

**Services and Supports for Missouri's Citizens with
Developmental Disabilities: An Update**

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Introduction

This report updates facts and figures that were contained in the 1997 HSRI report: *Services and Supports for Missouri's Citizens with Developmental Disabilities: Where the Dollars Come From and Go To*. There are some differences in the data sources employed in the preparation of this update than in the original report. This report starts with the 1997 report as the base and examines Missouri's performance in supporting its citizens with developmental disabilities over the ensuing five-year 1998 – 2002 period.

Broadly, the updated figures reveal that, between 1998 and 2002, there was some degradation in Missouri's performance in underwriting services and supports for people with developmental disabilities. In 1997, Missouri's overall level of financial effort fell in the mid-range when compared to all states. Missouri's budget – like that in most other states – has been adversely affected by the nationwide recession. The effect was to halt the growth in the real resources available in Missouri to pay for developmental disabilities services. In addition, while Missouri made some progress in reducing its above average reliance on state institutional services, in 2002 Missouri still exceeded the nationwide norm for such services. Along other lines, Missouri's performance in promoting other types of valued supports for people with developmental disabilities did not improve appreciably during this period.

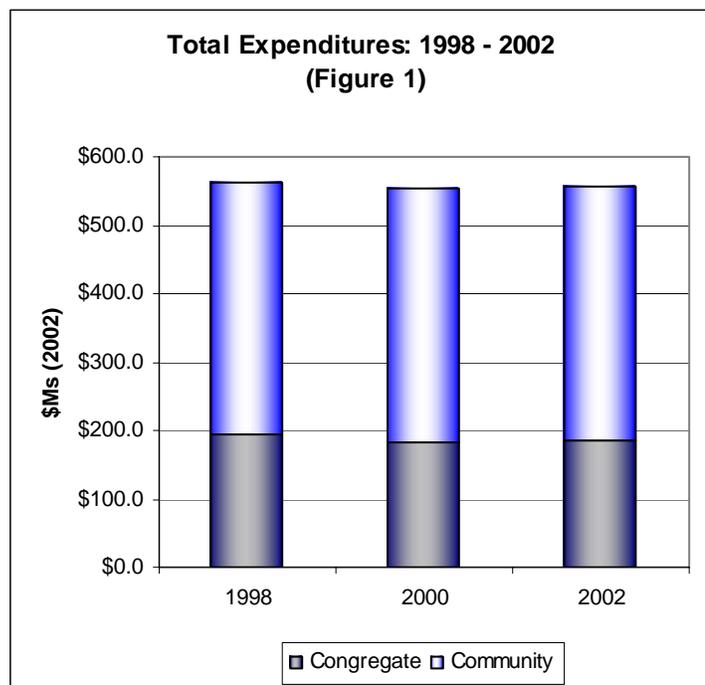
At the same time, it is important to acknowledge that more recently the state has announced initiatives to reduce the number of individuals served at the Habilitation Centers and reduce its growing backlog of persons who have been wait-listed for community services. These steps will contribute to improved performance in the future.

Overall Funding for Developmental Disabilities Services

Trends in Overall Expenditures¹

From 1990 through 1997, the dollars earmarked for developmental disabilities services in Missouri increased by about 50%, after adjustment for inflation. This strong rate of growth was spurred mainly by the expansion of Missouri's Medicaid Home and Community-based Waiver programs (HCBS) for people with developmental disabilities. The expansion of the HCBS waiver program permitted Missouri to leverage increased federal funding for services.

However, as Figure 1 shows, between 1998 – 2002 Missouri's overall developmental disabilities funding remained essentially unchanged after



¹ The figures in this section are based on: Mary C. Rizzolo, Richard Hemp, David Braddock, and Amy Pomeranz-Essley (2004). *The State of the States in Developmental Disabilities*. Washington DC: American Association on Mental Retardation.

taking inflation into account.² This means that the overall amount of resources available for developmental disabilities services neither increased nor decreased during this period. Expenditures for congregate services (i.e., services in facilities that serve 16 or more persons) declined slightly during this period while spending for community services (e.g., community residences, day programs and family support) increased by roughly one percent. In contrast, nationwide, total spending for developmental disabilities services in the same period increased by about 24% in real dollar terms. Except for Kansas, funding for developmental disabilities services in the states surrounding Missouri increased in real dollar terms during this period, although the amount of the increase varied from state-to-state.

Missouri's Level of Effort

In 1997, Missouri's expenditures for developmental disabilities services fell about in the mid-range of all states when measured in terms of "fiscal effort".³ By 2002, however, Missouri's fiscal effort had slipped to 12% below the nationwide average. In 2002, Missouri's overall fiscal effort ranked 35th among the states. When Missouri's level of effort is measured in this fashion, from 1998 to 2002, Missouri's performance deteriorated relative to other states.

"Outlays per citizen"⁴ is another way to measure the strength of a state's financial support for developmental disabilities services. By this measure, Missouri's expenditures for developmental disabilities services declined by 5.2% between 1998 and 2002, falling from \$103.59 per citizen to \$98.25 per citizen, again after adjusting for inflation. This decline occurred because expenditures for developmental disabilities services in Missouri did not keep pace with population growth. Since the demand for developmental disabilities services follows underlying population trends, deterioration in this measure means that Missouri's system lost ground in its capability to serve its citizens with developmental disabilities. For reference, in 2002 nationwide outlays per citizen for developmental disabilities services were \$120.77 per citizen or about 23% greater than the level in Missouri.⁵ In general, other states have made more resources available to serve their citizens with developmental disabilities than Missouri.

In 2002, then, compared to other states, Missouri made fewer dollars available to support its citizens with developmental disabilities, however measured. From 1998 to 2002, Missouri's overall total funding for developmental disabilities services remained largely unchanged after adjusting for inflation, but actually declined when measured against population.

Broad Distribution of Expenditures

In 1997, about 37% of Missouri's developmental disabilities expenditures were devoted to congregate services, principally at the Habilitation Centers. By 2002, the proportion of spending earmarked for congregate services in Missouri had declined to about 33%. Nationwide, 22% of total developmental disabilities expenditures underwrote congregate/ institutional services, a significantly lower percentage than was the case in Missouri. In order to match the nationwide

² "Adjusted for inflation" means that the dollar figures are expressed in 2002 dollars by adjusting the pre-2002 figures to take into account increases in the costs of furnishing services.

³ "Fiscal effort" is measured by dividing developmental disabilities expenditures by total state personal income. This measure of financial performance takes into account differences in the relevant economic well-being of states.

⁴ Total expenditures divided by total state population.

⁵ The difference between Missouri and the nationwide average is potentially overstated because general wages are lower in Missouri than the nation. Due to this labor cost differential, a dollar purchases more services in Missouri than elsewhere because labor is the principal cost of furnishing developmental disabilities services. Still, when broad wage measures are used to adjust the figures to take this difference into account, Missouri's outlays per citizen were still 12% below the nationwide average in 2002.

distribution of expenditures, Missouri's congregate/institutional spending would have had to have been one-third lower in 2002 and its spending for community services about one-sixth greater.

Sources of Funding

In 2002, there was relatively little difference in the sources of funding that underwrote developmental disabilities spending in Missouri than in 1997. In 1997, federal Medicaid dollars accounted for about 44% of Missouri's developmental disabilities expenditures;⁶ in 2002, they accounted for almost the same proportion. Compared to 1997, the share of expenditures underwritten by Missouri tax dollars was about one percent greater in 2002 and the proportion paid for with local tax dollars (through S.B. 40 Board mill levies) was a little less.

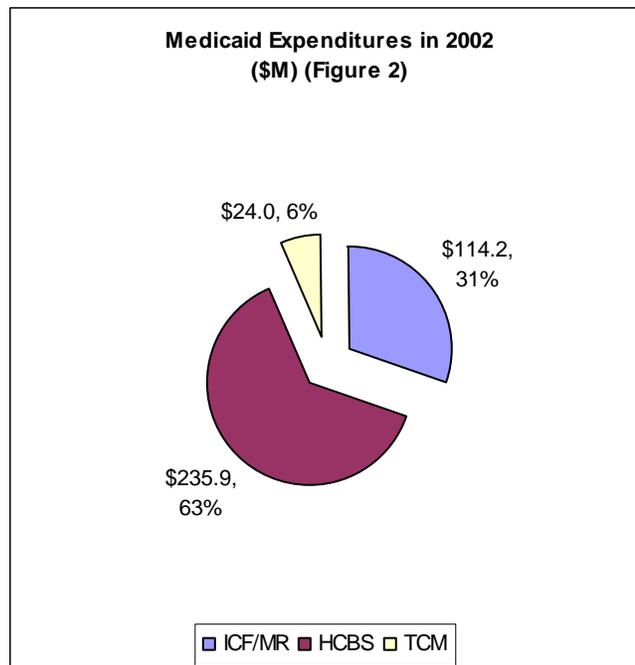
Trends in Medicaid Funding and Services⁷

As in other states, Medicaid plays an enormously important role in underwriting services and supports for people with developmental disabilities in Missouri. In 1997, total Medicaid spending for developmental disabilities services was approximately \$280 million. In Missouri, Medicaid underwrites:

- ICF/MR services at the Habilitation Centers and a few community facilities;
- Community residential and day services that are provided through Missouri's Medicaid home and community-based services (HCBS) waiver programs; and,
- Case management services that are furnished by the state Regional Center personnel and a growing number of the S.B. 40 boards.

As previously noted, the expansion of Missouri's waiver program played a linchpin role in financing the significant increase in Missouri's overall expenditures for developmental disabilities services during the first part of the 1990s.

In 2002, total Medicaid spending for developmental disabilities services was \$374 million, about 10% greater than 1998, after adjusting for inflation. As Figure 2 shows, 63% of Medicaid spending purchased Medicaid waiver services. Between 1998 and 2002, HCBS waiver program spending increased by about 24%, adjusted for inflation. ICF/MR expenditures declined by 8.2% in real dollar terms. Case management spending (through Missouri's coverage of Targeted



⁶ Excluding consumer SSI funds and miscellaneous other sources.

⁷ The figures in this section are based on: Robert W. Prouty, Gary Smith, and K. Charlie Lakin (eds.). *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002*. Minneapolis MN: University of Minnesota, Research and Training Center on Community Living.

Case Management (TCM) services under the Medicaid state plan) increased slightly between 1998 and 2002.

In 1997, Missouri was noteworthy because it devoted a greater share of its Medicaid funding to HCB waiver services than was the case nationwide. The HCBS waiver program affords states greater opportunities to cost-effectively furnish flexible supports to people with developmental disabilities than is possible through the ICF/MR program. This was still the case in 2002. Nationwide, in 2002, Medicaid spending for ICF/MR and HCB waiver services totaled \$24.1 billion. Some 55% of that amount was expended for waiver services. The comparable figure in Missouri was 67%.

While Missouri's 2002 expenditures for ICF/MR and HCB waiver services were substantial, in combination they were lower than the nationwide level. On an outlays per citizen basis, Missouri's Medicaid expenditures for developmental disabilities services were \$61.72/citizen versus \$83.61/citizen nationwide. Considering only waiver services, Missouri's expenditures were \$41.59/citizen versus the U.S. average of \$46.34. Missouri's relatively low level of Medicaid expenditure effort parallels and is an outgrowth of its relatively low overall level of financial effort in funding developmental disabilities services.

In 1997, approximately 7,800 Missourians with developmental disabilities received either ICF/MR or HCB waiver services. By 2002, this number had increased to 9,541 persons. However, the number of persons receiving these services did not change appreciably after 1998. In 2002, Missouri furnished ICF/MR and HCB waiver services in combination at a rate relative to its state population of 168.2 persons per 100,000 population. In 2002, the comparable nationwide average was about the same – 169.6 persons per 100,000. In 1997, the population-indexed rate at which Missouri furnished Medicaid services was significantly greater than the nationwide rate. However, in recent years, other states have expanded Medicaid services (especially via the HCBS waiver program) at a substantially faster pace than Missouri. In 2002, Missouri continued to serve a greater percentage of individuals who receive Medicaid funded services through the HCBS waiver program (85%) than was the case nationwide (77%).

In 2002, Missouri expended \$28,487 per HCBS waiver participant or about 75% of the nationwide average of \$37,816 per participant. In inflation-adjusted dollars, Missouri's expenditure per waiver participant was nearly exactly the same in 2002 as it was in 1998. Also, in 2002, Missouri expended \$83,390 per ICF/MR resident versus the nationwide average of \$95,746 per resident. Here again, expenditures per ICF/MR resident in Missouri were nearly the same in 2002 as in 1998, again after adjusting for inflation.

When the HCBS waiver and ICF/MR programs are combined, Missouri expended an average of \$36,276 per Medicaid beneficiary for these services. Nationwide, the comparable figure was \$51,781, or about 43% higher. Missouri's costs are lower than the nationwide average for two reasons: (a) a greater proportion of Medicaid beneficiaries receive services through the more economical HCBS waiver program than in ICFs/MR, and (b) Missouri's per beneficiary expenditures in both programs are below the nationwide norms.

During the period 1998 to 2002, Missouri did not significantly expand Medicaid ICF/MR and HCBS waiver services for persons with developmental disabilities. While total expenditures increased by about 10%; there was little change in the total number of people who received

these services after 1998. Going forward, federal approval of the Community Support Waiver will permit Missouri to increase the number of waiver participants. Another factor that will contribute to the expansion of Medicaid funded services are the ongoing efforts to leverage S.B. 40 local tax dollars through the HCBS waiver program to support more individuals.

Going forward, the HCBS waiver program continues to represent the best available opportunity for Missouri to acquire increased federal dollars to meet the needs of its citizens with developmental disabilities in the community.

Utilization of Medicaid Nursing Facility Services

In 1997, we noted that the number of individuals with developmental disabilities in Missouri served in Medicaid-funded general purpose nursing facilities was well above the nationwide norm. Except when utilized for post-hospitalization stays, nursing facilities are not appropriate settings for persons with developmental disabilities. In 2000, there were approximately 1,100 individuals with developmental disabilities served in general purpose nursing facilities in Missouri. In 2002, Missouri's rate of utilizing nursing facility services for persons with developmental disabilities was 19.5 persons per 100,000 in the general population. This rate was 58% greater than the nationwide rate of 12.3 persons per 100,000 in the general population.

Trends in Services and Supports

In this section of the report, various figures are reported concerning the extent of Missouri's services and supports for its citizens with developmental disabilities, both overall and by type of service.

Total Number of Persons Receiving Services⁸

For 2002, Missouri reported that it furnished services to 17,751 persons with developmental disabilities through the DMRDD specialized service delivery system, not counting individuals who received only case management services. This means that Missouri furnished services at the rate of 312.9 persons per 100,000 in the general population. Missouri's rate was slightly above the nationwide average of 303.5 persons per 100,000 in the general population. Missouri's performance in this regard was on a par with or better than most of its neighboring states except Kansas where 421.5 persons per 100,000 in the general population received services.

The period 1998 through 2002 saw the "consumer counts" in the Regional Center system grow substantially, increasing from approximately 23,000 individuals to almost 30,000.⁹ The number of persons who received services increased from about 13,000 to almost 17,000. Like other states, Missouri has been experiencing a surge in the number of individuals coming forward for services. This surge in demand first began to evidence itself in Missouri during the early 1990s and has continued since. In Missouri – as elsewhere – there is a large gap between the total number of persons with developmental disabilities in the population (about 1.6 – 1.8% of the general population have developmental disabilities according to national prevalence figures) and the number of individuals who receive services and supports (a little over 0.3%). In 2002,

⁸ *Ibid.* The figures in this section do not account for individuals who receive services outside the DMH/DMRDD system.

⁹ Division of Mental Retardation and Developmental Disabilities (2003). *Data and Statistics*.

Missouri served about the same percentage of the population with developmental disabilities as the nation as a whole, although there are several states where the gap was less wide.¹⁰

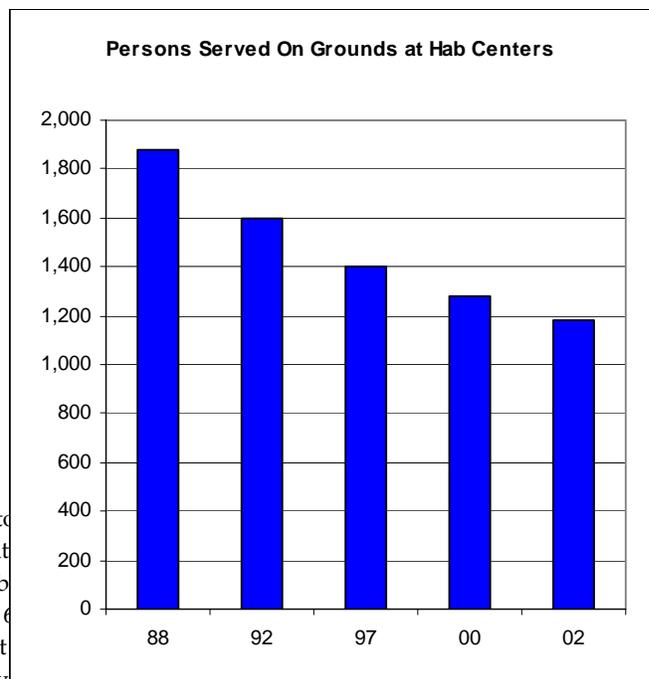
In 1997, it was not clear exactly how wide the gap in Missouri was between the number of people with developmental disabilities who received services and the number who were actively seeking services but had to be wait-listed for them. Today, Missouri has more solid figures about the size of this gap. In December 2003, there were 384 individuals wait-listed for residential services and an additional 2,335 persons wait-listed for in-home services.¹¹ Consequently, although the total number of individuals served through the DMRDD service system grew between 1998 and 2002, the growth was insufficient to meet expressed demand for services.

To the extent that the experiences of other states can serve as a barometer for Missouri, going forward Missouri will continue to experience substantial growth in the demand for developmental disabilities services. The appropriation of \$5 million in state funds in 2004 to reduce the waiting list for services is a step in the right direction for addressing this growing demand. However, unless Missouri's funding for developmental disabilities services grows at a rate that at least matches state population growth (which it did not in the period 1998 – 2002), the state will find itself with an ever growing gap between the capacity of its service system and the demand for services. Closing this gap will require making up for the lack of funding growth relative to population during the 1998 – 2002 period. Going forward, it is unlikely that Missouri will bring system capacity into alignment with expressed, legitimate service demand unless the capacity of its service system expands to the point where the system is serving at least 400 persons per 100,000 in the general population or about 30% greater than the 2002 rate.

Habilitation Center Services¹²

In 1997, Missouri differed markedly from other states in terms of the relative number of individuals who were served at its state-operated Habilitation Centers. While the number of people served at these facilities had declined appreciably since 1990, Missouri still served relatively more individuals at the Centers than was the norm in other states.

Between 1997 and 2003, the overall number of persons served at the Habilitation Centers dropped by about 5% as illustrated by Figure 3. However, not all persons served by the Habilitation Centers are served on the grounds of the facilities; some are served in community-based settings. The number of persons served "on the grounds" of the Habilitation Centers has continued to decline since 1997, dropping 15.4% between 1997 and 2002 as illustrated in the accompanying chart on the following page. Nationwide, the number of individuals served in these types of



¹⁰ For example, in California where there is an entitlement to 100,000 in the population received specialized development

¹¹ Division of Mental Retardation and Developmental Disabilities. *Need*. The figures cited above do not include an additional 600 residential services sometime in the future rather than right

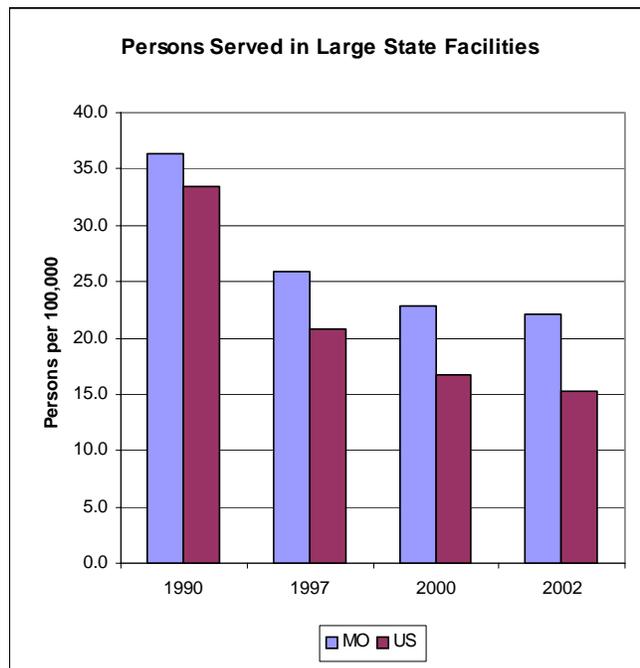
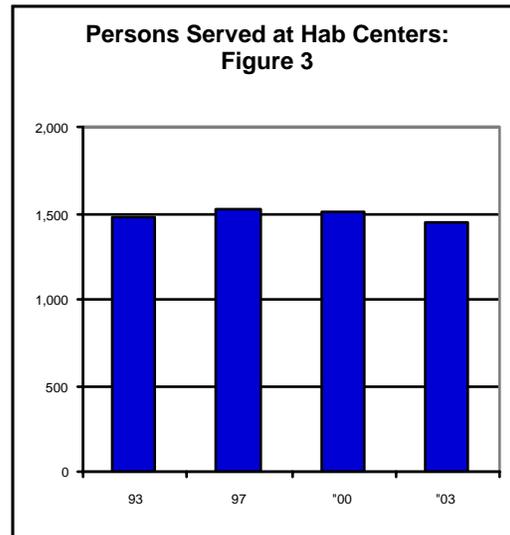
¹² The material in this section relies on the data compiled by

facilities dropped by about 21% during the same period. In light of the 1999 U.S. Supreme Court's *Olmstead* decision, Missouri made some headway in reducing its use of institutional services for people with developmental disabilities.

Still, in 2002, the rate at which people were served on the grounds of the Habilitation Centers continued to be well above the nationwide norm, as illustrated in the next graphic. In 2002, nationwide 15.3 persons per 100,000 in the population were served in facilities like those on the grounds of the Habilitation Centers. In Missouri, the comparable figure was about 37% higher – 20.9 persons per 100,000 in the general population. Historically, Missouri has utilized state institutions at a higher rate than most other states, although some of its neighboring states (e.g., Arkansas and Illinois) used institutional services at a greater rate than Missouri in 2002.

Until recently, Missouri has not had a solid plan regarding the future role of the Habilitation Centers in its overall developmental disabilities system. However, plans have been announced to reduce Habilitation Center census levels by 225 persons by FY 2006 and consolidate operations at some of the Centers.¹³ This plan provides for vacating some substandard facilities at the Habilitation Centers and, thereby, avoiding the expenditure of additional capital funds. Should this plan be carried out as envisioned, then Missouri's utilization of state institutional services will come into better alignment with the 2002 nationwide norm and aid Missouri in coming into better compliance with the principles laid down by the Supreme Court in the *Olmstead* decision.

Individuals served in Missouri's Habilitation Centers have somewhat different characteristics than those served in comparable facilities elsewhere. Nationwide, 4.5% of institutional residents are age 21 or younger; in Missouri, 6.8% of all residents fell into this



¹³ Missouri Department of Mental Health, Division of Mental Retardation and Developmental Disabilities (2004). *Habilitation Center Five Year plan*.

age range in 2002. Missouri's Hab Center residents tend to be younger than those served in facilities elsewhere (about 48% were under age 40 in 2002 versus 35% nationwide). However, the age of the Hab Center population is increasing. In 2003, 47% of Hab Center residents were age 45 or older compared to about 32% in 1997. There has been a significant reduction in the proportion of residents under age 18; in 2003, there were no residents younger than age 10. A somewhat higher proportion of Missouri Hab Center residents have been assessed as having behavioral and psychiatric disorders than in facilities in other states.

With respect to costs, nationwide in 2002, the average annual cost per resident in large state operated facilities was approximately \$126,000 per resident or about 35% greater than the cost of serving an individual in Missouri's facilities. Between 1997 and 2002, nationwide average costs increased at a somewhat greater rate (about 27% not adjusted for inflation) than in Missouri (where the increase was about 25%, not adjusted for inflation). Historically, Missouri's costs per resident have been lower than in other states, in part due to the relatively low wages paid to Habilitation Center direct care staff compared to their counterparts elsewhere.

Since the Habilitation Centers continue to be Missouri's most costly service setting (see below), reducing their utilization will contribute to improving the overall efficiency of its service delivery system. Going forward, the consolidation of Habilitation Center operations accompanied by the vacating of substandard buildings will aid Missouri in avoiding the upward spiraling per diem institutional costs that ensue when a state fails to reconfigure its large public facilities in the face of declining resident population levels.

Residential Services Overall

The Habilitation Centers are one form of residential services furnished to people with developmental disabilities in Missouri. Residential services also are furnished in community-based group home residences and Individualized Supported Living (ISL) services via the HCBS waiver program. Supporting adults with developmental disabilities in having their own living arrangement is important. The demand for community residential services is increasing, especially as a result of the aging of family caregivers of adults with developmental disabilities. Unfortunately, a leading source of "crisis services" in developmental disabilities is the collapse of the supports that sustain family caregiving.

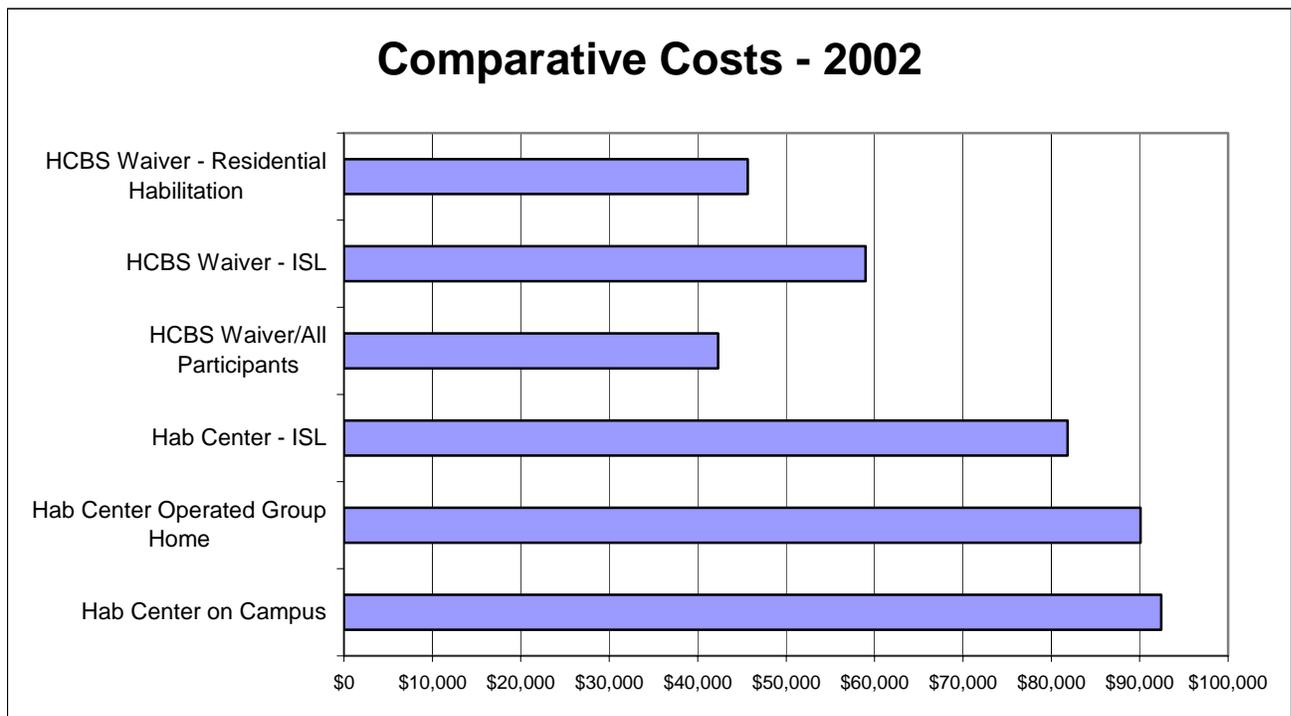
Nationwide, in 2002, states furnished residential services to people with developmental disabilities at the rate of 136.2 persons per 100,000 in the population. Predominantly, these services were furnished in small living arrangements that serve six or fewer individuals. In 2002, the average community living arrangement nationwide served 3.1 persons. Over the past several years, there has been an appreciable decline in the average size of community living arrangements as states strive to support individuals in living arrangements more like those of persons who do not have disabilities.

Since 1997, there appears to have been some degradation in the number of persons who receive residential services in Missouri.¹⁴ In 1997, Missouri furnished residential services to people with developmental disabilities at the rate of approximately 125 persons per 100,000 in the population, excluding persons in nursing facilities. The 2002 rate appears to have been

¹⁴ In 2002, the number of persons receiving such services in the figures that state officials reported to the University of Minnesota was 6,148, not including persons served in nursing facilities. The comparable figures reported to the Coleman Institute and included in the *State of the States* report were appreciably higher – about 7,100, excluding individuals served in nursing facilities and persons who received personal assistance. The reason for the difference in these figures is unclear and we have not attempted to resolve it. For present purposes, we split the difference and peg the number of people who received residential services at 6,600 individuals.

somewhat lower – about 116 persons per 100,000 in the population.¹⁵ Compared to the nationwide rate, Missouri’s rate of furnishing residential services was lower. This meant that there was less capacity available in Missouri than in the average state to respond to the need for residential services outside the family home. We observed that, in 1997, Missouri’s residential living arrangements for persons with developmental disabilities tended to be larger than those elsewhere (4.9 persons per setting versus the then nationwide average of 3.8 persons per setting). In 2002, the average residential setting in Missouri served 4.3 individuals. The size of living arrangements in Missouri, therefore, has declined (in part due to the reduction of the on-grounds population at the Habilitation Centers) but remains above nationwide norms.

In 2002, there continued to be major differences in the costs of furnishing residential services to persons with developmental disabilities in Missouri, depending on the type of setting employed. The chart below provides comparative figures by type of residential setting. The figures are expressed in full-year equivalent terms and take into account the room and board costs and health care costs of persons served through the HCBS waiver program so that the comparison to ICF/MR-funded settings is comparable.



The costs of community residential services in Missouri are appreciably lower than the costs of supporting individuals at the Habilitation Centers.

Other Types of Services and Supports

In 1997, it was evident that Missouri considerably lagged most other states in the extent to which it was successfully supporting individuals in community integrated employment. According to figures that DMH/DMRDD reported to the Coleman Institute, in 2002 Missouri’s performance along this important dimension of promoting community integration and self-sufficiency continued to lag well behind other states. Nationwide, about 24% of all persons

¹⁵ However, if the higher Coleman Institute figure were used, the rate would have been about the same as the 1997 rate.

who received day/vocational services at any time were being supported in competitive/ supported employment. In Missouri, the figure was much lower – about 10%. Even though funding for supported employment services is available through Missouri’s HCBS waiver program, it is a service that is infrequently utilized by waiver program participants. Admittedly, these figures do not include individuals served through the DESE sheltered workshop program or who receive vocational rehabilitation services, where there are indications that greater success is being achieved in securing community integrated work for people with developmental disabilities. Still, the relatively small number of individuals served in the DMH/DMRDD system who are in competitive or supported employment still is very low when compared to other states. With only few exceptions, other states have been much more successful than Missouri in promoting community integrated employment.

Finally, in the realm of family support – again according to figures reported by DMH/DMRDD to the Coleman Institute – Missouri’s level of financial effort in 2002 fell in about the middle of all states and the number of families receiving assistance relative to state population was about 20% lower than the nationwide level. However, it is unlikely that the figures include the considerable volume of family support services that are furnished through the S.B. 40 Boards. Unfortunately, the FY 2004 budget saw the elimination of the Family Stipend program. On the other hand, the launching of the Community Supports Waiver likely will result in Missouri’s picking up its pace of supporting individuals who live with their families.

Conclusion

In 1997, Missouri fell in about the middle of all states in terms of level of effort in support of its citizens with developmental disabilities. Available figures through 2002 provide indicators that Missouri’s performance slipped significantly. These figures, of course, do not take into account the state budget cutbacks that took place in 2003 and 2004 across the service system, including the Habilitation Centers, Regional Center operations and community services and supports, especially in the case of services for individuals who do not qualify for the HCBS waiver program. As a consequence, it is highly likely that Missouri’s performance has slipped even further over the past two years. The nationwide economic recession and ensuing slow recovery has taken its toll on developmental disabilities services in nearly every state, chiefly in the extent to which additional individuals who require services are being accommodated in state service delivery systems. Most states, however, have been able to avoid outright funding reductions or the elimination of categories of services. However, in 2002, it is important to keep in mind that the service delivery systems in most other states were more robustly funded than Missouri’s system and, hence, arguably, were in a somewhat better position to deal with budget problems. Missouri’s system faces the unenviable task of having to rebuild itself in the wake of its budget reductions in order for it to get back to where it was before the budget crisis.