NATIONAL COMMISSION on FAIR HOUSING and EQUAL OPPORTUNITY

Testimony on behalf of ADAPT


Houston Hearing, July 31, 2008

Attachments

Presented by:
David A. Kahne
Law Office of David A. Kahne
713-652-3966
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.

This research was done for the Housing Task Force of the Consortium for Citizens with Disabilities (CCD Housing Task Force). It was funded by the Melville Charitable Trust under a grant to the Technical Assistance Collaborative Inc. The author is grateful for the cooperation of HUD’s Office of Policy Development and the National Low Income Housing Coalition.
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 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. 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.

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. 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, 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 that the estimate of 694,000 that results from using the expanded AHS proxy that includes the new question on disability income (HUD, 2008).

---

1 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.

2 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.

3 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.

4 “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.

5 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.

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).

1. Because the ACS has essentially the same questions on income sources as the 2005 AHS, 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, is appropriate because severe rent burden—paying more than half of household income for housing—is the problem underlying 95% of worst case needs.

---

6 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.


8 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.

9 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.\(^{10}\) 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.

\(^{10}\) 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.¹¹

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.¹² 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.¹³ The new four-income

---

¹¹ The AHS estimates in these tables are drawn from HUD’s new Supplemental Findings.

¹² 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.

¹³ 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.14

14 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.\textsuperscript{15} 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.\textsuperscript{16} 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.\textsuperscript{17} 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.\textsuperscript{18} 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.

\textbf{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

\textsuperscript{15} 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.

\textsuperscript{16} Future research might usefully develop adjustment factors separately for childless renters and families with children.

\textsuperscript{17} The Technical Appendix summarizes these independent approaches and why the estimate of 1.1 million itself was probably low.

\textsuperscript{18} 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.19

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.

19 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 noneelderly adults with disabilities*

<table>
<thead>
<tr>
<th>Reporting income from:</th>
<th>With Disabilities*</th>
<th>Other</th>
<th>% with Disabilities*</th>
</tr>
</thead>
<tbody>
<tr>
<td>All non-elderly renter households without children</td>
<td>2,237,496</td>
<td>3,901,552</td>
<td>36%</td>
</tr>
<tr>
<td>Social Security/Railroad Retirement</td>
<td>656,330</td>
<td>110,266</td>
<td>86%</td>
</tr>
<tr>
<td>Supplemental Security Income</td>
<td>784,696</td>
<td>14,937</td>
<td>98%</td>
</tr>
<tr>
<td>Retirement, Survivor, or Disability Payments</td>
<td>210,556</td>
<td>62,317</td>
<td>77%</td>
</tr>
<tr>
<td>Public Assistance</td>
<td>201,861</td>
<td>91,501</td>
<td>69%</td>
</tr>
<tr>
<td>Reporting any of above 4 income sources</td>
<td>1,456,638</td>
<td>259,490</td>
<td>65%</td>
</tr>
<tr>
<td>as % of total with disabilities</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Families with children and non-elderly adults

<table>
<thead>
<tr>
<th>Reporting income from:</th>
<th>1,459,871</th>
<th>4,496,367</th>
<th>25%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Security/Railroad Retirement</td>
<td>303,991</td>
<td>155,218</td>
<td>66%</td>
</tr>
<tr>
<td>Supplemental Security Income</td>
<td>405,854</td>
<td>28,706</td>
<td>93%</td>
</tr>
<tr>
<td>Retirement, Survivor, or Disability Payments</td>
<td>98,077</td>
<td>62,774</td>
<td>59%</td>
</tr>
<tr>
<td>Public Assistance</td>
<td>397,675</td>
<td>663,151</td>
<td>37%</td>
</tr>
</tbody>
</table>

Source: NLHIC 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

<table>
<thead>
<tr>
<th>Data source:</th>
<th>Childless households with nonelderly adults with disabilities</th>
<th>Families with children with nonelderly adults with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACS, 2003</td>
<td>18,813</td>
<td>998</td>
</tr>
<tr>
<td>ACS(1,2)</td>
<td>2,237</td>
<td>1,460</td>
</tr>
<tr>
<td>Very-low-income renter households (000s)</td>
<td>1,767</td>
<td>998</td>
</tr>
<tr>
<td>with rent burden&gt;50% of income</td>
<td>946</td>
<td>485</td>
</tr>
<tr>
<td>reporting rental assistance</td>
<td>703</td>
<td>363</td>
</tr>
<tr>
<td>unassisted with burden&gt;50%</td>
<td>664</td>
<td>359</td>
</tr>
<tr>
<td>with worst case needs</td>
<td>694</td>
<td>365</td>
</tr>
<tr>
<td>worst case as % of unassisted</td>
<td>65%</td>
<td>57%</td>
</tr>
<tr>
<td>ACS worst case/AHS worst case:</td>
<td>1.34</td>
<td>1.70</td>
</tr>
</tbody>
</table>

Adjusting for SIPP and NHIS higher counts of adults 18-61 with disabling conditions

<table>
<thead>
<tr>
<th>Number of U.S. adults 18-61 with disabling conditions***</th>
<th>Ratio compared to ACS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHIS, 2002</td>
<td>25,318</td>
</tr>
<tr>
<td>SIPP, 2002</td>
<td>29,048</td>
</tr>
</tbody>
</table>

Adjusted estimates of worst case needs

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>conforming to NHIS control total</td>
<td>1,255</td>
</tr>
<tr>
<td>conforming to SIPP control total</td>
<td>1,440</td>
</tr>
<tr>
<td>Sources: *HUD/FIO &amp; OMB tabulations of AHS with 4-income proxy for Non-elderly disabled adults in households without children (HUD, 2008)</td>
<td></td>
</tr>
<tr>
<td>** HUD/FIO &amp; OMB tabulations of AHS with 3-income proxy for Non-elderly disabled in families with children (HUD, 2008)</td>
<td></td>
</tr>
<tr>
<td>(1) ACS data on very-low-income adults with disabilities and severely burdened from NLHIC tabulations of the 2005 ACS Public Use Microdata Sample</td>
<td></td>
</tr>
<tr>
<td>(2) Italics &quot;ACS&quot; estimates of worst case needs assume that the AHS ratio of worst case needs/severe rent burden holds for the ACS estimates.</td>
<td></td>
</tr>
<tr>
<td>*** ACS, NHIS, &amp; SIPP: Table 11, Robert R Weathers, 2005, A Guide to Disability Statistics from the American Community Survey, Cornell University Employment and Disability Institute</td>
<td></td>
</tr>
</tbody>
</table>
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
Judson James
U.S. Department of Housing
And Urban Development
451 7th Street, SW, Room 8140
Washington, DC 20410

Prepared by
Gretchen Locke
Sandra Nolden
Naomi Michlin
Kristin Winkel
Paul Elwood

Abt Associates Inc.
55 Wheeler Street
Cambridge, MA 02138
Acknowledgements

The authors of this report—Gretchen Locke, Sandra Nolden, Naomi Michlin, Kristin Winkel, and Paul Elwood—wish to acknowledge the assistance provided to this study by a variety of individuals and organizations. First, we appreciate the guidance and support of the task order’s Government Technical Monitor, Dr. Judson James. During the design phase, Lynn Rodgers of the Program Monitoring and Research Division of HUD’s Office of Policy Development and Research, undertook the challenging task of preparing a property-level database to our specifications. We also wish to recognize Ann O’Hara, Kathleen McGinley, and Andrew Sperling, all members of the Consortium for Citizens with Disabilities’ Housing Task Force, for providing us with suggestions for our sampling approach and with names and contact information for local organizations that serve people with disabilities in the ten metropolitan areas under study.

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.

At Abt Associates, several staff members played important roles on this task order. Dr. Judith Feins provided thoughtful and constructive technical review throughout the design, data collection, and report writing. Shirley Cui provided programming support for sample selection and Michele Robinson and Deb Welch produced the report. We thank them all for their diligent efforts.
# Table of Contents

Executive Summary ........................................................................................................ iii
1. Background for the Study .................................................................................. iii
2. Summary of Key Findings .............................................................................. vi
3. Conclusions and Recommendations for Further Research ..................... x

Chapter One - Background and Methodology .................................................. 1-1
  1.1 Background ................................................................................................ 1-1
  1.2 Research Design ...................................................................................... 1-3
  1.3 Sampling Approach ............................................................................... 1-4
  1.4 Summary of Study Data Collection ....................................................... 1-15
  1.5 Organization of the Report ................................................................... 1-17

Chapter Two - The Supply of HUD-Assisted Housing for Non-Elderly People with Disabilities in the Study Sites ......................................................... 2-1
  2.1 Property Characteristics ........................................................................ 2-1
  2.2 Occupancy Policies in the Study Properties ....................................... 2-7
  2.3 Factors Influencing Occupancy Policies in the Study Properties ......... 2-10
  2.4 Conclusions .......................................................................................... 2-19

Chapter Three - Other Sources of Affordable Housing for Non-Elderly People with Disabilities ................................................................. 3-1
  3.1 Tenant-Based Section 8 Vouchers and Certificates ......................... 3-2
  3.2 Public Housing ....................................................................................... 3-4
  3.3 Other Housing Options .......................................................................... 3-7
  3.4 Conclusions .......................................................................................... 3-9

Chapter Four - Nature of Demand for Affordable Housing Among Non-Elderly People with Disabilities ......................................................... 4-1
  4.1 Summary of Available National Data on People with Disabilities .... 4-1
  4.2 Challenges of Estimating Demand for Affordable Housing .......... 4-5
  4.3 Factors that Affect Demand for HUD-Assisted Housing ................ 4-7
  4.4 Conclusions .......................................................................................... 4-9
Chapter Five - Changes in the Availability of Assisted Housing for Non-Elderly People with Disabilities

5.1 The Effects of the 1992 Act ................................................................. 5-1
5.2 Other Factors Influencing Access to Housing for People with Disabilities .... 5-2
5.3 Challenges to Estimating Demand ...................................................... 5-3

Appendix A: - Detailed Sampling Information

Appendix B: - Data Collection Instruments

Appendix C: - Case Studies
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.¹ 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

¹ 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.²

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.”³ 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:

---


• 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

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

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. Of the 46 managers who were able to provide information on changes in occupancy policy, 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

---

4 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 electedelderly preferences.

5 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.

6 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. 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.

---

7 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.

8 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.\textsuperscript{9}

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

reported changes in occupancy policies.\textsuperscript{10} 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.

\textsuperscript{10} 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.
<table>
<thead>
<tr>
<th>State</th>
<th>Total</th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delaware</td>
<td>79.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Connecticut</td>
<td>77.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorado</td>
<td>76.5%</td>
<td>21.0%</td>
<td>22.7%</td>
</tr>
<tr>
<td>California</td>
<td>74.9%</td>
<td>25.5%</td>
<td>90.3%</td>
</tr>
<tr>
<td>Arizona</td>
<td>67.4%</td>
<td>32.6%</td>
<td>32.6%</td>
</tr>
<tr>
<td>Alaska</td>
<td>67.4%</td>
<td>32.6%</td>
<td>32.6%</td>
</tr>
<tr>
<td>Alabama</td>
<td>82.8%</td>
<td>17.2%</td>
<td>22.7%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>100%</td>
<td>100%</td>
</tr>
</tbody>
</table>

To view a description of the report table contents, click here.

*Q2A.* Discharge Potential and Overall Status

MDS Active Resident Information Report: Second Quarter 2008

MDS Active Resident Information Report

MDS 2.0 Public Reports

CMS Home > Research, Statistics, Data and Systems > MDS 2.0 Public Quality Indicator and Resident Reports

People with Medicare & Medicaid Questions | Contact CMS | Accessibility | CMS Home > Research, Statistics, Data and Systems > MDS 2.0 Public Quality Indicator and Resident Reports

Home > Medicare > MDS 2.0 Public Reports: About CMS | Regulations & Edibility | Research, Statistics, Data and Systems | Outreach & Education | Tools

Search now
<table>
<thead>
<tr>
<th>State</th>
<th>Population</th>
<th>Percentage</th>
<th>Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Mexico</td>
<td>20,000</td>
<td>72.8%</td>
<td>2.2%</td>
</tr>
<tr>
<td>New Jersey</td>
<td>30,000</td>
<td>78.2%</td>
<td>1.5%</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>10,000</td>
<td>77.9%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Nevada</td>
<td>50,000</td>
<td>70.6%</td>
<td>4.4%</td>
</tr>
<tr>
<td>Nebraska</td>
<td>10,000</td>
<td>78.3%</td>
<td>1.3%</td>
</tr>
<tr>
<td>Montana</td>
<td>15,000</td>
<td>73.1%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Michigan</td>
<td>10,000</td>
<td>76.8%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Minnesota</td>
<td>20,000</td>
<td>78.6%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>40,000</td>
<td>78.8%</td>
<td>3.3%</td>
</tr>
<tr>
<td>Maryland</td>
<td>20,000</td>
<td>75.2%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Maine</td>
<td>14,000</td>
<td>85.3%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Louisiana</td>
<td>10,000</td>
<td>79.3%</td>
<td>3.6%</td>
</tr>
<tr>
<td>Kentucky</td>
<td>10,000</td>
<td>80.4%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Kansas</td>
<td>10,000</td>
<td>80.2%</td>
<td>1.2%</td>
</tr>
<tr>
<td>Iowa</td>
<td>8,000</td>
<td>88.1%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Indiana</td>
<td>5,000</td>
<td>79.4%</td>
<td>3.2%</td>
</tr>
<tr>
<td>Illinois</td>
<td>10,000</td>
<td>74.8%</td>
<td>2.2%</td>
</tr>
<tr>
<td>Idaho</td>
<td>8,000</td>
<td>73.2%</td>
<td>3.4%</td>
</tr>
<tr>
<td>Hawaii</td>
<td>10,000</td>
<td>80.6%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Georgia</td>
<td>20,000</td>
<td>73.6%</td>
<td>3.0%</td>
</tr>
<tr>
<td>Florida</td>
<td>20,000</td>
<td>70.0%</td>
<td>5.2%</td>
</tr>
<tr>
<td>District of Columbia</td>
<td>0,000</td>
<td>80.2%</td>
<td>2.0%</td>
</tr>
<tr>
<td>State</td>
<td>Response Rate</td>
<td>National Total</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>---------------</td>
<td>----------------</td>
<td></td>
</tr>
<tr>
<td>Wyoming</td>
<td>77.4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wisconsin</td>
<td>75.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>West Virginia</td>
<td>69.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washington</td>
<td>78.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Virginia</td>
<td>75.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vermont</td>
<td>66.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utah</td>
<td>74.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>U.S. Virgin Islands</td>
<td>63.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Texas</td>
<td>79.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tennessee</td>
<td>77.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Dakota</td>
<td>82.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Carolina</td>
<td>80.4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rhode Island</td>
<td>80.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puerto Rico</td>
<td>78.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>75.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oregon</td>
<td>65.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oklahoma</td>
<td>73.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ohio</td>
<td>74.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Dakota</td>
<td>78.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Carolina</td>
<td>78.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New York</td>
<td>78.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>MDS Active Resident Information Report: Second Quarter 2008</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---------</td>
<td>-------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delaware</td>
<td>% 50.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Connecticut</td>
<td>% 49.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colorado</td>
<td>% 44.4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>California</td>
<td>% 43.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arkansas</td>
<td>% 43.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arizona</td>
<td>% 42.7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alaska</td>
<td>% 41.9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alabama</td>
<td>% 41.8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Total</td>
<td>% Yes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To view a description of the report table contents, click here.

A72: Identifiable and Background Information - Current Payment Sources For Nh Stay - Medical Per Diem

CMS Home > Research, Statistics, Data and Systems > MDS 2.0 Public Quality Indicators and Resident Reports > MDS Active Resident Information Report > CMS Home旋转图标。
<table>
<thead>
<tr>
<th>State</th>
<th>% 9.5%</th>
<th>% 7.5%</th>
<th>% 6.5%</th>
<th>% 5.5%</th>
<th>% 4.5%</th>
<th>% 3.5%</th>
<th>% 2.5%</th>
<th>% 1.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Mexico</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Jersey</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New Hampshire</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nevada</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nebraska</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Montana</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missouri</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mississippi</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minnesota</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Michigan</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Massachusetts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maryland</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maine</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Louisiana</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kentucky</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kansas</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iowa</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indiana</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illinois</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Idaho</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hawaii</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Georgia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Florida</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>District of Columbia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State</td>
<td>Percentage</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wyoming</td>
<td>46.9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wisconsin</td>
<td>51.9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>West Virginia</td>
<td>50.7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Washington</td>
<td>38.9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Virginia</td>
<td>69.4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vermont</td>
<td>44.6%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Utah</td>
<td>51.3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>U.S. Virgin Islands</td>
<td>47.4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Texas</td>
<td>49.5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tennessee</td>
<td>50.5%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Dakota</td>
<td>49.3%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>South Carolina</td>
<td>45.7%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rhode Island</td>
<td>45.9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Puerto Rico</td>
<td>45.1%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>49.1%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oregon</td>
<td>42.2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oklahoma</td>
<td>47.4%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ohio</td>
<td>44.2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Dakota</td>
<td>55.8%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>North Carolina</td>
<td>41.9%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New York</td>
<td>60.0%</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
United States: District Characteristics

American FactFinder

U.S. Census Bureau

Survey: 2000 American Community Survey

DATA SET: 2000 American Community Survey

ST10: District Characteristics

NOTE: Data are based on the residential population and exclude the population living in institutionalized subsets.
For the 1999-2004 American Community Survey, the data on mobility limitations 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 "dress, bathe, or get around inside the home." Respondents were instructed to mark "yes" or "no." Questionnaire item 16a is labeled as "Self-Care Disability" for some disability data products such as the ACS Detailed Tables.

**Comparability**

The 1999-2004 American Community Survey question on cognitive functioning was intended to be comparable to the Census 2000 questionnaire. For the 1999 decennial census, respondents were asked if they had a physical, mental, or emotional condition lasting 6 months or more that made it difficult to "learn, remember, or communicate." Questionnaire item 16a is labeled as "Mental Disability" for some disability data products such as the ACS Detailed Tables.

- **Self-Care Limitations**
- **Going-Outside-Home Limitations**
- **Comparability**

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 old 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 data products such as the ACS Detailed Tables.

- **Comparability**

The 2003 questionnaire introduced new skip instructions 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 16, which was asked of persons 16 years old and over. The question asked respondents if they had a long-lasting physical or mental condition that made it difficult to "go outside the home alone to shop or visit a doctor's office."
In the 1990 Census, respondents were asked if they were present or
working the day they were asked. Therefore, those who responded "yes"
were asked if they were present from
work, if they could. People who responded "yes" were asked if they were present from
work or the 1990 Census. However, it was not clear if the 1990 Census
question was the same as the

2000 Census. The Census Bureau does not recommend using these data.

Employment Limitations

The 1999-2002 American Community Survey was essentially the same as the

2000 Census. The Bureau has been examining the differences in the 1999-2002 American Community Survey and the 1990 Census. However, the

The 1999-2002 American Community Survey was essentially the same as the

2000 Census. The Bureau has been examining the differences in the 1999-2002 American Community Survey and the 1990 Census. However, the

The 1999-2002 American Community Survey was essentially the same as the

2000 Census. The Bureau has been examining the differences in the 1999-2002 American Community Survey and the 1990 Census. However, the
<table>
<thead>
<tr>
<th>Houshold Type</th>
<th>(A)</th>
<th>(B)</th>
<th>(C)</th>
<th>(D)</th>
<th>(E)</th>
<th>(F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owners</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1) x (2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>All Owners</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Large W/H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Small W/H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Member</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Members Only</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(2) x (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Members</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(1) x (3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Renter        |     |     |     |     |     |     |
| Total         |     |     |     |     |     |     |
| Other         |     |     |     |     |     |     |
| (1) x (2)     |     |     |     |     |     |     |
| All Renters   |     |     |     |     |     |     |
| Large W/H     |     |     |     |     |     |     |
| Small W/H     |     |     |     |     |     |     |
| Member        |     |     |     |     |     |     |
| Members Only  |     |     |     |     |     |     |
| (2) x (3)     |     |     |     |     |     |     |
| Other Members |     |     |     |     |     |     |
| (1) x (3)     |     |     |     |     |     |     |

**Housing Problems:**

- Income >= 50%
- Income < 30%
- Housing Costs
- Overcrowding

**Texas:**

- **Source of Data:** CHAS Data Book
- **Name of Data:** CHAS Data Report

**Note:** The table contains data for housing problems and housing type distribution across different income brackets and household types.
### Definitions:

Note: When using Internet Explorer, please save the file in Excel format.

Click the button below to get the data needed to fill out the CPM/P version 1.2 spreadsheet in MS Excel format arranged for a one-step process.

<table>
<thead>
<tr>
<th>Cost</th>
<th>Border &lt; 50%</th>
<th>Border &gt; 50%</th>
<th>Housing Problems</th>
<th>Household Size</th>
<th>Budget &lt; 80%</th>
<th>Household Size</th>
<th>Budget &gt; 80%</th>
</tr>
</thead>
<tbody>
<tr>
<td>101</td>
<td>11.9</td>
<td>23.6</td>
<td>18.7</td>
<td>17.8</td>
<td>21.0</td>
<td>32.4</td>
<td>33.6</td>
</tr>
<tr>
<td>67</td>
<td>9.3</td>
<td>15.2</td>
<td>16.4</td>
<td>15.9</td>
<td>20.6</td>
<td>32.0</td>
<td>44.5</td>
</tr>
<tr>
<td>31.1</td>
<td>4.9</td>
<td>28.5</td>
<td>42.5</td>
<td>28.0</td>
<td>42.6</td>
<td>72.1</td>
<td>36.2</td>
</tr>
<tr>
<td>73</td>
<td>32.8</td>
<td>66.1</td>
<td>39.4</td>
<td>52.9</td>
<td>84.9</td>
<td>11.7</td>
<td>44.6</td>
</tr>
<tr>
<td>11.4</td>
<td>28.8</td>
<td>11.6</td>
<td>14.8</td>
<td>12.4</td>
<td>12.2</td>
<td>12.2</td>
<td>11.1</td>
</tr>
<tr>
<td>4.3</td>
<td>73.4</td>
<td>32.7</td>
<td>41.5</td>
<td>39.7</td>
<td>41.2</td>
<td>41.2</td>
<td>41.2</td>
</tr>
<tr>
<td>5.4</td>
<td>73.8</td>
<td>13.0</td>
<td>20.5</td>
<td>27.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>38</td>
<td>7.0</td>
<td>13.4</td>
<td>14.8</td>
<td>14.8</td>
<td>23.4</td>
<td>23.4</td>
<td>23.4</td>
</tr>
<tr>
<td>26</td>
<td>9.1</td>
<td>13.3</td>
<td>21.6</td>
<td>27.0</td>
<td>23.1</td>
<td>23.1</td>
<td>23.1</td>
</tr>
<tr>
<td>14</td>
<td>5.8</td>
<td>13.0</td>
<td>20.7</td>
<td>27.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>23.8</td>
<td>9.0</td>
<td>13.0</td>
<td>21.6</td>
<td>27.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>14.4</td>
<td>3.0</td>
<td>4.1</td>
<td>6.8</td>
<td>4.3</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>30.8</td>
<td>1.6</td>
<td>4.3</td>
<td>6.8</td>
<td>4.3</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
<tr>
<td>39.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Source: Social Security Administration.
Cost Burden: Cost burden is the fraction of a household's total gross income spent on housing costs. For renters, housing costs include rent, utilities, and other expenses. For owners, housing costs include mortgage payment, taxes, insurance, and utilities.

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

Elderly households: 1 or 2 person household, elderly person 62 years or older.

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

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

Source: Tables F.5A, F.5B, F.3C, F.5D.
**Eligibility Notes:**
- Households with other persons 6 to 74 years old.
- Households with other persons 75 years or older.

**Definitions for Mobility & Self-Care:**
- 5 or 6 Member Households
- Other households
- Elderly 75 years or older

**Table:**

<table>
<thead>
<tr>
<th>Income Level</th>
<th>% with Mobility Problems</th>
<th>% with Any Housing Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $11,000</td>
<td>11.1%</td>
<td>26.4%</td>
</tr>
<tr>
<td>$11,000 to $15,999</td>
<td>12.8%</td>
<td>31.0%</td>
</tr>
<tr>
<td>$16,000 to $29,999</td>
<td>16.0%</td>
<td>38.2%</td>
</tr>
<tr>
<td>$30,000 to $44,999</td>
<td>20.0%</td>
<td>48.2%</td>
</tr>
<tr>
<td>$45,000 to $59,999</td>
<td>23.9%</td>
<td>57.1%</td>
</tr>
<tr>
<td>$60,000 to $99,999</td>
<td>31.3%</td>
<td>68.4%</td>
</tr>
<tr>
<td>$100,000 to $149,999</td>
<td>37.0%</td>
<td>79.4%</td>
</tr>
<tr>
<td>$150,000 to $199,999</td>
<td>47.2%</td>
<td>92.7%</td>
</tr>
<tr>
<td>$200,000 to $299,999</td>
<td>53.3%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

**Source of Data:**
- CHAS Data
- Texas Census Data

**Date:**
- 7/30/2008

**Note:** When using Internet Explorer, please save the file in Excel format.
condition that lasts for more than 6 months that causes difficulty with dressing, bathing, or getting around inside the home.

Mobility or Self-Care Limitations: This includes all households where one or more persons has (1) a long-lasting condition that substantially

Help://social.bu.edu/corp/reportservice/feedbackreport.htm

Source: Tables A1A, A7B, A7C
Testimony of Stephanie Thomas, National ADAPT

Submitted to the Energy and Commerce Committee Subcommittee on Health

January 16, 2008

ADAPT
1640A E. 2nd ST Suite 100
Austin, TX 78702
512/442-0252
www.adapt.org
adapt@adapt.org
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. 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.²

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

---

¹ See appendix for complete list. Or go to www.cms.hhs.gov/MDSPubQIandResRep/
² See the ADAPT website www.adapt.org for a transcript of the entire hearing, or contact me at adapt@adapt.org. Excerpts of the testimony are attached to my written testimony.

ADAPT testimony 1/16/08 p. 3
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 almshouses 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.

ADAPT testimony 1/16/08 p. 5
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

ADAPT testimony 1/16/08 p. 6
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.

ADAPT testimony 1/16/08 p. 8
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 Auburger 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.

ADAPT testimony 1/16/08 p. 11
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

ADAPT testimony 1/16/08 p. 12
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 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.

ADAPT testimony 1/16/08 p. 15
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.

**J.T. 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?

**ADAPT testimony 1/16/08 p. 17**
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
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

ADAPT testimony 1/16/08 p. 20
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

ADAPT testimony 1/16/08 p. 21
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

ADAPT testimony 1/16/08 p. 22
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

ADAPT testimony 1/16/08 p. 23
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

ADAPT testimony 1/16/08 p. 24
disAbility LINK GA Local
LIFE Inc GA Local
Savannah-Chatham 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

ADAPT testimony 1/16/08 p. 25
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

ADAPT testimony 1/16/08 p. 26
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
Vestia 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

ADAPT testimony 1/16/08 p. 27
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

ADAPT testimony 1/16/08 p. 28
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

ADAPT testimony 1/16/08 p. 29
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

ADAPT testimony 1/16/08 p. 30
San Juan CIL NM Local
Gov's Comm on Concerns of/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
Rockland City Commission on Human Rights NY Local
Saratoga County Options for IL NY Local
Southern Tier Independence Center NY Local

ADAPT testimony 1/16/08 p. 31
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 Envrn. 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

ADAPT testimony 1/16/08 p. 32
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 ft 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
TRIPIL PA Local

ADAPT testimony 1/16/08 p. 33
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

ADAPT testimony 1/16/08 p. 34
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 Disabes 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

ADAPT testimony 1/16/08 p. 35
Virginia
Blue Ridge Independent Living Center VA Local
Brain Injury Services Inc VA Local
disAbility Resource Center of the Rappahannock Area VA Local
Independence 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

ADAPT testimony 1/16/08 p. 36
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)

Total Medicaid ------------------ $300.3 billion
Total Long Term Care (LTC) --------- 94.5 billion
LTC - 31.78% of Medicaid

Nursing Homes ------------------ $ 47.24 billion 50.0% of LTC
ICF-MR (public)------------------ 7.54 billion 8.0%
ICF-MR (private)------------------ 4.56 billion 4.8%

Total Institutional --------------- 59.34 billion 62.8%

Personal Care ------------------- $ 8.57 billion
HCBS Waivers ------------------- 22.70 billion
Home Health --------------------- 3.57 billion
Home and Community Services-- .32 billion

Total Community ----------------- $ 35.16 billion 37.2%

HCBS WAIVER BREAKDOWN 2005 BY CATEGORY

Total HCBS Waivers -------------- $ 22.70 billion

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

Numbers are taken from a report by MEDSTAT (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 512/442-0252

ADAPT testimony 1/16/08 p. 38
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