to assist me. I graduated from the University of Tulsa. I worked full time as an Independent Living Councilor, bought my own home and raised my niece.

Now due to the progression of my MD, I use a ventilator part-time and Oxygen full time. I still live in my own home.

Pam Stover
Rochester, New York
2 years

My doctor sent me to a nursing home because the Home Health Aide Service assigned to me refused to cook the food that I requested. Instead, they only gave me sandwiches.

They told me that they were not allowed to cook for me. As a result, my health deteriorated. I was bleeding internally, and eventually, vomited 4 basins of blood. I was in the hospital for ten days. Then I was sent home briefly, and then I was admitted to a nursing home. My stay in the nursing home was dismal. The aides in hospital refused to dress me in the clothes I requested. They would ignore me and dress me in any manner they chose. I had to wear dirty, wrinkled, mismatched clothes. My family and friends would take me out on trips within the community. They would call the front desk before the came to pick me up to ask that I be dressed appropriately before they arrived. The staff would make a nasty face but they would comply to avoid a confrontation from my loved ones. I observed that residents who had their haircut by the hospital staff lacked style. They all looked like they had a bowl put over their head before cutting their hair. I chose not to have my hair cut. The recreation program was lacking in many ways. There were not a variety of activities available for the patient. Everything was focused on the older generation. There weren't any options for the younger adults. The weekends were very dreary. There were no activities at all.

My medical care was not up to par. I developed a very bad infection in my chest. Fortunately, my new caseworker from the Center for Disability Rights came to get me and took me to a doctor before it was too late. The nursing home was completely oblivious to the fact that I had an infection. I had complained about pain in my chest and was told, "You'll get over it." Fortunately my new case manager from CDR and concerned staff members, worked hard to get me released from this negligent environment.

My main goal is to help free others from facilities that do not provide quality care and are not concerned with the well being of their patients. My wish is that others may enjoy a free, content life that I am grateful to have.

Ross Sweat
Seminole, Texas
3 ½ years

My name is Ross Sweat, and I live in Seminole, Texas. I did not respond to the first request I saw for this information because my time in nursing homes was so long ago, and, while it was miserable, it was neither a wasted nor a useless experience for me. I was paralyzed in 1965, was in a hospital for almost a year, and then spent about 3 and 1/2 years in 6 different nursing homes in several Texas cities. I left nursing homes in late 1970 when I met and married a stubborn young lady who is still my wife and partner. After college, I became a Rehabilitation Counselor in New Mexico.
During my career there I was also an area supervisor and, for four years, the state director of the NM Division of Vocational Rehabilitation. I took disability retirement from NMDVR in1992 because of health issues. I returned to my hometown and now teach psychology and sociology (part time) at a small college. I also serve on the Texas SILC and Rehabilitation Council.

Doreen Talk
Gallup, New Mexico
15 years

I am Doreen Talk. I am Navajo. I speak and read English and speak Navajo.

When I was a child I was put in an Institution in North Dakota but my family lived in New Mexico. I think I was in this Institution from age 4 to 11. I did get out and went back home. Then I went to Special Education classes in high school. Then I was again put in an institution, where I did not want to go. A few years later I was moved into a Group Home. I did not like living in any of these institutions.

Now, I live in my own apartment and pay my own bills. I got my own apartment when I started working. I live by myself. I have a job a Wal-Mart. I have been working at Wal-Mart for eight years. I have friends all over town. People know me everywhere I go. I am angry about living in institutions and group homes all those years. I am happy now, I like living on my own and I like my job.

Tammy
Salt Lake City, Utah

Introduction:
“Tammy is a freedom fighter,” said Kay Fox, a community organizer at the Salt Lake Community Action Program. “The first weekend we met at a national action in DC, Tammy protested at then HUD Secretary Andrew Cuomo’s house and the next day demonstrated by jumping out of her wheelchair and crawling to the Executive Office Building to encourage the Clinton Administration to end institutional bias. At ht end of the day she was bruised and needed stitches. I ran to her to see if she was OK. “This was the best day of my life, Tammy said about the solidarity experienced after these activities. I knew she was in a real leader. It was no surprise that DRAC hired Tammy. She’s a real leader.”

Tammy’s story illustrates that even the toughest “freedom fighters” can come perilously close to total defeat when confronted by the lunacy of our institutionally biased system. A system whose first resort is a nursing home for a teenager who is aging out of the foster care system. A system that won’t provide a young adult with a disability the resources they need in the community; they must either wait years, and in Tammy’s case literally die waiting, or give up all that they hold dear—career, schooling, friends, apartment and personal possessions to enter a nursing home. Only after entering the nursing home with funding will be made available for community life. Only after giving up everything will you be given an opportunity to try and reclaim and rebuild the broken pieces of your life. Fortunately for Tammy, she had a strong group of friends who found this situation intolerable and would not accept it. Sadly, not everyone is so fortunate.

Tammy's Story:
Nineteen years old and a college freshman: I remember the day in November of 1997 that forever changed my life. Abby, my social worker, and a representative from Adult Protection Services appeared in the doorway of my class. I excused myself from the classroom as my professor continued to fantasize being the lead reporter during the death of Princess Diana. I was led in silence to the library, where a private room had been reserved for the occasion. Had I known what was about to happen, I would've took a sudden interest in the Princess Diana phenomenon and a new appreciation for my professor's every word.

They said they would escort met to my home to gather my things and to stay at the community hospital for a day or two until we found a nursing home that I "could live with". No amount of crying, begging, or pleading changed their minds. They did, however, agree to let me finish off the day at school to say goodbye to my friends. How kind of them!

Alas!-I was too quick for them! The next day I moved into my friend's apartment. This was only a temporary solution-John was a 21-year-old student from Brazil and had to go home in December for Winter Break. It, however, gave me almost one-and-a-half months of freedom and enabled me to finish the semester with my friends. I was lucky to have the friends that I did. John lived on the third floor of his apartment. Because a lot of my friends were in Student Government, every evening we would leave my wheelchair in their office, John would carry me to his car, then up the three flights of stairs to his apartment, where he and other friends did all of my care. I try not to think of the burden that was placed on my friend during this time-I am OK accepting help, but I believe I should be able to hire paid attendants for this and not expect services from my friends. And then on December 19.1997, the inevitable came.

No one should spend Christmas in a nursing home. I had never let my disability stand in my way- ever. Why was I being imprisoned all of a sudden? For the most part, I had believed in God all of my life, and not once had I felt any bitterness towards Him regarding my disability, I could not truly and completely control my own life. At nineteen, disability became a crime from which there was no parole. Everyone around me was three or four times my age – many had been captive for several years. Had I suddenly set foot into reality?

I have always been a fighter. Fighting to get out "till the end or spending the next several decades in a nursing home wishing I were dead wasn't much of a choice. I was probably no older than 5 when I adopted the concept of "Survival of the Fittest" and I have had plenty of opportunity to develop it.

To make a long story short, I got out. I ran away for days at a time, I broke other rules—in short, I was a "behavioral problem" and a "liability risk" that they finally didn't want to deal with. I got my own apartment, attendant care, went back to college, a job, got engaged, broke off my engagement in the name of independence, moved by myself to another state, organized a local disability rights group, adopted two cats, and the list goes on…

…All to be jeopardized by moving to Utah.

In May of 2001, ADAPT – a national grassroots disability rights organization – gathered in Washington DC to push for legislation for community attendant services and supports (MICASSA). Kay Fox, long-time organizer and strategist of ADAPT Utah, approached me about the opportunity to serve as an AmeriCorps *VISTA Member in the Disabled Rights Action Committee's (DRAC) Our Homes Not Nursing Homes Project. To be honest, I was less than thrilled about the location and leaving my friends, school and the wonderful Big Sky Country. However, my goal in life has been to get a job/career and eventually become financially self-sufficient. The Project represented my deepest passion – what I would like to do for the rest of my life, or until the threat to personal freedom is gone.

As a VISTA Member, I would receive a small living stipend, an education award at the completion of my first and second year and non-competitive eligibility status for appointments to U.S. government executive branch agencies for a short period. My service would pay off all of my outstanding Student Loans and I would be able to pay off any other debts I had acquired. If truth be known, even more enticing was the opportunity to learn under Barbara Toomer – one of the greatest disability rights activists in the nation.

Before I knew it, I was relocating to Salt lake City, Utah. While I was not ignorant to the work ahead of me in setting up all of the bureaucratic webbing that follows me wherever I go, I had not expected the Utah "booby-trap"!

I soon learned that Utah State Medicaid provides only sixty hours of in-home attendant services per month – broken down that is fourteen hours per week or two hours per day - a mere one-third what I was receiving in Montana. I don't know of one non-disabled person who can get out of bed in the morning, bathe/shower, dress, groom, prepare and eat breakfast, clean up get ready for work, later prepare and eat lunch, clean up, prepare and eat dinner, clean up, and finally get ready for bed – not to mention using the restroom throughout the day – all in two hours. There was no way I could survive on two hours of services a day. It would have only taken a couple of days for me to be in serious danger!

I applied for the Physical Disability Waiver – the only program in Utah that would enable me to receive the services and supports I need to live in the community. It was this waiver or institutionalization. Upon applying, I was informed that because I was not in a nursing home at the time, I be #25 on the waiting list, that people had been on for more than seven years. Basically, by being refused services because I started out in the community, I was being forced into a nursing home by the same program that funds people with disabilities transition from nursing homes into the community. It was even suggested that I go into a nursing home so that the waiver would provide me with services and supports upon return into the community.

Fortunately, Montana Medicaid funded my attendant care for the first month I was in Utah. I cannot begin to describe the fear and devastation I felt as the month passed. Then twenty-three years old, I had hoped for a 'land of opportunity', as should anyone moving to a new state for a job.

Fortunately, the people of ADAPT, Utah and DRAC were not about to take this ironic twist lying down. They mobilized, made calls, wrote letters and eventually descended en-masse on the Governor's office with the pointed message that it was unacceptable and most likely illegal that I be forced into a nursing home just to reapply for funds to move out. The Governor's representatives basically agreed, but countered that it would be unfair for me to get services before the then twenty-four who were ahead of me on the "waiting list." My friends at DRAC were not persuaded by this argument, though they agreed with the fairness issue. Finally, by some miracle the state officials agreed to fund all twenty-four persons on the waiting list ahead of me.

Never doubt the power of a committed group of friends who are willing to go to the mat for you and who have the law on their side. I narrowly avoided nursing home care, and in doing so helped twenty-four other people get needed services. However, my heart still goes out to those who don't have no choice but to accept the intolerable offer of the entitled nursing home stay.

Life is good now—I am working in two meaningful VISTA placements. I have a wonderful apartment with an extra room for an attendant. I have a cat. I have friends, I have a little income and I have a life—a life that I could not have in the nursing home. Believe me, I speak from experience.

Trish
Utah

Introduction: Trish's triumph over a system that ties services to a place instead of the person serves a beacon of light for those still struggling to be free. Cerebral palsy, clinical depression, asthma and a host of other medical problems make it difficult, if not impossible for Trish to live in the community without services. The personal Assistance Waiver For People with Disabilities makes it possible for Trish to get the services she needs to live independently in the community for a fraction of what it cost Trish to receive the same services in a nursing home. As a VISTA Volunteer for the Disabled Rights Action Committee, Trish help others make the transition from nursing home to independent living in the community. She is active in her church and takes civic duties very seriously.

Trish's Story: I write this in hopes of giving John Q. Public a bit of insight into what it is like to live in a nursing home.

I spent a year of my life transferring between three nursing homes, hoping to find a place that I could call “home”. To my dismay, I found nothing of the sort. All of the facilities were sterile in their environments. Each had overworked and underpaid staff. There was no personal attention. You slept and lived in a 10-foot-by-10-foot space, and ate in overcrowded dining rooms. The décor left much to be desired, and you could count on a monotonous, predictable routine. I’ve heard it likened to being in jail and believe me, the analogy fits.

I am not an elderly person. I am less than 40 years of age. The most important things I lost in the nursing home were my dignity and freedom. I felt as trapped as a caged animal with very little to say regarding anything that directly affected me. Your dignity suffers greatly when someone has to dress you, bathe you, put you to bed and dispense your medication on schedule.

I waited anxiously for a phone call or visit from my friends, my only connection to the outside world. To take a ride in a car with no particular destination in mind was a reason to celebrate. To do menial tasks such as a part-time job, or helping with the facility laundry was something I looked forward to because I had something to do that was productive.

Finally came the chance to live in the community once again. A group here in Salt Lake City called the Disabled Rights Action Committee (DRAC) launched a program called Our Homes Not Nursing Homes. The project was the result of the Supreme Court decision that said that a person should live in “the most integrated setting.” For me, that was definitely not a nursing home. In late 2000, I moved into my own apartment. I now have the freedom to choose what I do and when to do it. My dignity is restored as a productive citizen of this community. I supervise every aspect of my life and don’t have to answer to anyone but myself when it comes to making decisions affecting my life.

There were hurdles placed in front of me in my transition to the community, but it has been worth it, and I was able to overcome all of these hurdles with help from my friends. I was permitted $45 a month to provide all my personal needs while living in the skilled nursing facility. That left me nothing to save toward paying rent or buying household supplies, etc. Thanks to many people at DRAC, and the fact that I had some things in storage, everything I needed was patched together in a short time.

My little apartment is not Taj Mahal, but it is mine. From inside these four walls, I pay my bills and live my life as I choose from day-to-day. I treasure my freedom more each day, and have learned to appreciate the little things in life, even those things that can be a big hassle. If one can find blessings in having occupied a nursing home, then so be it. For me, there is no such thing..
life to live..

Gilbert Yazzie
Gallup, New Mexico

27 years

I am Gilbert Yazzie.

I lived with my family. The state sent me to live in an institution. I went all over the place, from one institution to another. It was a terrible thing.

I work at Pizza Hut. I have worked there for 10 years. I live in my own apartment, Sunset Hills Apartment #105. It's a great place to live. I go home to visit my family every year at Christmas and Thanksgiving. I go where I want, when I want. I have my own checking account and no one can sign my checks but me.

Ken Thomas
Philadelphia, Pennsylvania
10 years

In there, I lost my freedom; I lost my enjoyment of life. I was unable to meet people. The people in the institution were mean to me and told me what to do and when to do it. They took away my wheelchair, which was my only way to get around. Mostly, they took my heart away because they were evil to me.

Lou Ann Thompson
Florence, Kentucky
21 years

I was first put in a private mental hospital where I was for 3-1/2 years. I was forced to take shock treatment. When I got out I was in and out of the local hospital Psych Ward then they gave my dad a choice of putting me in the state mental hospital or a nursing home my dad choose the nursing where I was for the next fourteen years. I got sick physically and had to go to the hospital, the administrator wanted me revaluated before finished it after I got back to the nursing home. I spent another several years in the nursing home but they were working to get me out

June 8, 1991 I moved out of the Nursing Home. I moved into transition where they taught me how to live on my own. I lived there one year. July 1992 I moved into my own apartment. I was working 3 days a week and going to TRP 2 days a week. I got myself involved in the state. I was on the ATAK/MI Board, P&A Council, Department Mental Consumer Advisory Council. I am on the Statewide Independent Living Council, I have served on the Supported Living Council. The Governor appointed me to a task force on law, violet crimes and serious mental which I was the only consumer. I have given workshops at the State Consumer Conferences and National Conferences.

Thru my advocacy I have helped get several consumers out of nursing homes.

I have also received the Abilities Award in 1994 that is a state award given out every year.   I was employee of the year in 1993 and I was consumer of the year in 1994 for Northern Kentucky Comp Care.

Duc Van Le
Denver, Colorado
12 years

I was 22 when I came to the United States. Five years later, I was institutionalized. After 12 years, I was able to get out, and have lived in my own apartment for the last 15 years.

Rick Viator
Denver, Colorado
3 years

It was living hell and I had kids and had to get out. I love being in my own home. I had to move out of the state of Louisiana to get out.

Maria Valenzuela
Rochester, New York
25 years… the first time.

My father didn't like me, and so, when I was five years old, he put me in an institution. I worked for the next 25 years to get out. I didn't want to stay there all of my life.

As I grew up, I went to school in the institution, regular school and a cooking school. I had to do chores to prove I could leave. I ended up taking care of other patients and cleaned the whole place.

Finally, when I was 19 years old, they let me go. I got my own apartment and went to work.

Seven more months…

Maria Valenzuela a 66-year-old woman with complex medical issues through out her life. Maria was extremely determined to stay in her own home not a nursing home. Maria was placed in a state institution at the age of 5 and remained there for the next 25 years; her childhood and life was stolen from her. It was only after the state institution went on strike, did they even begin to think that Maria deserved and was capable of being on her own. During the strike there were only two people on the 25-bed unit to care for the patients left behind: Maria and the staff doctor. Maria did all the personal care and knew the entire routine including the medication of each resident. Shortly after, Maria was released and swore she would never go back! Maria always reminded us of her anniversary to freedom; each year -- that was over years ago!

Maria's health became more complex and fragile over time with numerous health issues. Once again, Maria's freedom was being threatened. Maria was hospitalized from a fall.

Maria refused to go to a nursing home and remained in the hospital for seven months. The hospital attempted to obtain a guardianship over Maria. The Center for Disability Rights began assisting Maria in order to avoid a nursing home. This would be done by coordinating community supports which would enable her to go home where she wanted to be.

Maria's long-time friend became her health care proxy and was a tremendous community advocate for Maria by suggesting proactive measures to ensure her continued safety and happiness. The entire organization assisted in Maria's 24-7 care needs. On June 12, 2003, with everyone's diligent efforts and with Maria's will power, she won her case. The judge terminated the temporary guardianship. Maria went HOME! Local providers stated that they were extremely pleased with Maria's exceptional care and Maria was so very proud of this great accomplishment. She was free once more!

Sadly now, Maria has since passed away, but thing is for sure, Maria was determined to be back in her own home, living life her way – FREE no one could tell her anything different!

Patty Winkel
Denver, Colorado
10 years

My dad left me out on the street. I was homeless. They put me in a group home where I stayed for 10 years. I have been free in my own apartment for the last 16 years.

Carol Young
Gloversville, New York
1 year

I am writing to tell you some of the benefits of living in the community as opposed to living in a nursing home. First a little background information about myself.
I am a traumatic brain injury and stroke survivor. I was 42 years old with a teen-age daughter graduating with college credits in engineering from high school. I had a great job working with Easter Seals as an Occupational Therapy Assistant. I worked with children and their families. Then I found myself in a nursing home in another state. Luckily in New York, they have TBI programs to bring people out of state, back to New York, in an effort to save Medicaid dollars. The program does work, not to mention how happy I am to be my family was to have me closer to them even if it was in another nursing home. I was told it was only temporary, until the local program for traumatic brain injured people have a room for me in a local home. I'd have a new home with a garden, my own room, and my own staff to assist with needed help. They are there to

help to become more independent so that one day I will be able to get a real job instead of working in a sheltered environment, and get my life back to normal.

The biggest difference between living in a nursing home and living in the community, is freedom. Freedom is being able to go where you want, when you want, and the ability to make your own choices.