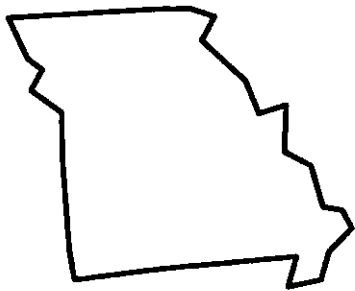


Show Me Change:



Building A Participant- Driven System For Missourians With Developmental Disabilities

Final Report

**The Missouri
Customer Leadership Initiative**

August 5, 1998

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1. Background

Developmental disability service systems are changing in every state. In response, the Missouri Planning Council for Developmental Disabilities initiated the **Missouri Customer Leadership Initiative**. This Initiative was composed of people with disabilities or family members and others who represented other relevant constituencies. Beginning in the Summer of 1997, we met nearly monthly during two-day retreats. During these working sessions, we worked to:

- ★ Create our vision for developing a community-centered response to developmental disabilities;
- ★ Establish principles to guide overall system design and service delivery;
- ★ Understand the circumstances surrounding service delivery for people with developmental disabilities, nationally and in Missouri;
- ★ Become familiar with the actions unfolding around the country to reform and improve developmental disability systems.
- ★ Consider what must be done in Missouri to assure that the entire developmental disabilities service system operates in ways that are consistent with our stated guiding principles.

Throughout, information and discussion concerning the factors that are driving change nationally and in Missouri guided our work. Since the early 1970s, thousands of people across the country have worked hard to establish “community based” systems for supporting people with developmental disabilities. Public institutions still exist, serving about 55,000 people in 46 states. However, the dominant service response is in the

Summary

Due to funding limitations, growing service waiting lists and evolving service practices, the developmental disabilities field is changing. In response, the Missouri Planning Council for Developmental Disabilities convened a working group to consider what could be done to re-structure the long-term support systems for people with developmental disabilities.

The Initiative established its vision for the future and a series of principles to guide the way. A series of recommendations were also developed revolving around: (a) employment, (b) participant-driven supports, (c) the role of the Regional Councils, and (d) building capacity for a person-centered system.

Note: A project Executive Summary is available through the MPCDD.

community, revolving around an array of service options including supported living, group homes, supported and sheltered employment, day habilitation, family support and a variety of ancillary supports.

Using 1996 national data, researchers report that 64% of the 388,941 persons living in publicly funded out-of-home settings reside in places serving 15 or fewer persons. Half of this total -- 194,990 people -- are living in settings for six or fewer, an increase of 51% from 1992 (Braddock, Hemp, Parish & Westrich, 1998). Regarding expenditures for developmental disability services, these same researchers found that in 1996, 68% of the \$22.8 billion that states spent on developmental disabilities services paid for services in the community. This compares to 44% of expenditures in 1986 and 25% in 1977.

These trends are pleasing to any that support community oriented responses to disability. Yet the field stands poised on the brink -- some say precipice -- of change over how service systems are structured and managed. A 1997 survey of state directors of developmental disability services "revealed that about half of the responding states were at some stage of launching a major change initiative. In most of the remaining states, major system change was actively discussed" (Smith & Gettings, 1998; p. 1). Among the several factors driving change, three of the most powerful are:

- ✓ The push for **self-determination** whereby systems are structured so that service recipients influence policy, and individuals have the freedom and authority to determine the substance and texture of their own lives, including control over the resources allocated for personal services or support.

As important as *what* services or supports are delivered, is *how* such assistance is offered.

Until recently, professional judgment was more heavily weighted than the choices and preferences of service recipients. In addition,

the choices available to people with disabilities were restricted to the residential and vocational slots available. Emerging practice, however, dictates that people with developmental disabilities should play leading roles in determining the substance of their lives, with a complementing emphasis on community inclusion and participation. Services are developed as needed to support these preferences. Moving past traditional professional or supply dominated approaches, the field is struggling to become more responsive to the demands of service recipients -- to promote and honor *self determined lifestyles*.

- ✓ The need to demonstrate **fiscal responsibility** for the resources already allocated to developmental disability systems. Public outlays for developmental disability

Self-determination

To act as the principal causal instrument in one's life and to make choices and decisions regarding one's chosen lifestyle independent of undue influence or interference from others.

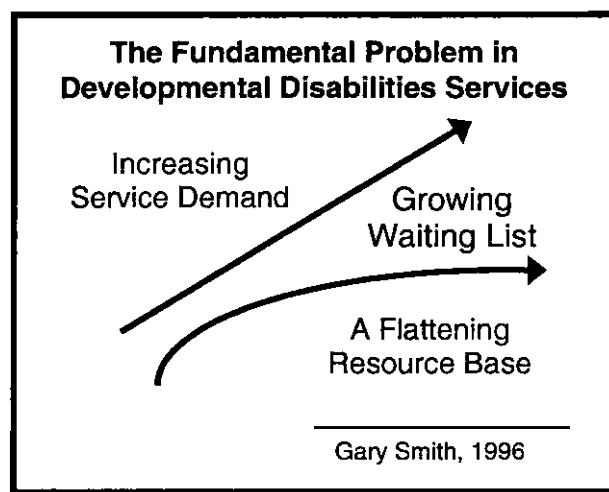
Wehmeyer, Kelchner & Richards (1996).
In the *American Journal on Mental Retardation*, 100(6), 632-642.

services increased at an after inflation rate of 168% between 1977-1996 (Braddock et al., 1998). Over the past few years, growth has averaged about 9-10% per year. Yet there are strong indications that public support is eroding for expanding a variety of government programs. While Smith (1998) observes that interest in some programs (e.g., public education, corrections, law enforcement) remains strong, other social service initiatives may be at risk. Certainly, there is continued concern for containing Medicaid spending at the federal and state levels. He concludes that "a strategy based on the assumption of a steady, double digit growth in public funding for developmental disability services is almost certain to fail" (p. ii). The result is the demand for fiscal efficiency, a call that has been answered by those wanting to inject managed care strategies into developmental disability systems.

- ✓ **Demand will grow for developmental disability services.** America is graying. People are living longer and that includes people with disabilities, circumstances that will drive the demand up for services, especially ones to accommodate seniors with disabilities. In addition, the parents of many adults with disabilities are growing too old to continue to provide care at home. Middle aged baby boomers that had children with disabilities are finding that their children are now aging into the adult system. Consequently, the pressures placed on the long-term supports system for adults with disabilities can only grow over the next several years.

Researchers at the University of Minnesota (Prouty & Lakin, 1998) estimate that state-local service systems would need to grow by 24% simply to meet current demand. Echoing such research, a recent National Arc study concludes that the nationwide shortfall of community support services has reached crisis proportions for people with mental retardation and their families. According to the report, more than 218,000 requests for support remain unanswered for people with mental retardation and their families (The Arc, 1997).

Admittedly, waiting lists are difficult to track. There is no standardized way to collect the information, nor is it often verified. Also, there is no easy way to estimate the "urgency of need" of any on the waiting list. As a result, some argue that the numbers are overstated, while others counter that the uncertainty in data collection means that the real numbers are under reported. While there are problems with waiting list data, the numbers cannot be discounted. The numbers – and accompanying personal stories -- reflect a growing problem for policy makers.



Mixing together the concern for funding and an increased demand for services, the developmental disabilities field is faced with an enormous problem. If present circumstances unfold without modification, the outcome can only be an increase in the waiting list. Despite encouraging isolated events where “new money” is allocated to state developmental disability authorities to accommodate portions of the waiting list (e.g., as in LA, NJ or OR), the field must face up to the sobering challenge it faces. No further dramatic increases in funding will be forthcoming, the demand for services is increasing, and means must be implemented to make service systems more efficient; That is, to do more with the resources already available.

What follows are the primary outcomes stemming from our work. The remainder of the document is divided into four sections:

Section 2. Guiding Principles: This section presents a series of guiding principles developed by the project participants, including “core” principles that must lie at the heart of any service system, and other complementing principles to guide service delivery and policy in Missouri.

Section 3. The State of the State: This section provides a data-based background to the project, offering information on the status of services, nationally and in Missouri.

Section 4. Recommendations: This section offers a series of policy recommendations that -- if enacted -- help assure that services are delivered in ways consistent with the guiding principles.

Section 5. Concluding Remarks: This final section offers a final word from participants regarding what we must all do in Missouri to translate the recommendations into practice.

Overall, this Final Report charts a new course for Missouri in supporting people with disabilities. It outlines changes that are needed to put community inclusion, self-determination, fiscal responsibility and collaboration at the forefront of how we support people in our communities.

2. What We Believe _____

The following principles illustrate what Initiative members value most concerning policy and practice for people with developmental disabilities in Missouri. We recognize that current actions in Missouri are not always consistent with these principles.

The principles are grouped according to the areas contained in the state's "Certification Principles" for Home and Community Based waiver services:

- ① Community Membership,
- ② Self-determination,
- ③ Rights,
- ④ Meeting Basic Needs,
- ⑤ System Management.

All these principles are shown below by category. Spanning all our beliefs is an overarching "**core principle**:" This core principle describes who is in control of how and where resources are allocated.

Resources for supports in the State of Missouri must be allocated and expended from a person-centered perspective rather than a provider centered perspective. Individuals must be in control of their allocated resources for services and supports and how they are delivered.



There exists a fundamental difference between a person and a provider-centered approach. It has to do with a shift of power (See the illustration on the next page.) A person-centered system will embrace the principles that follow. These guiding principles for Missouri's developmental disabilities systems must apply to all eligible people of all ages regardless of the severity of their disability.

Provider Centered System	Person Or Participant Centered System
<ul style="list-style-type: none"> ✓ Resources for support are given to those providing the supports. Decisions of what, how, and where supports are to be provided, at best, may be a shared activity with the person who is receiving the supports. However, more often these decisions are made with little direction from the person involved. Decisions are owned or controlled by individuals empowered by virtue of professionalization or position. ✓ Control of who provides the support almost always rests with the provider organization. ✓ People are labeled as "slots". 	<ul style="list-style-type: none"> ✓ Control of resources, decisions of how and where money is spent rests with the person who needs supports, and/or his or her family, friends or advocates. ✓ Control of who provides supports rests with the person and/or his or her family, friends or advocates. ✓ People are valued as people.

The Principles

① Community Membership

- ⇒ All people with developmental disabilities belong in their community.
- ⇒ Community inclusion is the basis of the services and supports that people receive. The concept carries the following characteristics:
 - ✓ People with developmental disabilities have contributions to make in our communities that are equal in worth and value to those of other citizens.
 - ✓ People with developmental disabilities are supported in their communities, near families and friends.
 - ✓ People with developmental disabilities have the same opportunity as other citizens to live in homes of their own, by themselves, with their family, or with friends of their choice.
 - ✓ People with developmental disabilities have the opportunity -- as do other citizens -- to find and hold competitive jobs and/or otherwise contribute to the community.

- ⇒ Services and supports promote a positive image and awareness of people with developmental disabilities.
- ⇒ Services and supports provide opportunities for people with developmental disabilities to be valued members of the community, making contributions as well as receiving needed supports.
- ⇒ The system promotes the use of community resources, and, in so doing, builds community capacity.
- ⇒ Services and supports promote the centrality of the family in the lives of individuals with developmental disabilities.

② Self-determination

- ⇒ People with developmental disabilities and family members have options in all areas of services and supports.
- ⇒ People with developmental disabilities are informed of the variety of options, as well as the benefits and risks associated with the choices they make.
- ⇒ People with developmental disabilities have the opportunity, with support as needed from those who care about them, to make choices and decisions about their every day lives.
- ⇒ Individuals have control over their allocated resources.
- ⇒ People with developmental disabilities can modify services and supports to accommodate their changing needs.

③ Rights

- ⇒ People with developmental disabilities have the same rights and responsibilities as other citizens, including the opportunity and responsibility to direct their own lives.
- ⇒ People with developmental disabilities are listened to and treated equally as other citizens without assumptions based on their disabilities.
- ⇒ People are not discriminated against due to cultural or ethnic differences.
- ⇒ People with developmental disabilities have the right to determine their needs and assume responsibility for the choices they make and the consequences of their decisions.
- ⇒ Services and supports are delivered in ways that recognize the centrality of the family in the lives of individuals with developmental disabilities.

- ⇒ Individuals have a right to grieve any decision or process that affects their quality of life.

④ Meeting Basic Needs

- ⇒ The system is responsive to individual needs, providing help when and in the manner that people need assistance.
- ⇒ People with developmental disabilities, family members and others have peace of mind that services and supports are reliable, both today and for the future.
- ⇒ Individuals have personal security in their everyday lives.
- ⇒ People with developmental disabilities, family members and others are confident that publicly-funded services assure and promote:
 - ✓ Good health;
 - ✓ Individual safety, including protection from abuse or harm;
 - ✓ Individual well-being, comfort and security;
 - ✓ Individual rights and freedoms.

⑤ Systems Management

- ⇒ There is an ethical responsibility to provide services in accord with these principles and “choice” shall not be used as a reason for shirking that responsibility.
- ⇒ Services and supports are accessible and easy to use.
- ⇒ Services and supports nurture the family structure, fostering and enhancing family unity.
- ⇒ Ethnic and cultural differences are recognized, valued and included in designing services and supports to fit individual needs.
- ⇒ The system is an active partner with people with developmental disabilities and families by providing helpful and accurate information about choices.
- ⇒ The system values and supports the choices made by individuals and families.

- ⇒ The system shall maintain effective oversight to ensure that individual rights are honored.
- ⇒ There is a grievance process available to address complaints without retribution.
- ⇒ People with developmental disabilities and family members are informed, active and equal partners in policy making.
- ⇒ There is collaboration among all stakeholders.
- ⇒ Direct support staff are well trained, competent, adequately compensated, and supported and respected by their employers.
- ⇒ The system promotes cost effectiveness, and any savings are reinvested in services and supports.

3. The State Of The State

Over the past 25 years services to people with developmental disabilities have undergone remarkable change. Central to this change was a *shift in focus from the institution to community-based facilities*. While conditions improved in the institutions, through the 1970's and 80's buildings were purchased or built in the community. Staff were hired and trained. A "facility-based" community system was born.

Missouri followed this trend. In recent decades, Missouri invested public resources to: (a) improve conditions at state habilitation centers, and (b) establish a facility-oriented community response to address the needs of people with developmental disabilities. Thousands of Missourians worked hard during this period to achieve these ends. Their work has resulted in an array of services to support people with developmental disabilities, including residential, vocational, family and other essential services.

Backing these direct services, an infrastructure evolved both to fund and manage the service system. Four primary funding sources include Federal Medicaid money, state tax dollars, county Senate Bill 40 mill tax dollars, and contributions from service recipients (e.g., Supplemental Security Income). In 1997, 486.5 million was spent on developmental disability services in Missouri. Management of the service system is divided among various state agencies (e.g., Department of Mental Health, Division of Mental Retardation and Developmental Disabilities (DMRDD), Department of Elementary and Secondary Education (DESE)) and local authorities (e.g., Senate Bill 40 County Boards).

Illustrating these circumstances, the accompanying table shows the money spent in Missouri in 1997 on developmental disability services, and what it was spent on.

Where the Money Comes From			What the Money Is Spent On		
Missouri tax dollars	\$196.8M	40.3%	Residential Service	\$323.2M	66.4%
Federal Medicaid money	\$189.6M	39.0%	Daytime services	\$71.3M	14.7%
Senate Bill 40 tax money	\$46.0M	9.5%	Family supports	\$13.3M	2.7%
Consumer SSI	\$26.1M	5.4%	Other community	\$41.2M	8.5%
Other sources	\$28.1M	5.7%	Service Coordination	\$27.8M	5.7%
			Administration	\$9.7M	2.0%
Total	\$486.5M	100%	Total	\$486.5M	100%

Source: Services and supports for Missourians with developmental disabilities: Where the dollars come from and go to. -- See Appendix A.

Beyond these aggregate numbers, we examined state funding and service utilization patterns in greater detail (See Appendix A). Further, we compared Missouri's patterns with:

- ✓ The spending and service utilization patterns of neighboring states and national averages,
- ✓ Funding and service trends in the field that emphasize community integration, self-determination and fiscal responsibility, and
- ✓ Our own guiding principles (See Chapter 2).

Based on our discussions, we find that:

- 1. Many Missourians who are eligible for services remain on waiting lists.** The amount of money spent on developmental disabilities in Missouri in 1997 totaled \$486.5 million to serve about 24,445 people. The services these individuals receive range from service coordination to around-the-clock supports. The number of people on waiting lists in Missouri is not precisely known, since the number is not systematically and reliably tracked across the state. A national Arc study estimates that in Missouri 1,786 people are on waiting lists (The Arc, 1997). Meanwhile, in June 1998, DMRDD reported that 1,181 eligible individuals across its 11 Regional Centers were on waiting lists. These people who have been found to need services, but are not receiving them.

The Missouri state population stands at about 5,414,000 people. A prevalence rate for developmental disabilities of 1.8% suggests that approximately 97,452 people in Missouri have a developmental disability. Having a developmental disability means that a person has substantial problems in meeting the challenges of everyday living. Not everyone with a developmental disability needs or wants government-funded services. Families and communities freely support many individuals. But the fact is that today there are people known to the system who have been identified as needing supports but who are not receiving them. There are others who today receive services, but the services are not the right kind. There are still others who will face crisis because their parents are aging and will not be able to continue to support them. When people are consigned to a "waiting list", the simple fact is that the public system is not meeting their needs.

When the scope of Missouri's system is compared to other states, Missouri's system emerges as "about average". But we know that "about average" means that many people will not be receiving the supports they need. Nationwide, "about average" means that there is a large and persistent shortfall in the capacity of public systems to deliver necessary services and supports. So it is in Missouri.

At issue is whether or not this fact is acceptable to Missourians.

- 2. The prevailing Missouri service system for people with developmental disabilities is not person-centered.** Our core principle clearly articulates that: (a) resources for supports in Missouri must be allocated and expended from a person-centered perspective, and (b) individuals must be in control of their allocated resources for services and supports and how they are delivered. Further, our service principles emphasize community inclusion and citizenship over other forms of services that congregate or segregate people with disabilities from their communities.

In specific, we find that in Missouri:

- ✓ There is a strong facility orientation regarding where people live. (See Appendix A). Missouri spends a great deal of its resources on service options that emphasize facility over community inclusion. For instance, 2,828 of the 8,010 (35.3%) people who received residential services in 1997 lived in facility oriented options. These included:

"Every time we identify a need in this field, we build a building."

Gunnar Dybwad

- ⇒ 1,381 people residing at habilitation centers, where the census has remained largely unchanged since 1993,
- ⇒ 1,314 more in nursing homes, ranking Missouri 5th nationally in terms of the number of people with developmental disabilities relative to state population who are served in these kinds of facilities, and
- ⇒ 133 people living in non-state operated community ICFs-MR.

The costs for these services amounted to \$151.3 million of the \$323.32 million (46.8%) spent on residential services. Broken down by category, this included \$115.9 million (36% of the total) spent on habilitation centers, \$28.8 million (9%) on nursing facilities, and \$6.6 million (2%) on community ICFs-MR.

The table on the next page illustrates these findings, adding a comparison of these patterns with other residential options that are more community centered (i.e., Home and Community Based community group homes, other non-waiver residential services). As shown, a significant proportion of residential resources is spent on relatively fewer people who live in facility-based options. In addition, about \$55,562 per person is spent on facility-based options, compared with \$33,173 per person that is spent on alternative community services.

**Comparison of Service Use and Spending Patterns In Missouri
For Residential Services in 1997**

	Number Served		Money Spent		Annual Cost/Person
Facility-Based Options (Habilitation Centers, Nursing Homes, ICFs-MR)	2,828	35%	\$151.3	47%	\$55,462
Community Based Options (HCB Services, Other non-waiver residential)	5,182	65%	\$171.9	53%	\$33,193
Totals	8,010	100%	\$323.2	100%	

Source: Services and supports for Missourians with developmental disabilities: Where the dollars come from and go to. -- See Appendix A.

- ✓ There is also a strong facility orientation related to where people in the community spend their day. The state's primary daytime supports for people with developmental disabilities who live in the community are day habilitation programs and sheltered workshops. Nearly 5,000 people receive day habilitation services funded by the state's Home and Community Based Waiver. Approximately another 8,100 people with developmental disabilities are employed at about 90 sheltered workshops across the state.¹ Other community options that emphasize support over facility, such as supported employment, are available in Missouri, but they are not frequently utilized. Fewer than 500 people receive supported employment services through DMRDD's HCB waiver, while others receive such services through vocational rehabilitation agencies and Senate Bill 40 Boards. Yet these options -- and their associated dollar investments -- do not nearly match the availability of facility based options.
- ✓ Missouri has policies in place that discourage people with developmental disabilities from working. (See Appendix B) Many people with developmental disabilities want to have an integrated community job -- a regular job. A regular job should mean that they are able to use the money they earn to support themselves. If the aim is that people become more independent and less reliant on the public system, then they need to be able to keep the dollars they earn.

But Missouri has various policies in effect that go in the opposite direction. When people with developmental disabilities "earn too much," they face the loss of Medicaid eligibility or can find themselves having to turn over what they earn

¹ Information regarding Missouri's sheltered workshops is available on the internet through the Department of Elementary and Secondary Education.
Contact: <http://services.dese.state.mo.us/divspeced/shelteredworkshops/index.html>

to the state in order to maintain eligibility. Missouri's policies in this respect are more punitive than federal policy dictates and less supportive of people benefiting from work than is the case in many other states. The signal that Missouri is sending to its citizens with developmental disabilities is that their getting a regular job will not allow them to get ahead. Missourians with developmental disabilities who get a job are taxed very heavily. This makes no sense. These policies need to change.

- ✓ People with developmental disabilities have little or no control over the funds allocated to them. At the core of a person-centered system is control over the resources used to provide one's services. Under terms of Missouri's Home and Community Based waiver participants are entitled to "freedom of choice" regarding their Medicaid provider; Individuals are free to choose their provider and to switch providers. This is an important freedom, though its potential is undercut by the absence of preferred and available service options (e.g., for supported employment) and inflexibility in the system that limits the choices people have regarding how they might spend Medicaid dollars.

Aside from Medicaid funded services, resource allocations are tied more to the provider than the service recipient. There are exceptions, such as the Choices For Families voucher program and the new Family Directed Support Program. These initiatives offer families great flexibility in spending their allocations. Overall, however, individuals cannot easily take the funds used to serve them from one provider and move them to another, or take the funds with them if they relocate. Many argue that the absence of such portability makes the system less effective and efficient than it could be. People simply are not free to "shop around" for the best services in terms of cost, preferences and outcomes.

Overall, the evidence in Missouri illustrates that policy and practice is not "person-centered" and does not typically favor community inclusion. At issue is whether or not this fact is acceptable to Missourians.

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- 3. Systems change unfolds too slowly in Missouri and without a proactive or collaborative commitment to a common vision.** Certainly, over the past 25-30 years the services in Missouri that are available to people with developmental disabilities have changed. And they continue to change. Yet Missourians do not jump at change for change sake. As a result, the pace of change is slower here than elsewhere, and in Missouri there is little commitment to pursuing bold proactive or innovative change.

In specific, consider these few observations:

- ✓ There is a trend for change but the pace is very slow. The number of people residing

I never give them hell. I just tell the truth and they think it's hell.

Harry Truman

at the habilitation centers has decreased since 1987. The number of people receiving Home and Community Based waiver services has gone up every year since 1989; 6,290 people received HCB services in 1997, up from 338 in 1989. And Missouri is presently expanding its family support efforts involving initiation of the "Family Directed Support Services" program resulting from recent \$4.2 million allocation. Yet when compared to progress in other states, these changes have come at a markedly slower pace. We note that:

- ⇒ Five states and the District of Columbia have closed their state institutions (i.e., RI, VT, WV, NM, ME), with several others seemingly on the verge (e.g., HI, AZ, MN, WY). Nationwide, from 1993 to 1997 the number of people served in public institutions has dropped by 23.7%, from 71,000 to a little less than 54,000 (Prouty & Lakin, 1998). Yet in Missouri, after a series of facility closures from 1988-1993, there has been little - if any -- reduction in the Habilitation Center census since then. There are no current plans in Missouri to affect the number of people living in Habilitation Centers. In 1997, 101 people were admitted to Habilitation Centers; there were 77 discharges and 22 residents passed away.
- ⇒ Over 110,000 people with developmental disabilities nationally enjoy the benefits of regular community jobs through application of supported employment services. Here in Missouri, Braddock et al. (1998) report that in 1996, 336 people received supported employment services funded through DMRDD. We are uncertain of the state's overall effort surrounded supported employment services, given that other state or local agencies (e.g., Division of Vocational Rehabilitation, county Senate Bill 40 Boards) may also be offering supported employment services. Yet, the evidence clearly suggests that Missouri has not kept pace with efforts in numerous other states to support people in integrated community jobs.
- ⇒ Most people with developmental disabilities live home with family or other loved ones. This is especially true where young children are concerned. Yet, in Missouri we find that only about \$13.3 million of the \$486.5 million (2.7%) spent on developmental disabilities services is spent on family support. The recent allocation of \$4.2 million for the Family Directed Supports Program will help, but Missouri could do more to support families. Yet several states have pushed well past Missouri to act more proactively to build better coordinated and funded efforts to support families (e.g., NH, PA, MI, AK, UT)
- ⇒ Many states are presently exploring the concept of self-determination and its implications for system reform. In 1997, the Robert Wood Johnson Foundation awarded planning grants of \$100,000 to \$400,000 to 18 states to develop new means for addressing individual needs consistent with the principles of self-determination. The next year, ten more states received

smaller grants to promote similar change. Missouri did not apply for either of these grants.

- ✓ Changes are made mostly at the margin. Most would agree that the service system can and must be improved. Yet without cohesive vision and purpose, efforts to improve services too often are undertaken in isolation and are built as a separate part of the existing system. New programs start up, but older programs remain. In some ways the Missouri system is a living museum where service programs generated over the past 25 years may be observed. Each program may have been “cutting edge” in its time, but now too many are time worn and out of sync with emerging best practices. Over time, the system has become a complicated puzzle that seems inaccessible and impenetrable to service recipients and their families. “Change” is pursued more as a means of simply trying something new, rather than as a means of revitalizing past practices while pushing forward.
- ✓ There are strong and separate service “silos” at work. In Missouri’s system there are “silos” of service delivery that promote inefficiency and fragmentation in purpose. This observation is not a new one. The Department of Mental Health’s *1997 Strategic Plan* plainly lists “Breaking Down Silos” as one of its top strategic issues to resolve. The issue is stated as follows:

“The degree of DMH division separation and autonomy causes inefficiency, confusion and conflict with other government agencies, internally in DMH and in the community” (DMH 1997 Strategic Plan, p. 40.)

Such silos are also easily observed regarding developmental disability services, especially when multiple state agencies are at work (e.g., DESE and DMRDD) and especially where department policies are inconsistent. For instance, where DMRDD may seek to expand supported work opportunities, DESE through its Sheltered Workshop Section may act to promote sheltered employment.

Separate silos may also be at work within state agencies. Within DMRDD, for example, actions may be taken to expand family support or supported employment services, even while equal action is taken to maintain habilitation centers or other congregate options.

Nothing is less productive
than to make efficient what
should not be done at all.

Peter Drucker

In each silo there are measures of success and people work hard to succeed. Each part succeeds on its own terms. But success in independent silos is less than what it could be overall. Further, it undercuts the application of cohesive statewide leadership for change. At issue is whether or not this fact is acceptable to Missourians.

- 4. There is an inconsistent application of developmental disabilities policy across Missouri.** Individuals and families have every right to expect equal access to publicly-funded services and supports. How the service system responds to their needs should be the same regardless of whether they live in Albany, Kirksville, Sikeston, St. Louis or Jefferson City. Even-handed treatment promotes citizen trust and confidence in the system.

The eleven DMRDD Regional Centers serve as the local point of entry for the majority of services and supports that are underwritten by public funds. The Regional Centers coordinate the development of consumer personal plans and make decisions about how state dollars are spent. DMRDD establishes policies that Regional Centers are to follow in interacting with individuals and families.

But today, it is too often the case that “what you get depends on where you live.” Services and supports authorized in some regions are not made available in others. Our discussions, for example, have revealed differences in how the Choices for Families program operates region-to-region. Further, there are differences among the regions in offering individuals and families choice of service provider and the extent to which preferences are honored.

As a consequence, the system’s customers are not certain that they are being treated evenhandedly. Policies followed in one region are out-of-bounds in others. Moreover, there are differences among the regions in the extent to which regional centers regularly and actively consult with individuals, families and other stakeholders to solicit feedback concerning regional center operations and how they might be improved.

These circumstances are clearly inconsistent with our stated principles. People with developmental disabilities and their families expect that the system’s response to their needs will be equitable and evenhanded regardless of where in the state they live. This is not always the case in Missouri. At issue is whether or not this fact is acceptable to Missourians.

Over the past 25 years, services for people with developmental disabilities in Missouri have come a long way. Many have worked hard to establish the system that serves so many in Missouri. In making our observations about the current system we do not intend to debase these past and current efforts. Rather, we seek to call attention to shortcomings in the present system that must be addressed. We ask again: **Are these facts acceptable to Missourians?**

Our system of services and supports for people with developmental disabilities must do better. The system works well for some, yet there are many barriers that prevent the system from serving as a reliable source of assistance so that all people with developmental disabilities can take their rightful place in our communities. We need to

attack these barriers and make fundamental changes in our system. We must make changes, not simply for change sake, but because it is indicated by the evidence. **From the “Show Me” perspective, we have been shown.**

4. Recommendations_____

In 1997, about 24,445 Missourians received developmental disability services. The human and fiscal effort expended to deliver these services is greatly appreciated. Yet, our analysis of the current system reveals numerous serious shortcomings that must be addressed if we are to continue to improve the system and meet the challenges ahead.

Reforms must be undertaken to assure that the system operates more consistently with our stated guiding principles. These principles emphasize community inclusion, self-determination, fiscal responsibility and collaboration among all those concerned. Underlying these intents is a simple core principle:

Resources for supports in the State of Missouri must be allocated and expended from a person-centered perspective rather than a provider centered perspective. Individuals must be in control of their allocated resources for services and supports and how they are delivered.

Members of the Customer Leadership Initiative generated and discussed numerous recommendations for reform related to developmental disability policy and practice. These recommendations touched upon changes regarding:

- ✓ The future of the habilitation centers;
- ✓ The continued residence of people with developmental disabilities in nursing homes;
- ✓ The numbers of people who are awaiting services -- the "waiting list;"
- ✓ The need for increased investment in family support services;
- ✓ The need for performance standards that are consistent with the guiding principles, and to spend money in ways that are consistent with these standards;
- ✓ The need for cohesive statewide leadership at the state and local levels to emphasize action that is consistent with the guiding principles;
- ✓ The need for greater consistency in services across the state;
- ✓ The need for additional resources, especially the need to increase participation in the community waiver program;
- ✓ The need for more options in the community for supported living and employment;

From this discussion, four primary recommendations stood out. Of all the actions -- large and small -- that could be taken to improve developmental disability services in Missouri, we urge that these four recommendations be embraced and put to practice.

In doing so, we recognize that the Missouri Planning Council for Developmental Disabilities (MPCDD) is the official advisory body for the state's developmental disability system. In that capacity we also recommend that the MPCDD assume the leadership role in organizing collaborative efforts to make these four recommendations a reality.

Four Primary Recommendations

1. Resources for supports in the state of Missouri must be allocated and expended from a person-centered rather than a provider centered perspective.
2. Missouri must provide people with developmental disabilities the opportunity to select, find and maintain integrated employment.
3. Regional Councils must play an active role as conduits for grassroots input to promote consistent application of policy throughout Missouri.
4. Missouri policy makers should build system capacity for serving people with developmental disabilities in ways that are consistent with our guiding principles.

1

Resources for supports in the state of Missouri must be allocated and expended from a person-centered rather than a provider centered perspective.

This recommendation lies at heart of our vision for system reform in Missouri. It is consistent with our stated core principle and other defining principles (See Chapter 2). It is consistent with momentum that is growing nationally in support of self-determination and community inclusion. And it signals that to succeed we must be willing to learn to do things differently, not simply get better at doing the things we are already doing.

In Missouri, the prevailing means for delivering supports are facility-based. We recognize that there are features of the present system or specific programs that exemplify person-centered practices. But these are more the exception than the rule. Generally, in Missouri resources for support are given to those providing the supports either by contract or through fee for service reimbursement. Decisions of

what, how, and where supports are to be provided, at best, may be a shared activity with the person who is receiving the supports. However, more often these decisions are made with little direction from the person involved. Decisions are primarily owned or controlled by individuals empowered by virtue of professionalization or position. In essence, control of who provides the support almost always rests with the provider organization.

Person-centered support systems dramatically depart from these traditional practices. In several states policy makers are exploring means establishing new service structures that promote self-determination, community inclusion and fiscal responsibility. "Participant-Driven Supports" is one term that is used to describe these emerging systems.

Reduced to its essence, participant-driven support systems require that people/families, rather than third parties, exercise choice over how dollars are used (within certain parameters); that supports be obtained within a fixed dollar budget; and the person/family carries some amount of risk if the budget is improperly used (See Smith, 1995). This approach is consistent with emerging trends in the field because it promotes community life, strengthens self-esteem and facilitates empowerment among service recipients. It may also contribute to cost containment. Proponents argue that the approach will improve provider performance because of its emphasis on "customer first" behavior. Customers (i.e., participants) who do not find what they want, at a price they consider fair, will go elsewhere to make their purchases.

While there may be countless variations on this theme (See Agosta & Kimmich, 1996), we note five fundamental characteristics (See Appendix C):

1. Individuals have a person-centered plan for support and control over pre-authorized budgets that can be used flexibly to accommodate the needs specified by the individual (within budget limits).
2. Individuals have a choice of service suppliers. Providers and others act as authorized merchants -- where participants may "shop."
3. A "risk pool" is established to help offset any risk that an individual accepts when working from a pre-set budget limit.
4. Funds are set aside to meet administrative and other overhead costs for managing the system, specialized services, or other administrative needs.
5. Individual have choice over the amount of control and responsibility one accepts in managing their own person-centered plan.

While considering participant-driven approaches we thought through two potential prototypes. One involved use of a "micro board" to assist individuals to gain

increased control over their services and supports. A micro board consists of family or friends who agree to participate with an individual with developmental disabilities to control his or her allocated resources. The board may even incorporate to formalize its relationship with the individual. Another prototype illustrated a conceptual sketch of how a participant-driven system could work in Missouri (See Appendix C).

To translate these concepts into practice, policy makers must step forward to plan, test and implement participant-driven approaches in Missouri. They may be both modest and bold in their course.

- ⇒ **At the least, means for assisting people with developmental disabilities to establish micro boards should be explored and tested.** By doing so, Missouri can go far to promote self-determination for individuals without needing to pursue dramatic system change at the onset.
- ⇒ **Past this modest step, DMRDD should work with people with developmental disabilities, family members and others to design an approach to participant-driven supports that fits Missouri.** As the concept unfolds, any statutory or fiscal barriers should be identified and systematically removed or accommodated. A final product of this work should be a prototype that could be tested in selected regions.
- ⇒ **DMRDD should commit to implementing in selected regions a participant-driven support system within two years.** Like other states who are participating in the RWJ Self-Determination Projects, there is no reason why Missourians could not work together to develop and implement one or more pilots to explore how best to proceed.

2 Missouri must provide people with developmental disabilities the opportunity to select, find and maintain community integrated employment.

Fundamental to life in the community is the opportunity to work. When community service systems were first established in the early 1970s, however, emphasis was placed on services that tended to cluster people with developmental disabilities together in various daytime activities, including sheltered workshops and day habilitation centers.

Since the early 1980s, best practices have steadily pushed away from these early models. Supported employment approaches promote the idea that people with developmental disabilities, given a variety of supports, are capable of working in regular community jobs. These supports can include direct support on the job from program staff or co-workers, worksite modifications, assistive technology, or

modifications to work routines (e.g., job carving). Workers may be placed on individual jobs or a few may work together at a job site.

The idea is to shape the job to the individual as much as possible, teach the worker how to perform the job, and set in place any human or material supports the individual needs to complete the work. Ideally, paid staff seek to fade out their presence, leaving individuals to work their jobs without program support, but with natural support as is needed (e.g., co-workers, existing employer sponsored training programs).

Integrated employment practices are more consistent with contemporary values that stress community inclusion and self-determination than previous service models. More than that, having a well paying job in the community promotes financial independence, improved self worth and a greater sense of participation and contribution to one's community. Yet a few may have disabilities so severe that regular work seems out of reach. Some may prefer continued attendance in a sheltered environment. And others may prefer not to work at all. Still, national experience shows that over 110,000 people with developmental disabilities are working in regular community jobs. At issue is the **opportunity** individuals have to seek and maintain community-integrated employment.

In Missouri, we find that such opportunity is limited in some areas and lacking in others. The first sheltered workshop in Missouri was established in Sedalia about 30 years ago with the passage of Senate Bill 52 in 1965. Today there are about 90 sheltered workshop (non-profit) corporations operating throughout the state, employing more than 8,000 people. Complementing these workshops, daytime habilitation centers serve approximately another 5,000 people across the state. Because of their Medicaid funding, in the past these centers cannot perform contract work, focusing instead on habilitative instruction (e.g., work readiness training, functional academics, daily living skills). Supported employment services, first made available in Missouri in the 1980s, are not available to a great many people.

Precise numbers were not available to us, but it is clear that the state's primary fiscal investment rests with sheltered approaches. Comparatively, less is spent on integrated employment. Not only is the state's performance out of step with our stated principles, but given the performance of other states we conclude that Missouri can do much to change these circumstances.

We recognize that the current spending patterns did not unfold overnight, but rather evolved over time given a steady line of policy decisions. From our view, we primarily observe a lack of cohesive commitment -- backed by fiscal investment -- across state agencies (e.g., DESE, DMRDD) and Senate Bill 40 Boards to supported employment. For example, we note that:

- ✓ There is a unit inside of DESE -- The Sheltered Workshop Section -- that is dedicated to the promotion and development of sheltered workshops. No other comparable unit exists for any other daytime option. In fact, the current DESE internet website posts a variety of information on sheltered workshops, including instructions on how to start one. There is no complementary information display related to supported employment.
- ✓ Missouri's policies governing eligibility for programs like Medicaid actually discourage individuals from earning a decent wage.
- ✓ Service providers indicate that it is very difficult to maintain integrated employment programs due to current billable rates.
- ✓ There are contradictory requirements regarding which agencies or individuals can deliver employment services. Sheltered workshops, for instance, are not required to be CARF certified while supported employment agencies must be. This requirement may pose a significant deterrent to small employment agencies.
- ✓ Sheltered workshops cannot legally hire workers without disabilities to perform contract work, thereby eliminating the potential for promoting "affirmative industry" practices where the shop itself becomes an integrated workplace. This regulation may also discourage shops from losing their best workers to supported employment, given a pressing need to complete contract work.
- ✓ Eligibility for sheltered workshops, determined by the Division of Vocational Rehabilitation (DVR) (under DESE), routinely pits sheltered work against supported employment. To become eligible for sheltered work an individual must be deemed "unemployable at this time," and so is ineligible for supported work. If deemed "employable" and eligible for supported employment, however, one cannot be eligible for sheltered work. These routines create an "all or nothing" predicament for workers with disabilities, ultimately discouraging individuals from trying a community job as an alternative to or in combination with sheltered employment. We understand that DVR is taking steps to alter this eligibility routine, but we are uncertain of the status of their efforts or its effects.

This circumstance also stirred our curiosity when we discovered that 69% of the total revenue for sheltered workshops in 1996 (\$54.6 million of \$79.2 million) was generated by contract work -- work performed by individuals judged to be "unemployable at this time." The revenue is largely used to pay for the costs of operating the workshops (e.g., staff wages, facility costs). In essence, sheltered work employees with disabilities, who earn on average \$1.64 an hour -- are in great part paying for the operating expenses of the sheltered workshops.

While the emphasis in Missouri surely is centered on sheltered day-time options, many policy makers are interested in expanding supported employment opportunities. DMRDD, for example, recently altered its Medicaid Home and Community Based waiver to include supported employment as a reimbursable service. Likewise, many providers indicate a willingness to offer supported employment services. Still, to promote a sure and steadfast commitment to community employment we recommend that several action steps be taken:

⇒ **Relevant state leaders should convene an “Employment Summit” to declare their commitment and take action to assist people with developmental disabilities to find, select, and maintain employment in real community jobs.**

Participants should include principle policy makers representing DMRDD, DESE, and the Division of Employment Security. At this summit, participants should take action on the following:

- ✓ Reaching consensus on a policy direction to emphasize employment opportunity for people with developmental disabilities.
- ✓ Reach consensus over a variety of steps that the participants will take cooperatively individually or collaboratively to remove barriers to and create incentives for integrated employment. This actions coiuyld include:
 - Making statutory changes as needed to establish a more coherent and productive decisionmaking structure regarding employment policy.
 - Working with Senate Bill 40 Boards and service providers to assure that people with developmental disabilities and their families are fully informed of the state’s commitment to community employment and of the options available to them. Support statutory change to the enabling statute for sheltered workshops to permit hiring of non-disabled workers to perform contract work.
 - Conducting a top-to-bottom review of Missouri’s current policies that govern eligibility for programs like Medicaid to pinpoint the changes necessary so that people who obtain regular jobs at decent wages will benefit from employment (See accompanying Box on the next page and Appendix B). This review should identify changes in state law or regulations that would align Missouri’s policies to take advantage of options in federal policy that would allow people to retain as much of what they earn as possible.
 - Altering the routine for determining eligibility for sheltered work and supported employment to encourage individuals to move more freely between sheltered and community work.

Eligibility For Medicaid, People With Developmental Disabilities and Missouri

Many people with developmental disabilities have very low income. They rely on the Medicaid program to pay for their health care. Also, in order to receive services through programs such as the home and community-based waiver, they must be qualified for Medicaid.

Generally, under federal law, people with disabilities qualify for Medicaid in one of two ways: they receive federal Supplemental Security Income (SSI) payments or they qualify under various "optional" categories that a state may establish. SSI recipients who work can keep some of the money they earn without losing benefits. For people who do not receive SSI, a state can establish its own rules concerning how earnings are treated for purposes of Medicaid eligibility.

As a result of decisions that were made when the federal SSI program was launched in 1972, Missouri decided to retain more restrictive eligibility policies. Technically, Missouri is what is termed a Section 209(b) state. One example of these more restrictive policies is that federal policy allows individuals to have up to \$2,000 in assets (e.g., money in a savings account). In Missouri the limit is only \$1,000. People who earn money that would take them over the \$1,000 amount are usually urged to spend their "excess" income to avoid losing Medicaid benefits. In other cases, people with "excess" income find their earnings attached to pay for the services they receive. When this happens, they in effect are being taxed at a 100% rate when they earn "too much".

By and large, the circumstance that Missourians with developmental disabilities find themselves in is that when they earn "too much", they will see their earnings taxed at a high rate or they will face the loss of Medicaid benefits. There are changes that can be made in Missouri's policies that would permit people to retain more of what they earn without facing the loss of vital benefits or finding themselves turning over what they earn to the state. One such change is to rethink Missouri's status as a Section 209(b) state so that Missouri's policies are no more punitive than federal SSI rules. The second change is to modify the rules for eligibility for long term services so that more of what people with disabilities earn can be protected.

- Correcting the contradictory requirements regarding certification of what individuals or agencies can deliver employment services. New policies must maximize the sources of employment services throughout the state.
 - Distributing information to people with developmental disabilities, families and providers regarding supported employment, including development of an informational website to complement the current DESE site on sheltered employment.
- ⇒ **State level policy makers should work with people with developmental disabilities, families, Senate Bill 40 County Boards, service providers, and others to develop a "Missouri Voucher to Work" service option.** Such a plan would establish a "employment voucher" where individuals can purchase their employment services from the provider of their choice, at an individually agreed price, and for the outcomes they seek. This plan is consistent with our core principle requiring that resources for support be allocated and expended from a person-centered perspective. In addition, it follows precedent in Missouri (i.e., the Personal Assistant Care Program administered by vocational rehabilitation) and nationally (e.g., employment voucher demonstration projects).
- ⇒ **DMRDD should strongly pursue its intent to fund increasing amounts of supported employment services through its Medicaid Home and Community Based waiver.** In doing so, it should offer providers the training and technical assistance they may require to offer the service.
-

3 Regional Advisory Councils must play an active role as conduits for grassroots input to promote consistent application of policy throughout Missouri.

Many years ago, Missouri set up its *Regional Advisory Council* network in parallel with the Regional Centers so that individuals, families and other stakeholders could come together to assess services from a local, grassroots perspective and advise Regional Centers. In some regions, there is an active and productive partnership between the Regional Center and the Regional Council. In others, however, there is a greater distance between the Regional Council and the Regional Center. Over the years, however, the Regional Advisory Councils' role has been eroded.

Asking for and listening to individuals and their families concerning how well the system is performing is important in achieving better results. The role of Regional Advisory Councils as conduits for innovation needs to be rekindled. Some of the best ideas and innovations that have improved Missouri's system have come from Councils.

To ensure that individuals and families are receiving even-handed treatment regardless of where in Missouri they happen to live, we strongly recommend that the

original role and purpose of the Regional Advisory Councils be reaffirmed. Regional Advisory Councils oversee consistent implementation of DMRDD policies around the state. DMRDD should value and affirm that Regional Advisory Councils can play an important role in promoting accountability and consistency in the application of state policies by Regional Centers. Asking and listening to customer views concerning how well the system is operating is important in achieving better results and improving trust.

The process of strengthening the role of Regional Advisory Councils should start with achieving the buy-in of all Regional Advisory Councils with the values and principles that have been articulated by the Missouri Customer Leadership Initiative. The Regional Advisory Councils should embrace the fundamental premise that publicly-funded services and supports must be framed by person-centered principles and that the system must be held accountable for respecting and acting upon the needs and preferences of each individual and family. Regional Advisory Councils should initiate dialogue with their Regional Center concerning how such principles will shape the provision of services and supports at the regional level.

The more specific steps we believe must be taken are these:

- ⇒ **DMRDD should reaffirm its support of the advisory role of the Regional Advisory Councils.** This means that DMRDD should affirm that it welcomes Regional Advisory Councils being active in: (a) monitoring the implementation of state policies at the regional level, and (b) initiating policy change initiatives.
- ⇒ **DMRDD should solicit and be willing to act upon Regional Council findings and recommendations concerning state policy implementation and change.** Regional Center directors must be held accountable for following state policies. When problems cannot be resolved locally, DMRDD should provide Regional Advisory Councils with a clear avenue for referring the problem to the Division and securing its quick resolution.
- ⇒ **A role for stakeholders and Regional Advisory Councils in anticipating, recommending, and supporting changes and improvements to services will be implemented.** Missouri needs to tap the knowledge and energy of all its citizens to improve the system's ability to deliver the supports that people and families want.
- ⇒ **A mechanism should be developed to promote collaboration and effective communication among the Regional Advisory Councils, the DMRDD and the Missouri Planning Council for Developmental Disabilities.** Clearly, if Regional Advisory Councils are to be more active in monitoring how consistently state policies are being implemented, then a mechanism will need to be put into place that promotes effective communication among the Councils. The Missouri Planning Council can and should facilitate this communication. Working with the

Regional Advisory Councils, the state planning council can aid in identifying possible topics that would be a focus of Regional Council monitoring activities and collaboration.

- ⇒ **Regional Council members will need more support in the form of training and learning opportunities in order to play this role.** Certainly, if the Regional Advisory Councils are to be more active in monitoring the application of state policies at the regional level they will need to be well-versed in those policies. Both DMRDD and each Regional Center should routinely make available opportunities for Regional Council members to be briefed on policies and procedures as well as observe Regional Center operations.
- ⇒ **The State of Missouri should invest in grassroots advocacy by furnishing financial and in-kind support to the Regional Advisory Councils.** The Regional Advisory Councils depend on Regional Centers for in-kind support. The extent to which such support is available to the Regional Advisory Councils varies from region-to-region. For Regional Centers to obtain grassroots input and leverage new community resources, the DMRDD must invest in Regional Advisory Councils.

4

Missouri policy makers should build system capacity for serving people with developmental disabilities consistent with our guiding principles.

The Missouri state population stands at about 5,414,000 people. A prevalence rate for developmental disabilities of 1.8% suggests that approximately 97,452 people in Missouri have a developmental disability. Yet in 1997, DMRDD served only about one quarter of this number, with many receiving case management services only. A recent DMRDD study of current consumers (DMRDD, 1998) shows that 314 people over age 65 and another 1,378 between 40-65 receive case management only. As these individuals and their caregivers grow older, one can easily speculate that many of these individuals will soon need more substantial support.

In addition, DMRDD also reports a continued stream of people that it finds eligible for services each year, placing increasing pressure on the system to expand its capacity:

- ✓ More than 600 children (under age 6) have been determined eligible in each of the past six years;
- ✓ Typical growth for DMRDD is 1,200 consumers per year;
- ✓ Between 400-500 students exit the school system each year, seeking major supports; and

- ✓ Few people who receive services from DMRDD exit the system.

And these are just the individuals that are known to DMRDD. One is left to imagine under what circumstances so many other Missourians with developmental disabilities have not come forward to request services. Some may have no present need for services, their needs are being met by independent means or by family or friends. Some may simply not request public assistance. Others may have needs that they feel the system cannot or will not meet. Within these categories individual factors may well change (e.g., an aging caregiver who can no longer provide support), resulting in that person coming forward to request services. But others may need and want services but have not yet been identified.

Missouri's present system falls short of meeting the legitimate needs of people with developmental disabilities today. The price of this shortfall is that people who need such supports to meet day-to-day challenges or become productive, contributing members of their communities are being short-changed. Demand for services and supports is greater than the public system is able to meet today. This demand will not disappear. Missouri needs to expand capacity today and adopt policies for the future that will ensure that people who have legitimate service needs will have those needs met. Parent caregivers need the assurance that supports will be there when they no longer are able to continue to provide care.

Underlying the three previous recommendations is an expectation for service approaches that are person-centered -- but also fiscally responsible. These recommendations have the potential for promoting self-determination, community inclusion, and a unified vision of the future.

We expect that such action will increase fiscal efficiencies and help to eliminate chronic system difficulties that make the system appear complicated, inaccessible and ultimately impenetrable to people with developmental disabilities and their families. Additionally, we expect that by using the money already available with greater direction and purpose, resulting increases in efficiency will expand the capacity of the system to serve more people. Indeed, the cost for not taking these steps should be unbearable to all Missourians. To help correct these circumstances, we recommend that the following steps be taken:

- ⇒ **DMRDD should design and implement a coordinated and reliable means for determining the current and future demand for developmental disability services.** Each day children with developmental disabilities are born. These are individuals who may well need developmental disability services during their lives. In addition, we recognize that America is graying, a trend that certainly includes people with developmental disabilities. And where these individuals live home with their families, we recognize that their family caregivers -- often their parents -- are aging as well. These population demographics are observable

and to some extent can be used to predict the future demand on developmental disability systems.

At present, waiting list data in Missouri is collected by multiple sources (e.g., Senate Bill 40 Boards, Regional Centers), but these data are not systematically tied together to assure their accuracy and reliability. Moreover, they do not always present a clear picture of the type of support a person or family needs.

To have a better understanding of what must be done to meet current and emerging service demand, DMRDD must develop a reliable tracking system to:

- ✓ Take accurate stock of relevant population demographics related to the incidence and prevalence of developmental disabilities, as well as to gauge the age of parent caregivers.
- ✓ Create an environment statewide where people can easily come forward to make their needs known.
- ✓ Assure that the needs indicated by individuals pertain to the “urgency of need” and the type of support that is needed. Individuals should not be encouraged to specify service types (e.g., sheltered workshop, supported living). Such practice amounts to a channeling of demand into preset categories, undercutting opportunity to explore preferences for emerging or innovative approaches to service delivery. Rather, individuals should be asked to specify the types of general support they need (e.g., help to get and keep a day time job, a place to live and needed residential support).
- ✓ Create a coordinated means of tracking needs across multiple data collection points. DMRDD offices should not be the only place where individuals can make their needs known. Other partners can be utilized, included county Senate Bill 40 Boards, parent networks and People First chapters. The idea is to create a statewide and decentralized means of tracking needs, but to do so systematically to assure data accuracy and reliability.

⇒ **Missouri state and local level policy makers should maximize use of Medicaid funding to expand system capacity consistent with previously stated guided principles.** Missouri’s present Medicaid matching rate is 60.7% (i.e., for every 39.3 cents that Missouri provides, the Medicaid program will supply another 60.7 cents). We recognize that much has already been done to increase the use of federal reimbursement through Medicaid to fund Missouri developmental disability services.

Policy makers must continue to examine ways to leverage additional federal

reimbursement to promote a person-centered service system. For instance, with supported employment now a waiver service option, dollars presently earmarked for day habilitation maybe matched for federal reimbursement to deliver supported employment services. Likewise, certain family support funds may also be creatively matched within the waiver. In this regard, new money recently allocated for "Family Directed Support Services" may in part be used within the waiver program.

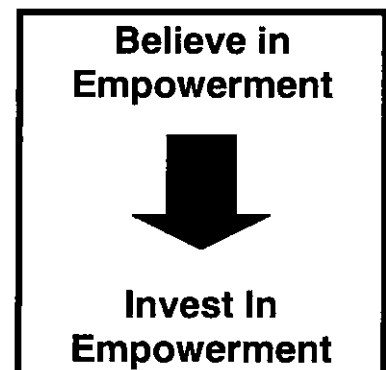
⇒ **Missouri policy makers and advocates should establish annual targets for service expansion and then actively seek appropriate appropriation increases.** Based on findings resulting from the waiting list initiative noted above, policy makers will be able to request with confidence increases in agency budgets to accommodate the documented demand. More than that, by engaging people statewide in collecting the data, needed political support for increased appropriations will be stimulated.

⇒ **Missouri policy makers and advocates should assure that any new money that comes into the developmental disabilities system is distributed consistent with person-centered principles.** As noted in Chapter 3, Missouri has developed a tradition of establishing a variety of programs, but without commitment to any unified vision. The result is that Missouri offers a living museum of all types of services, some contemporary and others clearly timeworn.

Breaking from this tradition, policy makers should commit to developing a person-centered system by investing any new money into approaches that are consistent with person-centered principles. The concepts and action steps previously presented in Recommendations 2 and 3, on participant-driven supports and employment, provide a clear direction for future spending.

⇒ **Missouri policy makers should forge partnerships with people with developmental disabilities and family members to shape policy and practice.** A commitment to person-centered principles and related dollar investments are good first steps. Successful system reform, however, will depend on establishing a strong partnership with the very people who are receiving services.

To assure their effective participation in a person-centered system, policy makers will need to invest directly in service recipients. They may do so by assuring that:



- ✓ At a systems or strategic level, people with disabilities (as well as family members and guardians) have opportunity to shape policy and practice. To assure such partnership, resources must be set aside to offset the costs of participation and/or for needed training or technical support.² Recommendation 3 on Regional Advisory Councils is certainly consistent with this action step.
- ✓ Make available to service recipients and family members information on how a person-centered system could work. Such information, delivered systematically through periodic newsletters, local focus groups, conferences and other means, will steadily develop an informed participant constituency, one that will be better prepared to press for and test innovative approaches to service delivery.

² HSRI is compiling a nine chapter "curriculum" designed for self advocates entitled *My Voice, My Choice*. Missouri is a participating field test state. The topics covered will provide self advocates with the information related to developmental disability systems, self-determination and fiscal responsibility.

5. Concluding Remarks _

This report summarizes a year's work by the Missouri Customer Leadership Initiative. During this time we explored numerous issues and learned a great deal about developmental disabilities services in Missouri. We did not always reach the same conclusions or agree about what needs to be done. Change always imposes choice, and choice often stimulates candid discussion and disagreement. For us, it also brought deliberation and finally consensus over what must be done in Missouri to improve services for people with developmental disabilities. We stand strongly committed to a core principle dedicated to a person-centered way of doing business. We believe that resources for supports in the State of Missouri must be expended so that individuals are in control of their allocated resources for services and supports and how they are delivered. This document reflects our strong expectation and commitment to translate this vision into practice across our state.

The four recommendations we offer (See Chapter 4) are consistent with this theme and we expect that they will serve as a basis for widespread systems change in Missouri. We are well aware that in pursuing this vision numerous procedural and mechanical issues must be resolved. Toward this end, we encourage the state's professional community to embrace the work we have done and apply their expertise to addressing these issues.

In addition, we recognize that there are political obstacles to overcome, given that there is a long history associated with the present way of delivering developmental disabilities services in Missouri and that hard change is seldom embraced with enthusiasm anywhere. Further, we recognize that the proposed system may not be for everybody. Some individuals may prefer to receive services as they do now.

Creating service options where people with developmental disabilities -- who are customers rather than service recipients -- control their lives is the cornerstone

"In the 1960's and earlier we were treated like plants. You fed us, clothed us, kept us warm, and wheeled us out to feel the sun.

In the 1970s and 80s you discovered we could be taught -- we could learn -- and we were treated like pets. You taught us all types of tricks and we stood by your side.

But now it is the 1990s. We are not plants. We are not your pets. We are people like you and we want to be treated as real people.

We want the same opportunities as anybody."



Dirk Wasano, Chair
Consumer Empowerment Committee
Hawaii Planning Council on
Developmental Disabilities, 1994

concept of a person-centered system. We are aware of the difficult steps that lie ahead to translate this vision into reality, and the need for collaborative action to guide a transition to the new system. Our recommendations can only be implemented if all parties concerned with the well-being of people with developmental disabilities in Missouri work together, including “customers,” Senate Bill 40 Boards, Regional Advisory Councils, service providers, the MPCDD and state agency policy makers.

In the end, no single constituency or group of people should be asked to bear the responsibility for change alone. We must all be willing to take on our own share of responsibility; We must be willing to leave the past for the future.

Such proactive action is not new to the developmental disabilities field. The service system has changed enormously over the past 25-30 years. Fundamental to the changes over these times has been a willingness to change and the acceptance of a degree of uncertainty associated with change and reform. People left institutions for life in the community. People left their group homes for apartment living. Others left their sheltered day program for an integrated community job. While such change was for the most part welcomed, these shifts were not unanimously cheered and came with some potential jeopardy mixed in. These changes required innovation and cooperation among many. We succeeded then. Together, we can succeed again.

For the moment, the most pressing issue centers on the amount of responsibility we all will be willing to take.

- ✓ **If you are a state policy maker or Senate Bill 40 Board member, what responsibility will you take** to develop the new administrative structures needed to place people with disabilities in control of the supports they receive?
- ✓ **If you are a service provider, what responsibility will you take** to be prepared to participate in a more competitive market, one that will reward agility and those who respond best to the support preferences of people with disabilities?
- ✓ **If you are involved with a local or state level developmental disability advisory agency or board, what responsibility will you take** to provide sound advice and leadership in helping to reform the service system?
- ✓ **If you are an advocate or concerned citizen, what responsibility will you take** to do what you can to assist individuals with developmental disabilities to participate in the planned changes or simply to assure that others do their job?

“You might be on the right track,
but you’ll get run over if you just sit
there.”

Will Rogers



- ✓ **If you are a parent or family member of a person with developmental disabilities, what responsibility will you take** to assure that your loved one receives the best supports possible but also receives the chance he or she deserves to live a self determined life?
- ✓ **If you are a self advocate -- a person with a developmental disability -- what responsibility will you take** to express your life needs and dreams, make responsible choices and live your life. Further, **what responsibility are you willing to take to help lead the way in the changes that lie ahead?**

The idea that the developmental disabilities system must be significantly changed to embrace a person-centered perspective is still gaining momentum, and the direction the field ultimately will take is by no means clear. We hope that all in Missouri will agree to shoulder their share of responsibility to improve services for people with developmental disabilities. We expect that this report will be used as a guide to the state and local discussions that must unfold over the next few years. Such discussions, however, must lead to action -- action of the sort that will ultimately ensure the well-being of people with developmental disabilities, and a life in the community shaped by their own preferences. We will expect and accept nothing less.

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Appendix A

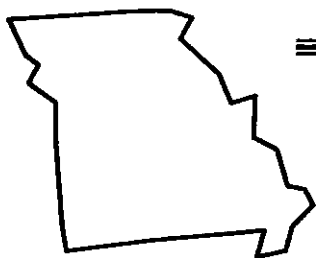
Services and Supports For Missouri's Citizens With Developmental Disabilities:

Where The Dollars Come From And Go To



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

**Where the Dollars
Come From and Go To**



The Missouri Customer Leadership Initiative

Introduction



Last September, the Missouri Customer Leadership Initiative (MCLI) convened to take stock of where our state stands in supporting its citizens with developmental disabilities and determine for ourselves whether changes should be made so that the "system" reflects values and principles that are important to individuals and families. Taking stock includes understanding the dimensions of Missouri's current funding for developmental disabilities services and how these dollars are used.

This report pulls together a considerable amount of information concerning state, federal, local and other funding of services and supports for Missouri citizens with developmental disabilities. We sought answers to the following questions:

- ✓ How much is spent overall on services and supports for people with developmental disabilities in Missouri?
- ✓ Where does the money come from to underwrite this spending?
- ✓ What types of services do these dollars buy?
- ✓ How well does this spending match up with the Initiative's principles concerning how individuals and families might best be supported?
- ✓ How does Missouri stack up in its funding for developmental disabilities services in comparison to other states and the nation as a whole?

Families, friends, neighbors and communities freely give immeasurable amounts of supports to people with developmental disabilities. But publicly funded supports are enormously important in assisting people with developmental disabilities. Taxpayer dollars underwrite personal assistance to help individuals in day-by-day living activities, gain skills to become more self-sufficient and participate in community life.

Public policy decisions concerning how public dollars are spent have enormous implications for people with developmental disabilities and their families. Twenty years ago, public policy mainly directed dollars into large state-operated public facilities (like Missouri's Habilitation Centers) and other large congregate-care living arrangements. In 1977, some 75% of all the dollars spent in Missouri and nationwide for developmental disabilities services underwrote the costs of these types of facilities¹. It was rare for tax dollars to purchase community services or aid families with a son or daughter with developmental disabilities living at home. Policy directed dollars so that services mainly were available outside rather than within the community.

Today, public dollars mainly underwrite services and supports within the community. Policy changes in Missouri and at the federal level now give individuals and families wider choices. But we still find that policies governing the flow of dollars frequently work at cross-purposes to the desires of individuals and the needs of families. There are funding "silos" that force

¹ Braddock, Hemp, Parish and Westrich (1998). *The State of the States in Developmental Disabilities* (5th Edition). Washington DC: American Association on Mental Retardation.

individuals and families to take what is available rather than the system's flexing to meet their needs.

The information contained in this report hopefully will enable all Missourians who have a keen interest in services for people with developmental disabilities to gain a better understanding of how dollars flow in our state and thereby join with us in a dialogue concerning changes that will promote a system of services and supports where services and support are person-centered.

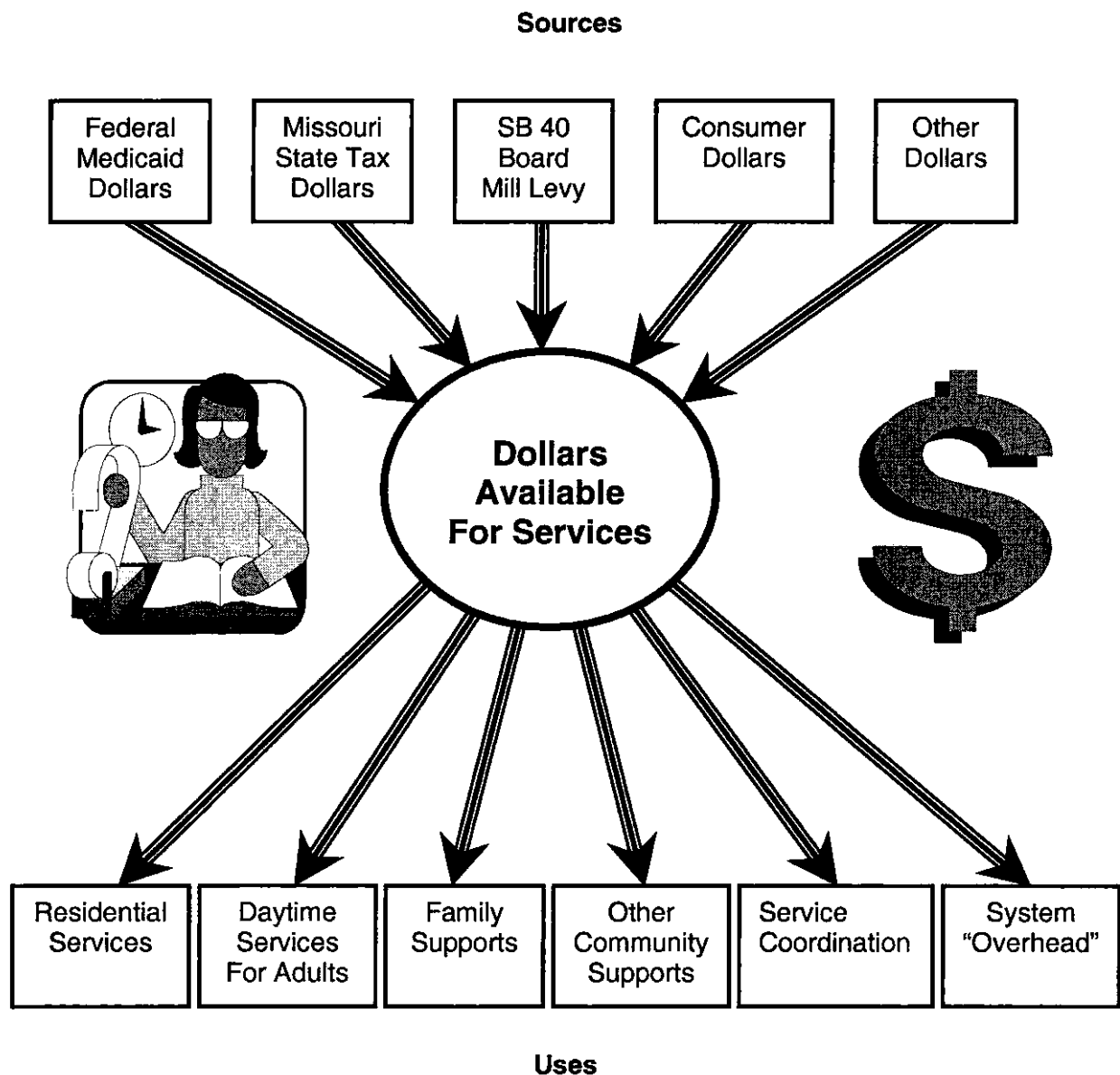
This report begins with a "Big Picture" overview of Missouri's funding for developmental disabilities services. Here, there is information concerning how many dollars overall are being spent, where these dollars come from, and what types of services they are purchasing. The report then zooms in on particular sources of funds and categories of services to provide more in-depth information. The Appendix provides the details concerning how these figures were compiled. The figures presented here are as solid as they can be given the nature of this project. But there are some caveats concerning some figures that are described in the Appendix. Despite some of the difficulties with the figures, we believe that you will find this report provides a comprehensive picture of where the dollars come from and go in Missouri in support of its citizens with developmental disabilities.

The Big Picture

How Dollars Flow ...

Federal, state, and local tax dollars are the major sources of funds to pay for services and supports for people with developmental disabilities in Missouri. There are other sources of funds as well. Each of these sources of funding will be described in more detail later.

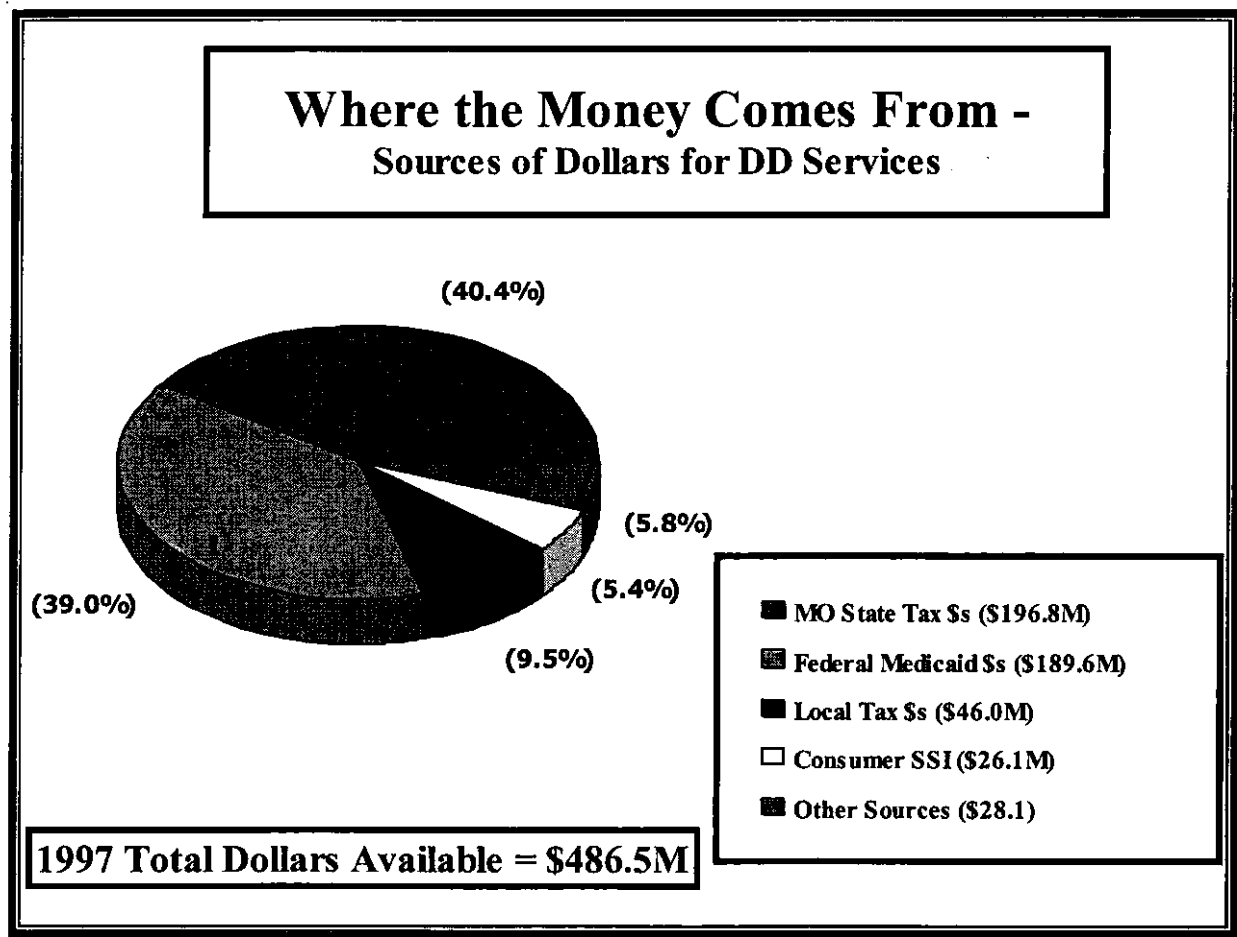
Residential and daytime services (sheltered work, day habilitation and community employment) are the two largest uses of available dollars. We will zoom in on each of these uses below.



How Many Dollars Are Available?

In 1997, all together Missouri spent \$486.5 million on developmental disabilities services. The pie chart below breaks down these dollars by source. The more detailed figures upon which this chart and many others are based can be found in the table at the end of this section of the report.

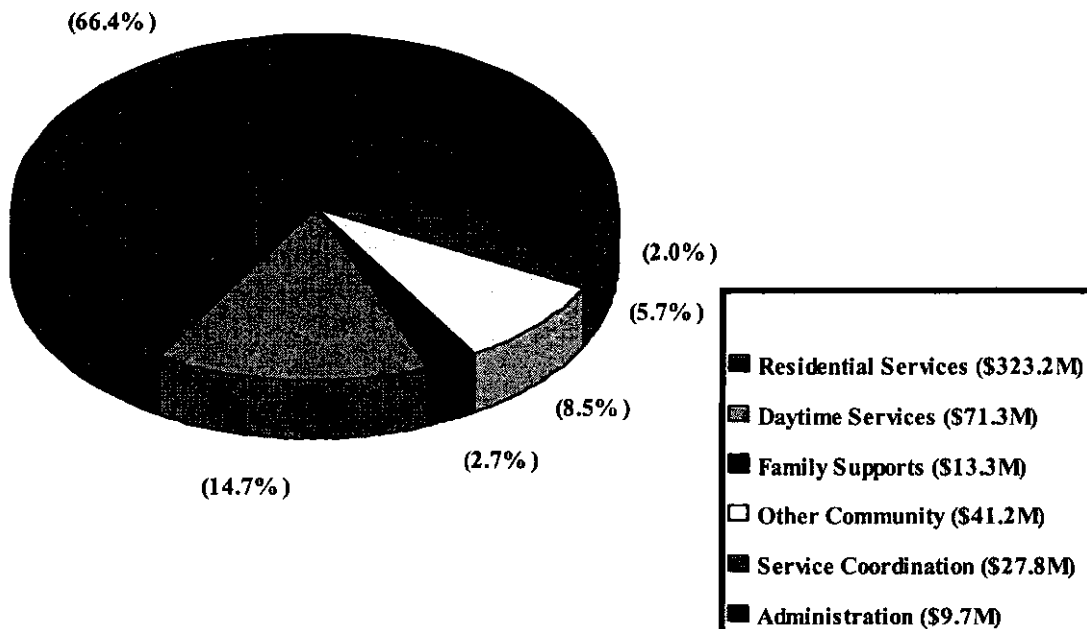
Missouri tax dollars were the single largest source of dollars to pay for services and supports for people with developmental disabilities but federal Medicaid dollars were a close second. Together these two sources accounted for nearly 80% of all the dollars expended. We will look more closely at Medicaid funded services below. S.B.40 Board mill levy dollars paid for a little under ten percent of all services. Consumer dollars – mainly in the form of payments for housing and other living expenses in community residences – accounted for another five-percent. Other sources of funds included other federal assistance (e.g., federal vocational rehabilitation funds) and some private dollars.



What Services Did These Dollars Buy?

The pie chart at the top of the following page breaks down this \$486.5 million in spending by major category of service. Obviously, residential services claim the biggest slice of the pie. About \$2 in every \$3 spent in Missouri for developmental disabilities services is earmarked for residential services. More detail about the composition of these services will be provided later.

How Missouri Uses Its Dollars: 1997 Spending by Type of Service



Total 1997 Spending = \$486.5M

The next largest use is daytime services. But, as can be seen from the chart, family support services claim only a small slice of the pie. Service coordination (provided by Division of Mental Retardation and Developmental Disabilities(DMRDD) Regional Center case managers) amounts to 5.7% of total spending.

Putting the Big Picture into Perspective ...

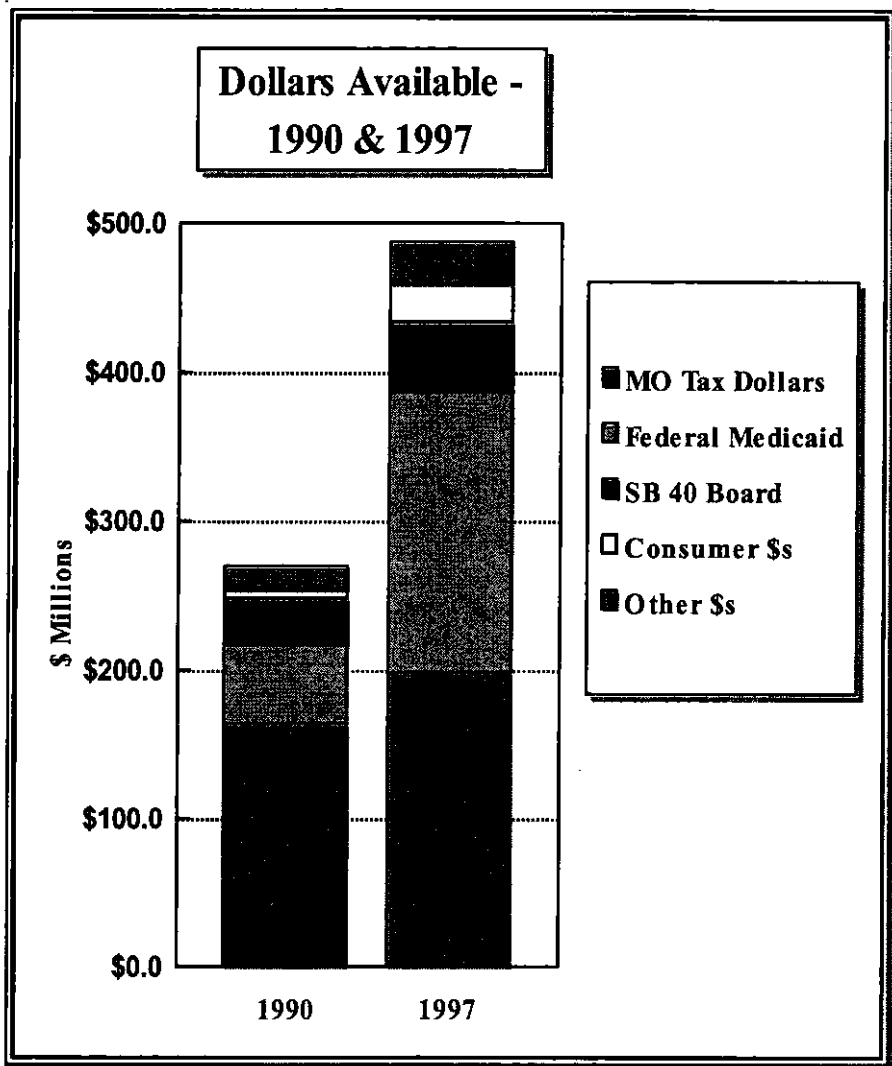
Spending for developmental disabilities services in Missouri has grown considerably in recent years. The chart on the next page shows total spending for developmental disabilities spending in Missouri for 1990 and 1997. Not adjusted for inflation, the dollars available increased from about \$269 million to about \$487 million. This was about an 80% increase over these eight years or a compound annual rate of growth of approximately 8.8% a year. Adjusted for inflation², the total dollars available grew by 50% over this period or 5.9% each year. Dollars

² Measured by the Bureau of Labor Statistics' deflator for state and local government services, it took \$1.21 in 1997 for government to purchase the same amount of goods and services that \$1 would buy in 1990.

available for developmental disabilities services in Missouri grew somewhat more quickly than was the case nationwide³.

The chart also shows that federal Medicaid dollars grew the most between 1990 and 1997. These dollars accounted for \$136 million (or 63%) of the \$218 million in new dollars that came into Missouri's system. Adjusted for inflation, the amount of federal Medicaid dollars tripled between 1990 and 1997, growing at an annual compound rate of 16.6%.

Missouri tax dollars underwriting developmental disabilities services increased by 20%. However, adjusted for inflation, state general fund support was about the same in 1997 as 1990. SB 40 Boards provided about 50% more dollars in 1997 than in 1990.



The dollars available for developmental disabilities have grown considerably. The major reason is that Missouri is now making far greater use of federal Medicaid dollars today than it did eight years ago.

How does Missouri's overall level of support for developmental disabilities compare to elsewhere? Missouri's level of "fiscal effort"⁴ with respect to supporting developmental disabilities services is about average. In other words, Missouri's citizens are willing to devote about as many dollars to developmental disabilities services as citizens in other states. Of the states surround Missouri, Iowans and Kansans devote relatively more dollars to developmental disabilities services; Nebraska, Oklahoma and Arkansas spend about the same amount;

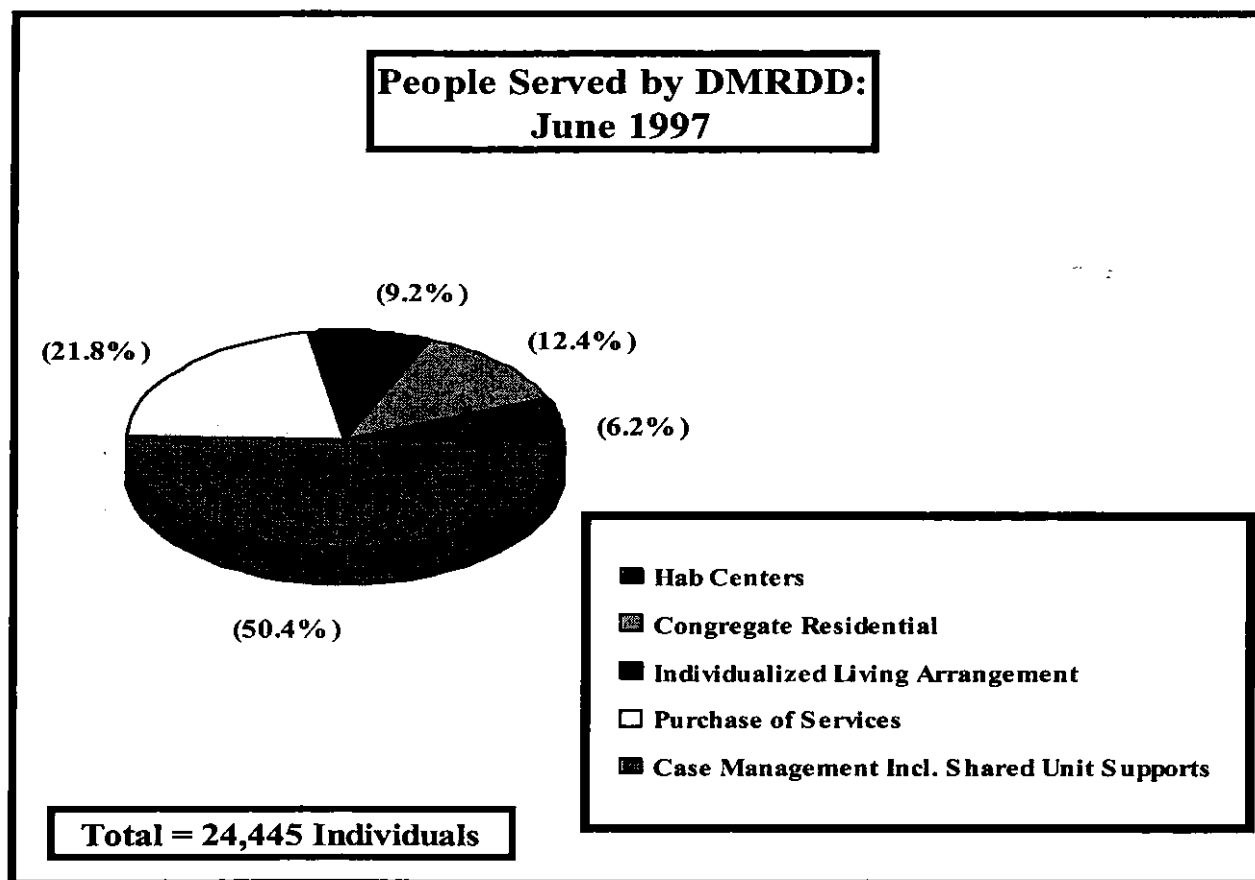
³ Between 1990 and 1996, spending for developmental disabilities services nationwide increased at an annual rate of 4.3% nationwide, adjusted for inflation. Gary Smith. "What the Numbers Tell Us - About the Past and Perhaps the Future". *Community Services Reporter* (April 1998): National Association of State Directors of Developmental Disabilities Services.

⁴ Fiscal effort is measured by dividing total spending for developmental disabilities services by total personal income in a state. Fiscal effort is a measure of how many dollars out of all those available a state's citizens are willing to use toward these services. Nationwide, in 1996 about \$3.65 out of every \$1,000 in personal income went toward developmental disabilities services. See Braddock et al., op. cit.

Tennessee, Illinois and Kentucky make considerably fewer dollars available to support their citizens with developmental disabilities.

How Many People Are Receiving Services?

There is no precise count of the total number of people with developmental disabilities who are being supported with these \$486.5 million. The services for some individuals are paid for by two or more funding sources, so simply adding up each agency's report about how many individuals are served would lead to counting some people twice. We know that in June 1997 that DMRDD had 24,445 "unduplicated" persons on its active caseload, including the individuals served by the Habilitation Centers. As the chart below shows, about 28% of these individuals were receiving some form of residential service.



The table at the end of this section provides statistics concerning the number of individuals who receive various kinds of services. But, as mentioned earlier, there is no good way to "unduplicate" these numbers. In some cases, there are no statistics readily available that tell how many people are supported by some funding sources. But, a reasonable estimate might be that the \$486.5 million is probably buying services and supports for about 29,000-30,000 Missourians with developmental disabilities. If that is right, then 0.5% of Missouri's population (or five citizens in every 1,000) depends on the services and supports that these dollars buy. The impact is actually larger when one takes into account the families of these individuals.

The Details

The Table below provides a more detailed breakdown of the sources and uses of the \$486.5 million that was available in 1997 for developmental disabilities services. Footnotes associated with the table are on the next page. Over the next several sections we will zoom in on various parts of this table to provide more in-depth information. How the figures contained in this table were derived is described in the Appendix.

Service/Support Category	Total Spending \$ Ms	Fund Sources						Average Number of Consumers
		Federal Medicaid	Other Federal	MO State GR \$s	Consumer SSI \$s	Local Tax \$s	Other/ Private	
Residential Services								
1. Habilitation Centers/Campus	\$115.9	\$58.9	\$0.0	\$57.0	\$0.0	\$0.0	\$0.0	1,381
2. Other ICFs/MR	6.6	3.9	0.0	2.7	0.0	0.0	0.0	133
3. HCB Waiver	149.1	77.2	0.0	47.3	20.6	4.0	0.0	4,082
4. Nursing Facilities	28.8	17.3	0.0	11.5	0.0	0.0	0.0	1,314
5. SB 40 Boards	4.9	0.0	0.0	0.0	0.0	4.4	0.5	n/a
6. Non-Waiver Residential	17.9	0.0	0.0	12.4	5.5	0.0	0.0	1,100
Sub-total: Residential	\$323.2	\$157.3	\$0.0	\$130.9	\$26.1	\$8.4	\$0.5	8,124
Day Services								
1. HCB Waiver/Day	\$19.7	\$11.8	\$0.0	\$7.3	\$0.0	\$0.6	\$0.0	4,907
2. HCB Waiver/SE	0.3	0.2	0.0	0.1	0.0	0.0	0.0	81
3. Sheltered Workshops	38.1	0.0	0.0	11.4	0.0	6.9	19.8	8,100
4. Vocational Rehabilitation	4.2	0.0	3.4	0.8	0.0	0.0	0.0	5,396
5. Other SB 40 Bd. Svcs.	3.8	0.0	0.0	0.0	0.0	3.4	0.4	n/a
6. SB 40 Bd S/E Services	5.2	0.0	0.0	0.0	0.0	4.6	0.6	n/a
Sub-total: Day Services	\$71.3	\$12.0	\$3.4	\$19.6	\$0.0	\$15.5	\$20.8	n/a
Family Supports								
1. Children's Model Waiver	\$0.9	\$0.5	\$0.0	\$0.4	\$0.0	\$0.0	\$0.0	80
2. SB 40 Boards	9.6	0.0	0.0	0.0	0.0	8.5	1.1	n/a
3. Family Subsidy/Loan	1.0	0.0	0.0	0.8	0.0	0.0	0.2	600
4. Other DMRDD	1.8	0.0	0.0	1.8	0.0	0.0	0.0	n/a
Sub-total: Family Supports	\$13.3	\$0.5	\$0.0	\$3.0	\$0.0	\$8.5	\$1.3	680
Other Community Svcs.								
1. HCB Waiver	\$5.2	\$3.1	\$0.0	\$2.0	\$0.0	\$0.1	\$0.0	n/a
2. Other SB 40 Bd. Svcs.	15.4	0.0	0.0	0.0	0.0	13.5	1.9	n/a
3. Other DMRDD	20.6	0.0	0.2	20.5	0.0	0.0	0.0	5,300
Subtotal-Other Comm.	\$41.2	\$3.1	\$0.2	\$22.5	\$0.0	\$13.6	\$1.9	5,300
Service Coordination								
- Regional Centers	\$27.8	\$16.7	\$0.0	\$11.1	\$0.0	\$0.0	\$0.0	22,922
Administration								
1. DMRDD Central Office	2.0	0.0	0.0	2.0	0.0	0.0	0.0	n/a
2. Other RC Ops	7.7	0.0	0.0	7.7	0.0	0.0	0.0	n/a
Subtotal: Administration	\$9.7	\$0.0	\$0.0	\$9.7	\$0.0	\$0.0	\$0.0	n/a
TOTAL -- ALL	\$486.5	\$189.6	\$3.6	\$196.8	\$26.1	\$46.0	\$24.5	

Footnotes:

1. Habilitation Centers/Campus
Total = DMR/DD operations appropriation + fringe benefits paid for by office of
 administration + capital dollars.
Funding = Federal Medicaid ICF/MR earnings (receipted to MO general fund).
2. Other ICFs/MR = State matching funds appropriate to DMR/DD; Federal Medicaid
dollars are in DSS budget.
3. HCB Waiver = Expenditures from MO initial HCFA 372 report for period 7/1/96 –
6/30/97. State GR Share + matching funds provided by SB40 Boards included in
DMR/DD budget. Federal funds are in DSS budget. Client funds paid to providers.
4. Nursing Facilities = fund appropriated to DSS.
5. SB40 Boards: MACDDDS Annual Report.
6. Non-Waiver Residential: DMRDD budget + estimated client funds paid to providers.
7. HCB Waiver Day: From HCFA 372 Report.
8. HCB Waiver S/E: From HCFA 372 Report.
9. Sheltered Workshops: Total outlays from DESE sheltered workshop 1996 Fiscal Report
adjusted to delete raw materials + client wages. GR appropriation to DESE/DSW. Local
tax dollars are SB40 Board payments to sheltered workshops.
10. Voc Rehab: Funds in DESE/DUR budget. Expenditures from special computer run.
11. Other SB 40 Expenditures: From MACDDDS Annual Report.
12. SB 40 Board S/E Services: From MACDDDS.
13. Children's Model Waiver (Sara Jean Lopez) State Matching Funds: DMRDD budget.
Federal Medicaid in DSS.
14. SB40 Boards: MACDDDS Annual Report.
15. Family Subsidy/Loan: DMRDD budget.
16. Other DMRDD: Other community services from DMRDD budget.
17. Other HCB Waiver: From HCFA 372 Report.
18. Other SB40 Budget Sucs: From MACDDDS Annual Report.
19. Other DMRDD: From DMRDD budget.
20. Service Coordination: Estimate provided by DMRDD. Expenditures include fringe
benefits paid for by office of administration.
21. DMRDD Central Office: DMRDD budget + fringe benefits.
22. Other RC Ops: DMRDD budget + fringe benefits.

Zooming In ...

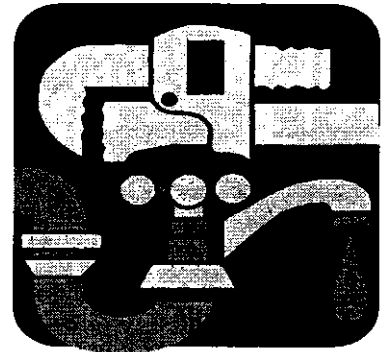
Where the Money Comes From



Here we provide some more details about the sources of the dollars that underwrite services and supports for Missourians with developmental disabilities. We start with a brief discussion of the “plumbing” (i.e., how dollars flow in the system) and “silos” (the extent to which dollars may only be used for narrow purposes). We provide a good deal of information about Medicaid funding of services and supports because it is very important. We also briefly describe some of the other funding sources.

Plumbing

Figuring out how much is spent on developmental disabilities services in Missouri can be hard because there is no single place where all the figures can be found. A major portion of the dollars is found in the DMRDD budget. But some of the dollars are located in the budgets of other Missouri state agencies. There are other dollars that flow directly from consumers to service providers. In Missouri, the SB 40 Boards raise and spend property tax mill levy dollars that are outside the Missouri state budget. Then there are federal dollars that flow into various Missouri state agencies which pass them along to other state and local agencies or use them to buy services. So “following the money” can be complicated. Other states have equally complicated financial “plumbing”. The Appendix to this report provides the details behind the figures in the chart on page 8 and contains information about the various funding “streams”.



Sorting it all out, what is mainly important probably is the following

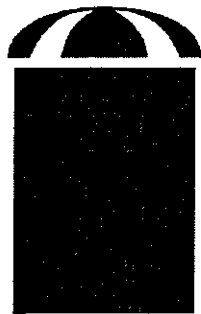
- ✓ Federal Medicaid dollars flow into Missouri as reimbursements for services that fit into various Medicaid funding categories. We will discuss these categories and provide more details later. All these dollars flow through the Missouri Department of Social Services. In order to obtain these dollars, Missouri must provide “matching” funds. Currently Missouri tax dollars (state or local) pay \$4 out of every \$10 that is spent on a Medicaid service and the federal government provides the remaining \$6. Some of the federal Medicaid dollars flow in the Missouri state treasury to pay back the state for dollars it already has spent for services (mainly at the Habilitation Centers and for Regional Center service coordination). When community services are being purchased, matching dollars in the DMRDD budget are combined with federal Medicaid dollars to make these payments. SB40 Boards also send some matching dollars to DMRDD in order to obtain federal Medicaid dollars in order to expand or enhance the services they underwrite.
- ✓ There are fringe benefit expenses state employees at the Habilitation Centers and DMRDD Regional Centers that are paid for out of the budget of the state Office of Administration. These dollars are not included in the DMRDD budget.

- ✓ State payments to sheltered workshops and for vocational rehabilitation services are located in the Department of Elementary and Secondary Education (DESE) budget. Federal vocational rehabilitation dollars flow into DESE. DMRDD also sends about \$500,000 of its dollars to the DESE Division of Vocational Rehabilitation to serve as matching funds for federal vocational rehabilitation funds in order to obtain services for people served by DMRDD. SB 40 boards use part of their dollars to help underwrite services at sheltered workshops. Dollars that sheltered workshops earn by selling their products also underwrite the costs of services for people served in sheltered workshops.
- ✓ When individuals are served in community residences operated by service provider agencies, they are expected to pay over a part of the federal Supplemental Security Income (SSI) they receive each month to meet what are termed “room and board” expenses (housing food and other costs). These dollars are paid directly to service providers.

There are other dollars that also flow to underwrite services and supports for Missouri citizens with developmental disabilities that we have not captured here. For example, many people with developmental disabilities rely on the Medicaid program to pay for their general health care expenses. State and federal “special education” dollars flow to local school districts to pay for education for children and youth with disabilities, including developmental disabilities. The resources available for this Initiative did not permit us to track down all of these dollars. In the main we followed the money that is attached to what may be termed “specialized developmental disabilities services.”

All these funding streams and the associated plumbing are fairly complicated. In pulling together this report, we have tried to avoid dwelling on these complications.

Funding Silos



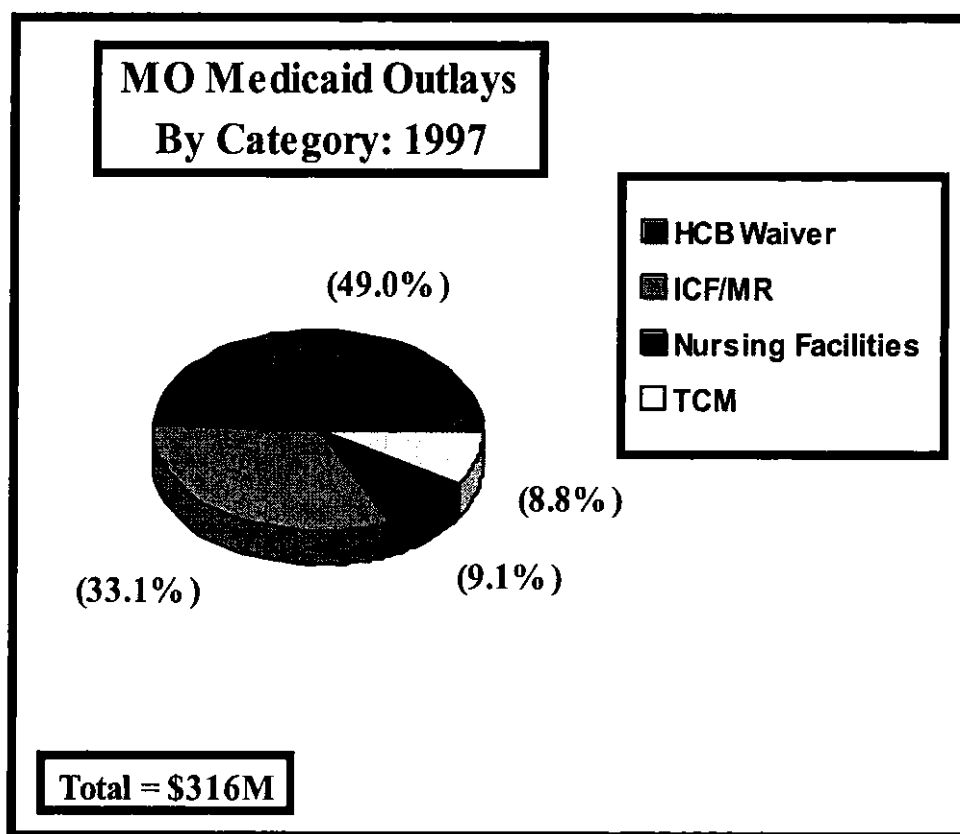
A major objective of the Missouri Department of Mental Health is to break down what are termed funding “silos”. This term describes instances when public dollars can be used only for very specific purposes in support of a group of individuals. In person-centered systems of services and supports, it is usually better if dollars are flexible so that they can flex with the needs of individuals or families. We use this term in some of the materials that follow, pointing out instances when dollars are very closely identified with relatively narrow “programs” or groups of individuals. We have some funding silos that affect developmental disabilities services in Missouri.

Medicaid Funded Services and Supports

Federal Medicaid dollars account for about 39% of all the dollars available in Missouri for developmental disabilities services. When the state and local matching dollars needed to “earn” these federal dollars also are included, the overall amount of services and supports paid for by Medicaid dollars is much bigger – approximately \$316 million or about 65% of all the dollars available. About \$126.4 million in state and local tax dollars are earmarked as Medicaid matching funds or about \$1 in every \$2 available. So it is fair to say that the financial health of Missouri’s services and supports for people with developmental disabilities is very closely tied to the Medicaid program. Medicaid payments to states are the biggest source of federal financial assistance for specialized developmental disabilities services. No other federal program is as important.

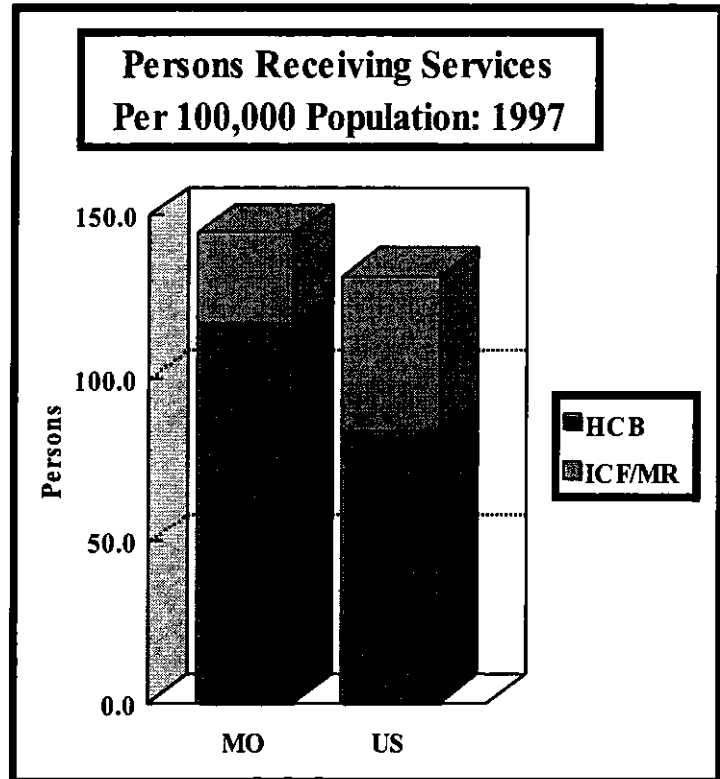
The pie chart shows how the \$316 million in federal, state and local Medicaid dollars were divided up in Missouri in 1997. In Missouri, there are four main types of Medicaid-funded developmental disabilities services. These are:

- ✓ **Intermediate Care Facilities for the Mentally Retarded (ICF/MR).** An ICF/MR is congregate living arrangement (for four or more individuals) that is certified as meeting an extensive set of federal regulations. In Missouri presently the “on campus” services at the Habilitation Centers are certified as ICFs/MR. There also are a small number of facilities operated by other agencies that are ICFs/MR.
- ✓ **Nursing Facilities.** Federal Medicaid dollars also pay for services in nursing facilities. In Missouri, there are a considerable number of individuals with developmental disabilities who reside in general nursing facilities.
- ✓ **Home and Community-Based Waiver Services.** Congress created the Medicaid home and community-based (HCB) waiver program in 1981 to give the states the option of redirecting Medicaid institutional dollars (e.g., dollars for ICF/MR or nursing facility services) to pay for other kinds of services and supports in the community. As we will discuss, the HCB waiver program is very important in funding community services in Missouri.
- ✓ **Targeted Case Management.** The last major source of federal Medicaid dollars flowing into Missouri are labeled “targeted case management” dollars. These dollars help pay for the costs of assisting Medicaid-eligible individuals to access health care and other services. In Missouri, these dollars underwrite a considerable amount of DMRDD Regional Center costs for service coordination.



Clearly, the HCB waiver program looms the largest in terms of how Missouri uses Medicaid dollars to pay for services and supports for people with developmental disabilities. In fact, because the state has stepped up its use of the HCB waiver program considerably, it has been the most significant source of all the new federal Medicaid dollars that have poured into Missouri's service system since 1990. In 1990, the HCB waiver program purchased about \$16.5 million in services and supports. By 1997, that total had increased to \$154.6 million, more than a nine-fold increase. We will zoom in on HCB waiver services below.

In contrast, Missouri used the ICF/MR program less in 1997 (when roughly 1,500 individuals were served in ICFs/MR) than in 1990 when there were 2,000 people served in these types of facilities. Many people who used to be served in ICFs/MR are now obtaining services through the HCB waiver program. People who receive ICF/MR or HCB waiver services need to pass the same eligibility test. Missouri serves a greater portion of these individuals through the HCB waiver program (81% of the 7,800 individuals who were receiving ICF/MR or HCB waiver services on June 30, 1997) than is the case nationwide, where about 64% participated in the HCB waiver program. The chart shows Missouri's use of ICF/MR and HCB waiver services versus the nation as a whole. To provide an "apples-to-apples" comparison, we show the number of individuals who received either kind of service relative to population⁵. As can be readily seen, Missouri serves relatively more individuals through the HCB waiver program than the nation as a whole but fewer people in ICFs/MR. In total, Missouri uses the Medicaid program to purchase long-term support services for about 10% more of its citizens with developmental disabilities than is the case elsewhere.



In Missouri (as is the case nationwide), ICF/MR services are more costly than HCB waiver services (supporting one person for a full year in a Missouri ICF/MR cost \$75,800 in 1997 versus \$27,600/person/year in the HCB waiver program). Nationwide, the average full-year equivalent cost of furnishing ICF/MR or HCB waiver services to an individual is \$46,300; in Missouri the figure is \$35,300 or about 24% lower, mainly because Missouri relies more extensively on the lower cost HCB waiver program than is the case elsewhere.

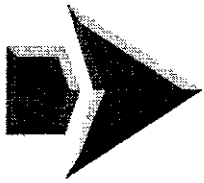
The ICF/MR program is an example of a "silo" program. State and federal dollars earmarked for ICF/MR services can only buy the types of services offered in a certified ICF/MR facility. The HCB waiver program is more flexible because dollars can buy services for people who live at home, on their own or in a community residence. There also is more diversity in the types of services that can be purchased with HCB waiver dollars. So by shrinking ICF/MR services and

⁵ We divide recipients by general state population and divide again by 100,000.

growing HCB waiver-funded services, Missouri has a less serious silo problem today than it did in the past.

Medicaid dollars that pay for services in nursing facilities are another funding “silo”. They buy only institutional services. They are very difficult to redirect to buy other types of services and supports. Federal Medicaid targeted case management dollars also can only be used to buy service coordination.

When we zoom in the services that are being provided to Missourians with developmental disabilities, we will provide some additional information about how these Medicaid dollars are used. The key points that need to be made are:

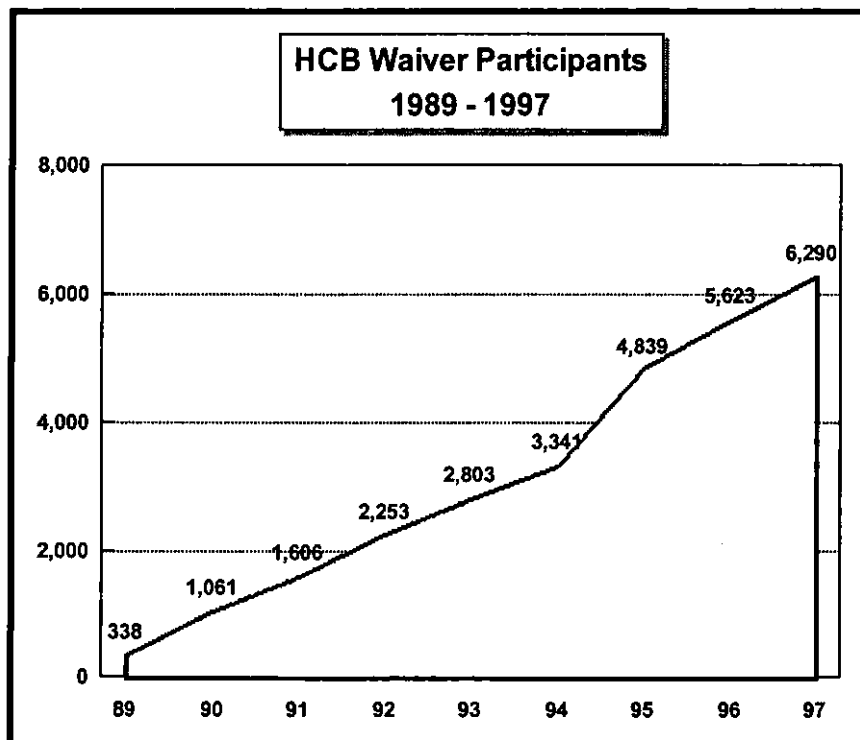


- ✓ Nearly \$2 in every \$3 Missouri spends on services and supports for people with developmental disabilities flow by way of the Medicaid program.
- ✓ Medicaid funding is much more important today than it was in 1990.
- ✓ Obviously, the Medicaid HCB waiver program is very important.
- ✓ Any discussion about changing what dollars buy in Missouri cannot ignore the Medicaid program

Zooming in Again: The HCB Waiver Program

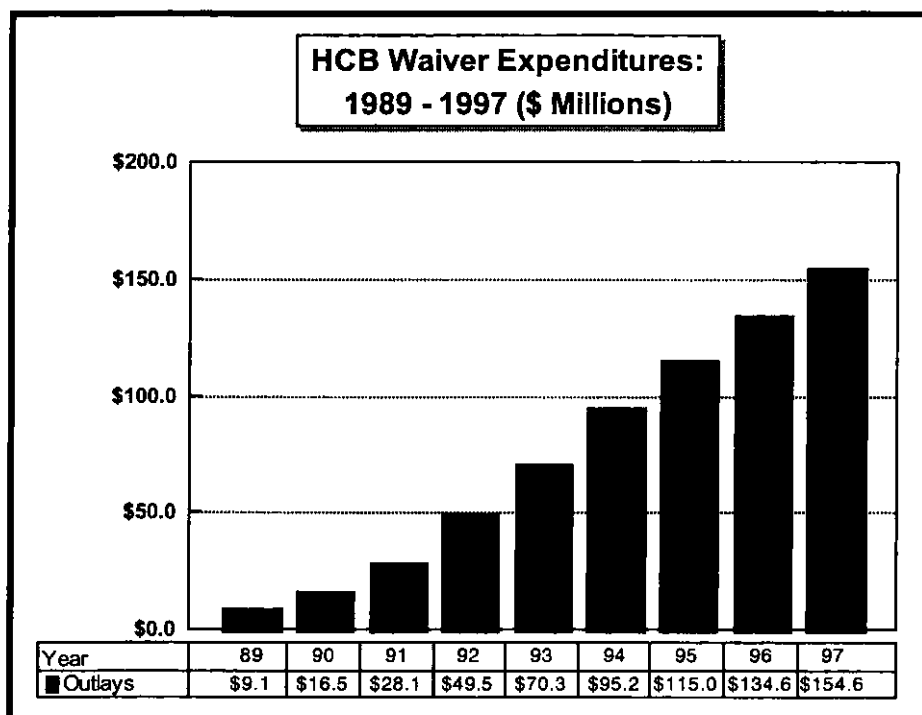
Because this funding source is so important in Missouri, it is worth providing some more information about it. The chart shows how many individuals participated in this program each year between 1990 and 1997. As can be seen, the program has grown a good deal.

Missouri actually has two HCB waiver programs for people with developmental disabilities. The largest is the one that has been in operation since July 1988 and principally serves adults with



developmental disabilities. In 1995, the Sarah Jian Lopez "model" waiver program was launched. This program provides services to children who live at home with their families who otherwise could not qualify for services. The main objective of this program is to prevent these children from having to leave the family home. In 1997, 84 children received services through this family/child oriented program.

Outlays for HCB waiver services have grown substantially since Missouri began to offer these services, as shown on the chart. Since 1990, about \$88 million new federal dollars have flowed into Missouri's service system for people with developmental disabilities by virtue of the expansion of this program. As can be seen from the table below, the program purchases various services and supports.



HCB Waiver Outlays by Service			Utilization by Type of Service		
Service	Outlays (\$ Ms)	Percent of Total	Service	Persons Receiving	Percent of Total
ISL	69.8	45.4%	ISL	2,179	35.1%
Residential Habilitation	58.7	38.2%	Residential Habilitation	2,363	38.1%
On-Site Day Hab	10.9	7.1%	On-Site Day Hab	2,208	35.6%
Off-Site Day Hab.	8.8	5.7%	Off-Site Day Hab.	3,252	52.4%
Transportation	3.4	2.2%	Transportation	1,438	23.2%
Therapies	0.8	0.5%	Therapies	870	14.0%
Respite	0.2	0.1%	Respite	80	1.3%
Supported Employment	0.3	0.2%	Supported Employment	81	1.3%
Crisis Intervention	0.2	0.1%	Crisis Intervention	180	2.9%
All Other	0.6	0.4%			

ISL services are Individualized Supported Living services that are furnished to individuals with developmental disabilities who live in regular community living arrangements. Residential habilitation services are residential services that are mainly provided in licensed, agency-controlled living arrangements. As can be seen from the table the lion's share of HCB waiver dollars go to buy residential or daytime services. In the next section we will distribute these dollars among the major service categories in Missouri.

SB 40 Board Dollars

In many ways, SB 40 Boards are a phenomenon that is unique to Missouri. Local government funding of developmental disabilities services is not uncommon nationwide. However, in 1996, local tax dollars only accounted for about 2.2% of all spending on developmental disabilities services. In Missouri, the share is far higher: 9.5%. So local tax dollars are much more important in Missouri than most other states.

Moreover, elsewhere local funding of services frequently is the result of a state mandate that localities pay for part of the costs of services. SB 40 Boards are the voluntary creations of county voters. The only state around Missouri where local dollars play a major role in paying for services and supports is Iowa. County funding of mental retardation services in Iowa is the result of state mandate.

The table at the end of the previous section shows how SB 40 Board dollars are distributed by service type. SB 40 Boards are significant funders of family support and supported employment services. Lastly, how flexible SB 40 Board dollars are is a matter of controversy.

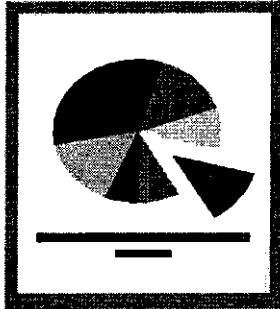
Other Dollars

The category labeled "other dollars" includes some non-Medicaid federal dollars. Mainly these are federal vocational rehabilitation dollars. We will discuss the uses of these dollars when we discuss daytime services in the next section. The other major source of other funds are dollars derived from the sale of sheltered workshop goods and services that are help provide services to individuals with developmental disabilities. These dollars are considerable. Again, we will look at these dollars in more detail in the next section.

A Last Few Words About Sources of Funds

Even though how money comes into and flows around Missouri's service system is complicated, in the main it can be sorted out. Out of the nearly \$500 million dollars that were available for developmental disabilities services in Missouri in 1997, most came from Missouri state tax dollars or federal tax dollars. Still, in Missouri local dollars are far more significant than is the case in most other states. How SB 40 Boards decide to use their funds does have an important impact at the local level.

Zooming In ... Where the Dollars Go



Here we provide information concerning how the \$486.5 million that Missouri had available in 1997 was put to use in underwriting services and supports for people with developmental disabilities. We zoom in on various service categories to provide in-depth information.

Residential Services

"Residential services" means providing services to an individual in a living arrangement that is outside his or her family home. Such services can include personal assistance, "supervision" and training. About \$2 in every \$3 that Missouri spends for developmental disabilities services goes to buy residential services. It also is worth pointing out that residential services also claim about 83% of all the Medicaid dollars that Missouri spends on these services. Since residential services obviously are very important, they deserve an in-depth look.

We start by describing the overall scope of residential services that Missouri provides or purchases for people with developmental disabilities (mainly through the Department of Mental Health). This information includes the type and size of settings in which these services are furnished.

Before turning to the details, some background is in order. At one time, "residential services" mainly meant those delivered in licensed settings (e.g., residential care facilities, group homes or child/adult foster care arrangements) that are operated, owned and controlled by public or private (nonprofit or proprietary) agencies. Since the mid-1980s, it has become more common for states to purchase services and supports that are delivered in regular community living arrangements that are controlled by the person (e.g., the person lives in home he or she owns or rents; often this arrangement is labeled "supported living"). The information reported here includes both types of service arrangements.



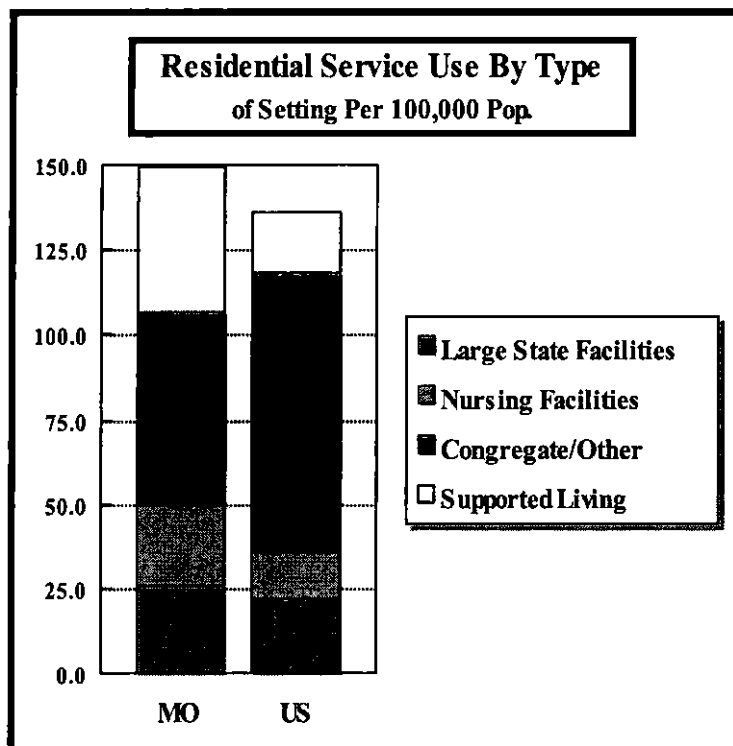
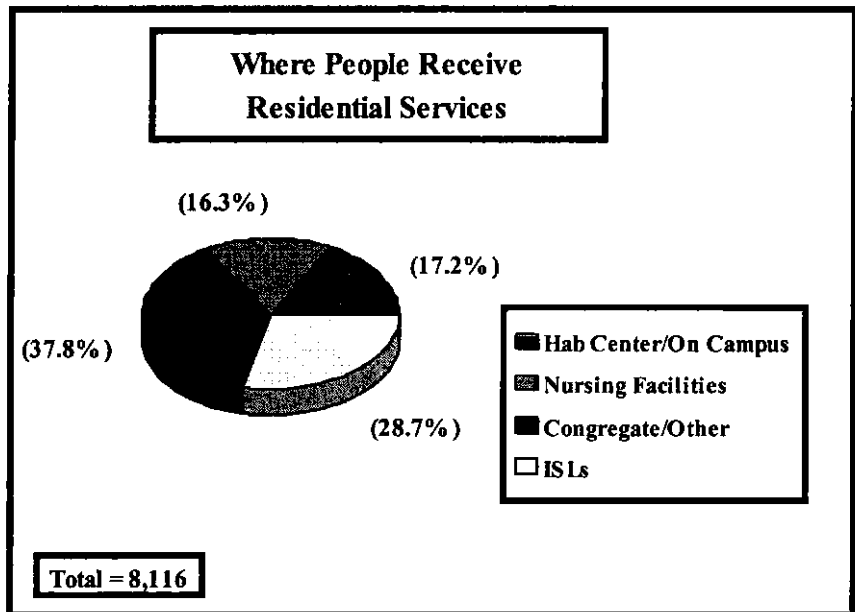
The "size" of the living arrangement where individuals are served also frequently is regarded as important. The classifications we use here are:

- ✓ "large" facility is a single site where 16 or more residents receive services;
- ✓ "medium" facility serves between 7 and 15 individuals;
- ✓ "small" facility serves 6 or fewer persons; and,
- ✓ "very small" facility or living arrangement serves 3 or fewer individuals

This labeling is not meant to be pejorative (e.g., "big is bad" or "small is beautiful"). We also provide information about the costs of the various types of residential services.

Residential Services: Utilization and Spending

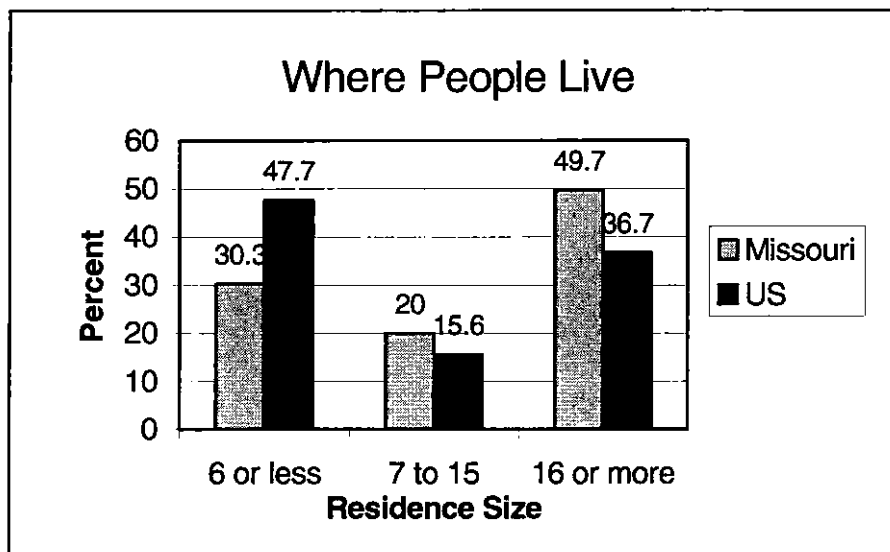
Including people with developmental disabilities who are served in Missouri nursing facilities, the \$323.2 million dollars that Missouri spent on residential services paid for services for 8,116 individuals⁶. The pie chart shows the types of settings where these individuals resided. About one-third lived on the grounds of the Hab Centers or in nursing facilities. The largest numbers were served in community-based residential settings, mainly group homes. Roughly 29% received services and supports in Individualized Supported Living (ISL) arrangements which are mainly funded through the HCB waiver program.



How Missouri stack up with regard to providing residential services for people with developmental disabilities? The chart at the left shows how many individuals received each type of residential service in Missouri per 100,000 people in the overall population compared to the nation as a whole⁷. According to these figures, Missouri provided residential services to about 10% more individuals relative to its population than was the case nationwide. But there are two major differences. First more Missourians with developmental disabilities reside in nursing facilities than is typical in other states (we will zoom in on this below). At the same time, Missouri also provides relatively more supported living services than is the case in other states (it is 2.5 times more common for Missourians to

⁶ As of June 30, 1997.

⁷ The national numbers are for 1996. More recent figures were not available when this report was prepared. However, the national totals change only a little year by year.



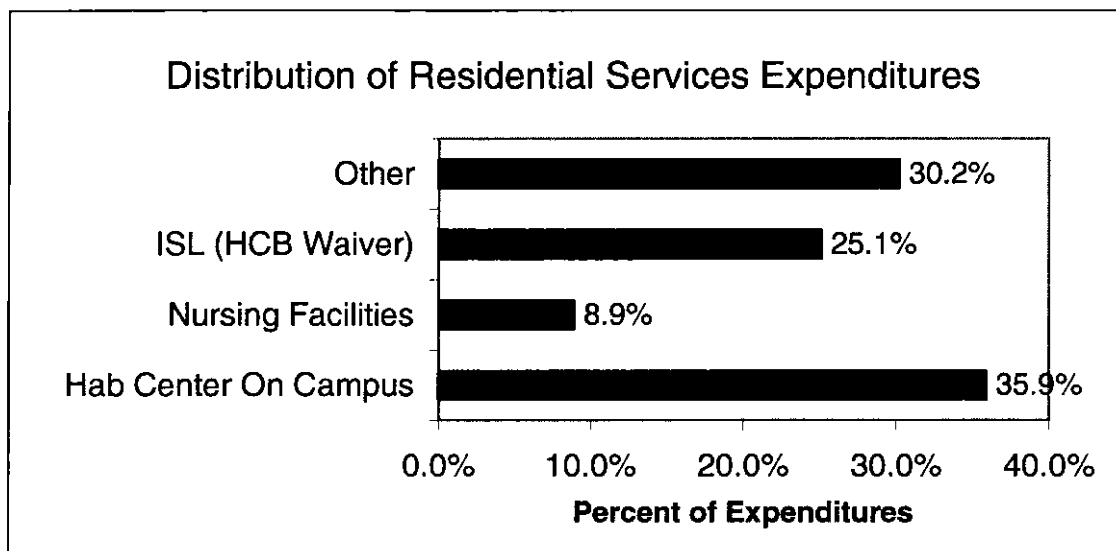
receive supported living than for people with developmental disabilities in other states).

When Missouri is compared to the nation, Missourians with developmental disabilities are more likely to be served in relatively larger settings than is the case elsewhere. Mainly, this is because of the relatively large number of individuals served in

nursing facilities. If those settings are excluded (and, thereby, only "specialized" developmental disabilities residential services are considered), in 1996 a Missourian receiving residential services lived in an arrangement that served 4.9 individuals. Elsewhere, the average size comparable setting served 3.8 individuals. So Missouri uses somewhat large settings than is the norm nationwide. At the same time, the use of very small settings (i.e., those serving three or fewer individuals) is much higher in Missouri than is the case in other states).

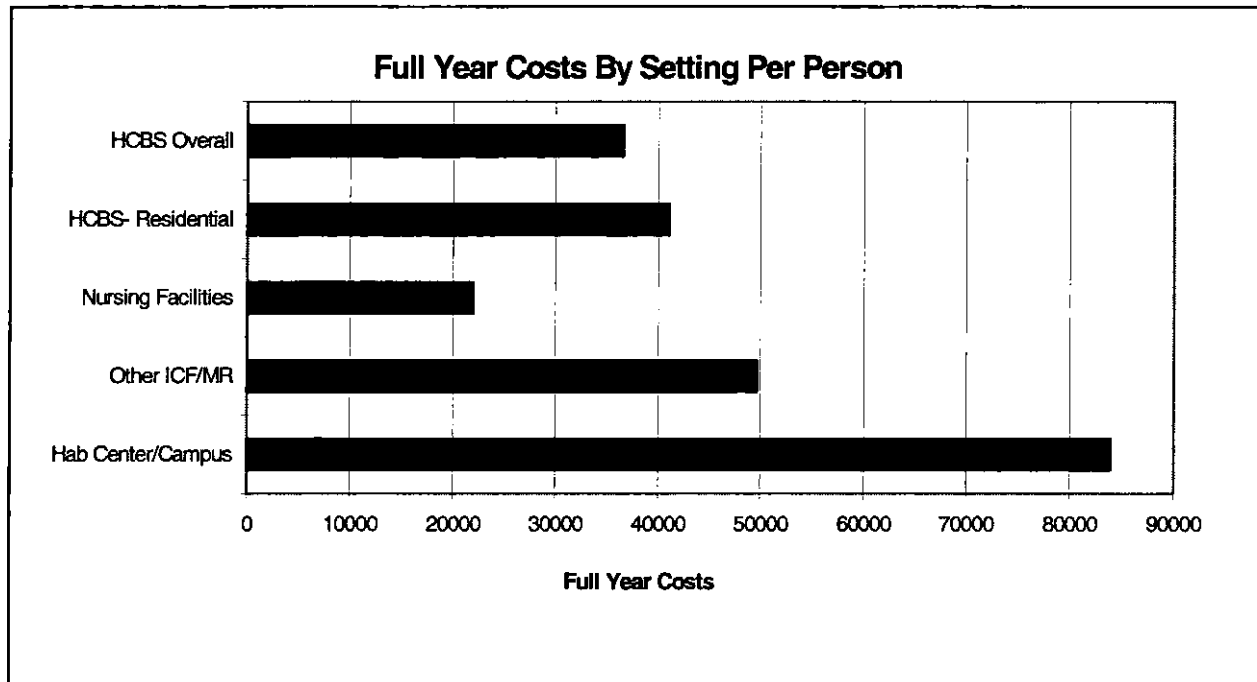
Spending and Costs of Residential Services

The chart below shows how the \$323.2 million that Missouri spent on residential services in 1997 was split by type of setting. The services provided on the grounds of the Hab Centers accounted for more than one-third of the total (but only 17.2% of the total number of people who received residential services). ISL services funded via the HCB waiver program accounted for about 25% of all spending.



There are big differences in the costs per person among the various types of residential service settings and program funding source. The chart below illustrates these differences⁸.

As can be seen, the per person costs at Hab Centers are relatively high. Costs are lower for people who receive residential services through the HCB waiver program than in either Hab Centers or other ICF/MR facilities. The lowest per person outlays occur for people served in nursing facilities. This pattern is similar to that observed in other states.



Residential Services Overall -- Highlights

With regard to residential services in general



- ✓ Missouri provides these services to about 10 percent more people than nationwide.
- ✓ Missouri's use of nursing facilities higher than the norm nationwide.
- ✓ Living arrangements are somewhat larger in Missouri than in other states.
- ✓ At the same time, Missouri makes more extensive use of very small supported living arrangements than is common else
- ✓ There is a wide range of costs among the types of living arrangements.

⁸ As best as possible, these full-year equivalent costs have been calculated on an "apples-to-apples" basis. By full-year equivalent, we mean the costs of serving one person continuously over a full year. Hab Center and ICF/MR costs are inclusive of room and board as well as day activities. The costs for HCB waiver services factor in approximations of similar costs.

Zooming In: Habilitation Center Services

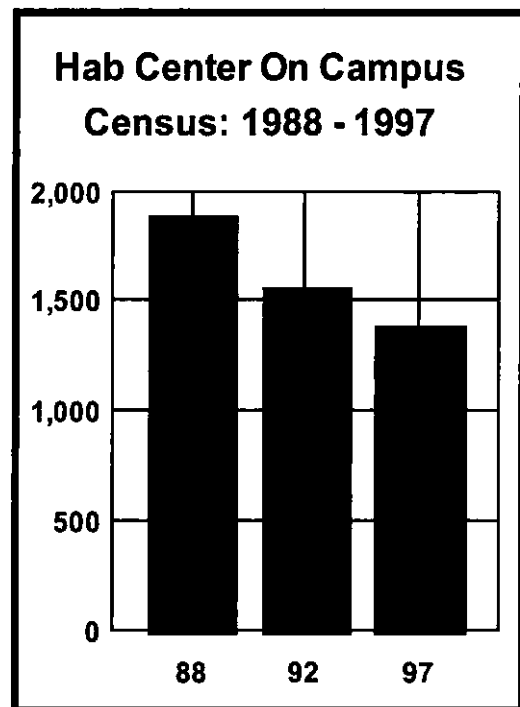
The Habilitation Center expenditures account for a significant share of Missouri's spending on residential services. Here we take a closer look at the Hab Centers. The table shows the distribution of the 1,523 individuals served by the Hab Centers on June 30, 1997. It distinguishes between people who live "on campus" and those served by Hab Centers in small community residences "off the grounds".

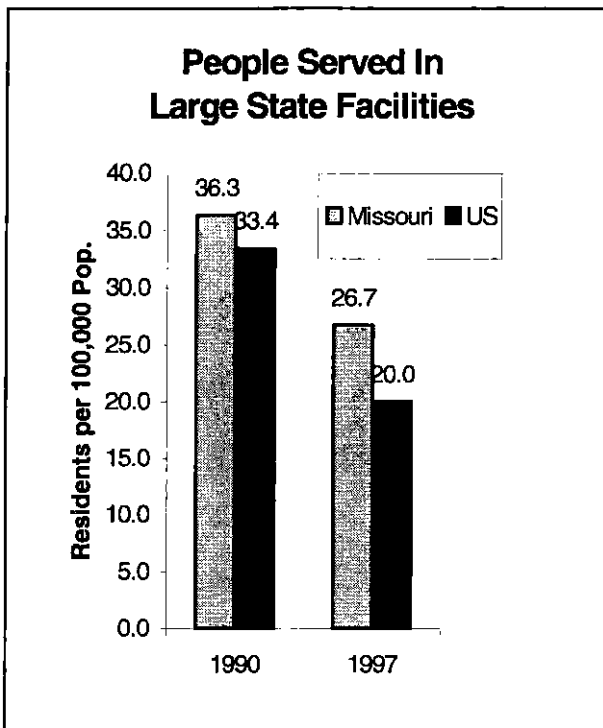
Habilitation Center	On Campus	Community Residences	Total
Marshall	326	41	367
Bellefontaine	376	5	381
Higginsville	165	50	215
Nevada	145	0	145
DDTC (St. Louis)	272	36	308
SE MO Residential Services	97	10	107
All Centers	1,381	142	1,523

Most of the individuals served in community residences by the Habilitation Centers live in settings that serve two or three individuals. These residences mainly are funded with HCB waiver dollars.

Over the years, the number of individuals served on the grounds at the Hab Centers has been declining. The chart at the right shows the number of persons served on campus for selected years. Between 1988 and 1997, the on campus Hab Center census declined by about 500 individuals or roughly 27%. Most of the decline between 1988 and 1992 occurred as a result of the closure of the larger residential units that were collocated at several of the regional centers. Since 1992, a good deal of the reduction in the on-campus population has occurred as a result of the Hab Centers serving an increasing number of individuals in off the grounds community residences. As can be seen from the table above, nearly one-quarter of the residents of Higginsville are served off the grounds. Marshall and DDTC also served a significant number of individuals in community residences.

Nationwide, the number of individuals served in large, state-operated residential facilities has been on the decline since 1967. There are many reasons for this decline, including the emergence of community-based services, more emphasis on community integration, litigation and economic reasons. Elsewhere, the decline in the use of these facilities has been

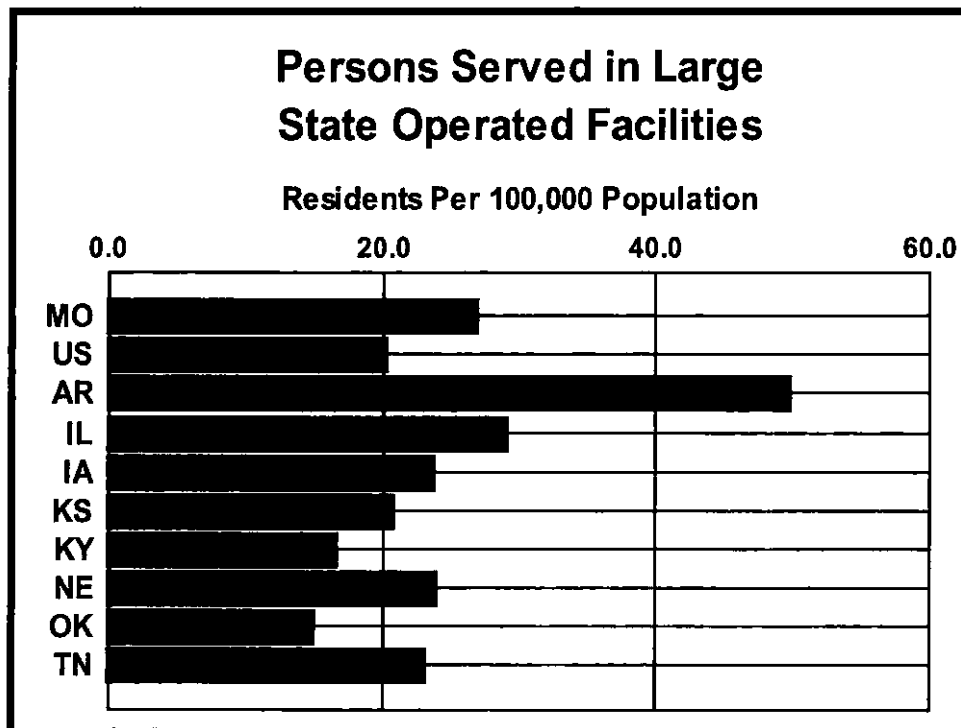




more pronounced than in Missouri. Between 1988 and 1997, nationwide the number of individuals served in large state operated facilities dropped from roughly 92,000 to a little under 54,000 or 41%. When measured relative to state population, Missouri's use of this type of setting has been higher than the case elsewhere, as shown by the chart at the top of the next page. In 1990, Missouri's use of these facilities was about 10% greater than elsewhere. Since other states have been placing individuals out of this type of facility at a greater rate than Missouri, in 1997 Missouri's use of large state-operated residential facilities was about one-third greater than in the nation as a whole.

In comparison to neighboring states, Missouri's use of large state operated facilities is higher than most, as illustrated by the next chart, which also measures the use relative to overall population. Arkansas and Illinois have higher utilization rates. Kentucky and Oklahoma have decidedly lower rates.

With respect to costs, nationwide in 1997 the average annual cost per resident in large state operated facilities was \$98,550 nationwide or about 20% higher than was the case in Missouri. Historically, Missouri's costs per resident have tended to be lower than those in other states.



Zooming In: People Served in Nursing Facilities

As discussed earlier, there are relatively more Missourians with developmental disabilities in nursing facilities than is the norm elsewhere. Nationwide in 1996, there were 14.1 individuals with developmental disabilities per 100,000 population served in general purpose nursing facilities. In Missouri, there were 24.4 individuals with developmental disabilities served in these facilities. This means that Missouri's use of these facilities for people with developmental disabilities is about 73% higher than is the case nationwide. As a general matter, nursing facilities are not preferred long-term placements for people with developmental disabilities. Missouri's high rate of use of these facilities raises a red flag.

Zooming In: ICF/MR Services

Nationwide, about 50% more dollars were spent on ICF/MR services than HCB waiver services in 1997. Also in 1997, roughly 64% of all the persons who received ICF/MR services were served in facilities operated by non-state public or private agencies. The nationwide utilization of non-state ICF/MR services in 1997 was 30.3 persons per 100,000 population. The utilization rate in Missouri was markedly lower: about 2.2 persons per 100,000 population. Missouri's use of ICF/MR services outside the Hab Centers has never been very extensive. In recent years, it has declined further, mainly because Missouri has placed considerable emphasis on expanding its HCB waiver program.

Zooming In: Children Receiving Residential Services

Over the past twenty years, there has been a major decline in the number of children and youth (under the age of 21) with developmental disabilities who are in placement away from the family home. In 1977, nationwide, there were a little over 91,000 0-21 year olds with developmental disabilities in placement; by 1997, that number had shrunk to just under 25,000⁹. This decline is attributed to a wide variety of factors, including the reforms in special education, the growing availability of family support services, and others. In 1977, there were 2,700 children and youth with developmental disabilities who had been placed in specialized residences in Missouri. They accounted for roughly 41.5% of all individuals in residential placement (and one third of all the individuals in the Habilitation Centers). By 1997, the number of children and youth in residential placement had dropped to 546 or 8.3% of all persons receiving specialized residential services (i.e., excluding individuals in nursing facilities)¹⁰. This placement rate was about 10% higher than the nationwide rate but still substantially reduced from the level twenty years ago. Moreover, in 1996 only about 6% of all Hab Center residents were children and youth; predominantly these were youth over the age of 14.



Daytime Services

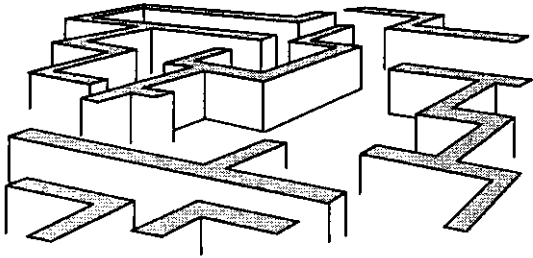
"Daytime services" are the next largest category of expenditures in Missouri. Daytime services can be divided into two broad categories. The first is labeled "day habilitation" and mainly involves programs that aim at teaching individuals skills in a setting away from their residence. The second broad category involves

⁹ Lakin, Anderson and Prouty (February 1998). *Children and Youth Receiving Residential Services for Persons with Developmental Disabilities Outside Their Family Homes: Trends from 1977 to 1997*. Minneapolis MN: University of Minnesota, Research and Training Center on Residential Services and Community Living.

¹⁰ Of these, 180 were ages birth through 14 and 366 were between the ages of 15 and 21.

work activities. Individuals receive services in a work-oriented environment where they have jobs and earn a wage. Work activities are further broken down into two more categories: sheltered work and integrated community employment. Sheltered workshops are facilities that are established to provide work experiences and jobs principally for people with disabilities. Sheltered workshops produce goods and services which they sell. This income pays for the operation of the workshop (including wages for people with disabilities). Community integrated employment (supported employment) aims at assisting people with disabilities to obtain jobs with community employers where their co-workers predominantly are individuals without disabilities.

Missouri's funding of daytime services is complicated. Day habilitation services are purchased mainly by DMRDD through the HCB waiver program and non-Medicaid state dollars. SB 40 Boards also purchase some day habilitation services. State funding for sheltered workshops flows through the DESE Division of Sheltered Workshops. Sheltered Workshops also receive



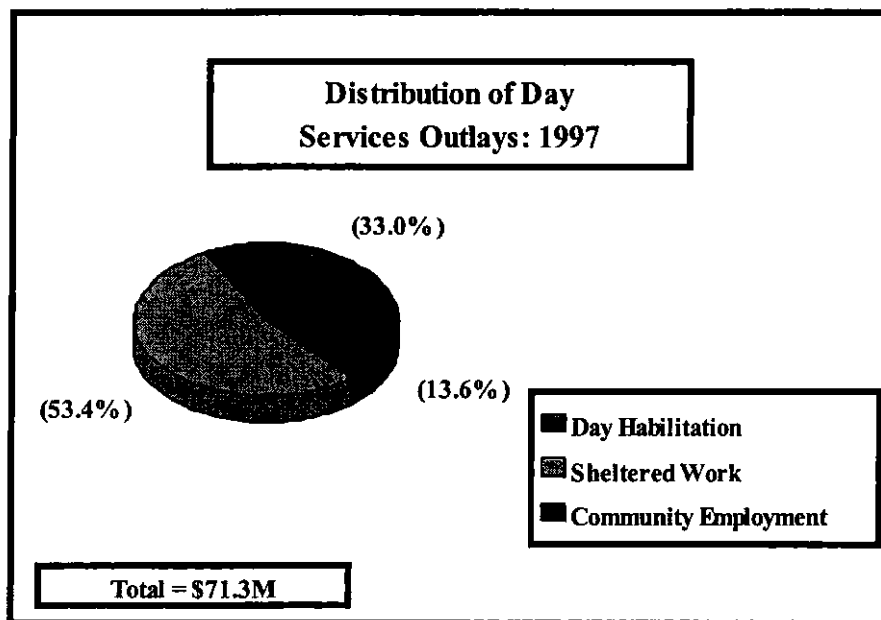
funding from SB 40 Boards. Community integrated employment services are purchased by DMRDD in the HCB waiver program. The DESE Division of Vocational Rehabilitation (DVR) also provides services to people with developmental disabilities aimed at assisting them to gain employment; DMRDD provides about \$500,000 in state matching funds to enable DVR to draw down \$2,000,000 in federal vocational rehabilitation funds in order to assist people served by

DMRDD to obtain employment. SB 40 Boards also earmark dollars for supported employment services. But it is even more complicated. For a sheltered workshop to receive state funding for an individual, the individual must be routed through the Division of Vocational Rehabilitation and found to be "unemployable". Missouri has complicated "plumbing" when it comes to funding daytime services.

As shown on the pie chart at the top of the next page, the majority of the \$71.3 million available in Missouri for daytime services pays for supported work services. About one-third pays for day habilitation services. Less than \$1 in \$7 is earmarked for supported employment services. It also is worth pointing out that Missouri state dollars only underwrite about 27% of all expenditures for daytime services. Most of the dollars that the state puts into daytime services take the form of matching funds for HCB waiver daytime services or in payments to sheltered workshops. Less than 5% are earmarked for supported employment services. SB 40 Boards underwrite about 22% of daytime expenditures; roughly one-third of all the dollars SB 40 Boards have available go to daytime services. A fairly large share (about 27%) of the dollars available for daytime services is money that sheltered workshops earn from the sale of goods and services that is reprogrammed into their operations.

Because the funding of daytime services is very complicated in Missouri, it is difficult to determine exactly how many individuals in total are receiving these services. Some individuals receive more than one kind of daytime service. Unlike residential services where it is simpler to determine an "unduplicated" count of persons who receive services, adding up the reported case counts of the various agencies that pay for or provide is not appropriate.

With that caveat in mind, it is known that roughly 5,000 persons received daytime services through the HCB waiver program and that sheltered workshops served at least 8,100 persons with developmental disabilities. DMRDD reported that in 1997 some 549 individuals were receiving supported employment services. The Division of Vocational Rehabilitation reports that

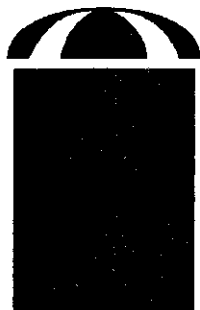


5,396 individuals with mental retardation were on its caseload in 1997. The Division also reported that 1,114 of the people with mental retardation it served were placed in competitive (non-workshop) employment. Because nationwide data for daytime services is nowhere as extensive as for residential services, it is not possible to assess very extensively how Missouri's efforts in this regard stack up to levels elsewhere.

Missouri's efforts in the arena of community

integrated employment do appear to be less robust than elsewhere. A 1996 study¹¹, for example, found that Missouri ranked 45th among the states in terms of spending for community integrated employment. Except for Arkansas, all the states that surround Missouri reported a higher number of individuals receiving these services and greater outlays for these types of supports than Missouri. For example, Iowa reported six times as many persons receiving integrated employment supports and about seven times the outlays for these supports than Missouri.

In 1997, state funding for sheltered workshop services took the form of a daily payment of \$9 per day per individual¹². This is a substantially lower payment level than is the case in most other states where public funds underwrite a greater share of the overall costs of these services. This makes it very important for sheltered workshops to market their goods and services in order to pay for operations. In 1996, people with developmental disabilities in sheltered workshops earned an average of \$1.64/day.



The funding for daytime services in Missouri is afflicted by the "silo" problem. In particular, DESE Division of Sheltered Workshop payments can only be used for services inside a workshop but not community integrated employment. Moreover, workshops cannot diversify their employees to include people without disabilities (except for workshop staff) and, hence, cannot become "affirmative industries". The Division has recognized these problems. HCB waiver dollars also have been limited largely to day habilitation services and so far only used in a limited way to pay for supported employment services (only 81 individuals out of the 6,200 served in Missouri's HCB waiver program received Medicaid-funded supported employment services in 1997). Recent

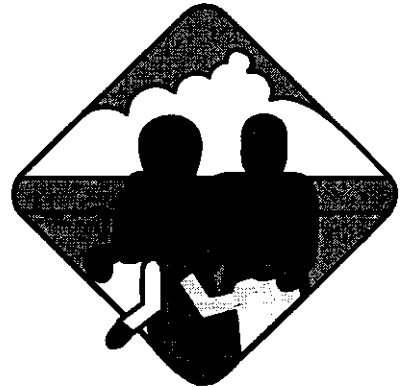
¹¹ Braddock et al., op. cit.

¹² This payment is going up to \$11/day.

federal policy changes give Missouri more flexibility in using HCB waiver dollars for supported employment¹³. There are three state agencies involved in the funding of daytime services. In addition, there are differences among the SB 40 Boards in terms of the types of services they are willing or able to fund under their charters. All these silos, “chutes and ladders”, and other complications make it difficult to figure out Missouri goals and directions with respect to daytime services. Overall, Missouri seems to be funneling most of its dollars into facility-based daytime services and far fewer dollars into community integrated employment supports.

Family Supports

Most people with developmental disabilities do not live in specialized residential arrangements. Most live with their families. Only about 30% of all the persons who are served by DMRDD are receiving residential services outside the family home. Family supports furnish direct assistance to families who have a family member (child or adult) with a developmental disability living with them.



The idea of furnishing assistance to families was late arriving in developmental disabilities services. Most service systems were constructed around providing services everywhere but inside the family home. This meant that where extensive supports were needed, the family member with a developmental disability had to go elsewhere to receive services. Over the past decade, many states have placed greater emphasis on providing services and supports in the family home.

In 1997, \$13.3 million or about 2.7% of the dollars Missouri had available for developmental disabilities services went toward family support. Missouri state government “programs” only accounted for about 28% of these dollars. The main family supports that Missouri tax dollars underwrote were the Sarah Jian Lopez HCB waiver program, the Family Subsidy and Loan programs as well as respite care. As best as we could determine, SB 40 Boards are the major funders of family support-type services in Missouri. Nationwide, in 1996 only about 2% of all the dollars spent for developmental disabilities went to family support¹⁴. So, Missouri’s level of effort in this regard is a little better than in most other states. Of the states surrounding Missouri, Kansas, Nebraska, Oklahoma and Tennessee allocate proportionately higher dollars for family supports than Missouri. Arkansas and Iowa spend proportionately fewer dollars.

DMRDD has launched a new initiative entitled “family-directed services” that aims at directing more resources toward families. One aim of this initiative is to permit some children who are in out-of-home placement to return to the family home.

But in the main, it remains true that Missouri uses relatively few of the dollars that it has available for developmental disabilities services to bring direct assistance into the family home.

Other Community Services

About 9% of the dollars that bought developmental disabilities services in Missouri during 1997 went to “other community services”. Some of these services are: (a) therapeutic and other specialized services

¹³ In particular, federal law used to restrict the use of HCB waiver dollars to buy supported employment to individuals who at one time had lived in an ICF/MR. In the Balanced Budget Act of 1997, Congress lifted this restriction so that all individuals with developmental disabilities who participate in the HCB waiver program may receive these services. Missouri already has amended its program to incorporate this change.

¹⁴ Braddock *et al.*, *op. cit.*

purchased on behalf of HCB waiver participants; (b) the DMRDD portion of the state's early intervention program; and, (c) specialized services for individuals with autism. The total of \$41.2 million also includes both DMRDD and SB 40 Board expenditures for community services that were difficult to classify exactly.

Service Coordination



Service coordination involves a variety of activities. These activities include assessment and eligibility determination, service/support planning, helping people connect with service providers or access other forms of assistance, the monitoring of services and crisis intervention. In Missouri, service coordination or case management is furnished by state workers who are employed at the DMRDD Regional Centers. In 1997, spending for service coordination totaled \$27.8 million or about 5.7% of the total. These services were furnished to roughly 23,000 individuals. In Missouri, these services are financed with Medicaid dollars (under the targeted case management federal category). Claiming the costs of case management under Medicaid has resulted in

considerable savings to the Missouri general revenue fund and thus freed up dollars to be used elsewhere. Missouri's costs per person for furnishing case management services are a little bit above the nationwide average but are roughly comparable to costs in states that operate case management systems that are similar in their organization and scope to Missouri's system.

Administrative Costs

Administrative costs that can be readily tracked down amount to about 2% of the dollars spent on developmental disabilities services in 1997. The costs include the DMRDD central office budget and Regional Center costs that are not tied to service coordination. In the main, the activities supported by these dollars include system management, managing federal funds, quality assurance and contracting.

Appendix:

Sources of the Numbers

The numbers in this report were compiled by John Agosta (Human Services Research Institute) and Gary Smith (National Association of State Directors of Developmental Disabilities Services – NASDDDS). These two individuals worked with the Missouri Customer Leadership Initiative over the course of the project.

Here, the data sources that were employed in developing this report are specified. We also describe how we developed the figures.

Data Sources

Many different information sources were tapped in compiling this report. National sources (which were used to compare spending and utilization patterns in Missouri to the nation as a whole and selected states) mainly included:

- ✓ Braddock, Hemp, Parish and Westrich (1998). *The State of the States in Developmental Disabilities Services* (5th Edition). Washington DC: American Association on Mental Retardation. This publication compiles nationwide and state-by-state expenditure information for developmental disabilities for the period 1977-1996.
- ✓ Robert Prouty and K. Charlie Lakin (1997). *Residential Services for Persons with Developmental Disabilities: State and Trends Through 1996*. Minneapolis MN: University of Minnesota, Research and Training Center on Community Living. This report contains nationwide and state-by-state information regarding residential services by type.

While this report was being compiled, researchers at the University of Minnesota shared with us various figures they had collected to update the aforementioned report through 1997.

While preparing this report, we discovered that some of the information reported in both of the aforementioned publications was not correct, apparently due to miscommunication between state officials and the researchers who compile the reports. Here, we have straightened the historical numbers as well as we can.

HCB waiver figures are those compiled by NASDDDS in its annual survey of states concerning this program. A publication containing state-by-state and nationwide figures for spending and utilization of HCB waiver services for people with developmental disabilities will be issued in May 1997.

In the main, the figures contained here are based on Missouri documents and consultation with state and other officials. Some of the key documents consulted included:

- ✓ The Division of Mental Retardation and Developmental Disabilities FY1998-99 budget request which contained information on 1997 expenditures. We also employed the Division's 1997 4th Quarter Demographic Information report;
- ✓ Missouri's federal report (HCFA 372) for 1997 concerning HCB waiver and ICF/MR expenditures;
- ✓ The figures for sheltered workshop expenditures are based on data published by the DESE Division of Sheltered Workshops on its World Wide Web page;

- ✓ The figures for Division of Vocational Rehabilitation-funded services were obtained directly from Division officials who performed a special data run to determine how much was spent for services for people with mental retardation; and,
- ✓ SB 40 Board figures are based on the Missouri Association of County Developmental Disabilities Services (MACDDDS) Annual Report for 1997.

Our data collection efforts also were aided considerably by Fordyce Mitchel and Glenn Bish at DMRDD who helped us better understand where various dollars are located in Missouri. We appreciate their help. However, if the figures are not exactly right, it is our fault, not theirs.

How the Figures Were Prepared

Here we briefly describe how we went about shifting through the foregoing Missouri data to come up with the figures that we did. We also describe some of the limitations in the figures.

With respect to the programs and services that DMRDD manages directly, our starting point was the spending figures for 1997 reported in the Division's most recent budget request. To those figures, we added funds that are spent on developmental disabilities services but are not reported in the DMRDD budget document. Mainly there are these funds were:

- ✓ **Fringe Benefits for DMRDD Employees.** These funds are budgeted and managed centrally by the state Office of Administration. We were informed that fringe benefits amounted to 30% of employee salary costs. As a consequence, we adjusted reported Habilitation Center, Regional Center and DMRDD Central Office personal services expenditures to include these dollars.
- ✓ **Federal Medicaid Payments for Non-DMRDD Provided Services.** The DMRDD budget contains the state matching funds for HCB waiver and ICF/MR services that are furnished by agencies other than DMRDD. However, the federal Medicaid matching funds do not appear in the DMRDD budget. Instead, they are located at the Missouri Department of Social Services. We added these federal funds into the total.
- ✓ **Consumer SSI Payments.** These payments are made directly to service providers by individuals who receive some kinds of residential services. We deemed these a "cost" of the service and included an estimate of the amount.

Also with respect to DMRDD-provided (as opposed to purchased) services, Missouri's practice is to receipt federal Medicaid payments into the state general fund and appropriate only general fund dollars to state agencies. In compiling the figures for DMRDD-provided services we decided to show the federal funds earned as if they went directly to DMRDD. This permits a more accurate portrayal of the level of federal financial participation in the costs of these services.

In the main, our process was to locate the overall money spent by "source" and then distribute these dollars by type of service (that distribution is contained in the table that appears on page 8). We made sure that sources and uses remained in balance as we made this distribution. By major funding source, our process was as follows:

- ✓ **Habilitation Centers.** We used the Centers' Medicaid payment rates and census levels to determine a total level of expenditures. We then divided this total between on-campus and community-residential programs. Federal Medicaid ICF/MR earnings were assigned to the Habilitation Center/Campus portion. Expenditures for the Hab Center operated community residences are located under HCB waiver-funded residential services. The total for Habilitation Centers also includes \$5.9 million in capital improvement funds spent during 1997.

- ✓ **Non-state ICFs/MR.** The figures here are based on the DMRDDD budget document.
- ✓ **HCB Waiver.** Our principal source document for distributing HCB waiver dollars by service type was Missouri's federal HCFA 372 report which provides a detailed breakdown of expenditures by service category. We distributed total spending reported in the same pattern as this report. We took into account that SB 40 Boards send matching funds to the state. We made the assumption that the overall spending that these dollars support is distributed in the same pattern as on the HCFA 372.
- ✓ **Service Coordination.** The federal Medicaid funds shown on the report are as reported by the Division to project staff. We determined Regional Center total expenditures and those attributable to service coordination. What was left over was assigned to the "administration" category.
- ✓ **Other DMRDD Residential Services.** The DMRDD budget reports a figure for residential services that supported with Missouri general fund dollars (i.e., these services are not paid for by the HCB waiver program). We used this figure adjusted upward for estimated consumer SSI funds.
- ✓ **Nursing Facilities.** The caseload figure was provided by DMRDD. We estimated expenditures by deriving an annual cost per nursing facility resident from Missouri's federal HCFA 2082 report.
- ✓ **Other Community Services.** The DMRDD budget contained included various expenditures for community services that could not be assigned to other service categories. These funds are included in the Other Community Services section of the table on page 8.
- ✓ **Vocational Rehabilitation.** The figures are as reported to us by the Division of Vocational Rehabilitation.
- ✓ **SB 40 Boards.** Our principal source document was the MACDDDS report that covered calendar year 1996. Not all SB 40 Boards are members of MACDDDS. In January a survey was sent to the non-MACDDDS SB 40 Boards asking them to report their expenditures so that a comprehensive picture of spending could be developed. Only a handful of these Boards responded. As a consequence, we were left with the figures contained in the MACDDDS report. The report included expenditures for various service categories. We used those expenditures to assign dollars to the service categories we used in preparing these figures. We also took into account where we had already counted expenditures (e.g., HCB waiver expenditures where the SB 40 Boards furnish the matching funds). We also adjusted the figures for the funds that the Boards were reported as sending to sheltered workshops so that we would not double-count these dollars. As with the DMRDD budget, where expenditures could not be clearly assigned to one of the service categories used in this report, we assigned it to "other community services".

At best, all that we were able to do is come up with very rough estimates of SB 40 Board expenditures overall and by service type. Since our primary information source did not include expenditures by all SB 40 Boards (although we understand that most of the larger Boards are members of MACDDDS), the total funds are likely understated. In addition, MACDDDS itself reports that there are variations among the SB 40 Boards with respect to how they report spending by service category. Consequently, all the figures associated with SB 40 Board expenditures are only rough guesses.

- ✓ **Sheltered Workshops.** Here we relied mainly on the figures posted on the Division of Sheltered Workshops World Wide Web site. From the total expenditures shown for 1996, we deducted the cost of raw materials and client wages in order to come up with a "net" cost

of these services. We also did not count capital expenditures since they are financed with restricted and largely donated funds.

Overall the figures contained in this report are relatively solid for state-administered or provided services. The SB 40 Board and Sheltered Workshop expenditures are less solid.

It also is worth mentioning that there are various expenditures that we did not attempt to track down or which are not included here. For example, we only captured the spending for early intervention services contained in the DMRDD budget. There is other spending for these services located in other state agency budgets. Arguments can be made that other kinds of special education expenditures should be included. We did not include them because that would have been a project unto itself. There probably other expenditures (in the Medicaid budget or for child welfare services) that also could have been included if time allowed. Mainly the figures here are for what may be labeled "specialized developmental disabilities services".

Appendix B

Memo Regarding Medicaid Eligibility in Missouri

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TO: Missouri Customer Leadership Initiative

FROM: Gary Smith

SUBJECT: Financial Charges Made To People Who Receive Services

At the April MCLI meeting, questions arose regarding Missouri's practices in making financial charges to individuals who work and receive services. These questions arose in the context of the Initiative's interest in promoting integrated employment opportunities for people with developmental disabilities in Missouri. Concerns were expressed that efforts to secure individuals well-paying jobs might result in whatever gain in income results from work being recaptured by the state in the form of higher charges for services. In other words, at the end of the day individuals who secure jobs would end up with no more money in their pockets. We promised to look into state policies in this regard and report what we found back to the Initiative.

As it turns out, sorting through Missouri's policies with regard to the treatment of individuals' income is not very simple. The state's policies in this arena differ from those in most other states. The net effect of these policies is to make it particularly difficult for an individual to come out ahead financially by virtue of obtaining a relatively well-paying job. The most serious problems lie in the effects of a person's earning money on his or her continuing eligibility for Medicaid-reimbursable services.

By way of background, in most states Medicaid eligibility for people with disabilities hinges on the individual's eligibility for the federal Supplemental Security Income (SSI) program. In most states, people who are eligible for SSI are considered categorically eligible for Medicaid-reimbursable services. This means that as long as they are SSI recipients, they will get a Medicaid card. In the case of SSI recipients, when they earn money from work (either in a workshop or in a community job), federal SSI rules apply with respect to how such earnings are treated. Under federal SSI rules, some earnings are disregarded (i.e., people keep the money and their SSI check is unaffected); at higher income levels, the SSI check is reduced by one-half of the dollars they earn. If earnings are relatively high and continue over several months, the person's ongoing eligibility for SSI may be affected. There are provisions in federal law (Sections 1619(a)

and 1619(b) of the Social Security Act) that maintain SSI eligibility (and thereby Medicaid eligibility) for people who have high earnings for an extended period. While these provisions do not provide protection in perpetuity, they keep people who earn significant amounts from falling over the eligibility cliff (e.g., facing an immediate cut-off in benefits). Generally speaking, where a state links Medicaid eligibility to SSI eligibility, only individuals with relatively high sustained earnings will lose Medicaid eligibility.

States may extend Medicaid eligibility to people who are not eligible for SSI. Some people are not eligible for SSI because they receive other federal benefits (e.g., OASDI) that have higher payment amounts than SSI. With respect to long-term care services (including the home and community-based waiver program), a state may establish what is termed a "special income" standard that makes people eligible for Medicaid who have income up to three times the federal SSI benefit level (roughly \$1,400 per month). In the case of individuals who are not eligible for SSI but qualify under other provisions, a state may make charges to people of the difference between their income and the SSI benefit level (or some different amount, depending on the state) and apply the amount of the charge to reduce the costs of services to the Medicaid program. Such charges are very common for institutional services where individuals are allowed to retain only a "personal needs allowance" with the remainder of their money used to offset the cost of institutional payments. With respect to individuals who participate in the home and community-based waiver program, many states have decided to allow these individuals to hold onto their income to pay for living expenses as well as provide an incentive for them to secure jobs. They do so by disregarding such income for the purpose of determining Medicaid financial eligibility.

Overall then, with respect to people earning and keeping money, federal policy permits a state to be no harsher than the SSI program for SSI recipients. Federal policy also permits a state to make people who are not SSI recipients to be eligible for Medicaid and retain their earnings. And this is the case in most states.

But Missouri is not like other states. When the federal SSI program was created in 1972, states had the option of agreeing to follow federal SSI rules or maintain the rules they had in place then for assistance payments under their "Aged, Blind and Disabled" public assistance programs. States that decided to maintain their existing rules are termed "Section 209(b)" states. Missouri is a Section 209(b) state. What this means is that people with disabilities in Missouri are not automatically extended Medicaid eligibility by virtue of being eligible for SSI. Instead, they must qualify under Missouri's rules. In the main, Missouri's rules with respect to the disability-basis of eligibility are not very different from federal SSI rules. But there are differences with respect to the financial eligibility dimension. One main difference is that, whereas the federal SSI program allows a person to keep up to \$2,000 in countable assets or resources (in addition to the individual's home) and still be eligible to receive a full SSI payment, in Missouri the asset limit is much lower: \$1,000. So a person who qualifies for the

federal SSI program may not automatically qualify for Medicaid in Missouri. As noted previously, the federal SSI program does permit a person to have earned income and still qualify for SSI payments (and, in most states, continue to automatically qualify for Medicaid). Missouri does not provide for similar disregards.

In Missouri, however, people who receive SSI payments and have earnings can still qualify for Medicaid but they do so by "spending down". Under "spenddown", a person must use some of his or her income to buy health care services in order to reduce his or her income down to the level established by the state to continue to qualify for the Medicaid program. While there is a "buffer zone", in essence, Missouri's policies mean that people with income above the "buffer zone" level will be taxed at a rate of 100% of their earnings in order to maintain Medicaid eligibility. This tax takes the form of their buying out of their own funds services that Medicaid would otherwise pay for. This buying process is not very direct. It takes the form of the state's notifying providers that they need to collect money from recipients and offset their billings to Medicaid program by the amount they collect. As a consequence, people who are successful in the job market face a dilemma: they can keep their earnings but lose eligibility for Medicaid or they can give up a substantial share of their earnings in order to continue to qualify for Medicaid.

At the April meeting, some participants reported receiving notices about charges due from some individuals. As best as we can figure out, these charges stem from instances where individuals have income that places them outside the buffer zone and the charges are necessary in order to maintain the person's Medicaid eligibility. Some of these charges also may stem from people having more assets/resources than Missouri allows (thereby forcing people to spend their savings in order to maintain Medicaid eligibility).

Missouri's policies in this arena obviously are hostile to employment for people with disabilities. Obtaining a relatively well-paying job can mean not being able to reap the benefits of the job (because excess earnings will be taxed by imposing a spenddown obligation) or being faced with the loss of other key services and supports (because Medicaid eligibility will be lost). It is worth pointing out that this problem affects not only people who hold integrated jobs but people in sheltered workshops. If someone in a sheltered workshop earns "too much", they also can see the money lost to spenddown. While federal SSI policies also are problematic, they are less harsh than Missouri's policies in this regard. Moreover, Missouri's narrower asset/resource limit means that people with disabilities cannot save very much of what they earn in any case.

Missouri's policies are more restrictive than federal policy allows. The policy problem, of course, is that liberalizing Missouri's policies will have financial consequences for the state. In the realm of Medicaid eligibility overall, changes in state policy cannot be limited to a narrow class of people (e.g., individuals with mental retardation and other

developmental disabilities). For example, Missouri can decide if it wants to stop being a Section 209(b) state and agree to follow federal SSI rules. However, if it did so, the change would affect all SSI recipients, not just those with developmental disabilities. Using more liberal rules would result in more individuals becoming eligible for Medicaid and higher state Medicaid payments because the state would be confiscating less money in the form of people meeting their spenddown obligations.

DMRDD officials are aware of the problems that Missouri's present policies pose for individuals. Without affecting the state's Section 209(b) status, they have identified changes that can be made with respect to eligibility for HCB waiver services that would largely resolve the problems for waiver participants, particularly those who have significant earnings from employment. However, they have been unable to secure agreement from state Medicaid officials to make these changes even though DMRDD would agree to provide the necessary state matching funds in order to cover the increased Medicaid outlays that might arise. So, for at least HCB waiver participants, the problem is fixable, provided that the state agencies involved can agree to make the necessary changes.

With respect to the MCLI's interest in this topic and what might appear in the final report, it probably is not the Initiative's task per se to offer highly detailed recommendations concerning how Missouri might make its eligibility policies more employment friendly. Highly detailed recommendations probably would have to be prefaced by a necessarily complicated discussion of the topic. There are steps the state can take to achieve this outcome and, thereby, it may be more in keeping with the Initiative's charge if it treated this topic globally rather than discussing it in all its complexity in the final report. The following language is offered for consideration:

It is important for Missouri to support people with developmental disabilities to secure jobs in the community. Having a job promotes financial independence. However, Missouri's policies that govern eligibility for Medicaid services discourage people from obtaining well-paying jobs. When people obtain a good job, Missouri applies a 100% tax rate and takes a major share of the dollars earned away from individuals. This is unfair. People with disabilities -- like other citizens -- should reap the benefits of work. Missouri can adopt other policies that would permit individuals with disabilities to keep more of the money they earn through their own efforts. We recommend that DMRDD and Medicaid officials take the steps necessary to change Medicaid policies so that they are resolutely supportive of people with disabilities securing regular jobs in the community and permitting people to benefit from their work.

Appendix C

Elements Of A Participant-Driven System

Appendix C: Elements Of A Participant-Driven System

Reduced to its essence, in participant-driven support systems the participant and/or family decide how limited service funds are spent. This approach is consistent with emerging trends in the field because it promotes community life, strengthens self-esteem and facilitates empowerment among service recipients.

It may also contribute to cost containment. Proponents argue that the approach will improve provider performance because of its emphasis on "customer first" behavior. Customers (i.e., participants) who do not find what they want, at a price they consider fair, will go elsewhere to make their purchases. In this context, participant-driven models do support the goal of cost containment. Smith & Ashbaugh (1995) argue that:

Service recipients, working on limited budgets, will spend more prudently to get the most value for their money, and participant-driven arrangements will spawn a market economy in which those providers representing the most value will survive.

This argument, which forms the basis of participant-driven approaches, promises cost containment within a context of "quality" that promotes self-determined lifestyles. For this to work, two shifts in practice are required: (a) decisions about what is "important" or "needed" should be left to the individual; and (b) only what is received will be paid for. Such an approach will increase efficiency and so reduce overall costs.

The underlying philosophy and evolving practices of the developmental disabilities field argue for participant-driven approaches. But how would the approach be structured and how would it work? Individuals with developmental disabilities and their families will need to be actively engaged to assure that the emerging service systems are:

- ☆ *At the systems level*, designed to maximally reflect the stated needs and preferences of service recipients regarding policy and practice; and

About That Word "Participant"

Participant: *One who participates or takes part in something.*

To Participate: *To take part; join or share with others. (American Heritage Dictionary)*

Over the years much attention has been directed toward the proper label to apply to those who utilize developmental disabilities services. Are these people "clients", "consumers", or "customers"? For a number of reasons, these words are not used in this primer to reflect the role that people with disabilities will play in future service systems. Instead, the word "participant" is used because it embraces an active role that pushes beyond a reflection of client-professional relationships or simple economic symbolism (consumers or customers).

In a participant-driven system, people with disabilities will help shape the structure of the system. And at a personal level, individuals will - alone or in association with others - make decisions about the lives they want to lead. In essence, they will be *active participants* in directing systems and their own lives.

- ☆ *At the individual level*, characterized by enough flexibility that service recipients and family members (with support as needed) can direct the provision of services and supports.

At a systems or strategic level, people with disabilities (as well as family members and guardians) must have opportunity to shape policy and practice. To assure such partnership, resources must be set aside to offset the costs of participation and/or for needed training or technical support.

At a personal or individual level, participant-driven approaches require that people/families, rather than third parties, exercise choice over how dollars are used (within certain parameters); that supports be obtained within a fixed dollar budget; and the person/family carries some amount of risk if the budget is improperly used (See Smith, 1995). While there may be countless variations on this theme, the approach has four fundamental characteristics:

1. **Individuals have a person-centered plan for support and control over pre-authorized budgets that can be used flexibly** to accommodate the needs specified by the individual (within budget limits). Individuals may act alone or in association with their family members or other concerned people. Along with a budget to work with, individuals must also have access to a qualified "broker" to identify what supports are being purchased and their cost (See item 5 below for a fuller description of the broker's potential responsibilities). The resulting plan will assure that the allocated dollars are accounted for, and that the risk for overspending the budget is minimized.
2. **Individuals have a choice of service suppliers.** Providers and others act as authorized merchants -- where participants may "shop." Having control of pre-authorized budgets and in consultation with a personal advocate/broker, participants will be free to decide what service provider they want to deliver needed supports. In fact, the participant may decide not to choose traditional services, opting instead for alternative or informal support arrangements.
3. **A "risk pool" is established to help offset any risk that an individual accepts when working from a pre-set budget limit.** Risk is defined as the danger or probability of suffering harm or loss. Where a person accepts a pre-authorized budget to address his or needs, he is also accepting some amount of risk. No matter how well conceived the associated plan may be, there is the possibility that unforeseen events (e.g., a medical emergency, changes in the availability of staff) will place the person in jeopardy of overspending his budget. A risk pool is designed to offset such risk. The state (or an equivalent managing entity) sets aside some amount of money to accommodate unexpected costs for all participants.

4. Funds to meet administrative and other overhead costs for managing the system. Administrative costs include expenses incurred by the managing entity related to overall operations of the service system. This could include costs for addressing: (a) collective concerns (e.g., determining eligibility, staff development, information management, reducing the waiting list), (b) offering specialized services, or (c) other administrative needs. Any amounts earmarked for these costs must be closely justified and subject to overall limits.

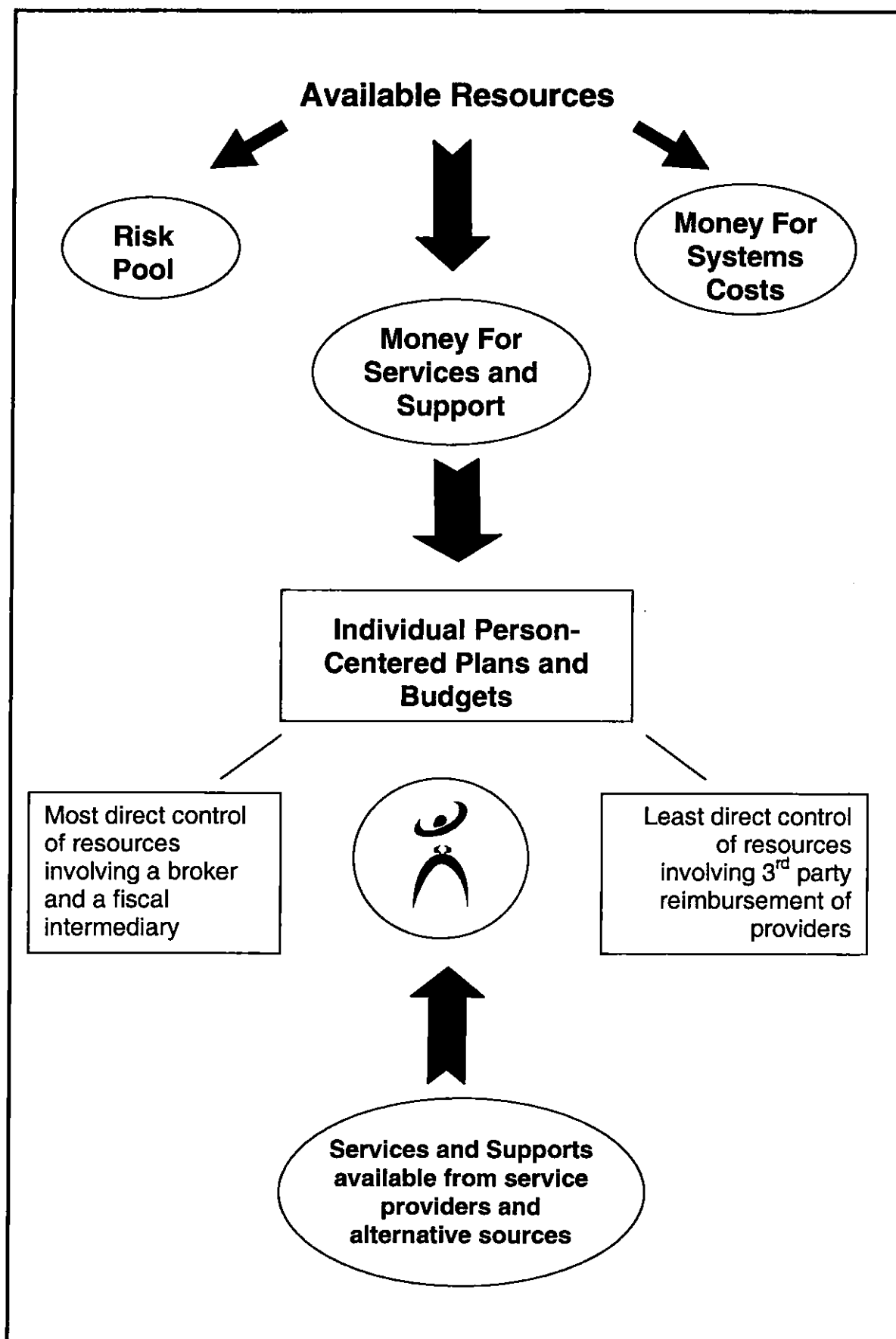
5. Individual choice in amount of control and responsibility one accepts.

We recognize that “one size will not fit all” and that individuals will vary in the amount of control they want to exercise. Some may want control over the types of services and supports they receive, but want no part of managing any of the fiscal transactions. For these people the system will function much as it does today, involving direct payments from payer to providers. Others, however, may want greater control over the finances; some may even prefer to pay their service providers directly. Under these circumstances, we anticipate that the individual will require the services of a “broker” or “personal advocate” and a “fiscal intermediary.”

- ✓ Brokers or personal advocates help individuals develop support plans and secure supports. The broker may well be the most important element in a participant-driven approach. This person has responsibility for assuring that the support plans: (a) honor the individual's support preferences, (b) are within budget, (c) are sufficient to meet the person's needs, and where a group is involved (d) are cognizant of the need to assure that sufficient funds are available to meet the needs of other members of the group. In many ways, the broker is *the* essential pivot point to the entire approach.
- ✓ A fiscal intermediary or “business agent” assists individuals to manage their budgets, satisfy any associated payroll obligations, and protect individuals from various liability claims.

The accompanying graphic (next page) illustrates how a participant-driven system could work.

- ⇒ The top of portion of the graphic shows available resources that are divided into three categories: (a) money to operate the system (item 4 above), (b) money set aside in a risk pool (item 3 above), and (c) all other money to pay for services and supports.
- ⇒ Next, individuals -- participants -- must develop person-centered plans given the confines of a personal budget (item 1 above).



Finally, individuals can choose from whom they receive supports (item 2 above).

- ⇒ Throughout the decision making process, individuals can choose the amount of responsibility they want to take in managing their own affairs (item 5 above). Participants could choose to have maximum control, opting to manage their own personal budget. In this instance, participants would most likely require the assistance of a “broker” to help them make decisions and a “fiscal intermediary” to handle finances. Or, they may seek the least amount of control. Here, they may set a person-centered plan, but have limited control over exactly how their allocated resources are spent, relying instead on traditional third party payment and contracting mechanisms.

Potential Prototypes Developed By the Customer Leadership Initiative

We understand that the description of a participant-driven support system given above is not at all complete and much additional work will be required to translate this concept into practice. In addition, our review of activities in several other states illustrates that there is no single way to proceed. For example, the Robert Wood Johnson Foundation recently made grants to 18 states to push ahead with their own “self-determination projects”. These projects promote new configurations of support, in combination with existing services, to empower individuals with developmental disabilities to gain control over their selection of needed services or supports. More recently, a smaller group of states was selected by the Foundation to receive a technical assistance grant to help resolve issues related to “customer driven” systems.³ Unfortunately, Missouri is not participating in these RWJ initiatives.

While considering participant-driven approaches, however, we thought through two potential prototypes. One involved use of a “micro board” to assist individuals to gain increased control over their services and supports. Another illustrated a conceptual sketch of how a participant-driven system could work in Missouri.

- ✓ **Micro Boards.** In brief, a micro board consists of family or friends who agree to participate with an individual with developmental disabilities to control his or her allocated resources. The board may even incorporate to formalize its relationship with the individual. The individual (and his board) is granted a person-centered budget or service allotment (e.g., voucher) to work with. Subsequently, the individual and board (and perhaps a case manager) work out a plan for using these resources to acquire needed services and supports. This approach places the individual and his micro board in control of his own support resources, allowing flexibility and choice in their use. While considering the

³ For more information about these planning grants, contact Donald Shumway at the Robert Wood Johnson Foundation Office on Self-determination for People with Developmental Disabilities; 10 Ferry Street (#14); Concord NH 03301 -- phone: 603-228-0602

approach, we realized that there are no particular barriers in the existing system that would prevent timely implementation of this approach in Missouri.

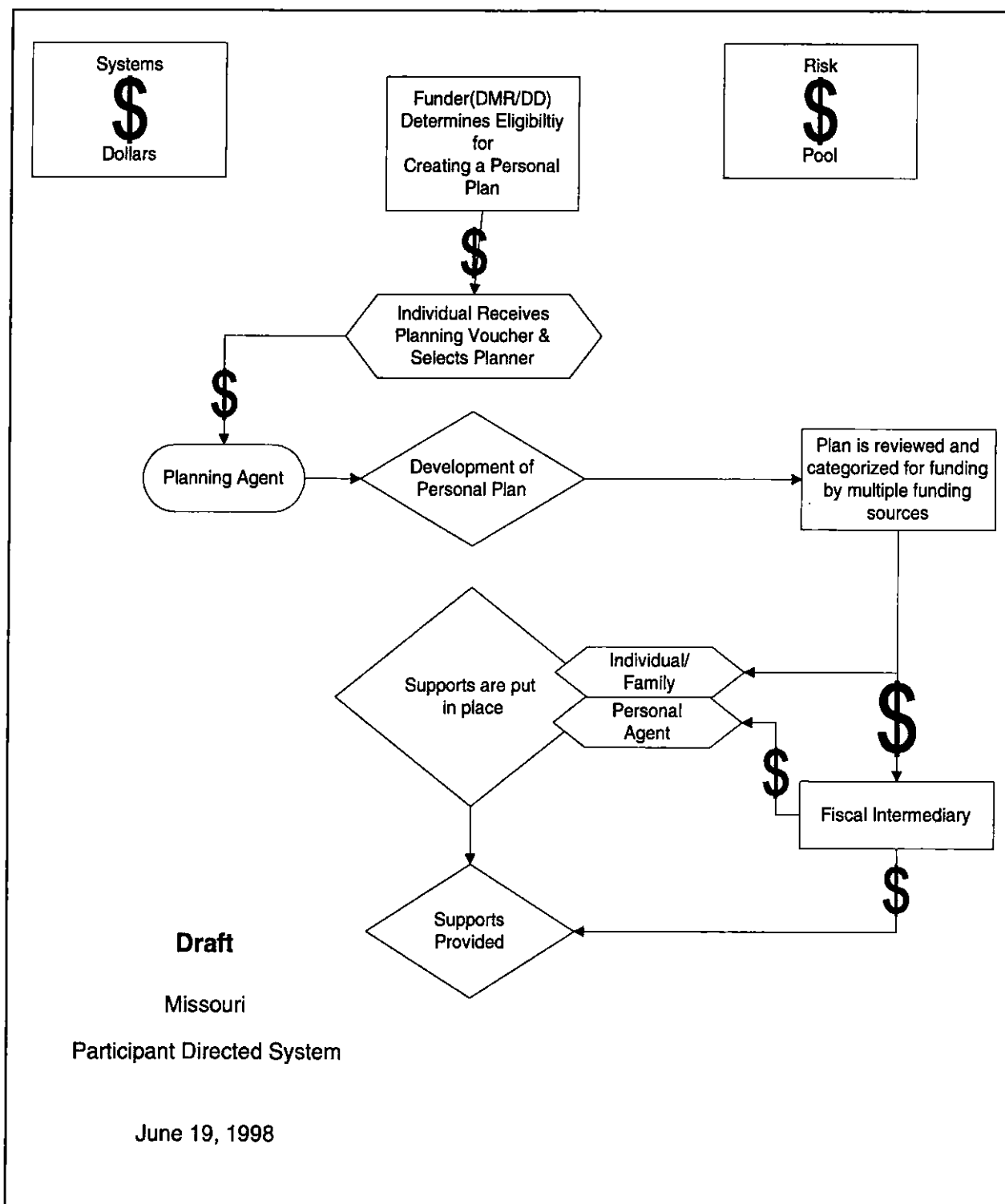
- ✓ **Conceptual sketch for a participant directed system.** The accompanying figure illustrates a potential flow of money and decisionmaking in a participant-driven system. The sketch represents just one iteration of a participant-driven system that was conceived by members of the Missouri Customer Leadership Initiative. It is by no means in “final” form, and we understand that much additional work would need to be done to work out all of the mechanics. Yet, the sketch offers a potentially useful model for implementing participant-driven supports in Missouri.

The sketch incorporates all of the five elements described earlier.

- ⇒ As shown, we anticipate resources being used for: (a) a risk pool, (b) systems management, and (c) services and support.
- ⇒ From the “services and supports” allotment, individuals would receive a “Planning Voucher” and select a “Planning Agent.” The agent could work for the State or a private concern. The State may even require that the Planning Agent be trained and “certified” to act in this role. The agent may also continue his or her relationship with the individual, serving as a “broker”. The idea here is simply to highlight the need at the start for someone to help the individual to craft a well thought out supports plan to address identified needs. The Planning Agent would help the individual to develop a “Personal Plan” that would specify how a personal budget would be spent.
- ⇒ After the plan is reviewed and funded by appropriate authorities, the individual may secure the specified services on his own, incurring all responsibilities for managing and accounting for the budget.

Or, the individual can get some help. To account for any financial transactions he may use a “Fiscal Intermediary.” And to help secure needed services, the individual may elect to utilize a “Personal Agent” or Broker.

- ⇒ After supports are provided, the whole cycle may begin again. In fact, we anticipate that the cycle will necessarily be repeated at least annually.



Other Resources on Participant-driven Supports:

To learn more about participant-driven supports and about what varying approaches are being tested around the country, please refer to any of the following resources:

- Agosta, J. & Kimmich, M. (1997). *Managing our own supports: A primer on participant driven managed supports*. Alexandria, VA: National association of State Directors of Developmental Disability Services.
- Agosta, J. (1998). *Meeting the challenges ahead: Self-determination, fiscal responsibility and participant driven supports*. Concord NH: The National Clearinghouse on Managed Long Term Services and Supports for People with Developmental Disabilities and Their Families, Institute on Disability, University of New Hampshire.
- Agosta, J., Melda, K. & Terrill, C. (1998). *My voice, my choice: A manual for self-advocates on participant driven supports*. Salem OR: Human Services Research Institute.
- Barrs, S. et al. (1995). The New Hampshire self determination project: An affirmation of community, revolution of vision and goals. *TASH Newsletter*, 21(7&9), 21-27 and 19-23.
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