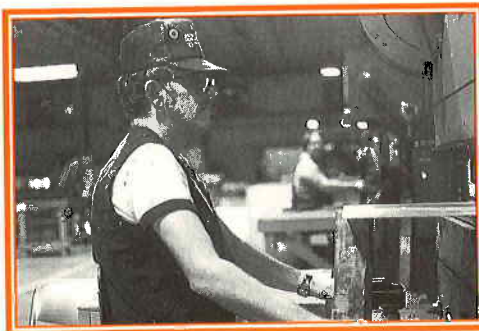
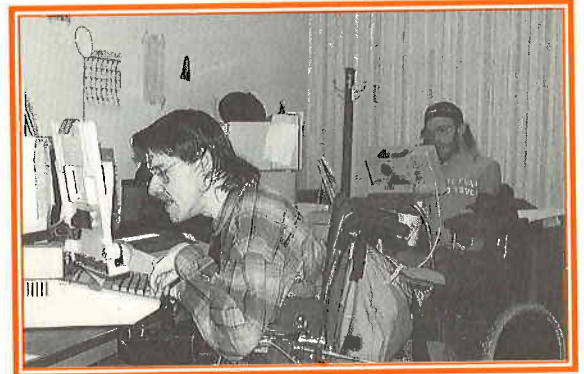
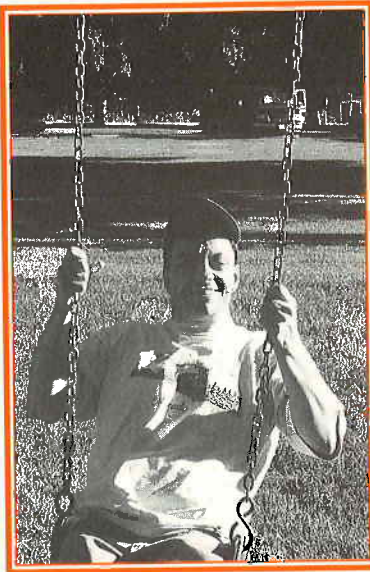
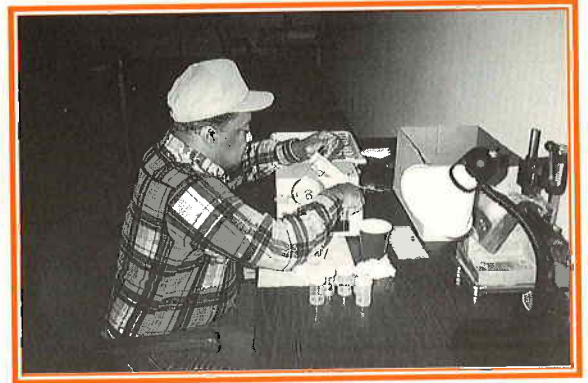
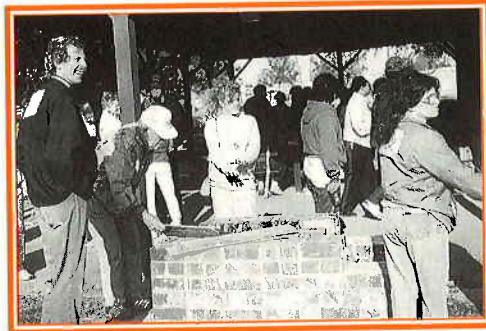


# A MACDDS REPORT



**MISSOURIANS WITH DEVELOPMENTAL DISABILITIES:  
THE POTENTIAL IMPACT OF GOVERNMENT REFORMS**

*October 1996*

# **Preliminary Report on the Potential Impact of Government Reforms**

Presented to  
*Senator James L. Mathewson*  
*President Pro Tem*



*“There are cities and companies, unions and political parties, in this country that are like dinosaurs waiting for the weather to change. The weather is not going to change. The very ground is shifting beneath us. And what is called for is nothing less than all of us reconceptualizing our roles.”*

*“People whose lives are affected by a decision must be part of the process of arriving at that decision.”*

*John Naisbitt*  
*“Megatrends:*  
*Ten New Directions*  
*Transforming our Lives”*  
*1982*

## **ABOUT MACDDS**

Organized in 1979, Missouri Association of County Developmental Disabilities Services (MACDDS) continues to provide a strong forum for its member county boards, related private organizations and affiliated public agencies to share information, discuss and create solutions to common problems involving persons with developmental disabilities.

A major purpose of MACDDS is to review state and federal regulations, policies and practices to determine how they relate to the delivery of community based-services for persons with developmental disabilities. Due to the blend of urban, suburban and rural member counties, the political strength and concerns of MACDDS collectively represent the voices of county boards and the persons we serve.

MACDDS strives to create the most effective services for person with developmental disabilities at a local level. MACDDS supports positions regarding:

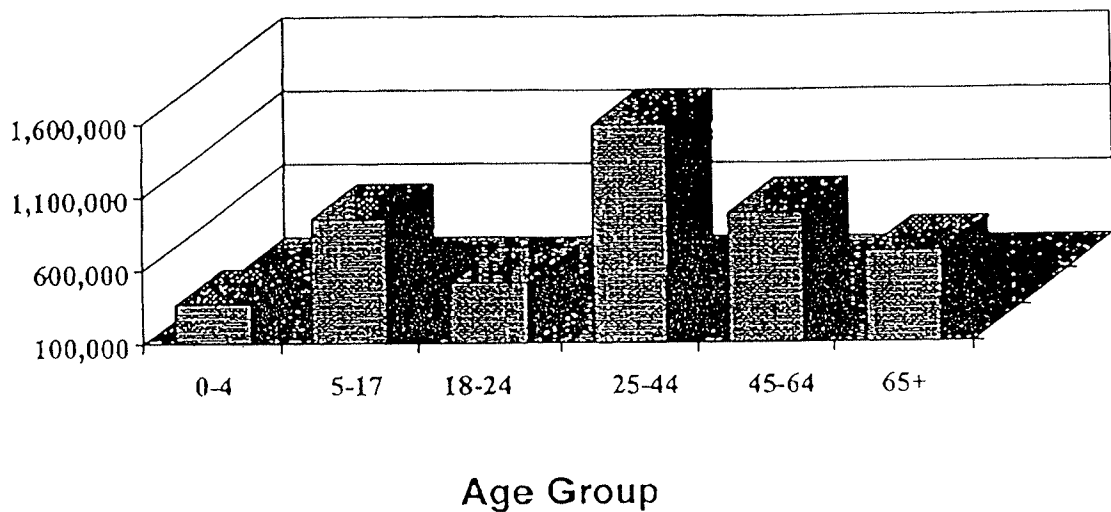
- *local solutions for local problems*
- *greater value for the public dollar*
- *local planning by local people that meets local needs with customer satisfaction, and enables future family-centered, locally coordinated human services.*

The goal of these suggestions is to achieve better quality and more efficient services for persons with developmental disabilities and their families.

**DEFINITION OF "Developmental Disability":**

- (a) Which is attributable to:
  - a. Mental retardation, cerebral palsy, epilepsy, head injury or autism, or a learning disability related to a brain dysfunction; or
  - b. any other mental or physical impairment or combination of mental or physical impairments; and
- (b) Is manifested before the person attains age twenty-two; and
- (c) Is likely to continue indefinitely; and
- (d) Results in substantial functional limitations in two or more of the following areas of major life activities:
  - a. Self-care;
  - b. Receptive and expressive language development and use;
  - c. Learning;
  - d. Self-direction;
  - e. Capacity of independent living or economic self-sufficiency;
  - f. Mobility; and
- (e) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, habilitation or other services which may be of lifelong or extended duration and are individually planned and coordinated.

## 1990 Missouri Population



## **BACKGROUND AND PERSPECTIVE**

In the fall of 1995, a whirlwind of activity was taking place in Washington, D.C. related to what many thought were imminent changes to laws, rules, and regulations governing Medicaid as well as the Federal financial commitment to the program.

In Missouri, and other states, state and local officials, advocates, providers and consumers met to hear predictions of the demise of our long-term care service delivery system for people with disabilities. A new term, "managed care" entered our vocabulary. A wave of confusion, fear, anger, and doubt invaded our thinking about the future for Missourians with disabilities.

On November 22, 1995, the President Pro Tem of the Missouri Senate, Jim Mathewson, in a letter to MACDDS President, Wes Buffington, requested a report from the SB40 County Board Association regarding its views on how Missouri's service delivery system might be "re-engineered" to meet the challenges of Medicaid reform and provide meaningful services and service outcomes to Missouri citizens with developmental disabilities and their families.

In the meantime, predicted dates for rapid changes to Medicaid came ..... and passed.

A MACDDS study committee was formed in early December, 1995.

As the committee began its work in earnest, a number of guiding principles emerged:

**People with developmental disabilities, and their families, represent one of the state's most vulnerable populations. They rely heavily on "outside" advocacy. Studies have found that persons with developmental disabilities are at substantial risk of abuse and neglect. Persons with disabilities represent a disproportionately large number of persons in foster homes, group homes, and out-of-care facilities. Abuse/neglect constitutes 72% of juvenile court referrals and 52% of out-of-home placement.**

- **Societal trends include more single parent families, a dramatic increase of women in the workforce, "baby boomers", and increasing populations of people over age 65. This challenge requires that we use our resources more effectively.**
- **Comprehensive approaches to service delivery are needed to meet the needs of the developmental disabilities population. More often than not, the service delivery needs of these individuals and families "cross-over" state/local agency lines and require integrated services/resources coordinated by a single entity.**

**Managing delivery of services to people with disabilities is better than a fragmented unmanaged system.**

- **Community-based, publicly accountable SB40 Boards and/or their agents/networks represent a viable, local alternative to best deliver services and incorporate major principles of “managed care” including utilization of service management, cost effectiveness, consumer responsiveness, high-quality, and multiple service options.**

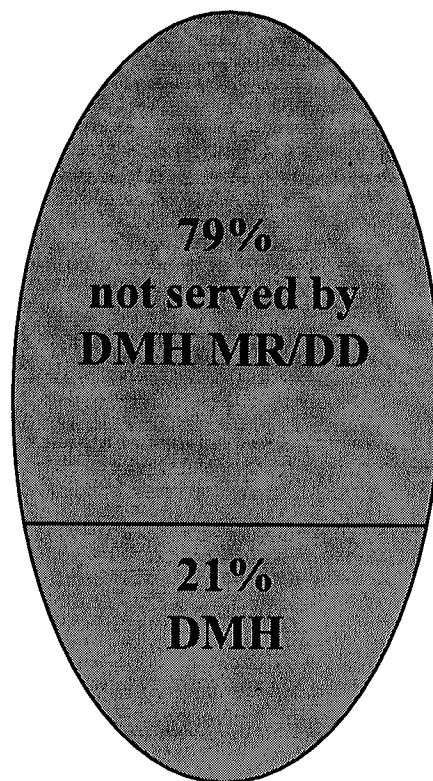
With these guiding principles in mind, the committee decided to limit the scope of our task. This paper focuses only on the long-term care and community/family aspects of service delivery, ... not primary and acute health care issues.

**AT ISSUE:  
WHAT IS MANAGED  
CARE?**

“Managed Care is a work in progress. Whatever it was two-and-a-half minutes ago, its different now.”

*-Bruce Fried,  
Director of the Office of  
Managed Care, HCFA*

# Developmental Disabilities in Missouri



Projected  
Incidence Rate: 1.8%  
94,180

*Nearly 80% of Missourians with Developmental Disabilities are not in the State Department of Mental Health MR/DD System; Their families and local communities are the primary caregivers.*

## **FACT FINDING**

The MACDDS study committee appointed by President Buffington included Chairperson Roger Garlich, Pettis/Saline Counties, and members Betsy Barnes, Pike County; Richard Goldbaum, St. Louis County; Ron Kruse, Franklin County; Peggy Kutchback, Cass County; Theresa Schulte, Washington County; Janice Tilman, Platte County, Amy Vasquez, Buchanan County; and Les Wagner, Boone County. Additionally, many MACDDS non-appointed members attended committee meetings to provide additional input. In the spirit of cooperation and collaboration, the committee also developed working relationships with staff from the Division of Medical Services/Department of Social Services, the Division of Mental Retardation/Developmental Disabilities, Department of Mental Health, Division of Vocational Rehabilitation, Department of Elementary and Secondary Education, and the Division of Early Childhood/Special Education also of DESE. Several committee members also participated on the Task Force on Medicaid Reform a statewide coalition of representatives from the disability community created with technical support from the United Cerebral Palsy Association, Inc., Washington D.C.

The fact-finding phase of committee work had two major thrusts:

- To gather data related to numbers of individuals served/unserved together with current resource levels, and
- To attend National Conferences and/or visit other states to educate ourselves on current service delivery systems and the extent to which "managed care" was being implemented relative to long-term, community habilitative care.

Summarized, the results of our fact-finding efforts are as follows:

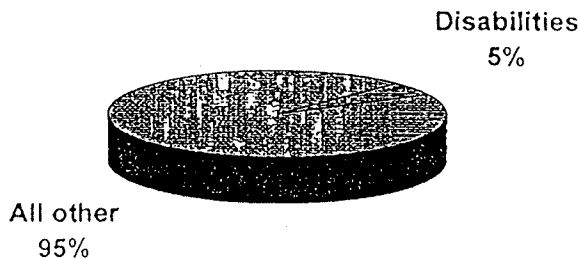
- In November, 1995, the predicted incidence of Missourians with developmental disabilities was **94,180** people. The Division of MR/DD has an active roll of 21,584 individuals, 10,089 of whom receive case management services only.
- FY 1996 DMH currently spends approximately **\$207 million** in state funds and received Federal Medicaid of **\$109 million**.

**FACT FINDING** (con't)

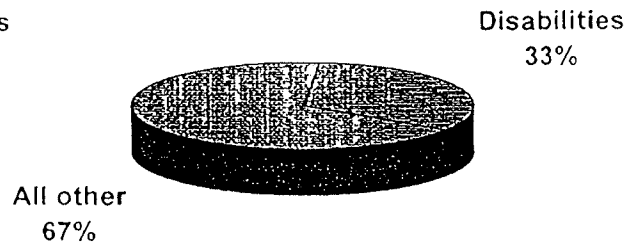
- SB40 County Boards serving people with developmental disabilities collect local property taxes exceeding **\$40 million**.
- Missouri's "First Steps" program for at-risk children ages 0-3 spends approximately **\$5 million** (includes health care expenditures).
- Community contributions serving people with developmental disabilities total approximately **\$40 million**.
- This total of **\$401 million** does not include funds spent through DESE for school aged special education or vocational training/employment. The total also does not include expenditures through the Department of Social Services for social welfare programs to many of these families.
- Study Committee members attended managed care conferences in New Orleans, Baltimore, and Arizona.
- Derrick Dufresne, a nationally known consultant, briefed the Committee on service delivery models operated in Wisconsin, Virginia, Ohio, Pennsylvania, Michigan, Minnesota, Colorado, and California.

## Why Long Term Care is Vulnerable

Medicaid Recipients



Medicaid Spending



## CONCLUSIONS

It is recognized that the subject of Medicaid reform and managed care is in its infancy. The application of managed care to the primary health care sector through the use of HMO's is currently under increasing review and scrutiny. Congress continues to debate the extent to which Medicaid needs "reform" and the best method of implementing reform (i.e. Federal vs. State control).

Within this context of ever-evolving information and discussion, and, after six months of committee work, we offer the following conclusions and recommendations:

### Conclusions

**AT ISSUE:  
MANAGING CARE WITH A  
SEAMLESS WEB OF  
SUPPORT**

When the Feds block grant to the state, how can we contain costs and make sure vulnerable persons with disabilities get help in my home town?

*- a local citizen*

**AT ISSUE:  
COORDINATED FAMILY  
FRIENDLY SERVICES**

Too often people with disabilities and their families are "ping-ponged" between state agencies trying to get the help they need.

*- a professional*

1. No state claims to have the "answers" to the challenges of Medicaid reform and whether or not managed care is an appropriate mechanism for long-term care issues. However, many states are experimenting with a system of locally-based "carve-outs" in their federal and state dollars.
2. Approximately 79% of the predicted incidence of 94,180 individuals who are developmentally disabled are not currently on the rolls of the Division of MR/DD. This means that the vast majority of MR/DD citizens live at home in their communities and have not been presented to the "system" for services.
3. The current service delivery system in Missouri, managed by multiple state agencies, is often fragmented, slow to respond, inefficient, costly, and overlapping. It does not provide for accountability or the best use of tax dollars.

4. The amount of money currently in the system from federal state, county and private funds represents a significant effort by Missourians to meet the needs of its citizens with developmental disabilities.
5. A minimum of \$40 million and literally thousands of volunteer hour/in-kind services is currently contributed by individuals and corporations to help fund local services for this population.
6. Approximately \$40 million is generated by local SB40 tax revenues throughout Missouri. The vast majority of these funds are not being matched with federal Medicaid dollars for eligible services.
7. Any system reform should include incentives encouraging continued citizen support of local services.

**AT ISSUE:  
VOLUNTEER AND  
DONOR SUPPORT**

"I'm proud I live where I do,  
because we care about  
people who need help."

*- a local citizen*

**AT ISSUE:  
A BIGGER BANG  
FOR THE BUCK**

If one-half of the \$40 million  
dollars of County SB40 tax  
funds were used to match  
eligible Medicaid services  
an additional \$30 million in  
revenue would be  
generated.

## RECOMMENDATIONS

- 1. Current levels of financial resources supporting individuals with developmental disabilities and their families should be protected either through statute or legislative appropriation (carve-out) to assure current and future needs can be met. A formula for controlled growth should also be examined. In an atmosphere of shifting responsibility from the federal to state level, and, as the legislature and administration look for ways to share risks and contain costs, look first to local partnerships.*
- 2. A fundamental shift in the service delivery system should occur with at least one option being a transfer of the responsibility, authority, and state funds to receptive and qualified county-based SB40 entities and/or their agent cooperatives. People with disabilities require a wide array of services on a long-term, supportive basis. Typically, there is no "system" of services, but rather a fragmented array of providers, none of whom are responsible for total care. More often than not, there are multiple case managers representing different state agencies serving the same family. In responding to the needs of persons with developmental disabilities living in communities, SB40 County Boards and/or their agents/networks offer proven potential for local coordination of services through a central point of accountability.*
- 3. A significant amount of locally generated county tax revenue is not currently being used to "match" federal Medicaid funds. Greater utilization of the "match" potential would generate new dollars for MR/DD services.*
- 4. A number of mechanisms exist within Missouri law/regulations which would allow cooperative agreements between the state and local governments to be piloted in promoting greater economy and efficiency of services*
- 5. MACDDS should have a representative(s) on or to any legislative or gubernatorial committee studying the issues related to the reform of services impacting persons with developmental disabilities..*

**AT ISSUE:  
MORE LOCAL INVOLVEMENT IN HUMAN SERVICE DELIVERY.**

"Missouri, like all other states, provides a wide array of human services to children and families in need. These services range from health care to family counseling to alcohol and drug prevention, just to name a few. But there's a basic problem that continues to hinder the effective and efficient administration of services."

"The problem is that while it's people in Jefferson City who are responsible for administering these services, it's the people in the communities across our state who really understand what services their communities need and how best to provide them.

The fact is, we need more local involvement in human service delivery to children and families.

Each community has different needs and what they don't need is Jefferson City making all the decisions about what's best for our communities."

*- Mel Carnahan  
Governor of Missouri  
State of the State Address  
December, 1995*