HOME AND COMMUNITY-BASED SERVICES FOR OLDER PEOPLE AND YOUNGER ADULTS WITH PHYSICAL DISABILITIES IN INDIANA

Final Report

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Prepared by:
Jane Tilly and Susan M. Goldenson
The Urban Institute
The Lewin Group

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INTRODUCTION

Indiana, a mid-western state with about 6 million people in 1999,\(^1\) provides home and community services to about 2,300 beneficiaries through its Aged/Disabled Medicaid waiver and an additional 10,000 persons with disabilities through its state-funded Community and Home Options to Institutional Care for the Elderly (CHOICE) program. The Medicaid waiver and the CHOICE program rely on an agency-based model for provision of home care services; with CHOICE providing a particularly flexible set of services. The state also funds two small programs that provide supplemental payments to people in board and care homes.

Medicaid’s role in Indiana’s home and community services system has grown since the mid-1990s because the state views these services as a mechanism for reducing long-run cost growth in the institutional sector. The state received HCFA approval for a total of 12,500 waiver slots in 2003. The state made this request so it could begin to move people off the waiver waiting list but state funds are currently not available to use the newly approved slots. The increased slots will be used should the state shift money from its institutions to its home and community services sector. To date, the state has limited the number of slots it will fund to 2,500.

This paper analyzes the home and community-based service system for older people and younger adults with physical disabilities in Indiana, focusing on the state administrative structure for home and community-based services, eligibility and assessment, services covered by Medicaid and other programs, cost containment and quality assurance. This report also summarizes government officials’ and key stakeholders’ opinions about how well the Medicaid and state-funded programs work.

Information was obtained from public documents, state of Indiana web sites, and interviews with state officials, consumer representatives and provider associations. Interviews were conducted in person in Indianapolis, Indiana, during December 1999. Questions were asked using a structured, open-ended interview protocol. To encourage
candor in their answers, respondents were told that they would not be quoted by name or identified by type of respondent within a state (e.g. home health industry representative in Indiana).

**THE LONG-TERM CARE SYSTEM IN INDIANA**

Indiana has a much higher-than-average supply of nursing home beds and a substantial number of home health agencies. The state had 571 nursing facilities with 63,350 beds in 1998—85.6 beds per 1,000 persons age 65 and over, compared with a national average of 52.5.\(^2\) Probably due to the large supply of beds, Indiana’s nursing home occupancy rate was 76 percent in 1998, well below the national average.\(^3\) In 1998, Indiana had a relatively low supply of nonmedical residential facilities—42 licensed residential facilities with a total of 3,088 beds—4.2 beds per 1,000 persons age 65 and over compared to the national average of 25.5.\(^4\) In the same year, the state had 277 licensed home health agencies.

Indiana’s Medicaid long-term care expenditures (nursing facility, ICF/MR, home and community-based services waivers, and home health) totaled $1.08 billion in fiscal year 1998, nine percent of which were for home and community-based waiver services and home health.\(^5\) Thus, the vast majority of expenditures are for institutional care.

*Chart 1* summarizes the characteristics of Indiana's programs for home and community services. The state uses Medicaid waivers but does not cover the optional personal care service. The aged/disabled waiver was authorized to spend $18.4 million on 2,500 "slots" in state fiscal year 2000.

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### Chart 1: Indiana Medicaid and State-Funded Home and Community Services Programs

<table>
<thead>
<tr>
<th></th>
<th>Aged/Disabled (A/D) Medicaid Waiver</th>
<th>Community and Home Options to Institutional Care for the Elderly (CHOICE)</th>
<th>Residential Care Assistance Program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year program started</td>
<td>1984</td>
<td>1987</td>
<td>1975 – Assistance to Residents in County homes (ARCH); 1976 – Room and Board Assistance Program (RBA)</td>
</tr>
<tr>
<td>Administrative responsibility</td>
<td>Family and Social Services Administration (FSSA) at state level and Area Agencies on Aging (AAAs) at local level.</td>
<td>FSSA at state level, AAAs are single point of entry at local level.</td>
<td>FSSA</td>
</tr>
<tr>
<td>Functional eligibility</td>
<td>People must have difficulty with 3 of 14 ADLs and IADLs.</td>
<td>People must be unable to perform 2 of 14 ADLs and IADLs. CHOICE is funding of last resort after Medicaid.</td>
<td>Must be a resident of an approved residential care facility or a county home; 65+, blind or disabled.</td>
</tr>
<tr>
<td>Financial eligibility</td>
<td>People must be categorically needy or have countable incomes at or below 300% of SSI. Indiana is a 209(b) state with an asset test of $1,500. No spousal impoverishment protections.</td>
<td>Sliding fee scale that requires persons with countable income at or above 351 percent of poverty to pay the full cost of services.</td>
<td>Income must be less than the facility’s rate.</td>
</tr>
<tr>
<td>Number of beneficiaries</td>
<td>Calendar year (CY) 1999: A/D waiver – 2,336 active cases with 48% &lt;65</td>
<td>State fiscal year (SFY) 1998: CHOICE – 9,948 of whom 24% are age 60 - 64 As of January 1999 a waiting list of 5,551 persons.</td>
<td>SFY98: ARCH – 476, RBA - 1005</td>
</tr>
<tr>
<td>Funding source</td>
<td>Medicaid</td>
<td>State funds</td>
<td>State funds</td>
</tr>
<tr>
<td>Expenditures (FY00)</td>
<td>SFY2000: A/D waiver has 2,500 slots and $18.4 million available.</td>
<td>SFY2000: CHOICE - $46.7 million</td>
<td>SFY1998: ARCH - $3.03 million, RBA- $6.36 million</td>
</tr>
<tr>
<td>Covered services</td>
<td>Case management, homemaker, attendant care, respite, home modifications, adaptive aids and devices, adult day care, and home delivered meals</td>
<td>Case management, home health supplies and services, attendant care, homemaker, respite, meals, adult day care, transportation, other necessary services.</td>
<td>Pays for facility charges exceeding residents’ income and give residents a personal needs allowance.</td>
</tr>
<tr>
<td>Consumer-direction</td>
<td>None</td>
<td>Very limited. Each AAA must set up consumer-direction pilot programs.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Cost containment mechanisms</td>
<td>The Bureau of Aging and In-Home Services in FSSA reviews plans of care for cost-effectiveness. Waiver had a waiting list of 734 persons in January 1999. Caps on waiver services, with reimbursement rates ranging from $8 an hour for a homemaker to $30 for an RN. Group average waiver cost plus other Medicaid costs cannot exceed the average statewide nursing home per diem rate for skilled or intermediate care.</td>
<td>Cost-sharing for services based on a sliding fee scale. Providers have to competitively bid for CHOICE contracts with AAAs CHCIE had a waiting list of 5,561 persons in January 1999.</td>
<td>Not available</td>
</tr>
<tr>
<td>Quality assurance mechanisms</td>
<td>Case managers must review plans of care quarterly. The Dept. of Health annually surveys home health agencies. A random sample of at least 10% of participants completes a consumer satisfaction survey.</td>
<td>Case manager must have regular contact with beneficiary, within 90 days of implementation of care plan and periodically as agreed upon with beneficiary. Case managers visit participants in their homes annually.</td>
<td>Not available</td>
</tr>
</tbody>
</table>
CHOICE is a state-funded program designed to complement Medicaid with more flexible services and more generous eligibility standards. Although primarily a program for older persons, 20 percent of program funds are spent on younger persons with disabilities. CHOICE served about 10,000 people of all ages in state fiscal year 1998 at a cost of $31.7 million; the program has $46.7 million available in state fiscal year 2000. CHOICE is by far the largest program serving adults with disabilities and is popular among advocates because the program has flexible services and no means test. The program's popularity has helped it achieve higher levels of funding than Medicaid-funded home and community services despite the fact that it receives no federal matching funds.

In addition to CHOICE, Indiana has two small, state-only-funded programs that help subsidize the costs for persons who live in group residential settings and are aged, blind, or disabled. The programs, which are components of the Residential Care Assistance Program (RCAP), served about 1,500 residents at a cost of about $9.4 million in state fiscal year 1998.

Indiana, unlike many other states, has a two-decade long history of consumer groups uniting to advocate for expansion of home and community services. The Home Care Task Force, a consumer coalition, is composed of groups representing older persons, unions, teachers, people with disabilities, and others. Many observers credit the Task Force for passage of the large state-funded CHOICE program in 1987 and its continued expansions.

**ADMINISTRATIVE STRUCTURE**

The IN-Home Services Program housed within the Family and Social Services Administration (FSSA), administers all home and community services for older persons and younger adults with physical disabilities, including Medicaid benefits. The FSSA’s Medicaid Waiver Unit, which is part of the IN-Home Services Program, administers four waivers, among them the aged/disabled waiver. A separate Office of Medicaid Planning and Policy within FSSA sets overall policy for the waivers. In addition to housing the Medicaid aged/disabled waiver, the IN-Home Services Program administers CHOICE.
The IN-Home Services Program contracts with Area Agencies on Aging to serve as the single-points-of-entry for administration of all home and community services programs at the local level, including those for people with mental retardation or developmental disabilities. State staff and stakeholders report that there is local variation in how the state’s 16 Area Agencies on Aging operate the home and community services programs. For example, each agency gets its own "pot" of CHOICE money and is the decision-maker regarding use of funds. Application of certain state Medicaid requirements varies among Area Agencies on Aging.

**ACCESSING THE SYSTEM**

The state has few active outreach efforts for the aged/disabled waiver and CHOICE because the programs have extensive waiting lists, but the state maintains a web site that describes all waivers and will expand it in 2000 to include a list of providers, case manager qualifications, and manuals for providers and case managers. Area Agencies on Aging are linked to a statewide toll-free number that consumers can use to get information about services.

The state’s 16 Area Agencies on Aging, each with their own catchment area, serve as the single-point-of-entry for the long-term care system by performing functional assessments with a uniform tool, providing case management, and doing pre-admission screening for all nursing home applicants. State staff said that Indiana’s single-point-of-entry is a national model, with 28 states having come to observe it. Each agency has a liaison who works with the state Medicaid waiver unit when issues arise and relations are said to be good between agencies and the waiver unit.

When an applicant is authorized to receive services through the waiver or CHOICE, the case manager writes the service plan, and brokers services. When a person receives a Medicaid waiver slot, he or she can choose a private case manager. Most older persons and younger adults with physical disabilities do not choose private case managers. CHOICE beneficiaries do not have the option of choosing a private case manager. The effectiveness of case managers reportedly varies among the Area Agencies.
on Aging, with some case managers needing more training. Low pay for these professionals is said to cause high turnover rates.

Medicaid funds Indiana’s pre-admission screening program, which is required for all nursing home applicants regardless of payment source. The program screened 40,265 persons in state fiscal year 1998. One stakeholder argued that screening for nursing home placement is unnecessary paperwork that does not divert applicants from facilities because people only apply when they really need that type of care.

**ELIGIBILITY CRITERIA AND ASSESSMENT**

Functional eligibility for the Medicaid aged/disabled waiver and CHOICE is very broad. To be eligible for the waiver, adults must have difficulty with three of 14 activities of daily living and instrumental activities of daily living (ADLs and IADLs); for CHOICE the standard is two of 14 activities. However, stakeholders claimed that some Area Agencies on Aging do not approve waiver services for beneficiaries who are capable of leaving their homes, even with help. State officials say that Medicaid has no homebound requirement for waiver services.

Medicaid’s financial standards are quite low. For example, Indiana is a "209(b)" state and limits financial assets to $1,500 rather than $2,000 as in most other states. In addition, institutional spousal impoverishment protections are not extended to spouses of waiver beneficiaries. Many stakeholders complained about the restrictive nature of Indiana’s Medicaid financial eligibility requirements.

In contrast, CHOICE relies on an income-related cost-sharing system where beneficiaries with countable incomes at or below 150 percent of the federal poverty level pay nothing for services and beneficiaries with incomes at or above 351 percent of the federal poverty level bear the full cost of services. Thus, beneficiaries are not prevented from accessing services if they have moderate incomes.

**CASE MANAGEMENT AND SERVICE PLANNING**

Case managers are required by state policy to involve consumers and caregivers in the assessment process and to make care plans “person-centered.” That is, case
managers are supposed to negotiate the service plans with the beneficiary and caregiver with the goals of keeping people at home and maintaining the current level of informal support. State officials report that case managers are not instructed to try to increase informal support because caregivers can become overburdened and burn out. State staff said that older persons do not necessarily have preferences for services and often go along with case managers’ recommendations about what they need. One stakeholder complained that person-centered planning does not occur in some Area Agencies on Aging.

The typical case manager has a caseload of 25 to 30 participants but the number varies among the area agencies, and can be as high as 50 to 60 people. Case managers who specialize in a particular type of disability (e.g., traumatic brain injury) may have a high number of participants because case managers with special expertise are hard to recruit. This is complicated by job descriptions that require case managers to have expertise with the populations they will serve before starting employment.

Views of the state’s case management system varied. Most stakeholders said that the case management system is one of the best parts of the state’s home and community services system for adults with disabilities. State staff contended that case managers are very resourceful in terms of leveraging community services, such as those available from charitable organizations, to meet the needs of beneficiaries. One stakeholder’s remarks supported the contention that case management is working well by saying that case managers are dedicated, know the care system, and are well trained. However, two stakeholders argued that case management systems vary among the Area Agencies on Aging with some case managers lacking the training to do their jobs properly.

SERVICES

The aged/disabled waiver and CHOICE have a similar, relatively broad list of services including case management, homemaker, attendant care, respite, adult day care, and home delivered meals. Neither program covers services in nonmedical residential facilities, such as adult family homes or assisted living facilities. In addition, CHOICE
covers transportation and a category of service called “other necessary services.” This category, according to stakeholders, enables CHOICE to provide virtually any service that a person needs to stay at home. Examples of these services included vermin eradication and Russian translation. Flexibility is seen as a key factor in the popularity of CHOICE and many stakeholders want to see the Medicaid waiver programs have similar flexibility. State staff report that about 25 percent of aged/disabled waiver participants also receive CHOICE because they need services the waiver does not cover.

Waiver services with the highest use were case management, homemaker, and attendant care (i.e., personal care) services. State staff said that personal care is the most widely used waiver service and attendants may accompany people outside the home. Medicaid policy allows attendant services to be delivered in the work place, but the waiver does not offer habilitation nor is it designed to return people to work. Rather, state staff added, the waiver is designed primarily for the older population. Area Agencies on Aging can refer the younger population to a separate vocational rehabilitation program.

Stakeholders believed that waiver services should be expanded in two ways: 1) increase the amount of hours of personal assistance because “beneficiaries are lucky to get six hours a day,” and 2) add services such as transportation and companion services. Most observers agreed that the most important change to the waiver would be the addition of an “other” category that would extend the type of flexibility that CHOICE has.

The state role in-group residential settings for the adult population with disabilities is limited to two small, state-funded programs. The state formed several workgroups to consider expanding Medicaid waiver coverage to assisted living facilities. Most stakeholders are supportive of this effort because people would have more options that would enable them to remain independent in the community, but this option is still under discussion by state officials.

State staff and stakeholders’ views of which group fares best in Indiana varied. Some said that because of the strength of the developmental disabilities lobby, that
population gets better treatment and access to increased funding, but another stakeholder said that the population with developmental disabilities is underserved and too many people are in institutions. Some stakeholders said that the aged/disabled waiver gets more slots than the other waivers and that there are few slots for those with mental retardation, developmental disabilities, and autism.

**CONSUMER DIRECTION**

State staff report that aged/disabled waiver and CHOICE beneficiaries can choose among home care agencies and most agencies are responsive to consumer preferences when possible. However, one consumer advocate complained that beneficiaries do not get enough information about their rights to choose a provider nor do home care workers receive training to promote responsiveness to consumer preferences.

A number of years ago, nine of 16 Area Agencies on Aging used CHOICE funds to permit beneficiaries to hire and fire their own workers. However, after a U.S. Internal Revenue Service ruling that might have required area agencies to treat these workers as employees, the number of agencies offering this option dropped to three. Some stakeholders reported that the 1999 Indiana legislature proposed mandating the offer of consumer-direction in all Medicaid and CHOICE programs, but the executive branch convinced the legislators to authorize a CHOICE-based pilot program instead. State officials were concerned that consumer-direction would create risks for beneficiaries. Most Area Agencies on Aging have been reluctant to implement the pilot program because they believe case managers’ would have additional burdens related to monitoring individual workers and because of fears of being held liable for individual workers’ injuries on the job or delivery of poor quality care. There are also concerns about workers not showing up when scheduled and the attendant risks to beneficiaries.

Stakeholders’ had varying views of consumer-direction. State staff said that consumer-direction should be permitted if it does not increase total program costs. One stakeholder believes benefit dollars would go farther under consumer-direction because payment rates for individual workers would be lower than rates for agency services and workers would “listen more to consumers.” Stakeholders representing participants
generally support consumer-direction but point out some possible downsides including: older persons not being capable of or wanting to take on the administrative burden associated with consumer-direction, beneficiaries being put at risk of fraud and abuse, and a lack of backup workers in an emergency. Some stakeholders argued that consumers should be able to choose between agencies and independent workers but all attendants should be subject to the same certification or training requirements. Currently, training requirements for home health agency workers are more stringent than for individual workers.

**COST CONTAINMENT**

Most stakeholders believe that home and community services receive inadequate funding in Indiana but views differ about how the budgetary process works for these services. Some state staff and stakeholders believe that the Medicaid aged/disabled waiver and the CHOICE programs are more vulnerable to funding cuts than nursing home services, because the former are tied to individual line items in the state budget while the latter are included in Medicaid’s line item in the budget. However, other state staff said that CHOICE, which transfers some of its funds to the aged/disabled waiver each year, realizes funding increases every year because of the program’s political popularity.

Indiana uses waiting lists to contain costs for the aged/disabled waiver and CHOICE, which combined had 6,300 people awaiting services in January 1999. In addition, providers have been conscious of costs as they competitively bid for CHOICE contracts with each Area Agency on Aging.

A stakeholder noted that, as a result of the Balanced Budget Act of 1997 payment changes to Medicare home health agencies, the waiting list for CHOICE has doubled in the last several years, extending waiting times up to 22 months. It is now very hard to use Medicare benefits to get people through the CHOICE waiting period.

Medicaid contains waiver costs by targeting services to those at high risk of institutionalization and by monitoring the cost of care plans. Medicaid program staff receive a weekly report on service plans, review them based on benchmarks for plan
costs, and discuss them with area agency staff if the plans seem overly expensive. The area agencies are asked to reevaluate high cost plans to determine if costs can be reduced, but there is no absolute cap on the cost of an individual beneficiary’s services.

Another method of controlling costs is controlling provider payment rates. Medicaid sets maximum statewide rates for home health agency services, but the cost containment effect of these payment rates is minimal because the Medicaid home health expenditures are small. The state sets prospective payment limits for waiver services, with consumer advocates reporting that waiver payment rates are too low to attract a sufficient number of providers to the program. Two other stakeholders reported that providers are dropping out of Medicaid because rates have not been raised for years and, as a result, some rural areas have difficulty enrolling providers.

Another major deterrent to provider participation in Medicaid is the billing system, which has payment delays of as much as 11 months, according to some stakeholders. Two observers claimed that the fiscal intermediary makes data entry errors, does not answer the phone, and then closes the books if payments are not made within 12 months. In defense of the fiscal intermediary, state staff indicated that many late payments are due to providers not following procedures. In these cases, a state provider relations specialist is available to troubleshoot billing problems.

QUALITY ASSURANCE

Different quality assurance systems exist for licensed home health agencies and for unlicensed agencies and independent workers. Home health agency workers must be certified and agencies licensed, but these requirements do not apply to agencies that only provide personal care. All agencies are expected to provide some type of training to workers and perform criminal background checks. One observer complained that home health agency standards are too rigid and that state regulations are poorly written.

Area Agencies on Aging have a central role in assuring quality for the aged/disabled waiver and CHOICE. These agencies must take a random sample of at least 10 percent of all waiver beneficiaries and conduct a consumer satisfaction survey, with some Area Agencies on Aging including all beneficiaries. The survey involves area
agency on aging staff going into beneficiaries’ homes and asking a series of questions related to worker skills, timeliness, and continuity and case managers’ treatment of beneficiaries. The survey results are aggregated and fed back to the provider agencies and Area Agencies on Aging staff who reportedly receive them enthusiastically. State staff have future plans to give consumers a report card on providers. A troubling note is that one stakeholder said that provider staff often serve as proxies for consumers in responding to the surveys, creating an obvious conflict of interest and making the data less useful.

In addition to the consumer satisfaction survey for waiver beneficiaries, case managers contact Medicaid waiver beneficiaries quarterly and CHOICE participants annually to determine their perceptions of their service providers. Two stakeholders reported that case managers only monitor quality for CHOICE participants during annual home visits.

Case managers also respond to waiver and CHOICE beneficiary complaints. If the case managers find problems, providers first receive a letter advising them of the problems. If the provider does not respond, a second letter is sent. Case managers and providers negotiate action plans to correct problems. If there is beneficiary abuse, then the case is referred to Adult Protective Services and immediate action is supposed to be taken. One stakeholder said that “no one knows what happens to complaints when they are filed with Adult Protective Services.” As a last resort, providers can be de-certified.

Stakeholder views of quality varied. One stakeholder alleged that neglect is common in the aged/disabled waiver. Reportedly, agency workers often do not show up and people are afraid to complain because they fear agencies will retaliate by not providing staff to assist them. Some observers said that the labor shortage has reached the crisis stage and is affecting quality because people are not showing up to provide services. Proposals to extend the nursing home ombudsman program to home and community services were viewed by some as an effective way of improving quality.

Financial fraud is not reported to be a major problem and could be discovered in several ways. State staff said that the Medicaid program relies on case managers to find
financial fraud. Staff from one Area Agency on Aging said that it conducts a monthly audit to ensure that authorized services are delivered and estimates that providers have a 70 percent compliance rate in terms of delivering the services the care plan authorizes. The Area Agency on Aging also learns about fraud from participants. When problems are identified, they are referred to the fiscal intermediary for action. Reportedly, the state’s utilization review program rarely audits home health agencies because the program focuses primarily on “big ticket” items by targeting audits to the largest providers. Another stakeholder claimed that the fraud detection system does not work because no response was made to this individual’s complaint.

FEDERALISM ISSUES

State staff said that HCFA is trying to work well with the states and that there are not any major federal regulatory barriers to operating the home and community services programs. State staff and stakeholders did make a several suggestions for program improvement. These include:

1. Home and community services should be an option that can be exercised via a state plan amendment. There should be an entitlement to long-term care in the most appropriate setting, including institutions. Waivers should only be necessary for pilot projects.

2. The waiver approval process is said to be resource intensive. Responding to questions is time-consuming for staff, and each phase seems to take a great deal of time to complete. The state receives inquiries from HCFA on waiver applications at the end of the 90 day comment period.

3. State staff wanted more specificity regarding desired national outcomes for waiver programs.

4. The HCFA requirement that each waiver "slot" be used only once in a year should be eliminated.
ISSUES FOR THE FUTURE

Indiana has a long-term care system that provides a very generous array of home and community services, the most flexible of which is an “other” category under CHOICE, which permits case managers to arrange for virtually any service a beneficiary needs to remain at home. CHOICE is also extraordinary because it has no means test and has over $40 million in state funds. Stakeholders praised CHOICE, particularly for the flexibility of its services. In addition, Indiana has a single point of entry for all persons entering the state’s home and community services system that many states have studied.

In contrast, the state’s Medicaid program has unusually tight financial eligibility requirements, and a standard set of home and community services. Indiana’s Medicaid program stands out in that only nine percent of its long-term care expenditures are devoted to home and community services. The corresponding figure for the U.S. was 28.4 percent.\(^6\)

The state’s challenges for the future include addressing the imbalance in Medicaid funding and building on the popularity of the state-funded CHOICE program. Most people interviewed agreed that future expansions in Medicaid will be incremental but some government staff want to add services to make waivers more flexible, such as providing home modifications, habilitation, rehabilitation, assisted living, and companionship services. They believe expanding the Medicaid waivers would maximize federal funding and lead to shorter waiting lists for the waiver programs and CHOICE. Some observers said that younger adults with disabilities are becoming more active politically and will be able to influence future developments to a greater degree than in the past.

State staff reportedly view the Supreme Court's Olmstead decision as a chance to promote choice for people with disabilities. The decision is considered one more step in recognizing that the state has an obligation to provide community-based alternatives to people with disabilities.

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\(^6\) Urban Institute estimates (2000) based on data from HCFA-64 reports.