

NATIONAL COMMISSION on FAIR HOUSING and EQUAL OPPORTUNITY

Testimony on behalf of ADAPT

[www.adapt.org](http://www.adapt.org) & [www.adapt25.org](http://www.adapt25.org) (25<sup>th</sup> Anniversary Celebration Page)

Houston Hearing, July 31, 2008

Attachments

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## **HOUSING ADVOCACY GOALS**

*The following is a summary of our national housing advocacy goals for Affordable, Accessible and Integrated Housing.*

In the area of **AFFORDABLE HOUSING** we fight for:

### ***Access Across America***

- a) HUD to partner with HHS to provide DI (DeInstitutionalization) housing
- b) advocate at State and local PHAs for DI vouchers

### ***Incremental Vouchers***

- a) demand that HUD's NOFAs include incremental vouchers for people with disabilities in PHAs waiting lists

### ***Fair Share Vouchers***

- a) demand that HUD's NOFAs award extra points to PHAs that work with state Medicaid waivers for vouchers to get people out of nh.

### ***Recapture Misused Vouchers***

- b) Thousands of Vouchers designated for people with disabilities were misused.
- c) We demand HUD assurance that unused vouchers designated to p/w/d are given to p/w/d

In the area of **ACCESSIBLE HOUSING** we fight for:

Advocate for a national modification fund for section 8 holders

· Increase the 5% and 2% in public assisted housing, under 504, to 10% and 5%

Demand that HUD increases 504 evaluations of Public Housing Authorities in all of their services, programs and activities

Increase Enforcement of 504 and the Fair Housing Amendments Act

Pass National Visitability Legislation ....the Inclusive Home Design Act

In the area of **INTEGRATED HOUSING** we fight for:

***"Access to Integration" the Re-direction of 811 program funds***

HR 5772 was introduced in the House April 10, 2008, when passed 5772 will reform the 811 program

**We advocate for stronger language in HR 5772:**

HR 5772 must indicate that only 50% of its annual funding be used for group homes; put a cap of only four individuals to reside in a group home; mandate that incremental vouchers for people with disabilities should go to people with disabilities.

We demand the integration of all government funded housing silos currently segregating our people



**The Hidden Housing Crisis: Worst Case Housing Needs Among Adults With Disabilities**

Kathryn P. Nelson

Kathryn P. Nelson retired from the U.S. Department of Housing and Urban Development's Office of Policy Development and Research in 2003, after working there as Research Economist for 25 years. She was the principal author of HUD's first eight reports to Congress on worst case needs for housing assistance.

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## The Hidden Housing Crisis: Worst Case Housing Needs Among Adults With Disabilities

Kathryn P. Nelson

In HUD's 2007 report to Congress, *Affordable Housing Needs 2005*, the American Housing Survey (AHS) proxy used to estimate the worst case housing needs<sup>1</sup> of disabled non-elderly very-low-income renters without children was incomplete because it did not incorporate a new 2005 AHS question about disability income.<sup>2</sup> Moreover, the AHS proxy results were not compared to independent sources of better data on numbers of very-low-income renters with disabilities and increased to agree with these control totals, as had repeatedly been done in previous HUD Worst Case reports.<sup>3</sup>

This study uses data about households with severe rent burdens from the 2005 American Community Survey (ACS) to overcome these two weaknesses and develop more accurate estimates of worst case needs among households containing non-elderly adult renters with disabilities.<sup>4</sup> The ACS identifies disabilities through direct questions about six disabling conditions, and thus has better data on persons with disabilities than any AHS proxy could provide. Yet the ACS does not have all the data elements needed to measure worst case needs as well as the AHS does, so the estimates developed here are based on AHS relationships between severe rent burdens and worst case needs. Then, because two other national surveys have better questions about disabling conditions than does the ACS,<sup>5</sup> the estimates of worst case needs made from the ACS were adjusted to be consistent with control totals from those two other surveys.

The resulting estimates imply that some 1.3-1.4 million childless very-low-income renter households with non-elderly adults with disabilities had worst case housing needs in 2005. This range is more than double the estimate of 542,000 disabled households published by HUD in their 2007 report, and also much higher than the estimate of 694,000 that results from using the expanded AHS proxy that includes the new question on disability income (HUD, 2008).

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<sup>1</sup> Worst case needs, a concept intended to measure renters with acute needs for housing assistance, are unassisted renters with income below half of their area's median income ("very-low-income" renters) who pay more than half of their income for housing or live in severely substandard housing. Homeless individuals should be included in this measure, but the necessary data are not available.

<sup>2</sup> In February, 2008, HUD released *Housing Needs of Persons With Disabilities: Supplemental Findings to the Affordable Housing Needs 2005 Report*. This supplement uses the new AHS question on disability income ("Did [this person] receive any disability payments such as SSDI, worker's compensation, veteran's disability or other disability payments?") in the AHS proxies recommended by this study.

<sup>3</sup> Reasons and procedures for adjusting AHS estimates to control totals drawn from more complete data on adults with disabilities are described in Appendix C of HUD's 2003 report, *Trends in Worst Case Needs for Housing, 1978-1999*. The desirability of including "all nonelderly households with adults with significant physical or mental disabilities" is also cited in HUD's 2007 report (on p. 84). These issues, and HUD's previous practice in making such adjustments, are further described in the technical appendix to this study.

<sup>4</sup> "Non-elderly" adults are between 18 and 61 years old, because persons aged 62 and older are eligible for HUD's rental assistance programs for the elderly such as Section 202 housing. All of the adults considered in this paper are "non-elderly", and all estimates made are for households rather than persons. Elderly households are those in which the head or spouse is 62 or older.

<sup>5</sup> The Survey of Income and Program Participation (SIPP) and the National Health Interview Survey (NHIS) identify 35% to 54 % more non-elderly adults as having disabling conditions than does the ACS. Cornell Guide to Disability Statistics from the ACS (Weathers, 2005) Table 11.

Direct data on disabilities among non-elderly adults living in families with children, and their severe rent burdens, were also produced from the ACS. With procedures and adjustments similar to those used for non-elderly adults *without* children, this study produces the first estimates of worst case needs among families with children and disabled non-elderly adults ever made. The results reveal that close to one million of the very-low-income renter families with children who had worst case needs in 2005 housed non-elderly adults with disabilities.

These improved estimates of worst case needs for housing assistance among non-elderly adults with disabilities do not question or change HUD's published finding that six million renter households had worst case needs in 2005. They do, however, clearly imply that households with non-elderly adults with disabilities constitute a much larger share of total worst case needs than HUD's published estimates for 2005 imply. Rather than making up 9 to 12% of the total, as the unadjusted AHS proxies suggest, non-elderly adults with disabilities live in 35 to 40% of the 6 million households with worst case needs. Moreover, almost half of the 4.7 million non-elderly renter households with worst case needs for housing assistance have adults with disabilities.<sup>6</sup>

### *Overview of Study Procedures and Organization.*

This study improves measurements of worst case needs among non-elderly adult renters with disabilities by building in three ways on ACS estimates of very-low-income renter households and their rent burdens prepared by the National Low Income Housing Coalition (NLIHC).<sup>7</sup>

1. Because the ACS has essentially the same questions on income sources as the 2005 AHS,<sup>8</sup> sources of income reported by non-elderly adult renters with disabling conditions were examined to recommend better AHS proxies for identifying non-elderly adult renters with disabilities from AHS data and thus tracking their housing conditions. ACS data allowed evaluation of possible AHS proxies for both households without children and families with children. HUD's *Supplemental Findings* are based on estimates that use both of the AHS proxies recommended by this study.
2. Households with and without non-elderly adult renters with disabilities were identified within each of the household types used by HUD in their Worst Case reports to provide a basis for estimating worst case needs of non-elderly adult renters with disabilities. As detailed below, because the ACS lacks data on rental assistance and severely inadequate housing, worst case needs were then estimated from ACS counts of renter households with housing costs above 50% of income based on AHS relationships between severe rent burden and worst case needs. This approach, previously used by HUD in five worst case reports to adjust AHS estimates to control totals from the SSI Stewardship Review sample,<sup>9</sup> is appropriate because severe rent burden—paying more than half of household income for housing—is the problem underlying 95% of worst case needs.

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<sup>6</sup> The remaining 1.3 million households with worst case needs in 2005 had elderly heads or spouses. Many elderly persons in these households also had disabling conditions, but this study focuses on how to best estimate worst case needs among households with non-elderly adults.

<sup>7</sup> Danilo Pelletiere and Keith Wardrip, *Housing at the Half: A Mid-Decade Progress Report from the 2005 American Community Survey*, NLIHC 2008.

<sup>8</sup> As Susin (2007) discusses, the 2005 AHS adopted "a series of income questions similar to the questions used in the ACS". However, the new AHS question about disability income is more specific than that in the ACS. HUD 2008 gives the exact wording of all these questions.

<sup>9</sup> As shown in the Technical Appendix, however, many disabled adults do not receive SSI payments, so the SSI Stewardship Review control totals themselves undoubtedly undercounted eligible adults with disabilities.

3. Cornell University's Employment and Disability Institute compared ACS disability statistics to those available in five other national data sets in its *Guide to Disability Statistics from the American Community Survey* (Weathers, 2005). This comparison showed that for persons between the ages of 18 and 61, the ACS estimates of numbers of persons with some disability are appreciably below those from the Survey of Income and Program Participation (SIPP) and the National Health Interview Survey (NHIS). SIPP and NHIS "both use a much larger set of survey questions to identify persons with disabilities" (Weathers 2005, p. 28). Following a procedure similar to the one used in five previous HUD worst case reports, this study accordingly adjusts its ACS and AHS based estimates of worst case needs to be consistent with the higher, and presumably more accurate, counts produced by the SIPP and NHIS. Although procedures for accurately counting persons with disabilities continue to be studied, I strongly recommend that HUD similarly adjust future AHS-based estimates to the best available national counts of persons with disabilities.

***Recommendations for AHS proxies for non-elderly renters with disabilities.***

In HUD's last three reports on worst case needs, the proxy for adults with disabilities used among non-elderly renters without children was income from Social Security, SSI, or public assistance reported by the household head.<sup>10</sup> No attempt was made to proxy the presence of disabled adults among families with children because it was assumed that most of those reporting public assistance income were participating in a program such as TANF rather than being disabled. The new income question added to the AHS in 2005 specifically asks about income from disability payments: "Did [this person] receive any disability payments such as SSDI, worker's compensation, veteran's disability or other disability payments?" Beginning in 2005, all AHS questions about income sources are asked for every adult in each household.

As the first panel of Table 1 shows, ACS tabulations of four income sources reported by very-low-income childless non-elderly adult renter households (hereafter "VLICNEAR" households!) with or without disabilities imply that the corrected AHS disabled proxy definitely should include the new AHS disability income question. Over three-fourths (77%) of those renters reporting such income on the ACS did have disabling conditions. Nonetheless, fewer than 10% of the total 2.2 million VLICNEAR households that contain adults with disabilities report income from retirement, survivor or disability payments. These results imply the corrected AHS proxy should continue to retain income reported from Social Security, SSI, or public assistance as reliable indicators of disabilities among childless adults. Clear majorities of the VLICNEAR households reporting these three income sources on the ACS – from 98% to 69% – did include non-elderly adults with disabilities.

The table also reveals that these four sources of income fail to identify all of the VLICNEAR households that do have adults with disabilities. Because some of these households have income from more than one of these sources, the ACS results imply that only two-thirds (65%) of the childless households with disabled adults may be identified by an AHS proxy based on these four income-source questions. This finding reinforces the importance of comparing, and adjusting, future AHS results from this recommended new proxy to the best available independent data on persons with disabilities.

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<sup>10</sup> Appendix C of HUD 2003 discusses the research on which this proxy was based, why it represented an improvement over HUD's earlier proxy, and why it probably still undercounted the total number of adults with disabilities. HUD's new *Supplemental Findings* (HUD 2008) detail the questions underlying this proxy.

The ACS identifies one-fourth of the 6 million very-low-income renter families *with* children as having non-elderly adults with disabilities, including 826,000 households with severe rent burden (Table 1). Among these families, the ACS tabulations confirm that receipt of public assistance income does not reliably indicate the presence of an adult with disabilities, as HUD had assumed in not previously attempting a proxy for disabilities among this household type. Only 37% of the ACS very-low-income family renters reporting public assistance income contained a disabled adult. However, three-fifths or more of those reporting income from Social Security, SSI, or disability benefits do have adults with disabilities. Moreover, those three income sources identify more than half of the very-low-income renter families with children who have non-elderly adults with disabilities in the household. These ACS results imply that an AHS proxy that includes income from Social Security, SSI, or disability benefits, but not from public assistance, could usefully identify those families with children that housed non-elderly adults with disabilities, and thus provide estimates of their worst case needs and other housing problems. I recommend that HUD use this three-income proxy to track housing problems among this important group.

To summarize these recommendations,

- The AHS proxy to identify childless non-elderly adult renters with disabilities should include households that report income from the new AHS disability income question. It should, however, also retain income reported from Social Security, SSI, or public assistance sources because the ACS tabulations show that each of these income sources is a reliable indicator of the presence of non-elderly adults with disabilities in the households. Below, I sometimes refer to this as a “four-income” proxy.
- A new AHS proxy to identify families with children that have non-elderly adult renters with disabilities should include *three* AHS questions on income source: the new AHS disability income question, income reported from Social Security or retirement benefits, and income from SSI payments.

***Estimates of worst case needs for renter households with non-elderly adults with disabilities.***

*Childless adult renters with disabilities.* ACS data show that almost three-fifths (57%) of the 2.2 million VLICNEAR households with adults with disabilities had severe rent burdens in 2005 (Table 2, third column). As the first two columns of Table 2 show, this prevalence rate is quite similar to the 54% with severe rent burdens found when recommended four-income source proxy identifies 1.8 million likely childless renters with disabilities from the AHS.<sup>11</sup>

Because worst case needs were originally defined to identify renters most in need of housing assistance, the concept has from its start excluded renters reporting rental assistance.<sup>12</sup> The 694,000 childless disabled renter households counted by the AHS new proxy as having worst case needs, therefore, include only 664,000 unassisted renters with severe rent burden plus more than 30,000 unassisted renters living in severely substandard housing.<sup>13</sup> The new four-income

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<sup>11</sup> The AHS estimates in these tables are drawn from HUD’s new *Supplemental Findings*.

<sup>12</sup> As Shroder has shown, the AHS questions used to measure receipt of rental assistance do not do so accurately in all cases. Mark Shroder, “Does Housing Assistance Perversely Affect Self-Sufficiency?” *Journal of Housing Economics*, Volume 11: 4, December 2002, Pages 381-417.

<sup>13</sup> Among these disabled renters as among all with worst case needs, severe rent burdens characterize 95% or more of those with worst case needs. The remainder live in severely inadequate housing without a severe rent burden, and a small fraction have both severe rent burdens and severely inadequate housing.

AHS proxy, therefore, shows 39% of childless disabled renter households as having worst case needs.

As the 'NA's in the ACS column of Table 2 suggest, the ACS asks no questions about rental assistance. The ACS does record whether a household lacks complete kitchen or plumbing facilities, but can not measure severely inadequate housing as defined in the AHS. To estimate how many of the ACS's 2.24 million very-low-income childless disabled renters had worst case needs, therefore, this study assumes that the new AHS proxy's relationship between severe rent burden and worst case needs among VLICNEAR households with disabilities holds for the equivalent households identified from the ACS. This is the same assumption used in HUD's previous worst case reports to estimate worst case needs for this group based on data and control totals from the SSI Stewardship Review Sample (HUD 2003, Exhibit C-2). This assumption implies that 932,000 of these renter households, 42% of the VLICNEAR group with disabilities, had worst case needs in 2005.

*Family renters with children who have non-elderly adults with disabilities in the household.* As Table 1 showed, the ACS identifies one-fourth of the 6 million very-low-income renter families with children as having non-elderly adults with disabilities. As the right side of Table 2 repeats, this represents 1.46 million households, 826,000 of them (57%) with severe rent burden. Using the three income sources recommended above as an AHS proxy for disabled families with children, 49% of the one million such families identified by the AHS have severe rent burdens, and 37% have worst case needs. Assuming that the relationship between severe rent burdens and worst case needs shown by the AHS for such families with children also holds for equivalent ACS families, some 620 thousand of the very-low-income renter families with children who have worst case needs have adults with disabilities in the household.

***Should AHS estimates of very-low-income renters with disabilities and their worst case needs be compared to control totals from better data sources and adjusted if appropriate?***

For reasons discussed in more detail in the Technical Appendix, not least of which is HUD's history of doing this over more than a decade, I judge that AHS estimates derived from proxies indicating the presence of non-elderly adults with disabilities should continue to be compared to national data sources with better data on persons with disabilities and adjusted to conform to those data. Even the improved AHS proxies that I recommend above can not pretend to accurately identify all households with disabled non-elderly adults.

At the very least, estimates derived from the new AHS proxies should be adjusted to be consistent with the better counts of adults with disabilities that are available from the ACS through its six questions on disabling conditions. Adopting the approach pioneered by HUD in conforming AHS estimates to control totals from the 1994-1999 SSI Stewardship Review samples, Table 2 used 2005 AHS relationships between worst case needs and severe rent burdens to estimate worst case needs among the households with disabled adults identified by the ACS. Compared to AHS estimates made with my recommended proxy, the results raise estimates of worst case needs among non-elderly childless adult renters with disabilities in 2005 by a third, from 694 to 922 thousand. Worst case needs among renter families with children and non-elderly adults with disabilities increase by 70%, from 365 to 622 thousand.<sup>14</sup>

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<sup>14</sup> In this regard, it is highly pertinent that the ACS evidence that the four income sources only count 65% of VLICNEAR disabled also implies that AHS proxy results should be increased. Multiplying the AHS results by 1/0.65, for example, would imply that 1.07 million non-elderly childless adult households had worst case needs.

More fundamentally, although research on improving counts of disabled persons continues, at present the SIPP and NHIS clearly provide more complete counts of non-elderly adults with disabilities living in housing units than the ACS does.<sup>15</sup> As the middle panel of Table 2 illustrates, Cornell's direct comparisons of SIPP, NHIS and ACS counts of adults aged 18-61 can be used to provide adjustment factors that are recent as well as directly relevant to this study. The bottom panel of Table 2, accordingly, uses these factors to adjust the ACS estimates.<sup>16</sup> I conclude that some 1.3 to 1.4 million VLICNEAR households with adults with disabilities had worst case needs for rental housing assistance in 2005, as did some 840 to 960 thousand families with children and non-elderly adults with disabilities present.

Compared to the AHS estimate of 694,000 for worst case needs among VLICNEAR households with adults with disabilities, a range of 1.3 to 1.4 million may seem implausibly high. But two considerations suggest that it may even be low. 1) The range is only 14-30% above the estimate of 1.1 million derived from 2 different approaches for 1999.<sup>17</sup> 2) Comparison of estimates for years between 1987 and 2005 derived from the three-income AHS proxy that was consistently defined over those years show worst case needs among VLICNEAR households with disabilities rising by 43% between 1999 and 2005.<sup>18</sup> If this growth rate were accurate, the 1.1 million in 1999 would have risen to 1.6 million in 2005, rather than "only" 1.3 to 1.4 million.

### *Conclusion*

Following a procedure like the one used in six worst case reports to Congress between 1994 and 2003, this study adjusts its ACS and AHS based estimates of worst case needs among very-low-income renter households with non-elderly adults with disabilities to be consistent with more accurate counts from the SIPP and NHIS. Although procedures for accurately counting persons with disabilities continue to be studied, I strongly recommend that HUD similarly adjust future AHS-based estimates of housing needs and conditions among households with disabled persons to the best available national counts of persons with disabilities. I also recommend that they continue their past practice of actively studying how such adjustments can be improved.

In addition to estimating that worst case needs affected 1.3-1.4 million childless households with non-elderly adults with disabilities, this study found that 0.9-1.0 million families with children with worst case needs in 2005 had non-elderly adults with disabilities in the household. Thus, overall, the study finds that almost half of the nation's 4.7 million non-elderly households with worst case needs include adults with disabilities. The remaining 1.3 million worst case households have elderly heads or spouses.

These improved estimates of worst case needs for housing assistance among non-elderly adults with disabilities do not question or change HUD's published finding that six million renter households had worst case needs in 2005. They do, however, clearly imply that households with non-elderly adults with disabilities constitute a much larger share of total worst case needs than

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<sup>15</sup> One reason for the better coverage of SIPP and NHIS is that their questions better identify persons with physical impairments than does the ACS. Because of HUD's continuing interest in needs for housing with physical modifications, such data should be of particular interest for future research.

<sup>16</sup> Future research might usefully develop adjustment factors separately for childless renters and families with children.

<sup>17</sup> The Technical Appendix summarizes these independent approaches and why the estimate of 1.1 million itself was probably low.

<sup>18</sup> Author's calculation of change between 378,000 in 1999 (Exhibit C-2, HUD 2003) and 542,000 in 2005 (Table A-5, HUD 2007).

had previously been thought. Rather than making up 9 to 12% of the total, as the unadjusted AHS proxies suggest, in 2005 non-elderly adults with disabilities lived in 35 to 40% of the 6 million households with worst case needs.

These estimates offer the hope that the ACS can track needs among persons with disabilities annually in the future. The ACS will also provide much more geographic detail about the location of persons with disabilities and housing problems when multiyear ACS data are released.

Finally, the new AHS proxy to identify families with children that contain a non-elderly adult with disabilities should provide a basis for obtaining hitherto unavailable information about the housing problems and household characteristics of these families. For example, preliminary tabulations of the AHS suggest that in three-fourths of these families the disabled adult is a female head.

***Technical Appendix: Adjusting AHS estimates of persons with disabilities and their housing problems to control totals derived from more complete estimates of persons with disabilities***

*Practice in HUD's past Worst Case reports.* In response to a 1990 request from the Senate Appropriations Committee, HUD has been producing reports on worst case needs since 1991, when its first report, *Priority Problems and "Worst Case" Needs in 1989*, was published. The third report, *Worst Case Needs for Housing Assistance in 1990 and 1991*, began the practice of estimating needs for non-elderly adults with disabilities. Based on research with the 1978 AHS Housing Modifications Supplement, receipt of SSI income was identified then as a useful AHS proxy to identify adults with disabilities, although the report acknowledged that this proxy "is likely to seriously undercount the number of households with disabled individuals present" (HUD, 1994, p.44).

The fourth worst case report, *Rental Housing Assistance at a Crossroads*, then reported on HUD's first attempts to estimate more complete counts of worst case needs among adults with disabilities by comparing estimates of worst case needs among persons receiving SSI from the 1993 AHS against better control totals. From counts of non-elderly adults with disabilities who had severe rent burdens from the 1994 SSI Stewardship Review Sample, coupled with AHS proxy data on the relationship between worst case needs and such burdens, the report concluded that "At least 17 percent of worst case households have adults with disabilities present" (HUD 1996, Figure 14, page 29).

Each subsequent report continued and improved this approach, as described in Appendix C of HUD's 2003 report, pp A-46 to A-50 of HUD 2003, *Trends in Worst Case Needs for Housing, 1978-1999*. That appendix also discusses the basis for the report's estimate that 1.1 million renter households with nonelderly adults had worst case needs in 1999. This estimate was derived from two independent procedures. The first used data from the 1995 AHS Physical Modifications Supplement to estimate the number of renters with physical disabilities (and also extend the AHS proxy used to identify households with adults with disabilities). The second approach compared AHS proxy results to data from on non-elderly renters with severe rent burdens from SSI Stewardship Review sample for the years 1994-1999. Then, because payment levels for SSI provide incomes well below 30% of HAMFI, the SSI total was raised by 10% to approximate disabled renters with incomes too high to qualify for SSI but still below the very-low-income cutoff of 50% of HAMFI.

After 1999, the SSI Stewardship Review sample no longer provided all the data elements needed to identify very-low-income renter households with severe rent burdens for this purpose so adjustments to control totals from SSI data could not be made in the reports published in 2005 and 2007. But both reports cite the desirability of such adjustments, however, and note that even such adjusted estimates are likely to be incomplete.<sup>19</sup>

*Approach of this study.* Because the SSI Review sample data previously used as control totals have not been available since 1999, I reviewed alternative sources of national data on adults with disabilities to identify appropriate control totals for estimates in 2005. In doing so, I discovered that SSI program statistics show that many disabled adults receive both SSI and Social Security disability benefits, while still others receive only Social Security payments. Specifically, Table 15 of the 2005 SSI Annual Statistical Report counted 6 million disabled adults as receiving only Social Security benefits, 2.9 million as receiving only SSI benefits, and 1.2 million as receiving both. Some of these 10 million adults were undoubtedly owners, and some receiving only Social Security payments probably had incomes above the very-low-income limit. Nevertheless, this evidence that SSI recipients make up only some 40% of disabled adults receiving Social Security or SSI payments implies strongly that the control totals from SSI Review Sample data used in HUD's previous reports were themselves far from complete.

My search for better data on persons with disabilities led to the *Guide to Disability Statistics from the American Community Survey* (Weathers, 2005), prepared by Cornell University's Employment and Disability Institute. This resource reviews sources of data on disabilities and past research on the strengths and weakness of different questions asked over the past several decades in efforts to improve disability statistics. It also compares ACS disability statistics to those available in five other national data sets, including explicit comparisons of ACS and other disability statistics for persons between the ages of 18 and 61, the exact ages of interest in this study. This comparison showed that for persons between the ages of 18 and 61, the ACS estimates of persons with a disability are appreciably below those from SIPP and the NHIS, "which both use a much larger set of survey questions to identify persons with disabilities" (Weathers 2005, p. 28).

To conclude, this history of past HUD efforts to better count all of the eligible renters with disabilities, combined with evidence that much better data on adults with disabilities than the SSI Stewardship Review sample are now available and should continue to improve, is the basis of my considered judgment:

- AHS estimates derived from proxies indicating the presence of non-elderly adults with disabilities should continue to be compared to national data sources with better data on persons with disabilities and adjusted to conform to those data.

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<sup>19</sup> Footnote 43 of HUD 2007, for example, states "Social Security Administration (SSA) data on SSA recipients who are blind or have other disabilities provide a basis for making more complete estimates of the number of very low-income renters with SSI income who receive HUD assistance or who have a severe rent burden. But even the SSA data are incomplete because they exclude very low-income persons with disabilities who have incomes above SSI cutoffs."

Table 1

**Sources of income of non-elderly adult very-low-income renters without or with children  
by presence or absence of nonelderly adults with disabilities\***

	With <u>Disabilities*</u>	Other	% with <u>Disabilities*</u>
<u>All non-elderly renter households without children</u>	2,237,466	3,901,552	36%
Reporting income from:			
Social Security/Railroad Retirement	656,330	110,266	86%
Supplemental Security Income	784,696	14,937	98%
Retirement, Survivor, or Disability Payments	210,556	62,317	77%
Public Assistance	201,861	91,561	69%
Reporting any of above 4 income sources as % of total with disabilities	1,456,638 65%	259,490	
 <u>Families with children and non-elderly adults</u>	 1,459,871	 4,496,367	 25%
Reporting income from:			
Social Security/Railroad Retirement	303,991	155,218	66%
Supplemental Security Income	405,854	28,706	93%
Retirement, Survivor, or Disability Payments	98,077	67,274	59%
Public Assistance	397,675	663,151	37%

Source: NLHC tabulations of the 2005 American Community Survey Public Use Microdata Sample.

\*Any member age 18-61 responded 'yes' to one or more of six disability limitation questions - or if the "reference person" was <18 and responded "yes".

Table 2

**Estimating worst case needs among very-low-income renters with non-elderly adults  
with disabilities in 2005 from AHS, ACS and NHIS and SIPP data**

Data source:	Childless households with <u>nonelderly adults with disabilities</u>			Families with children with <u>nonelderly adults with disabilities</u>			
	<u>AHS*</u>		<u>ACS(1,2)</u>	<u>AHS**</u>		<u>ACS(1,2)</u>	
Very-low-income renter households (000s)	1,767		2,237	998		1,460	
with rent burden >50% of income	946	54%	1,271	485	49%	826	57%
reporting rental assistance	703	40%	NA	363	36%	NA	
unassisted with burden >50%	664	38%	NA	359	36%	NA	
with worst case needs	694	39%	932	365	37%	622	43%
worst case as % of unassisted		65%			57%		
ACS worst case/AHS worst case:			1.34			1.70	
 <u>Adjusting for SIPP and NHIS higher counts of adults 18-61 with disabling conditions</u>							
<u>Number of U.S. adults 18-61 with disabling conditions***</u>							
ACS, 2003	18,813						
NHIS, 2002	25,318						
SIPP, 2002	29,046						
			Ratio compared to ACS:				
			1.35				
			1.54				
 <u>Adjusted estimates of worst case needs</u>							
conforming to NHIS control total			1,255			837	
conforming to SIPP control total			1,440			960	

Sources: \*HUD/PD&R tabulations of AHS with 4-income proxy for Non-elderly disabled adults in households without children (HUD, 2008)

\*\* HUD/PD&R tabulations of AHS with 3-income proxy for non-elderly disabled in families with children (HUD, 2008)

(1) ACS data on very-low-income adults with disabilities and severely burdened from NLHC tabulations of the 2005 ACS Public Use Microdata Sample

(2) Italicized "ACS" estimates of worst case needs assume that the AHS ratio of worst case needs/severe rent burden holds for the ACS estimates.

\*\*\* ACS, NHIS, & SIPP: Table 11, Robert R Weathers, 2005. *A Guide to Disability Statistics from the American Community Survey*, Cornell University Employment and Disability Institute





**U.S. Department of Housing and Urban Development**  
Office of Policy Development and Research



## **Report to Congress**

# **Assessment of the Loss of Housing for Non-Elderly People with Disabilities**

## **Final Report**

**Assessment of the  
Loss of Housing  
for Non-Elderly  
People with  
Disabilities**

**Final Report**

October 2, 2000

*Prepared for*

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Perhaps most importantly, thanks are due to the property managers and occupancy specialists from the fifty HUD-assisted study properties for volunteering their time and sharing their experiences with the Abt research staff. We appreciate the assistance provided by state officials, HUD field office staff, and public housing agency staff in clarifying issues surrounding the affordable housing supply in the studied metropolitan areas. We are also indebted to the local advocates and service providers for people with disabilities and local housing experts who shared their time and expertise on the challenges faced by people with disabilities when searching for affordable housing.

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# Executive Summary

This research addresses the issues facing non-elderly people with disabilities as they seek affordable housing in their communities. The primary focus of this exploratory research is the influence of provisions of the Housing and Community Development Act of 1992 that permitted owners of certain HUD-assisted elderly housing (which may have previously served non-elderly people with disabilities) to limit admissions to elderly households. This report presents case studies of ten purposively selected metropolitan areas and a cross-site analysis assessing the issues facing low-income, non-elderly people with disabilities who are seeking affordable housing.

## 1. Background for the Study

Nationwide, the HUD-assisted multifamily housing stock includes an estimated 4,157 properties built primarily to serve the elderly. Historically, federal housing statutes defined “elderly” to include disabled persons, with the result that younger disabled persons were eligible to live in these properties.<sup>1</sup> The eligibility criteria for persons with disabilities depend on the HUD program under which the property was developed, the year it was developed and the definition of disability in effect for that year. In most cases, property managers were not permitted to give preference to elderly persons over non-elderly disabled persons in their tenant selection policies. In general, however, prior to the 1992 legislation, properties built primarily to serve the elderly originally had one of the following types of occupancy policy:

- restriction of eligibility to elderly applicants; or
- a fixed set-aside of units (usually 10 percent) for people with mobility impairments (elderly or non-elderly); or
- a policy that permits admission of non-elderly people with disabilities *either* for a fixed set-aside of units, *or* for all units.

In the late 1980s and early 1990s, the statutory requirements that some properties serving primarily elderly tenants set aside a percentage of units for young disabled persons created considerable controversy. Congress responded by including in Sections 651 and 658 of the Housing and Community Development Act of 1992 provisions that redefined “elderly” strictly in terms of age (62 years of age or older) for future properties and allowed existing

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<sup>1</sup> U.S. Housing Act of 1937, Section 3(b)

property owners in some cases to give preference to the elderly in tenant selection or in other cases to exclude non-elderly people with disabilities entirely.

The legislation affected different properties in different ways. Section 658 covers properties that initially had an elderly-only policy. These properties were only affected if they had, over time, expanded admission to non-elderly people with disabilities. Managers of these properties could choose to go back to their original policy of accepting only elderly applicants. Section 651 covers properties with Section 8 project-based assistance and permits managers to give a preference to elderly households while still maintaining a set-aside of units (typically 10 percent or less) for non-elderly persons with disabilities.

In 1997, Congress mandated that HUD and the General Accounting Office (GAO) investigate the extent to which those provisions of the Housing and Community Development Act of 1992 resulted in a loss of assisted housing for non-elderly people with disabilities. The GAO completed a study in 1998, concluding that the statute had affected few non-elderly people with disabilities. The GAO researchers surveyed managers of a random sample of HUD-assisted properties that were potentially eligible to restrict occupancy under the legislation. According to the GAO report,

The majority of housing properties designed for the elderly have not used the 1992 act to restrict the occupancy of nonelderly persons with disabilities. Almost three-quarters of the officials for the properties designed for the elderly reported that they had adopted their current policies before 1993, when the law went in effect. That is, the policies for these properties have not changed as a result of the act.<sup>2</sup>

In 1999, HUD responded to Congress with an analysis of HUD administrative data, also finding “no downward trend in the admission of non-elderly disabled persons to units of HUD-assisted housing in recent years.”<sup>3</sup> However, HUD’s analyses did indicate that there might be differences in admission rates by HUD program and/or by geographic location.

## 1.1 Goals of the Research

This study was designed to examine trends in admissions of the non-elderly disabled to HUD-assisted housing that would not show up in aggregate analyses. The research design also called for a broader inquiry into the general issues facing low income, non-elderly people with disabilities who are looking for affordable housing. The primary goals of this research were to:

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<sup>2</sup> *Assisted Housing: Occupancy Restrictions on Persons with Disabilities*; General Accounting Office, November 1998.

<sup>3</sup> *An Interim Report to Congress on the Admission of Non-elderly Persons with Disabilities to HUD-Assisted Housing*, Office of Housing and Office of Policy Development and Research, U.S. Department of Housing and Urban Development, March 1999.

- examine the issues facing non-elderly people with disabilities as they seek affordable housing in their communities; and
- explore factors that may influence property owner/managers' decisions to change their occupancy policies regarding admission of non-elderly disabled persons.

We hoped to learn about the influence of such factors as geographic location, the assistance program, and local market tightness on occupancy decisions property managers and owners made after the 1992 Act. We also hoped to learn how managers' policies, as well as applicant screening and admissions practices, affect disabled applicants' access to assisted housing.

## **1.2 Research Approach**

This study's primary methodology was in-depth field data collection in ten purposively selected metropolitan statistical areas (MSAs). The ten MSAs were selected based on metropolitan area-level rates of admissions of non-elderly people with disabilities to HUD-assisted housing built primarily to serve the elderly. HUD administrative data on admissions and occupancy in 1996 and 1999 were used to categorize metropolitan areas according to whether non-elderly admissions appeared to be increasing, decreasing, or staying the same. In addition, metropolitan areas with particularly high or low rates of admissions were identified. The MSAs selected for study and their MSA-level sampling category are identified in Exhibit ES-1 below.

Within each metropolitan area, five properties were selected purposively for more intensive study during the field data collection phase of the study. In each MSA, we attempted to identify two properties that mirrored the trend in admissions at the metropolitan level and, for contrast, at least one property that seemed to be "bucking the trend" (i.e., a property showing an increase in admissions of non-elderly people with disabilities in a metropolitan area with an overall decrease in non-elderly admissions.)

The data collection was carried out between March and June 2000. It included field visits to the ten metropolitan areas, and in-person and telephone discussions with several types of key informants in each area: the property managers at the five study properties; local HUD officials; public housing agency staff; representatives of advocacy organizations who work with people with disabilities; and representatives of local apartment management associations. In addition to the discussions with local informants, we toured each study property and the surrounding neighborhood to assess property and neighborhood condition.

## Exhibit ES-1

### Admissions Rate Categories and MSAs Selected for Study

Non-elderly Admissions Rate Category (1996-1999)	MSA
Low rate of non-elderly admissions	Miami/Dade County, FL Bergen/Passaic, NJ
Average rate of non-elderly admissions	New York City, NY Oakland, CA
High rate of non-elderly admissions	Denver, CO Kansas City, MO/KS
Decreasing rate of non-elderly admissions	Memphis, TN Detroit, MI
Increasing rate of non-elderly admissions	Akron, OH Phoenix-Mesa, AZ <sup>4</sup>

## 2. Summary of Key Findings

### 2.1 Findings Regarding the Supply of Housing Available to Non-elderly People with Disabilities

#### *Changes in Occupancy Policies*

Managers at the 50 study properties were asked whether their occupancy policy had changed in recent years and whether any changes could be attributed (entirely or in part) to the 1992 Act.<sup>5</sup> Of the 46 managers who were able to provide information on changes in occupancy policy,<sup>6</sup> 32 managers (70 percent of those responding) said the building's occupancy policy had not changed since the passage of the Act. Only two of these managers indicated they might change their policies in the future. Among the 14 managers (30 percent) who reported a change in policy, 10 (22 percent) linked the change to the 1992 legislation, while the remaining 4 managers were not sure what caused the change.

#### *Occupancy Policies in the Study Properties*

At the time of the field visits in the spring of 2000, property managers at 9 of the 50 study properties reported their occupancy policies do not permit admission of non-elderly

<sup>4</sup> As discussed in detail in the Phoenix case study in Appendix C, an increase in admissions of non-elderly people with disabilities at a small number of properties caused the MSA-level increase. At the majority of properties in the sampling frame, no non-elderly people with disabilities were admitted in 1996 or 1999. Notably, the Phoenix property managers interviewed for this study were uniformly familiar with the 1992 Act and consistently convinced that elderly and non-elderly residents should not live together. Management at four of the five properties had elected elderly preferences.

<sup>5</sup> It is important to note that the properties included in this study are a purposive rather than a random sample of HUD-assisted properties built primarily for the elderly. These findings may not be representative of the incidence of election of elderly preferences in the stock over-all.

<sup>6</sup> Four managers did not know whether their property's policy had changed.

residents; all applicants at these properties had to be at least 62 years old. The remaining property managers (41 of the 50) indicated that they accept applications from non-elderly people with disabilities, although the conditions for eligibility vary:

- Property managers at 22 properties reported their policies allow them to consider all non-elderly applicants, regardless of the nature of their disability, either for a fixed set-aside of units (4 properties) or for all units (18 properties).
- Managers at 19 properties said they have a fixed number of wheelchair-accessible units (typically 10 percent of the development's total units) for people with mobility impairments. Both elderly and non-elderly applicants with mobility impairments are eligible for admission to these units.

The reported occupancy rates of non-elderly people with disabilities at the study properties in the spring of 2000 ranged widely. Property managers at 7 properties reported no non-elderly disabled households, and another 7 managers said that no more than 3 percent of their units were occupied by non-elderly people with disabilities. Just under half the property managers (for 24 properties) reported that 3 to 12 percent of their units were occupied by non-elderly tenants with disabilities. Among the remaining 12 properties, non-elderly occupancy rates were between 13 and 50 percent at 9 properties, and over 50 percent in 3 properties.

The proportion of non-elderly residents with disabilities living in a study property was sometimes different from the proportion expected based on the property's occupancy policy. For example:

- 4 of the 7 properties with no non-elderly residents actually had occupancy policies that permitted admissions of non-elderly people with disabilities;
- 6 of the 19 properties with 10 percent set-asides for people with mobility impairments had non-elderly disabled occupancy rates of less than 3 percent

These data suggest managers may have employed practices that illegally discriminate against people with disabilities.

### ***Factors Influencing Properties' Occupancy Policies***

The Housing and Community Development Act of 1992 was considered to be one factor influencing occupancy decisions. However, local respondents commonly cited several additional factors, including:

- **Owner or sponsor mission**—Some managers reported they choose to serve non-elderly people with disabilities because it is part of their mission. These managers reported they would not change their policies even though they were eligible to do so.

- Living environment for elderly residents—Creating a comfortable living environment for elderly residents was often cited as managers’ primary goal, even when the HUD funding agreement required that non-elderly people with disabilities also be served. Key housing informants of all types commonly expressed concerns about the management issues that arise when elderly and non-elderly disabled residents live together, often referring to the “different lifestyles” of the two groups. However, practices that would discourage non-elderly people with disabilities from applying or denying eligible applicants admission are illegal.
- Property strength—Local respondents commonly said that a combination of factors related to property marketability (which we refer to as “property strength”) contribute to occupancy policy decisions. Managers of properties in better condition and located in better neighborhoods are more likely to change their policies to restrict new admissions to elderly applicants. Further, managers with such properties that also have low vacancy rates at their own properties and strong elderly demand for HUD-assisted housing in their metropolitan market appear more likely to limit occupancy by non-elderly people with disabilities. Weaker properties had higher rates of non-elderly disabled occupancy.

Our findings also indicate that the policy in place at the study properties is not necessarily a good predictor of the proportion of current tenants who are non-elderly people with disabilities. Property strength—as proxied by property condition, neighborhood condition, and elderly demand for HUD-assisted housing in the metropolitan area—appears to be a stronger predictor of non-elderly occupancy. Property strength also seems to be related to whether property managers are content with their current occupancy mix or plan to reduce non-elderly occupancy through attrition or policy change.

***Other Sources of Affordable Housing for People with Disabilities***

In addition to the HUD-assisted stock, non-elderly people with disabilities may also be eligible for several other affordable housing options, including public housing, tenant-based rental assistance, and several targeted programs. Key findings on the availability of these options to people with disabilities include these:

- Public housing seems to be the most available resource, with relatively shorter waiting lists and generally accommodating admissions policies. Although it is not always the housing of choice, in some places it offers some advantages to people with disabilities, such as on-site service coordinators, willingness to make changes to the units to accommodate residents’ disabilities, and small units that are relatively easy to maintain. Among the primary public housing agencies serving the metropolitan areas studied, most had designated at least some of their

elderly public housing for elderly-only occupancy.<sup>7</sup> But at least some non-designated elderly developments continue to accept non-elderly people with disabilities in almost all the study areas, and family public housing developments are available to people with disabilities.

- According to advocates and housing officials, tenant-based assistance appears to be more popular with non-elderly people with disabilities than public housing (as it is with most applicants), but it is difficult to obtain and use. A few of the states in which our study sites were located offer state-wide programs that provide tenant-based assistance to people with disabilities, although demand far outstrips the supply of certificates and vouchers.
- Other housing options such as HUD's Section 811, Shelter Plus Care, and HOME programs are typically targeted to specific sub-populations and are available in very limited numbers.

### *Challenges to Obtaining Housing*

It is clear that people with disabilities face a number of barriers to finding and obtaining housing. The lack of affordable housing is a significant barrier for low-income people with disabilities. Further, there is generally no central source of information on housing options for people with disabilities. In particular, people with mental disabilities reportedly have very few housing options. Managers frequently say they are wary of housing this population, because of potentially prejudicial concerns the prospective tenant will not take his or her medication as prescribed, will not be able to manage household finances and take care of the apartment, and may be disruptive or bothersome to other tenants. Some managers seem to have developed these attitudes based on their own direct experiences managing properties with both non-elderly residents with disabilities and elderly residents. Others seem to have made judgements that are not based on personal experience, but rather on second-hand information about other managers' experiences, or, perhaps, on prejudice rooted in stereotypes about people with disabilities.

HUD-assisted property managers do not view assisting tenants with daily living skills to be part of management's job. As one local respondent put it, managers are trained to manage the asset, not the people. Assumptions about such needs for assistance, as well as attitudes based on bias or prejudice, may lead managers to deter non-elderly people with disabilities from applying for or moving into HUD-assisted housing. Some of these practices violate fair housing laws that prohibit discrimination against people with disabilities.<sup>8</sup>

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<sup>7</sup> The Housing and Community Development Act of 1992 also had provisions allowing public housing agencies to restrict occupancy in elderly public housing to elderly households.

<sup>8</sup> Title VIII of the Civil Rights Act of 1968, as amended by the Fair Housing Amendments Act of 1998; see also Section 504 of the Rehabilitation Act of 1973.

## **2.2 Findings Regarding the Demand for Housing for Non-elderly People with Disabilities**

In all of the ten study sites, local respondents said demand for affordable housing among non-elderly people with disabilities outpaces supply. Evidence cited includes tightening housing markets and increasing rents, long waiting lists for Section 8 assistance and assisted housing, anecdotes of lengthy and fruitless housing searches, and reports of discriminatory treatment.

Research conducted in 1998 highlighted the housing affordability crisis for people with disabilities who rely on SSI as their primary income source. In every county and metropolitan area in the country, a person whose income is limited to SSI must pay more than 30 percent of monthly income to rent a one-bedroom apartment at HUD's Fair Market Rent. The national average is 69 percent, considerably higher than the 50 percent of income for rent considered to represent a severe rent burden.<sup>9</sup>

However, estimating the demand for affordable housing among people with disabilities was the most significant challenge in carrying out this research. People with disabilities are not a monolithic group. The population includes persons with all types of disabilities, a wide range of levels of severity, and a variety of housing preferences and needs. Given the diverse housing needs of people with various types of disabilities, accurately assessing demand for HUD-assisted housing (or, for affordable housing in general) requires reliable data on the number of people with various types of disabilities in the study areas. Such data were not available.

No respondents were able to provide us with precise estimates of need or demand among people with disabilities for HUD-assisted housing—that is, those who are single or part of a small household, are under age 62, have a disability, are able to comply with lease requirements, and are interested in living in a HUD-assisted apartment. Metropolitan area-level data are available on the number of non-elderly people with disabilities, and on the number of people receiving SSI benefits, but these are imperfect proxies for the number of people who would be interested in and eligible for HUD-assisted housing and capable of living in these properties.

## **3. Conclusions and Recommendations for Further Research**

Our findings on the influence of the provisions of the Housing and Community Development Act of 1992 are consistent with the GAO's findings in its 1998 study. Relatively few owners

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<sup>9</sup> *Priced Out in 1998: The Housing Crisis for People with Disabilities*, Technical Assistance Collaborative and Consortium for Citizens with Disabilities Housing Task Force, March 1999.

reported changes in occupancy policies.<sup>10</sup> However, the primary lesson from this exploratory research is that, in general, marketing and management practices appear to have more influence on tenant mix than the occupancy policy, even though policy changes do make a difference when they occur. More importantly, this research indicates that even when non-elderly people with disabilities may be eligible for HUD-assisted housing, they may only be eligible for the less desirable properties. Access was somewhat limited before the 1992 legislation and may be more limited now (because of generally tighter housing markets), but the statute makes relatively little difference in managers' decisions.

Managers do report illegal discriminatory practices that could discourage people with disabilities from applying for HUD-assisted housing, even though the potential applicant is eligible under the property's occupancy policy. Fair housing testing to determine how potential applicants are treated by managers would identify those who are inappropriately limiting access to housing for people with disabilities.

Local respondents in all ten sites noted that the shortage of affordable housing is a barrier facing all low-income renters, regardless of disability status. Local respondents also indicate the need for additional resources for case management and other supportive services to aid non-elderly people with disabilities in private market housing (as well as in public housing). In addition, better communication between advocates and service providers and assisted housing providers would improve the connection between housing supply and demand. Local clearinghouses with information such as property locations, occupancy policies, and availability of wheelchair-accessible units would be extremely valuable and would improve the functioning of these markets.

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<sup>10</sup> It is important to note that the properties included in this study are a purposive rather than a random sample of HUD-assisted properties built primarily for the elderly. These findings may not be representative of the incidence of election of elderly preferences in the stock over-all.



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MDS Quality

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Report

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Assessment Counts Report

MDS Q1a Report

MDS RUGs Report

MDS RUGs by Assessment Report

**MDS Active Resident Information Report**

**MDS Active Resident Information Report: Second Quarter 2008**

**Q1a: Discharge Potential and Overall Status**

Resident Expresses/Indicates Preference to Return to the Community

To view a description of the report table contents, [click here](#)

State	No	Yes	State Total
Alabama	82.8%	17.2%	22,712
Alaska	67.4%	32.6%	598
Arizona	67.4%	32.6%	11,557
Arkansas	80.3%	19.7%	18,223
California	74.5%	25.5%	99,512
Colorado	76.5%	23.5%	15,671
Connecticut	77.3%	22.7%	26,130
Delaware	79.0%	21.0%	4,037

District of Columbia	82.0%	18.0%	2,401
Florida	73.2%	26.8%	68,886
Georgia	82.4%	17.6%	34,449
Hawaii	80.6%	19.4%	3,773
Idaho	73.2%	26.8%	4,337
Illinois	74.8%	25.2%	74,345
Indiana	79.4%	20.6%	38,799
Iowa	80.1%	19.9%	25,402
Kansas	80.8%	19.2%	18,549
Kentucky	80.4%	19.6%	22,649
Louisiana	85.3%	14.7%	25,220
Maine	78.2%	21.8%	6,126
Maryland	75.2%	24.8%	23,998
Massachusetts	78.1%	21.9%	41,653
Michigan	71.4%	28.6%	39,647
Minnesota	78.6%	21.4%	29,948
Mississippi	87.9%	12.1%	15,784
Missouri	76.2%	23.8%	37,041
Montana	75.7%	24.3%	5,013
Nebraska	78.1%	21.9%	12,511
Nevada	70.6%	29.4%	4,535
New Hampshire	80.3%	19.7%	6,653
New Jersey	79.2%	20.8%	43,861
New Mexico	72.8%	27.2%	5,802

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No. 9003 P. 3/17

New York	78.9%	21.1%	106,653
North Carolina	78.8%	21.2%	37,253
North Dakota	84.2%	15.8%	5,674
Ohio	74.1%	25.9%	76,433
Oklahoma	78.0%	22.0%	18,995
Oregon	65.2%	34.8%	7,866
Pennsylvania	79.7%	20.3%	76,100
Puerto Rico	26.5%	73.5%	185
Rhode Island	80.7%	19.3%	7,625
South Carolina	80.4%	19.6%	16,583
South Dakota	82.9%	17.1%	6,360
Tennessee	77.3%	22.7%	31,793
Texas	79.7%	20.3%	91,000
U.S. Virgin Islands	46.4%	53.6%	28
Utah	66.1%	33.9%	5,219
Vermont	73.6%	26.4%	2,882
Virginia	75.8%	24.2%	27,535
Washington	69.5%	30.5%	18,067
West Virginia	78.1%	21.9%	9,686
Wisconsin	75.1%	24.9%	31,679
Wyoming	80.2%	19.8%	2,389
<b>NATIONAL TOTAL</b>	<b>77.4%</b>	<b>22.6%</b>	<b>1,369,827</b>

Table counts exclude missing responses or responses in cells with 10 or less responses. A cell entry of "<0.05%" indicates that there were at least 11 responses

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### MDS Active Resident Information Report

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- MDS Quality Measure/Indicator Report
- MDS Quality Indicator Report
- MDS Active Resident Information Report**
- Assessment Counts Report
- MDS Q1a Report
- MDS RUGs Report
- MDS RUGs by Assessment Report

### MDS Active Resident Information Report: Second Quarter 2008

**A7a: Identification And Background Information - Current Payment Sources for M.H. Stay - Medicaid per diem**

To view a description of the report table contents, [click here](#)

State	No	Yes	State Total
Alabama	44.3%	55.7%	22,386
Alaska	30.6%	69.4%	591
Arizona	49.1%	50.9%	11,374
Arkansas	47.2%	52.8%	17,718
California	45.4%	54.6%	97,646
Colorado	51.3%	48.7%	15,623
Connecticut	44.4%	55.6%	25,862
Delaware	49.3%	50.7%	4,011



New York	40.0%	60.0%	104,835
North Carolina	48.1%	51.9%	36,853
North Dakota	55.8%	44.2%	5,635
Ohio	43.6%	56.4%	75,695
Oklahoma	47.4%	52.6%	18,266
Oregon	52.2%	47.8%	7,603
Pennsylvania	48.8%	51.2%	75,634
Puerto Rico	91.3%	8.8%	160
Rhode Island	45.7%	54.3%	7,604
South Carolina	45.9%	54.1%	16,358
South Dakota	49.5%	50.5%	6,348
Tennessee	49.5%	50.5%	31,385
Texas	51.1%	48.9%	89,711
U.S. Virgin Islands	52.4%	47.6%	21
Utah	51.3%	48.7%	5,112
Vermont	40.6%	59.4%	2,852
Virginia	49.4%	50.6%	27,445
Washington	39.1%	60.9%	17,949
West Virginia	38.9%	61.1%	9,564
Wisconsin	50.7%	49.3%	31,497
Wyoming	51.9%	48.1%	2,370
<b>NATIONAL TOTAL</b>	46.9%	53.1%	1,352,787

Table counts exclude missing responses or responses in cells with 10 or less responses. A cell entry of "<0.05%" indicates that there were at least 11 responses

United States  
S1801. Disability Characteristics  
Data Set: 2005 American Community Survey  
Survey: 2005 American Community Survey

NOTE: Data are limited to the household population and exclude the population living in institutions, college dormitories, and other group quarters. For information on confidentiality protection, sampling error, nonsampling error, and definitions, see Survey Methodology.

Subject	Total	Male	Female	Margin of Error
Population 5 years and over	267,387,983	130,301,787	137,086,196	+/-20,361
Without any disability	39,840,809	18,449,770	21,391,038	+/-0.1
With one type of disability	18,449,770	9,391,038	9,058,732	+/-0.1
With two or more types of disabilities	2,598,404	1,317,032	1,281,372	+/-0.1
Population 5 to 15 years	44,588,147	22,810,520	21,777,627	+/-23,066
With any disability	4,588,147	2,291,211	2,296,936	+/-0.1
With a sensory disability	1.2%	1.3%	1.1%	+/-0.1
With a physical disability	1.2%	1.3%	1.1%	+/-0.1
With a mental disability	5.2%	6.8%	3.6%	+/-0.1
With a self-care disability	0.9%	1.1%	0.7%	+/-0.1
Population 16 to 64 years	188,041,309	92,647,138	95,394,171	+/-25,786
With any disability	12.1%	12.0%	12.2%	+/-0.1
With a sensory disability	2.8%	3.3%	2.4%	+/-0.1
With a physical disability	7.2%	6.7%	7.7%	+/-0.1
With a mental disability	4.5%	4.5%	4.5%	+/-0.1
With a self-care disability	2.0%	1.8%	2.2%	+/-0.1
With a go-outside-home disability	3.0%	2.6%	3.4%	+/-0.1
With an employment disability	6.8%	6.6%	7.1%	+/-0.1
Population 65 years and over	34,760,527	14,844,129	19,916,398	+/-10,859
With any disability	40.6%	38.2%	42.1%	+/-0.2
With a sensory disability	16.4%	18.2%	15.1%	+/-0.1
With a physical disability	30.8%	27.4%	33.3%	+/-0.1
With a mental disability	11.5%	10.6%	12.1%	+/-0.1
With a self-care disability	9.7%	7.8%	11.0%	+/-0.1
With a go-outside-home disability	16.6%	12.0%	20.0%	+/-0.1
SCHOOL ENROLLMENT				
Population 18 to 24 years	64,647,330	32,333,573	32,313,753	+/-20,400
With any disability	4,505,696	2,353,977	2,151,719	+/-23,508
Enrolled in college or graduate school	13.9%	12.8%	15.2%	+/-0.5
Not enrolled and without a bachelor's degree or higher	73.2%	74.4%	71.9%	+/-0.6
With a sensory disability	997,637	568,055	429,572	+/-12,169
Enrolled in college or graduate school	14.0%	13.4%	14.9%	+/-1.0
Not enrolled and without a bachelor's degree or higher	72.4%	73.8%	70.6%	+/-1.3
With a physical disability	1,720,223	829,908	890,315	+/-18,206
Enrolled in college or graduate school	11.7%	10.5%	12.8%	+/-0.6
Not enrolled and without a bachelor's degree or higher	77.6%	78.8%	76.5%	+/-0.9
With a mental disability	2,227,927	1,217,382	1,010,545	+/-17,162
Enrolled in college or graduate school	13.4%	12.0%	15.1%	+/-0.7
Not enrolled and without a bachelor's degree or higher	72.7%	73.5%	71.8%	+/-0.9

seven years - 19,600  
16+ yrs = 43,669,156  
Self-care disability = 11,712  
26,067,812

Subject	Total	Margin of Error	Male	Female	Margin of Error
No disability	60,141,634	+/-48,867	28,979,600	30,162,034	+/-28,661
Enrolled in college or graduate school	21.8%	+/-0.1	19.5%	24.0%	+/-0.1
Not enrolled and without a bachelor's degree or higher	56.0%	+/-0.2	59.8%	52.2%	+/-0.2


EMPLOYMENT STATUS					
Population 16 to 64 years	188,041,309	+/-35,238	82,647,138	95,394,171	+/-26,786
With any disability	22,790,299	+/-89,803	11,130,352	11,659,947	+/-55,925
Employed	37.5%	+/-0.2	41.1%	34.2%	+/-0.2
With a sensory disability	5,310,142	+/-42,618	3,054,203	2,255,939	+/-26,444
Employed	47.2%	+/-0.4	62.0%	40.7%	+/-0.6
With a physical disability	13,506,366	+/-71,024	6,236,494	7,369,862	+/-46,424
Employed	31.8%	+/-0.2	33.4%	30.5%	+/-0.3
With a mental disability	8,398,104	+/-48,509	4,135,685	4,262,419	+/-30,656
Employed	28.7%	+/-0.3	31.1%	26.3%	+/-0.3
No disability	165,251,010	+/-89,170	81,516,786	83,734,224	+/-62,626
Employed	74.4%	+/-0.1	80.8%	68.2%	+/-0.1

POVERTY STATUS					
Population 5 years and over	266,688,142	+/-26,189	129,890,020	136,698,122	+/-24,159
With any disability	39,846,722	+/-114,103	18,585,861	21,060,861	+/-70,597
Below poverty level	21.1%	+/-0.1	18.6%	23.3%	+/-0.2
With a sensory disability	11,561,860	+/-59,905	6,044,331	5,507,529	+/-37,641
Below poverty level	18.7%	+/-0.2	15.3%	22.5%	+/-0.3
With a physical disability	24,821,998	+/-87,569	10,591,116	14,230,882	+/-54,150
Below poverty level	51.8%	+/-0.2	18.6%	22.7%	+/-0.2
With a mental disability	14,638,611	+/-71,777	7,206,720	7,431,891	+/-43,144
Below poverty level	26.4%	+/-0.3	23.8%	29.0%	+/-0.3
No disability	226,941,420	+/-112,977	111,304,159	115,637,261	+/-71,873
Below poverty level	11.3%	+/-0.1	9.8%	12.7%	+/-0.1

PERCENT IMPUTED					
With any disability	4.3%	(X)	(X)	(X)	(X)
With a sensory disability	2.5%	(X)	(X)	(X)	(X)
With a physical disability	3.1%	(X)	(X)	(X)	(X)
With a mental disability	2.1%	(X)	(X)	(X)	(X)
With a self-care disability	2.2%	(X)	(X)	(X)	(X)
With a go-outside-home disability	2.1%	(X)	(X)	(X)	(X)
With an employment disability	2.2%	(X)	(X)	(X)	(X)

Data are based on a sample and are subject to sampling variability. The degree of uncertainty for an estimate arising from sampling variability is represented through the use of a margin of error. The value shown here is the 90 percent margin of error. The margin of error can be interpreted roughly as providing a 90 percent probability that the interval defined by the estimate minus the margin of error and the estimate plus the margin of error (the lower and upper confidence bounds) contains the true value. In addition to sampling variability, the ACS estimates are subject to nonsampling error (for a discussion of nonsampling variability, see Accuracy of the Data). The effect of nonsampling error is not represented in these tables.

- Explanation of Symbols:
1. An "X" entry in the margin of error column indicates that too few sample observations were available to compute a standard error and thus the margin of error. A statistical test is not appropriate.
  2. An "X" entry in the margin of error column indicates that no sample observations were available to compute a standard error and thus the margin of error. A statistical test is not appropriate.
  3. An "X" entry in the estimate column indicates that no sample observations were available to compute an estimate, or a ratio of medians cannot be calculated because one or both of the median estimates falls in the lowest interval or upper interval of an open-ended distribution.
  4. An "+" following a median estimate means the median falls in the upper interval of an open-ended distribution.
  5. An "-" following a median estimate means the median falls in the lower interval of an open-ended distribution.
  6. An "X" entry in the margin of error column indicates that the median falls in the lowest interval or upper interval of an open-ended distribution. A statistical test is not appropriate.
  7. An "X" entry in the margin of error column indicates that the estimate is controlled. A statistical test for sampling variability is not appropriate.
  8. An "N" entry in the estimate and margin of error columns indicates that data for this geographic area cannot be displayed because the number of sample cases is too small.
  9. An "(X)" means that the estimate is not applicable or not available.

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Proposed draft 33  
→ "walking, climbing stairs, reaching, grasping, etc."

The 2003 questionnaire introduced a new skip instruction between questionnaire items 16 and 17. In 1999-2002, questionnaire item 17a was part of question 16. For the 1996-1998 American Community Survey, the data on going-outside-home limitations were derived from answers to questionnaire item 16a, which was asked of persons 16 years old and over. The questionnaire item was slightly different from the 1999-2002 item and asked the respondents if they had a long-lasting physical or mental condition that made it difficult to "go outside the

For the 2003-2004 American Community Survey, the data on mobility limitations were derived from answers to questionnaire item 17a. Although item 17a was asked of people 15 years and over, the data products only report this type of disability for people 16 years and over. The questionnaire item asked respondents if they had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to "go outside the home alone to shop or visit a doctor's office." Respondents were instructed to mark "yes" or "no." Questionnaire item 17a is labeled as "Go-outside-home Disability" for some disability products such as the ACS Detailed Tables.

### Going-Outside-Home Limitations

Comparison - The 1999-2004 American Community Survey question is essentially the same as the Census 2000 question. It is also similar to the 1990 decennial census. However, due to differences in the wording and layout of this question, direct cross-decennial comparison is discouraged. This question was not asked on the 1996-1998 American Community Survey.

For the 1999-2004 American Community Survey, the data on self-care limitations were derived from answers to questionnaire item 16b, which was asked of people 5 years and over. The questionnaire item asked respondents if they had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to "dress, bathe, or get around inside the home." Respondents were instructed to mark "yes" or "no." Questionnaire item 16b is labeled as "Self-Care Disability" for some disability data products such as the ACS Detailed Tables.

### Self-Care Limitations

Comparison - The 1999-2004 American Community Survey item on cognitive functioning limitations was intended to be comparable to the Census 2000 item labeled "Mental Disability" in Summary File 3 and other data products. No comparable data were obtained in the 1990 decennial census or the 1996-1998 American Community Survey.

For the 1999-2004 American Community Survey, the data on cognitive functioning were derived from answers to questionnaire item 16a, which was asked of people 5 years old and over. The questionnaire item asked respondents if they had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to "learn, remember, or concentrate." Respondents were instructed to mark "yes" or "no." Questionnaire item 16a is labeled as "Mental Disability" for some disability data products such as the ACS Detailed Tables.

### Limitations in Cognitive Functioning ("Mental Disability")

The 1999-2002 American Community Survey question was essentially the same as the Census 2000 question. However, it was quite different from the 1990 decennial census item in the 1990 census, respondents were asked if they were "limited in the kind or amount of work" they could do. People who responded "yes" were asked if they were prevented from working. Therefore, direct cross-decennial comparison is strongly discouraged.

*Comparability* - The Census Bureau does not recommend trend analysis using the 2003 or 2004 data with years prior to 2003 due to the 2003 questionnaire change. For more information regarding the 2003 questionnaire change, view "Disability Data From the American Community Survey: A Brief Examination of the Effects of a Question Redesign in 2003" ([http://www.census.gov/hhes/www/disability/ACS\\_disability.pdf](http://www.census.gov/hhes/www/disability/ACS_disability.pdf)).

For the 1996-1998 American Community Survey, the data on employment limitations were derived from answers to questionnaire Item 16b, which was asked of persons 16 years old and over. The questionnaire item was slightly different from the 1999-2003 item and asked the respondents if they had a long-lasting physical or mental condition that "prevents this person from working at a job or business." Respondents were instructed to mark "yes" or "no."

The 2003 questionnaire introduced a new skip instruction between questionnaire Items 16 and 17. In 1999-2002, questionnaire Item 17b was part of question 16.

For the 2003-2004 American Community Survey, the data on work limitations were derived from answers to questionnaire Item 17b. Although Item 17b was asked of people 15 years and over, the data products only report this type of disability for people 16 years and over. The questionnaire item asked the respondents if they had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to "work at a job or a business." Respondents were instructed to mark "yes" or "no." Questionnaire Item 17b is labeled as "Employment Disability" for some disability data products such as the ACS Detailed Tables.

**Employment Limitations**

The 1999-2002 American Community Survey question was essentially the same as the Census 2000 question. It was also similar to the 1990 decennial census. However, due to differences in the wording and layout of this question, direct cross-decennial comparison is discouraged.

*Comparability* - The Census Bureau does not recommend trend analysis using the 2003 or 2004 data with years prior to 2003 due to the 2003 questionnaire change. For more information regarding the 2003 questionnaire change, view "Disability Data From the American Community Survey: A Brief Examination of the Effects of a Question Redesign in 2003" ([http://www.census.gov/hhes/www/disability/ACS\\_disability.pdf](http://www.census.gov/hhes/www/disability/ACS_disability.pdf)).

home alone to shop or visit a doctor's office." Respondents were instructed to mark "yes" or "no."

# SOCDS CHAS Data: Housing Problems Output for All Households

Name of Jurisdiction: Texas

Source of Data: CHAS Data Book

Data Current as of: 2000

Household by Type, Income, & Housing Problem	Renters					Owners					
	(A) Elderly (1 & 2 members)	(B) Small Related (2 to 4 members)	(C) Large Related (5 or more members)	(D) All Other	(E) Total Renters	(F) Elderly (1 & 2 members)	(G) Small Related (2 to 4 members)	(H) Large Related (5 or more members)	(I) All Other	(J) Total Owners	(K) Total Households
1. Household Income <= 50% MFI	158,225	385,705	137,255	309,420	990,605	323,505	234,070	112,690	100,495	770,760	1,761,365
2. Household Income <= 30% MFI	96,125	204,810	69,690	182,505	553,130	153,445	103,275	44,570	59,440	360,730	913,860
3. % with any housing problems	62.0	79.2	91.8	72.8	75.7	66.4	74.5	88.7	66.5	71.5	74.0
4. % Cost Burden > 30%	60.4	72.8	72.8	71.3	70.2	65.4	70.5	68.3	64.3	67.0	68.9
5. % Cost Burden > 50%	42.6	56.6	48.2	63.3	55.3	40.0	55.4	49.0	51.5	47.4	52.2
6. Household Income > 30 to <= 50% MFI	62,100	180,895	67,565	126,915	437,475	170,060	130,795	68,120	41,055	410,030	847,505
7. % with any housing problems	59.9	73.8	86.3	80.3	75.6	37.5	61.0	79.4	59.8	54.2	65.3
8. % Cost Burden > 30%	58.3	62.9	42.2	78.4	63.6	36.6	55.7	47.4	57.7	46.6	55.3
9. % Cost Burden > 50%	24.7	13.9	6.1	26.2	17.8	14.8	27.6	15.3	33.1	20.8	19.3
10. Household Income > 50 to	48,310	250,730	82,180	210,785	592,005	212,499	282,920	133,055	80,635	709,109	1,301,114

*11/11/00*  
*Self*  
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*audit*

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**Any housing problems:** cost burden greater than 30% of income and/or overcrowding and/or without complete kitchen or plumbing facilities.

**Other housing problems:** overcrowding (1.01 or more persons per room) and/or without complete kitchen or plumbing facilities.

**Elderly households:** 1 or 2 person household, either person 62 years old or older.

**Renter:** Data do not include renters living on boats, RVs or vans. This excludes approximately 25,000 households nationwide.

**Cost Burden:** Cost burden is the fraction of a household's total gross income spent on housing costs. For renters, housing costs include rent paid by the tenant plus utilities. For owners, housing costs include mortgage payment, taxes, insurance, and utilities.

**Source:** Tables F5A, F5B, F5C, F5D

# SOCDS CHAS Data: Housing Problems Output for Mobility & Self Care Limitation

Household by Type, Income, & Housing Problem	Name of Jurisdiction:		Source of Data:		Data Current as of:					
	Texas		CHAS Data Book		2000					
	Renters			Owners						
	Extra Elderly 1 & 2 Member Households	Elderly 1 & 2 Member Households	All Other Households	Total Renters	Extra Elderly 1 & 2 Member Households	Elderly 1 & 2 Member Households	All Other Households	Total Owners	Total Households	
	(A)	(B)	(C)	(D)	(E)	(F)	(G)	(H)	(I)	
1. Household Income <=50% MFI	44,765	36,475	130,695	211,935	82,395	60,585	112,355	255,335	467,270	
2. Household Income <=30% MFI	26,495	23,475	81,525	131,495	39,590	29,390	55,875	124,855	256,350	
% with any housing problems	58.6	62.4	75.9	70.0	62.8	69.4	75.5	70.1	70.0	
3. Household Income >30 to <=50% MFI	18,270	13,000	49,170	80,440	42,805	31,195	56,480	130,480	210,920	
% with any housing problems	57.7	55.0	73.1	66.7	33.0	39.7	58.2	45.5	53.6	
4. Household Income >50 to <=80% MFI	11,920	8,625	54,725	75,270	44,205	36,695	93,165	174,065	249,335	
% with any housing problems	50.9	33.1	45.1	44.7	15.4	22.0	42.2	31.1	35.2	
5. Household Income >80% MFI	14,520	10,255	79,125	103,900	79,720	86,595	302,525	468,840	572,740	
% with any housing problems	33.5	9.1	20.9	21.5	4.4	7.4	15.3	12.0	13.7	
6. Total Households	71,205	55,355	264,545	391,105	206,320	183,875	508,045	898,240	1,289,345	
% with any housing problems	52.0	46.2	52.6	51.6	23.9	25.7	31.6	28.6	35.6	

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## Definitions for Mobility & Self-Care Table:

Extra Elderly: 1 or 2 Member households, either person 75 years or older

Elderly: 1 or 2 Member Households, either person 62 to 74 years

**Mobility or Self Care Limitations:** This includes all households where one or more persons has 1) a long-lasting condition that substantially limits one or more basic physical activity, such as walking, climbing stairs, reaching, lifting, or carrying and/or 2) a physical, mental, or emotional condition lasting more than 6 months that creates difficulty with dressing, bathing, or getting around inside the home.

**Source:** Tables A7A, A7B, A7C



**Testimony of Stephanie Thomas, National ADAPT**

**Submitted to the Energy and Commerce Committee Subcommittee on Health**

**January 16, 2008**

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Good Morning. I am Stephanie Thomas, a National Organizer for the grassroots disability rights organization ADAPT. I appreciate the opportunity to speak to you today.

Over 17 years ago the Americans with Disabilities Act was signed into law. The disability community celebrated, but as we celebrated we realized that there were members of our community who were being left behind. Stuck in nursing homes and other institutions, they had neither liberty nor pursuit of happiness; they were virtual prisoners of a system that basically uses them as a cash crop to draw down dollars for others to enjoy. Many of the members of the group I represent, ADAPT, have themselves been trapped in nursing homes and other institutions and had to fight their way out to live in the community. Many of the rest of us see this bleak picture as our future, a future that haunts us every day.

We have listened to our friends who have lived through being institutionalized against their will. They told us of living in an 8' by 8' room with another person – not of their choosing, being told when to get up, when to go to bed, what and when to eat. We have gone to visit them and been told they can not leave the building, that we cannot go to see them because we raise up their hopes. We have heard them explain how “your life is not your own.” We have heard them say “I would rather die than go back.” I have never in my life heard someone say, “I am looking forward to moving into a nursing home.” We know of children born with disabilities who have been forced away from their families into institutional placements because this was the only “support” option available to their families; children belong in families, not in institutions. Being institutionalized by one’s

own choice is one thing, being trapped there because you have no alternatives is something very different.

According to CMS' own numbers, nationally over 300,000 people, in nursing homes alone, have expressed a preference for home and community services, yet they are stuck inside – unable to connect with any community options that might exist. 8,787 are from NJ, 5,762 from GA.<sup>1</sup> This does not even count those trapped in other kinds of institutions, and those in the community scraping by as they wait year after year to move up a waiting list. What I want to talk to you about today is a way to give those people choices, and help the states and Federal government at the same time. Why do we invest so much to keep people locked away?

In 2005 ADAPT held a hearing in Nashville Tennessee and invited people who had previously been institutionalized to come and testify. People flocked from across the nation to give testimony, and the hearing lasted over six hours. You have all been given a DVD which summarizes what was said.<sup>2</sup>

People continue to have to move out of state - away from family and friends - to be free. They fight brain washing and intimidation. They believe in themselves beyond what all around them believe, in spite of the doubt and oppression from the current service system. And these are the lucky ones. Those who got out did not “get better” from their

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<sup>1</sup> See appendix for complete list. Or go to [www.cms.hhs.gov/MDSPubQIandResRep/](http://www.cms.hhs.gov/MDSPubQIandResRep/)

<sup>2</sup> See the ADAPT website [www.adapt.org](http://www.adapt.org) for a transcript of the entire hearing, or contact me at [adapt@adapt.org](mailto:adapt@adapt.org). Excerpts of the testimony are attached to my written testimony.

disabilities, they simply got out – and now live in the community with attendant services and supports,

But I am not here to talk about how awful nursing homes or other institutions are. I am here to urge you to take action to give people a real choice in long term care, to pass Representative Danny Davis and John Shimkus' bill HR 1621 The Community Choice Act, CCA, and to squarely address the institutional bias in Medicaid long term care.

Medicaid has helped millions of people with disabilities of all ages; it has saved people from alms houses and even death. It has played a vital role in assisting people to achieve independence, dignity and health. But it has done this with its hands tied behind its back. The glaring problem of institutional bias grows more pronounced every day as the awareness and values of our nation change, as the medical and scientific breakthroughs promise more independence and autonomy for children, adults and seniors with significant disabilities – yet Medicaid stays so wed to the institutional mode. Even Money Follows the Person, an important new demonstration program funded in the DRA, requires that the person must be in an institution to get out and receive services.

Our current system is backwards. The institutional bias has led to a system wherein the institutional service is mandated, and the community is optional; where 67% of the Medicaid long term care funds go to the institutions and just 33% are left for community services, despite the fact that there are long waiting lists – sometimes as long as 10 years – for community services. Ironically, these same community services cost only about 2/3

of their institutional equivalent. We could be serving 3 people for every 2 we are serving now, and doing it more humanely.

Services are fragmented, based on disease categories and age, instead of on functional need. If you have a traumatic brain injury at the age of 18 you may be eligible for extensive support services, but if you have that same injury six years later you are out of luck. If you have a spinal cord injury, a boutique program may cover your needs, but if you have Multiple Sclerosis and need the exact same tasks done your only option may be Villa Siesta Nursing Facility. It makes absolutely no sense, unless you are into Byzantine policy history, and even then ...

We hear about fear of the “woodwork effect,” an insulting term that actually refers to unmet need of real live human beings. We are not cockroaches and this is not pest control. Let’s look at the reality of this issue: People eligible for the Community Choice Act are people who are currently meeting the income and medical necessity requirements of nursing home or other institutional services. They are people with significant disabilities. Without any services they will eventually endanger their health and wind up using much more costly medical services: going without eating, staying in one position for too long, or consistently urinating or defecating on yourself leads to serious problems like malnutrition, bedsores, and worse. Getting by with no support services is not an option. Forcing people to get by on nothing is not good policy and does not solve the money issue in the long run.

Many states would like to even the playing field, but when the Federal Government says you **must** fund nursing homes -- and **if you want you can** fund these other community services, States are going to be darn sure the finite dollars they get go to covering the mandated programs first -- and community waiting lists will grow.

We even believe the Community Choice Act would help to improve the services in nursing homes and other institutions because it would give them real competition. If people knew they could go somewhere else, like their own home, nursing homes and other institutions would have to provide an option people would freely choose.

Over 700 national state and local organizations have signed on supporting the Community Choice Act, from the American Medical Association to the National Council on Independent Living; from the United States Conference of Catholic Bishops, and Service Employees International Union to the NAACP and NOW; from the Oglala Sioux Nation to the Christopher and Dana Reeve Foundation and Not Dead Yet. I could go on and on, but the list is included with my written testimony.

#### WHAT THE COMMUNITY CHOICE ACT, HR 1621, DOES

This bill is based on a very simple concept. By reforming Title XIX of the Social Security Act (Medicaid) it takes a huge step toward ending the institutional bias. It makes an existing mandated service more flexible, to meet the needs of those who are currently eligible for its services. The Community Choice Act allows individuals eligible

for services in a Nursing Facility, Intermediate Care Facility for the Mentally Retarded (ICF-MR), or Institutions for Mental Disease (IMD) the opportunity to *choose* instead a new alternative, "Community-based Attendant Services and Supports." It doesn't force anyone to move out, as some have claimed. It simply gives people a choice.

In addition, by providing an enhanced match and grants before October 2011 when the benefit becomes permanent, the Community Choice Act offers states financial assistance to reform their long term service and support system to provide services in the most integrated setting. This is already beginning to happen but in an ad-hoc, piecemeal basis, and often people must be in institutions in order to choose community services.

Specifically what does this bill do?

It provides community-based attendant services and supports that include 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, phoning, participating in the community),
- \* and health-related functions.

CCA includes hands-on assistance, supervision and/or cueing (like reminding someone), as well as help to learn, keep and enhance skills to accomplish such activities.

It requires services be provided in the most integrated setting appropriate to the needs of the individual.

CCA provides Community-based Attendant Services and Supports that are:

- \* based on functional need, rather than diagnosis or age;
  - \* provided in home or community settings like -- 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;
- and that include *voluntary* training on selecting, managing and dismissing attendants.

This bill allows consumers to choose among various service delivery models including vouchers, direct cash payments, fiscal agents and agency providers. All models are required to be consumer controlled and comply with federal and state labor laws.

For consumers who are not able to direct their own care independently, the Community Choice Act allows for an individual's representative to be authorized by the consumer to assist. A representative might be a friend, family member, guardian, or advocate.

It allows health-related functions or tasks to be assigned to, delegated to, or performed by unlicensed personal attendants, according to state laws.

It covers individuals' transition costs from a nursing facility, ICF-MR or IMD to a home setting, for example: rent and utility deposits, bedding, basic kitchen supplies and other necessities required for the transition.

CCA serves individuals with incomes above the current institutional income limitation -- *if a state chooses* to waive this limitation to enhance employment potential.

In addition, CCA provides for quality assurance programs which promote consumer control and satisfaction.

The bill also provides a maintenance of effort requirement so that states can not diminish more enriched programs already being provided.

CCA allows enhanced match (up to 90% Federal funding) for individuals whose costs exceed 150% of average nursing home costs. This protects against discrimination based on severity of disability, so people with more significant disabilities who require more services can still receive services on the community.

For the first five years (2007 through 2011) after which the services become permanent, CCA provides enhanced matches (10% more federal funds each) 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.

And, in the area of systems change:

CCA provides grants for Systems Change Initiatives to help the states transition from their current institutionally dominated service systems to ones more focused on community based services and supports, guided by a Consumer Task Force.

It also calls for national 5 -10 year demonstration project, in 5 states, to enhance coordination of services for individuals dually eligible for Medicaid AND Medicare.

## CONCLUSION

Ten years ago I and hundreds of other members of the disability community sat in the audience of this committee for a similar bill called MiCASSA. Mike Auberger and Justin Dart Jr. among others, testified to this Committee [several of you were here at that time too] about the urgent need to end the institutional bias in our long term care system. At that time the Congressional Budget Office gave the bill a fiscal note that included costs for people who are actually not eligible for the bill and services that are not included in this bill. Since then, the University of California at San Francisco has done a statistically valid and peer reviewed re-calculation of the cost and found it would be \$1.4 to \$3.7 billion dollars, a fraction of the original, erroneous CBO scoring.

In those past 10 years there has been a rising frustration as Congress refuses to act on this critical issue,

For the women on this committee, and the women who staff this committee and it's members -- take heed. The vast majority of people in nursing homes are women over the age of 65, the vast majority of the underpaid direct care workers are women, and the vast majority of women who are providing long term care to family and friends for "free" are women. Is this issue swept so completely under the rug because of this? Who can say? What we can say is that most of you, men and women alike, will have to face this issue in the near future from one of these angles -- a recipient of personal care services, a family provider, or through paid service provision.

I faced it when my father-in-law came to live with my husband and me. A diabetic who had a stroke, he stubbed his toe and soon had to have first that leg amputated and then the other. His eyesight was going and so was his memory of things like whether he left the stove on. It would have been so simple for him to go to a nursing home; "professionals" of various ilks urged us to do it again and again! Despite the fact that my husband and I both have disabilities, we were able to keep him out of a nursing home, and living with us -- with the help of attendant services. Today however, he would be on the bottom of an over 40,000-person waiting list and it is doubtful he would have reached the top before he passed away. I will face this again as my quadriplegic husband comes to need even a little more assistance, as my parents get older and -- hopefully last but not least, as I too age and need more assistance.

America is aging, and as America grays this issue looms larger and larger. It is not a question of *if* we will be dealing with long term care, it is a question of *how* we will be dealing with it. We must pull our heads out of the sand and face the issue. Like most monsters under the bed, once we confront this we will find it is not what we feared.

Long term care insurance may help some people, but for people who are eligible for the CCA, in other words eligible for Medicaid nursing home and other institutional services, it is not an option. They can not afford it, and frankly the community options such insurance offers are often woefully short of the need – despite the fact that they often offer much more expansive and expensive institutional services as a “benefit.”

Vouchering the services for everyone is not the solution either. As my friend Doris put it “I don’t want to have to become a small business, doing taxes, recruiting workers and all that, just to be able to get out of bed and take a bath!” Unlike many who would be eligible for services, Doris does not have any kind of cognitive disabilities which would make such a solution even more complex. And it is a lot easier to cut dollars for vouchers than to slash services for individuals. When Senior and disability advocates have sought vouchers, it has been as part of the system, not the entire system. We do not support block grants; we support choice.

Passage of the Community Choice Act would put these service choices in the hands of the individuals who are affected, not in the hands of a Federal Bureaucracy which has

ratcheted down on spending for Medicaid long term care, despite the growing need. We are facing a terrible example of this ratcheting down right now: Even as CMS is encouraging states to assist people who want out of nursing homes or other institutions to move out (a good thing!), it has bizarrely decided to cut Case Management Services by almost 70%. This assistance is vital for people who have lost everything once they have been institutionalized, who need help getting everything they need to move out -- from a social security card to an apartment. This devastating cut shows the lack of understanding of the reality of people's lives -- the distortion in priorities and understanding of what long term care is all about. You need to reverse this terrible decision on Case Management and reverse the overall institutional bias in Medicaid. Passing the Community Choice Act is an important piece in this overall effort.

Thank you for the opportunity to speak today. I would be happy to answer any questions.

## APPENDIX ONE

### CMS MDS Active Resident Information Report: Third Quarter 2007 Q1a: Discharge Potential and Overall Status

#### Resident Expresses/Indicates Preference to Return to the Community

Responding Yes to the above question from States represented on the Energy and Commerce Subcommittee on Health:

Arizona	3,683	people who want out
Arkansas	3,429	
California	24,772	
Colorado	3,611	
Georgia	5,762	
Illinois	18,319	
Indiana	7,800	
Maine	1,445	
Michigan	10,878	
New Jersey	8,787	
New York	22,584	
North Carolina	7,512	
Oklahoma	3,871	
Oregon	2,600	
Pennsylvania	15,003	
Tennessee	6,956	
Texas	18,403	
Wisconsin	7,448	
Wyoming	505	

National Total 302,637

## APPENDIX 2

**The following are excerpted quotes from the testimony in Nashville. Over six hours of testimony was given on that day. The entire transcript of the testimony is available on the ADAPT website [www.adapt.org](http://www.adapt.org) Look for Nashville Testimony.**

Samuel Mitchell >> I was an ordained minister and also a truck driver who became disabled. I had a ministry to nursing homes. I went in nursing homes and preached. I thought I knew a little bit about them. After becoming disabled, a year later I suffered a stroke. That's when I entered a nursing home, and I found out just how much I didn't know about nursing homes....  
The prevailing atmosphere in nursing homes is that we now own you. We own you and everything about you. You become a non-person. Your rights, human rights and civil rights are routinely violated. ... Dignity, there was no dignity. I can remember sitting using the rest room and having a CNA come in the door and start washing something out and I told her "you can't be in here." She said, "I'm going to only be a minute, don't worry, Mr. Mitchell." I would say "get out." "I'm only going to be here a minute." "Get out!" I don't know anybody that wants prying eyes on them while they're sitting on the throne in all their glory.

LATONYA REEVES >> I'm originally from Tennessee. When I was younger I was put in a nursing home that was supposed to be a Rehab center. ... The abuse I received was one day I had an accident and the aide made me wash my face in it. ...a therapist from hell, she put me in the bathtub and turned cold water on me and on my face and made me stay there for two hours and said if you don't stop screaming I'll drown you. So I let relatives know about this and I got taken home for Christmas and never brought back... I was trying to get services in Tennessee, which I couldn't, so I went on my first ADAPT Action in Baltimore and met Wade Blank at Atlantis Community and he told me about Atlantis/ADAPT and I moved there, but I've been there for going on 16 years living in my own apartment and also my job there is to free our people from nursing homes!

**Randy Alexander** "I was continually told there wasn't the services I needed to live in an apartment. I couldn't get the hours I wanted. I couldn't get simply somebody to help me transfer in and out of bed, so I had to stay there. And during that time all my decisions were basically taken away from that point in time because there wasn't the option for me to have freedom to choose what I wanted.

Steve Schaefer >> Without insurance and not qualifying otherwise for assistance she needed to live there in order to stay alive. There was no choice. ...In a short time I watched her change from a spirited courageous intellectual to a compliant forgetful and timid woman. Finally after a six-month period, required period of wait she qualified for social security disability. As a disabled adult she now qualified for medical assistance in her home.

Jamie Ziegler >> when I first went there, I found that as a resident you have no locks. You know your bedroom has no lock, your bathroom has no lock. You have no privacy whatsoever and very, very, very few people knock on the door. And then, when I very first came, I still had modesty and dignity and it bothered me people walked in all the time.

Michelle McCandless >> When my friends would leave, I found out that the nurses got back at me by giving me cold showers, putting me in bed early, because the only way I could get around is if I was in my chair. Once they put me in bed, I was stuck. I couldn't get around. That was my punishment.

I'm Renee Ford from Memphis and I'm reading Michael Taylor's statement. He desperately wanted to be here but the nursing home would not let him out. "... Here they gave me a measly \$30 every month and think didn't need more because they took care of all my needs. That's BS. For example, I can't always use their telephone so I have to have my own cell phone. If I didn't have a little extra help from somebody else I wouldn't even be able to make a simple phone call. "

Diane Scotin GA >> They kept me in a lock-up for an eight by eight and I had to use the rest room, both urine and the bowel, it had to go down a drain. I had no clothes on. It was freezing cold, sleeping on a cement floor. And, the one incident, she came in and said, are you ready to take your medication now? I said, no, I'm not going to take it. And she says, well, here is your water. You take a bath. And she threw a rag and it actually gave me third degree burns on my chest. And everybody has a -- everybody has a breaking point, and I guess at that time that was my breaking point...

**Ed Hahn -- And then my grandfather died, and even though I had come from Philadelphia to Erie by myself in a manual wheelchair -- it's a 12-hour bus ride -- they wouldn't let me ride home on a train for two hours to go to his funeral. And that was the beginning of the end.**

John Gladstone -- We have to end these nursing homes and we have to close these nursing homes. And I don't care -- they say it can't be done. I say it can. ... It won't happen over night. There will be lots of discouragement, but they can be closed. They can be shut down. They're warehouses. They're prisons. They're murderers.

*Barbara Heinz -- When they found out I wanted out, they try and brainwash you into thinking you can't do nothing for yourself, but I got out. Since I've been out I have been on a board of directors for CBFL and I... so I'm not letting nothing hold me back.*

Dawn Green from Milwaukee, Wisconsin >>The care there was awful and, I mean, I had to wait anywhere from half an hour to two hours to go to the bathroom, ... and the reason why I was discharged into the nursing home is because I couldn't wipe my butt or take care of myself in my home.... How about now? Life is great. It's nice to be home. Home is where -- home is where you should be. I have my own apartment and I'm independent with help from aides. I have help in the morning and help in the evening, so life is good.

JIMMY >> ... from Four Corners area, Farmington New Mexico... I was brutally beaten on March 12, 2001...I was ... with a closed head injury. I was hospitalized for three years on and off and after that I got released from the hospital. I didn't have no place to go and no insurance. So the next place I went to was a nursing home.... Which I can relate everybody that's been up here that these things do happen. And I complained a lot but they said,

you've got a brain injury, you don't know what you're talking about.

**Kurt Breslaw** – I spent 7 years in a nursing home. It was a corporate government center. ... Now I'm out and I'm going to stay out.

**JT TEMPLETON** >> I lived in for 30 years. In a State School [a state institution for people with mental retardation - nothing to do with education]... I got out because, because of a lawsuit! ... After I got out, I live in my own house...

**Mike Clark** >> As I look back, I can remember the only people who told me about my options of living outside the nursing home was my friend and advocate from independent living resource center. Without the option to live at home I might be dead or worse. [but] I'm alive and very well.

**Daniel Remick** >> I am 58 years old. I was institutionalized at 8 and a half. My rights were taken away from me because of my disability. My mom and dad were told that I would never be able to live on my own because I did not have physical ability to do normal activity. Which it was a lie. ... I was sexually assaulted by an aide there...

**Teresa Grove** >> I'm from Illinois. I am emotionally and mentally disabled. I've been in an institution since I was 14 years old.... I was initiated in an institution by all the girls with a broom handle. I was told by a staff person and a security guard that I was with whining and I should be quiet and grow up... [Now] I live in the community, but I live under an ongoing threat of one more admission anywhere, and I will be placed forever in a nursing home. Thank you.

**LARRY RUIZ** >> Most of the people in the youth wing also grew up in institutions and we did not realize that we were living in substandard conditions. ...We had an activities director named Wade Blank. He helped us form a residents council. Wade discovered that there were a lot of things to do for entertainment. We saw shows such as Elvis and Grateful Dead and our eyes were opened to the outside world and we began to grow restless. Wade had a vision of us being able to live on our own. He helped us realize this possibility. Once nursing home caught wind of our ideas of independence things began to get ugly. We were treated worse. We were even threatened by the administrator with a middle of the night eviction. Wade was fired and a restraining order was taken out against him. He used this time to look for an alternative for us. He found us apartments in the Las Casitas housing projects and then he came back to Heritage House the last time to break us out. It was June 1975 and the Atlantis community was born.

**Carrie Fowler** >> Shady acres is the nursing home I was in. At first everyone put on this act just like they do when people are there, when the people are there to check them out. All of you know what I'm talking about. You have been there. You know exactly what I'm talking about. Because when they are here to check the out for the month, the year, whatever, it's yes, ma'am, no, ma'am, yes, sir, no, sir. We'll do it just as fast as you want. But watch them leave and their attitude is what do you want now?

Angela Miller >> I thought about mainly getting out to be with my children. Now, after I did get out, I still have visitation with my children, but I think about it, I can't get up and run any more like I used to, but at least I can sit and be with them thanks to ADAPT.

Mike McCarty >> I was there for seven years and did a whole bunch of things there, very active, but there was like invisible bars at the doors, just like you can - you can only go so far until, like, some one sees you leaving and, oh, mike's leaving, you know, so they come out and tell you to come back...

Linda Merkle >> I'm a nursing home survivor. I was put in a nursing home after I suffered a stroke at the age of 45 because my family didn't know I could stay at home and get the same help that I was getting at the nursing home... And the nursing home -- the food was awful. Oh, it tasted terrible. There were nights when it was -- guess what you're having for dinner. Cause that's what it was; you couldn't tell what it was.

Sarah Wendell >> I have a psychiatric disability called multiple personality disorder. I was in and out of institutions for 3 years... I would find myself in restraints, in what they would call the quiet room, which was a seclusionary room where people outside the room heard quiet. But for me it was a re-traumatizing and horrific event. I very rarely saw a doctor. The nurses and psychiatric aides would not speak to me unless I first identified myself as Sarah, adding to the confusion and stigma attached to my disability.

Sarah Wendell >> I was not allowed to leave without supervision. The basic civil rights I had were gone. I was a prisoner. So, how did I get out? I started picking up on what I had to do and say to get out. At first I started small. I noticed that smokers were allowed to go outside, so I picked up smoking. I was allowed to go outside under supervision for four-ten-minute breaks a day. The fresh air I longed for became a nasty addiction I did not need, but my experiment worked.

Glen Barnhill >> Sitting in my chair, I usually do pretty good [breathing] the whole day. But when I'm laying down is when I had the majority of my respiratory trouble. And when I'm in a bed, I am totally dependent on someone to come help me. I can't get back up to seek help. I can't -- I don't have enough use of either one of my arms to help myself. Anyway, there were more times that I could count that my nurses aide or CNA ...had been in my room as many as four times on countless occasions, realize I was in respiratory distress and go back and tell the nurse. A lot of the CNA's I had, I had good relationships with and I know these people went back and told the nurses that I needed help. But yet the nurse would not come. And sometimes -- usually it was at night when I was in bed, but I could hear the med cart usually right down the hall from my door and half the time it was simply a matter of the nurse doing her med pass and she was not going to come to my room until she made it up to my room passing her meds. and I was literally laying almost flat on my back gasping for air, scared to death, not knowing if I'm going to have a stroke, die, or you know, if I did wake back up, if I was going to be a vegetable or what. My life was filled with constant fear and we got to the point that I was scared to death to get out of this wheelchair and lay down in a bed, and that's no life for anyone.

Carol Jones >> I have worked in institutions and nursing homes for over 35 years... I've had many people in the community thank me, say how happy they are to be in the community. I have never in 35 years had anyone say "gee, I wish I was in an institution."

Spitfire >> I call nursing homes death camps. You see what I am wearing? No more T-4. I am Jewish, I qualify... What they did to me? Stage 4 bedsores, rape and torture sound familiar? I don't call it oxygen stew for nothing. But I live independently now... I was rescued by a friendly visitor with an ADAPT T-shirt. I love living on my own. ... I'm a good cook. I do my own ADLs. I know when to go to sleep. I'm not going to be raped at night. I know I won't have bed sores. I have a wonderful attendant. ... Nancy Salandra said I was at death's door. Well Nancy, I block doors.

## **APPENDIX 3**

### **Community Choice Act Supporters**

#### **National**

ABLED Publications: ABLED Woman Magazine  
ADAPT  
ADA Watch  
Ad Hoc Comm on Healthcare Reform & Disab.  
American Association of People with Disabilities  
American Association on Mental Retardation  
American Geriatrics Society  
American Hospital Association  
American Medical Association  
American Rehabilitation Counseling Association  
Americans with Disabilities Vote  
Association of Health Insurance Plans - AHIP  
Assoc of Programs for Rural Independent Living - APRIL  
Association for Persons in Supported Employment, APSE  
Association for Protection of the Elderly Exec. Advoc. Adv. Brd  
Autism National Committee - AutCom  
Bazelon Center for Mental Health Law  
Brain Injury Association  
Catholic Health Association (CHA)  
Center for Self-Determination  
Center on Human Policy  
CHANCE, Center for Housing & New Comm Economics  
Christopher Reeve Paralysis Foundation  
Concrete Change  
Consortium of Developmental Disabilities Councils  
Consumer Research & Advocacy  
Democratic National Committee  
DIMENET  
Disabled People's Direct Action Network, Great Britain  
Disability News Service  
Disability Rights Action Coalition for Housing  
Disability Rights Center  
Disability Rights Ed.and Defense Fund, DREDF  
Dykes, Disability & Stuff Quarterly  
Eastlake, Derry and Associates  
Families USA  
Family Voices  
GnarlyBone News/GnarlyBone Productions  
Gerstmann Syndrome Support Network

Gray Panthers  
HalfthePlanet.com  
Independent Living Research and Utilization, ILRU  
Institute for Disability Access  
Institute on Disability Culture  
Justice for All  
Mainstream Magazine  
Mouth  
NAACP  
National Assn for Rights Protection & Advocacy  
National Assn of Area Agencies on Aging  
National Assn of DD Councils  
National Assn of the Deaf  
National Assn of Home Care  
National Assn of Protection and Advocacy Services  
National Assn of State Head Injury Admins.  
National Catholic Partnership on Disability (NCPD)  
National Catholic Office for People with Disabilities  
National Center for Latinos with Disabilities  
National Citizens Coalition for Nursing Home Reform  
National Coalition of the Chemically Injured  
National Coalition on Self-Determination  
National Council on Independent Living  
National Council on the Aging  
National Family Caregivers Assoc.  
National Home of Your Own Alliance  
National Organization for Women, NOW  
National Organization on Disability  
National Rehabilitation Association  
National Spinal Cord Injury Association  
New Mobility  
Not Dead Yet  
Oglala Sioux Tribe  
On A Roll Radio  
Paralyzed Veterans of America, PVA  
Post-Polio Health Int./Internat Ventilators Users Network  
Ragged Edge  
Research & Training Center on IL at Univ of KS  
Rural Institute, University of Montana  
SABE, Self Advocates Becoming Empowered  
Senior Support Network  
Service Employees International Union, SEIU  
Shepherd Center  
Socialist Party - USA  
Southern Disability Law Center  
TASH

The Arc  
The Bridge  
The Disabled Womyn's Educational Project  
Universal Health Care Action Network UHCAN!  
United Cerebral Palsy  
United Spinal Association  
United States Conference of Catholic Bishops (USCCB)  
US Conference of Mayors  
VSA arts  
World Association of Persons with Disabilities  
World Institute on Disabilities

## **STATE & LOCAL**

### *Alaska*

AK SILC AK State  
Alaska Division of Vocational Rehab. AK State  
Alaska Gov's Comm on Employment & Rehab of People with Disabilities AK  
State Alaska Transition Initiative AK State  
Assistive Technology of Alaska AK State  
Disability Law Center of Alaska AK State  
Governor's Council on Disabilities & Special Ed AK State  
Kenai Peninsula IL Center AK Local  
Kenai Peninsula IL Center AK Local

### *Alabama*

Birmingham Independent Living Center AL Local  
AL Dept of MH/MR AL State

### *Arkansas*

Delta Resource Center for Independent Living AR Local  
Sources AR Local  
Spa Area Independent Living Services AR Local  
UPWARD PROJECT AR Local  
Independent Living Council AR State  
Arkansas Support Network AR State  
The Arc of Arkansas AR State

### *Arizona*

ABIL, A Bridge to Independent Living AZ Local  
DIRECT AZ Local  
AZ Governor's Council on D.D. AZ State  
AZ Governor's S.I.L.C. AZ State  
AZ State Rehabilitation Advisory Council AZ State

*California*

Alameda County DD Planning & Advisory Council CA Local  
Californians for Disability Rights CA State  
Center for Independence of the Disabled CA Local  
Center for Independent Living South Valley CA Local  
Community Resources for Independence, CRI CA Local  
Disability Resource Agency for IL CA Local  
Disability Rights Enforcement, Education, Services CA Local  
East Bay Innovations CA Local  
Glad to Be Here, Inc CA Local  
Green Party of Santa Cruz, CA Local  
Humboldt Community Access & Resource Center CA Local  
Independent Living Resource Center-SF CA Local  
Independent Living Resource of Fairfield CA Local  
Mainstream Supported Living Services CA Local  
Marin - CIL CA Local  
Placer Independent Resource Services, Inc CA Local  
Planning for Elders in the Central City CA Local  
Resources for Independent Living CA Local  
Rolling Start CA Local  
So-Lo Center for Independent Living CA Local  
Sun Valley Independent Living Center CA Local  
UCP of Central CA Local  
Valley Mountain Regional Center CA Local  
CA Coalition of UCP Associations CA State  
CA Disability Alliance CA State  
CA SILC CA State  
California Alliance for Inclusive Communities CA State  
Jay Nolan Community Services CA State  
People First of California CA State  
The Oaks Group CA State

*Colorado*

Atlantis Community CO Local  
Center for Independence CO Local  
Center for People with Disabilities CO Local  
Colorado Springs Independence Center CO Local  
Connections for IL CO Local  
Disability Center for IL CO Local  
Disabled Resource Services CO Local  
Rocky Mountain MS Cen King Adult Day Enrich Prog CO Local  
Southwest Center for Independence CO Local  
Assn. of CO Independent Living Centers CO State  
CO Developmental Disab Planning Council CO State  
CO Gov's Council for People with Disabilities CO State  
CO Nurses Association CO State

CO SILC CO State  
Colorado Democrats CO State  
Lupus Foundation of Colorado CO State  
PEAK Parent Center CO State  
Speaking for Ourselves Colorado CO State  
Denver City Council CO Local  
CHANCE, Center for Housing & New Comm Econ. CO National  
Colorado Cross-Disability Coalition CO State

*Connecticut*

Disabilities Network of Eastern Conn. CT Local  
Disability Resources Center of Fairfield County CT Local  
Independence Unlimited CT Local  
Law Offices of Mark Partin CT Local  
Office for Persons with Disabilities CT Local  
Conn. Coalition of Citizens with Disabilities CT State  
Conn. Council on Developmental Disabilities CT State  
Conn. Legal Rights Project CT State  
Conn. State Independent Living Council CT State  
New England Health Care Employees Union Dist. 1199 CT State  
Office of Protection and Advocacy CT State  
Rammler & Wood, Consultants LLC CT State

*Delaware*

Freedom Center for IL DE Local  
Independent Resources Inc DE Local  
DE Statewide IL Council DE State  
Delaware Maryland PVA DE State  
Easter Seals DE & MD's Eastern Shore DE State  
State Council for Persons with Disabilities DE State  
U DE Center for Disabilities Studies DE State

*Florida*

CIL of Broward FL Local  
Leon Advocacy and Resource Center FL Local  
West Coast FL MCS & Chemical Injury Support Grp FL Local  
Florida Independent Living Council FL State  
Florida SCI Research Center FL State  
Paralyzed Veterans Assoc of FL State

*Georgia*

Access Center for IL GA Local  
Arc Cobb GA Local  
Bainbridge Advocacy Individual Network GA Local  
Brain Injury Family Assistance Center GA Local  
Disability Connection MGCIL GA Local

disAbility LINK GA Local  
LIFE Inc GA Local  
Savannah-Chatman County Fair Housing Council, Inc GA Local  
Walton Options for Independent Living Inc GA Local  
Concrete Change GA National  
Shepherd Center GA National  
Atlanta Alliance on Developmental Disabilities GA State  
Coalition on Disabilities Education (C.O.D.E.) GA State  
Demanding Equal Access for All (D.E.A.F.) GA State  
Federation of Families for Children's MH GA State  
GA DD Council GA State  
Georgia Advocacy Office GA State  
Georgia Parent Support Network GA State  
Georgia State Independent Living Council GA State  
Let's Get Together GA State  
North GA Wheelers GA State  
Osteogenesis Imperfecta Council of GA State  
Roosevelt Warm Springs Institute for Rehab. GA State  
People First of GA State

*Hawaii*

Environmental Illness Assn of Hawaii HI Local  
Disability Rights Hawaii HI State  
Environmental Illness Assn of HI State  
HI SILC HI State

*Iowa*

Evert Conner Rights & Resources CIL IA Local  
South Central Iowa CIL IA Local  
Three Rivers Independent Living Center IA Local  
IA Dept of Human Rights Div. of Persons w Disabilities IA State  
IA Human Rights Commission IA State  
Iowa Creative Employment Options IA State  
Iowa SILC IA State  
Iowans with Disabilities Exercising Advocacy Skills IA State  
the Arc of Iowa IA State

*Idaho*

Disability Action Center - NW, Inc ID Local  
Living Independently for Everyone, LIFE ID Local  
Comprehensive Advocacy ID State  
Idaho State Independent Living Council ID State  
Intermountain Fair Housing Council ID State

*Illinois*

Access Living IL Local

CCE IL Local  
Community Service Options IL Local  
Council for Disability Rights IL Local  
Headlines: Brain Injury Support Group IL Local  
Health & Policy Research Group IL Local  
Illinois Client Assistance Program IL Local  
Illinois/Iowa Center for Independent Living IL Local  
IMPACT IL Local  
LIFE CIL IL Local  
Metro Seniors in Action IL Local  
Multiple Chemical Sensitivities: Health & Environment IL Local  
Mycare Home Medical Supplies Inc IL Local  
Northwestern ILC for IL Local  
Options CIL IL Local  
PACE Inc IL Local  
Progress Center for IL IL Local  
RAMP Center for Independent Living IL Local  
Soyland Access to Independence IL Local  
Springfield Center for IL IL Local  
United Cerebral Palsy /Greater Chicago IL Local  
Campaign for Better Health Care IL State  
Coalition of Citizens with Disabilities in IL IL State  
Equip for Equality IL State  
Great Lakes ADA IL State  
IL Network of C.I.L.s IL State  
IL State Council of Senior Citizens IL State  
IL State Rehabilitation Council IL State  
IL Valley Center for IL IL State  
Statewide Independent Living Council of IL IL State

#### *Indiana*

Everybody Counts IN Local  
Indianapolis Resource Center for Independent Living IN Local  
League for the Blind & Disabled IN Local  
SICIL IN Local  
IN Institute on Disability & Culture - IU IN State  
Indiana Council on IL IN State

#### *Kansas*

American Legion Post 400 SAL KS Local  
CIL of SW KS Local  
Coalition for Independence KS Local  
Community Accessibility Awareness Task Force KS Local  
Developmental Services of NW KS Local  
Grandmothers, Aunts, Mothers, Sisters & Supports KS Local  
Head Injury Support Group KS Local

Independence Inc KS Local  
LINK KS Local  
Prairie Independent Living Resource Center KS Local  
Professional Home Health Services KS Local  
Resource CIL KS Local  
Self Help for the Hard of Hearing Western KS Grp KS Local  
Southeast Kansas Independent Living KS Local  
Three Rivers KS Local  
Topeka IL Resource Center KS Local  
Western KS Association on Concerns of the Disabled KS Local  
Youth Advocacy KS Local  
CLASS CTD KS State  
Kansas Assn of Centers for Independent Living KS State  
Kansas Association of the Deaf KS State  
Kansas Commission on Disability Concerns KS State  
Kansas Disability Rights Action Coalition for Hsg KS State  
Kansas Nurses Association KS State  
KS Council on DD KS State  
KS SILC KS State  
KS State Chapter WAPD KS State  
KS TASH KS State

#### *Kentucky*

Innovative Solutions Inc KY Local  
Access to the Arts KY State  
KY DD Council KY State  
KY SILC KY State

#### *Louisiana*

Absolute Care Enterprises, Inc LA Local  
Families Helping Families LA Local  
New Horizons Independent Living Center LA Local  
Resources for Independent Living LA Local  
Resources for Independent Living LA Local  
Southwest Louisiana Independence Center LA Local  
Vestial Home Health Care Resources Corp. LA Local  
Families Helping Families of Greater New Orleans LA State  
Advocacy Center LA State

#### *Massachusetts*

Boston Center for Independent Living MA Local  
Cape Organization for Rights of/the Disabled CORD MA Local  
Center for Living and Working MA Local  
Greater Boston Arc, Inc. MA Local  
ILC - the North Shore & Cape Ann MA Local  
JAM Specialists MA Local

Metrowest Center for Independent Living MA Local  
North Shore Arc MA Local  
Northeast Independent Living Program MA Local  
Rights for Equality and Dignity for the Disabled MA Local  
Stavros ILC MA Local  
Disability Law Center MA State  
MA Arc MA State  
MA Office on Disability MA State  
MA Statewide Independent Living Council MA State  
MA Statewide Personal Assistance Coalit MA State

*Maryland*

Baltimoreans Against disAbility Discrimination. MD Local  
Calvert County Comm for Indivs w Disabs MD Local  
Independence NOW MD Local  
MCIL Resources for Independent Living MD Local  
Montgomery Co Comm on People w Disabilities MD Local  
Resources for Independence MD Local  
Southern MD Center for LIFE MD Local  
Southern MD Independent Living MD Local  
The Freedom Center MD Local  
Chemical Sensitivity Disorders Assn. MD State  
MD Assoc. of Community Services MD State  
MD Developmental Disabilities Council MD State  
MD Disabilities Forum MD State  
MD Statewide IL Council MD State  
The Arc of Maryland MD State

*Maine*

Alpha One ME State  
Maine Disabilities Coalition ME State

*Michigan*

Ann Arbor Center for Independent Living MI Local  
ARC Detroit MI Local  
Association for Community Advocacy MI Local  
Blue Water Center for Independent Living MI Local  
CIL of Mid Michigan MI Local  
Kalamazoo Handicappers United Organization MI Local  
People of Livonia Addressing Issues of Diversity MI Local  
The Disability Network MI Local  
Autism Society of Michigan MI State  
MI Assn of Centers for Independent Living MI State  
MI Developmental Disabilities Council MI State  
MI Protection and Advocacy Service MI State  
Michigan Disability Rights Center MI State

The Arc Michigan MI State  
The Howell Group MI State  
The Self Advocacy Network of MI State

*Minnesota*

Advocating Change Together MN Local  
Center for IL of Northeastern MN Local  
Independent Lifestyles, Inc MN Local  
Metropolitan Center for Independent Living MN Local  
S.M.I.L.E.S. MN Local  
S.M.I.L.E.S. MN Local  
S.M.I.L.E.S. MN Local  
Southwestern Center for Independent Living MN Local  
Stillwater Human Rights MN Local  
The Disability Institute MN Local  
MN Assoc. of Centers for Independent Living MN State  
MN Governor's Council on Developmental Disability MN State  
MN SILC MN State  
Options IRCIL MN State  
Out in the Valley MN State

*Missouri*

Access II Independent Living Center MO Local  
Aging & Disability Coalition of Metro Kansas City MO Local  
Bootheel Area Independent Living Services MO Local  
Delta Center for Independent Living MO Local  
Disabled Citizens Alliance for Independence MO Local  
Independent Living Resource Center Inc MO Local  
Jefferson County ARC MO Local  
Living Independently for Everyone MO Local  
Midland Empire Resources for Independent Living MO Local  
NAPH Nat'l Assoc of Physically Handicapped MO Local  
PARAQUAD Inc MO Local  
Rural Advocates for Independent Living MO Local  
St Francis Catholic Worker Community MO Local  
St. Louis Civil Rights Enforcement Commission MO Local  
The Whole Person MO Local  
Tri-County Center for Independent Living MO Local  
Warrensburg Independent Living Services MO Local  
Disability Resource Association MO State  
MO Governor's Council on Disability MO State  
MO Head Injury Advisory Council MO State  
MO Planning Council for DD MO State  
MO Statewide Independent Living Council MO State  
Special Education Associates, SEA MO State

*Mississippi*

Coalition of Citizens with Disabilities (MS) State  
Living Independence for Everyone of Central MS Local  
Living Independence is for Everyone of North MS Local  
Living Independence is for Everyone of South MS Local  
Parents United Together in Mississippi MS State

*Montana*

Living Independently for Today & Tomorrow LIFTT MT Local  
Montana Independent Living Project MT Local  
Summit Independent Living Center, Inc MT Local  
Coalition of Montanans Concerned with Disabilities MT State  
Montana Advocacy Program MT State  
MT Independent Living Project MT State  
Parents, Let's Unite for Kids PLUK MT State

*Nebraska*

The Arc of Lincoln/Lancaster County NE Local  
League of Human Dignity NE State  
NE Advocacy Services NE State  
Nebraska Statewide Independent Living Council NE State

*New Hampshire*

Governor's Commission on Disability in NH State  
Granite State IL Foundation NH State  
Institute on Disability UAP @ UNH NH State  
NH DD Council NH State  
NH SILC NH State  
NHHomeless@egroups.com NH State

*New Jersey*

Alliance for Disabled in Action NJ Local  
Camden City ILC NJ Local  
Center for Independent Living of South Jersey NJ Local  
Disabled Advocates Working for Northwest DAWN NJ Local  
Personal Assistant Service Program NJ Local  
Progressive Center for Independent Living NJ Local  
Warren County Advisory Council on Disabilities NJ Local  
Monday Morning Proj - NJ DD Council NJ State  
NJ DD Council NJ State  
NJ MiCASSA Advocacy Coalition NJ State  
NJ SILC NJ State

*New Mexico*

Independent Living Resource Center Albq NM Local  
Independent Living Resources NM Local

San Juan CIL NM Local  
Gov's Comm on Concerns o/t Handicapped NM State  
NM DD Planning Council NM State  
NM Legislative Health & Human Services Committee NM State  
NM State Agency on Aging NM State  
NM Statewide Independent Living Council NM State  
Zia Chapter of the Paralyzed Veterans of America NM State

*New York*

SABE, Self Advocates Becoming Empowered NY  
504 Democratic Club NY Local  
Access to Independence of Cortland County NY Local  
Action for a Better Community NY Local  
Americans Demanding Access of NY Local  
ARISE NY Local  
Bronx Independent Living Services NY Local  
Brooklyn Center for Ind. of the Disabled NY Local  
Capital District Center for Independence NY Local  
Cent. NY Self Adv. Grassroots Reg Organizing Prog NY Local  
Center for Disability Rights NY Local  
Disabled in Action of Greater Syracuse NY Local  
Disabled in Action of Metro NY Local  
Family Empowerment Council NY Local  
Finger Lakes Independence Center NY Local  
Greater Rochester Spina Bifida Association NY Local  
Lakretz Creative Support Services NY Local  
League of Women Voters of the Rochester Metro Area NY Local  
Long Island Advocacy Center NY Local  
Massena ILC NY Local  
Mental Health Assoc. of the Southern Tier NY Local  
Mental Health Association of Rochester/Monroe Co. NY Local  
Metro Justice of Rochester NY Local  
Niagara Frontier Center for Independent Living, Inc NY Local  
North Country Center for Independence NY Local  
Northern Regional CIL NY Local  
P-FLAG Parents Family & Friends of Gays, Lesbians, Bisexuals &  
Transgendered NY Local  
Public Interest Law Office of Rochester NY Local  
Queens Independent Living Center NY Local  
Resource Center for Accessible Living NY Local  
Resource Center for Independent Living NY Local  
Rochester Center for IL NY Local  
Rochester Chpt. National Spinal Cord Inj. Assn NY Local  
Rockland City Commission on Human Rights NY Local  
Saratoga County Options for IL NY Local  
Southern Tier Independence Center NY Local

Southwestern Independent Living Center NY Local  
Staten Island CIL NY Local  
Staten Island Independent Living Assoc. NY Local  
Suffolk Independent Living Org. SILO NY Local  
Taconic Resources for Independent Living NY Local  
The Arc of Monroe County NY Local  
The Health Association NY Local  
Tomorrow's Future Self Advocacy Group NY Local  
Westchester Disabled on the Move, Inc NY Local  
Access to Independence & Mobility NY State  
Grassroots Regional Organizing Program NY State  
Mental Patients Liberation Alliance of NY State  
NY SILC NY State  
NY State DD Planning Council NY State  
NY State Independent Living Council NY State  
NY State Institute on Disability, Inc NY State  
Self-Advocacy Association of New York State NY State

*North Carolina*

Gaston Residential Services Inc NC Local  
Pathways for the Future NC Local  
Ron Mace Center for Disability Community Devel. NC Local  
Western Alliance NC Local  
NC Statewide Independent Living Council NC State

*North Dakota*

Dakota CIL ND Local  
Freedom Resource Center, Fargo ND Local  
North Dakota Disabilities Advocacy Consortium ND State

*Ohio*

Ability Center of Greater Toledo OH Local  
Access Center for Independent Living OH Local  
Center for IL Options OH Local  
Hamilton County Early Intervention Collaborative OH Local  
ILC of N Central OH Local  
LEAP Center for IL OH Local  
Lorain County Coalition of Citizens w/ Disabs. OH Local  
Mid-Ohio Board for IL Environ. MOBILE OH Local  
Services for Independent Living, Inc OH Local  
Society for Equal Access OH Local  
the Inclusion Network OH Local  
Tri-County Independent Living Center OH Local  
Irene Ward & Associates OH State  
Ohio Assoc. of Centers for Independent Living OH State  
Ohio DD Council OH State

Ohio Personal Assistance for IL, OPAIL OH State  
Ohio Personal Assistance Services Coalition OH State  
Ohio Statewide Independent Living Council OH State  
OH Disability Action Coalition OH State

*Oklahoma*

Ability Resources OK Local  
Progressive Independence OK Local  
National MS Society - OK Chapter OK State  
Office of Handicapped Concerns OK State  
OK SILC OK State  
Oklahoma Conference of Churches Impact Committee OK State  
Oklahoma Parent Network OK State  
Oklahomans for IL OK State

*Oregon*

Community Partnerships OR Local  
Independent Living Resources OR Local  
OR SILC OR State  
Oregon Developmental Disabilities Coalition OR State  
Oregon Disabilities Commission OR State

*Pennsylvania*

Abilities In Motion PA Local  
Anthracite Reg Cen for Independent Living PA Local  
Area Agency on Aging Office of Human Services PA Local  
Bucks County Area Agency on Aging PA Local  
CARIE Cent for Advcy f/t Rights Intrts of the Elderly PA Local  
CIL of Central PA Local  
CIL of North Central PA PA Local  
CIL of South Central PA Local  
Citizens for Independence and Access PA Local  
Consumer Connection PA Local  
Disabled in Action of Philadelphia PA Local  
Freedom Valley Disability Center PA Local  
Lawrence County Comm on Disability PA Local  
Lehigh Valley Center for Independent Living PA Local  
Liberty Resources PA Local  
LIFT PA Local  
Lupus Foundation of SE PA Local  
National MS Society - Greater Delaware Valley Chpt PA Local  
NE PA Center for Independent Living PA Local  
Partnership for Choice PA Local  
Pittsburgh Area Brain Injury Alliance PA Local  
Three Rivers Center for Independent Living PA Local  
TRIPIIL PA Local

United Cerebral Palsy of Philadelphia PA Local  
United Cerebral Palsy of Pittsburgh PA Local  
Voices for Independence PA Local  
Disabilities Law Project PA State  
PA Action Coalition in Disability Rights in Housing PA State  
PA Assn of Area Agency on Aging PA State  
PA Coalition of Citizens with Disabilities PA State  
PA Council of the Blind PA State  
PA Council on Independent Living PA State  
PA Developmental Disabilities Council PA State  
PA Statewide Independent Living Council PA State  
Speaking for Ourselves PA State  
UCP of PA State  
Interfaith Specialty Services PA Local

*South Carolina*

Access Resorts Inc. SC Local  
Disability Resource Center SC Local  
Pathways For the Future SC Local  
SC SILC SC State  
SC State Chapter WAPD SC State

*Tennessee*

Buffalo River Services TN Local  
CIL of Middle Tennessee TN Local  
Disability Resource Center TN Local  
East TN Technology Center TN Local  
Memphis Center for Independent Living TN Local  
Restructuring for Inclusive School Environments TN Local  
Tennessee Disability Coalition TN State  
Tennessee Network for Community Economic Devel TN State  
TN Association for Disability Rights TN State  
TN DD Council TN State

*Texas*

ABLE Area Base for Living Enrichment CIL TX Local  
Austin Mayor's Committee for People w Disabilities TX Local  
Austin Resource Cen for Independent Living TX Local  
Brazoria County Center for IL BCCIL TX Local  
Central TX Coalition on Aging & DD TX Local  
Central TX Rehab Assn TX Local  
Crockett Resource Center for Independent Living TX Local  
GMSA Management Group TX Local  
Greater Austin PVA TX Local  
Houston Area Women's Center TX Local  
Houston Center for Independent Living TX Local

Panhandle Independent Living Center TX Local  
Parents as Case Managers TX Local  
REACH Resource Centers on IL TX Local  
RISE TX Local  
San Antonio Independent Living Services, SAILS TX Local  
TATP TX Local  
Volar Center for Independent Living TX Local  
Advocacy Inc. TX State  
Advocates for Texans with Brain Injuries TX State  
Brain Injury Association of Texas TX State  
Coalition of Texans with Disabilities TX State  
Disability Policy Consortium TX State  
Disability Services of the Southwest TX State  
Mental Health Association in Texas TX State  
National Assoc of Social Workers - TX Chapter TX State  
Texas Advocates TX State  
Texas Advocates for Supporting Kids with Disabilities TX State  
Texas Assn of Centers for Independent Living TX State  
Texas Mental Health Consumers TX State  
Texas Nurses Association TX State  
Texas Planning Council for Devel Disabs TX State  
Texas Rehabilitation Commission TX State  
TX Civil Rights Project TX State  
TX Health and Human Services Commission TX State  
TX PVA TX State  
TX SILC TX State  
TX State Chapter WAPD TX State  
United Cerebral Palsy of Texas TX State  
University Affiliated Program, UT TX State

*Utah*

Active Re-Entry UT Local  
Area Agency on Aging of Price UT Local  
Concerned Citizens with Disabilities CCDC UT Local  
Disabled Rights Action Committee, DRAC UT Local  
Options for Independence UT Local  
Red Rock Center for Independence UT Local  
Utah Independent Living Center UT Local  
ADA Consortium of Utah UT State  
Association for Independent Living of Utah UT State  
Disability Law Center UT State  
Legislative Coalition for People with Disabilities UT State  
Utah State Democratic Committee UT State  
Utah Statewide Independent Living Council UT State

*Virginia*

Blue Ridge Independent Living Center VA Local  
Brain Injury Services Inc VA Local  
disAbility Resource Center of the Rappahannock Area VA Local  
Endeppendence Center - Norfolk VA Local  
Commonwealth Coalition for Community VA State  
VA Statewide Independent Living Council VA State  
VA TASH VA State  
Virginia Assoc of People in Supported Employment VA State

*Vermont*

Vermont CIL VT State  
Vermont Coalition for Disability Rights VT State

*Washington*

Coastal Community Advocates WA Local  
CORD WA Local  
disAbility Resource Center WA Local  
Inclusion Daily Express WA Local  
Tacoma Area Coalition of Individuals w Disabilities TACID WA Local  
Alzheimers Society of Washington WA State  
Arc of Washington State WA State  
disAbility Resources of Southwest WA State  
Gov's Comm on Disability Issues & Emp - WA State WA State  
Project PAS-Port for Change WA State  
WA Protection and Advocacy WA State  
WA SILC WA State  
Washington Coalition of Citizens with Disabilities WA State

*Wisconsin*

Access to Independence, Madison WI Local  
ARC-Milwaukee WI Local  
Aurora Community Services WI Local  
CIL for Western Wisconsin WI Local  
Community Living Alliance WI Local  
Disabled Womyn's Education Project WI Local  
Easter Seals of SE Wisconsin WI Local  
Employment Resources Inc. WI Local  
Independence First WI Local  
North Country Independent Living WI Local  
Options for Independent Living WI Local  
Pierce County Dept. of Human Services WI Local  
Ranch Community Services WI Local  
St. Clare Management, Inc WI Local  
United Cerebral Palsy of SE Wisconsin WI Local  
ARC - Wisconsin WI State

Aurora Residential Services WI State  
Brain Injury Assoc. of WI State  
Client Assistance Program of WI State  
National Multiple Sclerosis Society of WI State  
Older Adult Service Provider's Consortium WI State  
People First Wisconsin WI State  
Rehabilitation for Wisconsin WI State  
State Independent Living Council WI State  
State Rehabilitation Planning & Advisory Council WI State  
United Cerebral Palsy of WI State  
WI Coalition for Advocacy - Milwaukee WI State  
WI Coalition of IL Centers WI State  
WI Council on Developmental Disabilities WI State  
WI Council on Physical Disabilities WI State  
WI Gov's Comm for People w Disabilities WI State  
WI Nurses Assoc WI State  
WI Rehabilitation Assn. WI State  
WI SILC WI State  
WI Coalition for Advocacy - Madison WI  
Parents Education Project of WI State

*West Virginia*

Huntington WV Grassroots Advocacy Project WV Local  
Mountain State CILs - Huntington WV Local  
Northern WV CIL WV Local  
WV SILC WV State  
WY SILC WY State

Appendix 4

**MEDICAID LONG TERM CARE DATA – 2005**

(September 2004 through September 2005)

<b>Total Medicaid</b> -----	<b>\$300.3 billion</b>	
<b>Total Long Term Care (LTC)</b> -----	<b>94.5 billion</b>	
	<b>LTC - 31.78% of Medicaid</b>	
#####		
<b>Nursing Homes</b> -----	<b>\$ 47.24 billion</b>	<b>50.0% of LTC</b>
<b>ICF-MR (public)</b> -----	<b>7.54 billion</b>	<b>8.0%</b>
<b>ICF-MR (private)</b> -----	<b>4.56 billion</b>	<b>4.8%</b>
<b>Total Institutional</b> -----	<b>59.34 billion</b>	<b>62.8%</b>
<b>Personal Care</b> -----	<b>\$ 8.57 billion</b>	
<b>HCBS Waivers</b> -----	<b>22.70 billion</b>	
<b>Home Health</b> -----	<b>3.57 billion</b>	
<b>Home and Community Services</b> ---	<b>.32 billion</b>	
<b>Total Community</b> -----	<b>\$ 35.16 billion</b>	<b>37.2%</b>

#####

**HCBS WAIVER BREAKDOWN 2005 BY CATEGORY**

<b>Total HCBS Waivers</b> -----	<b>\$ 22.70 billion</b>	
<b>MR/DD</b> -----	<b>\$ 17.03 billion</b>	<b>75.34%</b>
<b>Aged/Disabled</b> -----	<b>3.942 billion</b>	<b>17.44%</b>
<b>Physical Disability</b> -----	<b>.722 billion</b>	<b>3.20%</b>
<b>Aged</b> -----	<b>.470 billion</b>	<b>2.07%</b>
<b>Tech Dependent</b> -----	<b>.109 billion</b>	<b>.48%</b>
<b>Brain Injury</b> -----	<b>.230 billion</b>	<b>1.02%</b>
<b>HIV/AIDS</b> -----	<b>.062 billion</b>	<b>.27%</b>
<b>Mental Illness/SED</b> -----	<b>.040 billion</b>	<b>.18%</b>

Numbers are taken from a report by MEDSTAT ([www.medstat.com](http://www.medstat.com))

The MEDSTAT Group Inc. – (617)492-9300

MEDSTAT data taken from CMS 64 reports submitted by the states

Compiled by ADAPT – July 2006 (All numbers are rounded off)

[www.adapt.org](http://www.adapt.org) 512/442-0252



## ACCESSIBLE, AFFORDABLE INTEGRATED HOUSING ACCESS ACROSS AMERICA (AAA)

### SCOPE OF PROBLEM

Even with the increased availability of Medicaid community-based services and supports, people with disabilities are being stopped from relocating to housing in the community because they cannot get access to vouchers or accessible, affordable, and integrated housing options. This affects all disabled people who have gone into nursing homes and due to Katrina the situation has worsened. There are thousands of disabled and elderly people who were waiting to get out before Katrina and continue to wait. Many people have dropped out of transitioning programs, losing hope when they could not get any assistance to coordinate their Medicaid community-based services and supports with any real access to affordable, accessible, integrated housing.

### WHAT IS ACCESS ACROSS AMERICA?

*Access Across America* is a proposal to HUD for a national program that would help people coming out of nursing homes or at risk of going into a nursing homes because they cannot access affordable, safe, and accessible housing. This program coordinates the receipt of subsidized housing vouchers with Medicaid-eligible persons transitioning out of nursing homes or at risk of going into a nursing home due to a housing crisis, who are receiving home and community-based services and supports.

### WHY ACCESS ACROSS AMERICA?

Directs HUD and HHS/CMS to collaborate, coordinate and improve services to low income persons with disabilities, thus ensuring that they can truly live in the most integrated setting.

- Improve the timing and coordination of affordable, accessible, integrated housing with the receipt of home and community support services;
- To facilitate the rebalancing of the long term care system;
- Implement the goals of the New Freedom Initiative;
- Assist states in implementing the Supreme Court's Olmstead decision.

## WHO IS ELIGIBLE FOR *ACCESS ACROSS AMERICA*?

- Individuals with disabilities and older Americans who are in nursing homes or other institutions;
- Those who have chosen to leave the nursing home or other institution;
- Individuals who will be transitioning from the nursing home or other institution within the next 60 days or may be forced back into a nursing home over a housing problem.
- Individuals at imminent risk of going into nursing homes or other institutions

## HOW WILL *ACCESS ACROSS AMERICA* BE IMPLEMENTED?

HUD in coordination with HHS/CMS will work at the state level and local levels with federally authorized community-based organizations such as Independent Living Centers and Area Agencies on Aging, to facilitate the coordination of and implementation of the *ACCESS ACROSS AMERICA* program.

For information: Cassie James, ADAPT, 215/634-2000    [www.adapt.org](http://www.adapt.org)