

**Congress
on
Disability
Policy**

*Committed to Bringing About Positive Change for
Missourians with Disabilities Through Education,
Advocacy, and Action!*



Member Organizations

American Association on Mental
Retardation – Missouri Chapter
(AAMR)

Missouri Network of Community
Options and Resources
(MOANCOR)

Brain Injury Association of
Missouri

Encouraging Families with
Exceptional Children Together
(EFFECT)

Missouri Association of County
Boards of Developmental
Disabilities Services (MACDDS)

The Arc of the U.S. –
Missouri Chapter

Missouri APSE: The Network on
Employment (APSE-MO)

Missouri Association of
Psychosocial Rehabilitation
Services (MOAPSRs)

Missouri Association of
Rehabilitation Facilities (MARF)

Missouri Centers for Independent
Living (MOCIL)

Missouri Governor's Council
on Disability

Missouri Head Injury
Advisory Council

Missouri Planning Council for
Developmental Disabilities

Missouri Rehabilitation
Association (MRA)

Missouri – TASH

People First of Missouri

CONGRESS ON DISABILITY POLICY:

2005

White Paper Regarding Public Policy Priorities and Positions



*A Missouri Coalition of State Associations and
Councils Established in 2003*

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INTRODUCTION

The Congress on Disability Policy is a broad based coalition of Missouri associations and councils that represent people with disabilities, their families, community providers, and others. Our membership consists of 16 statewide organizations with over 10,000 individual or organizational members who provide services and supports to over 100,000 Missourians with disabilities. Our purpose is to “advocate for an enhanced quality of life for Missourians with disabilities and their families by identifying common values that drive shared policy positions.” We are committed to bringing about positive change for Missourians with disabilities through education, advocacy, and action.

People with disabilities constitute our nation's largest minority group, one which any person can become a part of at any time. Some join at birth, others join in the split second of an accident, through illness, or by the aging process. Disability includes all genders, all ages, all religions, all socioeconomic levels, and every ethnicity. People with disabilities are Moms and Dads; Sons and Daughters; Employees and Employers; Friends and Neighbors; and Students and Teachers. Disability is a natural part of life. It is estimated that 20% of us will experience a disability at sometime in our lives.

In support of this purpose, we have identified the following policy positions that are shared by our membership. The purpose of this paper is to more clearly articulate our positions related to these priorities and to discuss how these positions enhance the health, safety, and quality of life for people with disabilities in Missouri.

Our Public Policy Priorities are:

- 1. The Congress on Disability Policy supports the health, safety, and quality of life of people with disabilities through preserving and maintaining Medicaid services and eligibility.**
- 2. The Congress on Disability Policy supports the health, safety, and quality of life of people with disabilities through enhancing community resources and supports.**

Medicaid Summary

The Congress on Disability Policy supports the health, safety, and quality of life of people with disability through preserving and maintaining **Medicaid** services and eligibility.

a. Medicaid is good for Missouri's economy, health care system and citizens.

- The percentage of General Revenue funds within the Department of Social Services budget spent on Medicaid has been very steady (increased from 16.3% to 17.8% from FY 1990 to FY 2004)
- Medicaid allows Missouri to leverage federal dollars to meet the medical needs of its most vulnerable citizens.
- Last year alone, Missouri received approximately \$4 billion in federal Medicaid dollars. Without state appropriations, these federal dollars simply would not come to Missouri.
- Missouri reaps \$3.39 in new business activity for every \$1 spent on the Medicaid program
- Medicaid costs are lower than private insurance – 30% less for adults, and 10% less for children
- The Congress on Disability Policy strongly supports the continuation of this program at current levels. Any changes that lessen or weaken this program will be devastating to individuals who rely on Medicaid as well as to the state economy.

b. People with disabilities in Missouri should continue to access needed Medicaid services.

- Optional Medicaid services are needed by people with disabilities to live productive lives in their communities
- Optional Medicaid services are not optional to the individuals who need them (e.g. prescription drugs, dental, rehabilitation services)
- The Congress on Disability Policy supports the provision of optional Medicaid services at current levels

c. To encourage people with disabilities to go to work by maintaining access to the Medical Assistance for Workers with Disability (MA-WD) program.

- Many people with disabilities, are reluctant to go back to work because their income might push them out of the income bracket for Medicaid eligibility
- The MA-WD program allows people with disabilities to return to work, earn a higher income, and purchase affordable health care and personal assistance services on a sliding fee scale
- Without MA-WD, more people with disabilities will be unable to work and will return to the regular Medicaid program, which will cost the state
- The Congress on Disability Policy supports funding for the MA-WD program at current levels

d. The Medicaid asset limit should be raised to \$2,000 per individual and \$3,000 per couple.

- The asset limit in Missouri has been \$999.99 (individual) and \$2,000 (couple) since at least 1971. The asset limit is antiquated and needs to be adjusted.
- These are not sufficient funds to allow individuals to deal with personal emergencies (e.g. fix furnace, car repairs)
- The Congress on Disability Policy supports adopting the federal SSI limit of \$2,000 (individual) and \$3,000 (couple). We believe this will save the state money in personnel used to investigate actual asset limits. In other words, if one is eligible for SSI, then there is no need to research the individual's or couple's asset limit.

Community Resources and Supports Summary

The Congress on Disability Policy supports the health, safety, and quality of life of people with disability through enhancing **community resources and supports**.

a. An annual cost of living adjustment should be provided for community service providers.

- Community providers provide vital services to persons with disabilities across the state of Missouri.
- For the past 15 years, provider rate increases have been minimal while costs have risen dramatically (e.g. health insurance coverage, worker's compensation, unemployment insurance, energy)
- The Congress on Disability Policy advocates an annual cost of living adjustment (COLA) to remedy this situation

b. The state of Missouri should work toward livable wages and benefits for Direct Support Professionals (DSP).

- DSPs assume a primary responsibility for meeting the needs of individuals with disabilities who require support or assistance to live in their communities
- In FY2002 DMH estimated the average annual turnover rate of DSPs who work for community residential contractors within the state to be 70%
- With the cost of living and employer costs increasing and reimbursement staying the same, it is difficult to maintain, let alone provide an increase in Direct Support Professional wages.
- The Congress on Disability Policy supports the appropriation of additional funds (state and federal) to raise DSP wages to a level that achieves wage parity between public and private DSP wages.

c. The state of Missouri should address and reduce all waiting lists for services for people with disabilities.

- Waiting lists are a major barrier to living in the community, obtaining jobs with benefits, and ultimately saving the state money
- State agencies and service providers must deliver appropriate services and supports when requested and when needed by people with disabilities and their families
- The Congress on Disability Policy strongly supports addressing and reducing waiting lists through additional appropriations for needed services

d. The state of Missouri should continue to actively implementation the recommendations of the Missouri Home and Community-Based Services and Consumer-Directed Care Commission Report.

- The Supreme Court ruled that states are required under the Americans with Disabilities Act to provide services in the "most integrated setting" and that isolating people with disabilities in institutions is discrimination
- The Congress on Disability Policy wants to encourage the State of Missouri to implement the many recommendations of the Home and Community-Based Services and Consumer-Directed Care Commission Report as published on December 31, 2000.

MEDICAID SERVICES

Medicaid, the state-federal government sponsored health insurance program for nearly one million low-income, children, seniors, and Missourians with disabilities, is a program vital to Missouri. The Congress on Disability Policy strongly supports the continuation of this program at current levels. Any changes that lessen or weaken this program will be devastating to individuals who rely on Medicaid as well as to the state economy.

Medicaid is an outgrowth of the Social Security Act signed into law by President Franklin Delano Roosevelt on August 14, 1935. Among the many amendments of the original Social Security Act, Medicaid was authorized by federal legislation in 1965. In fact, the provisions of Medicaid were signed into law at the Truman Library in Independence, Missouri on July 30, 1965.

In October 1967, the 74th Missouri General Assembly enacted legislation establishing a medical services program under Title XIX of the Social Security Act (source: www.dss.mo.gov/dms/: Division of Medical Services website). Thus, the Missouri Medicaid program was established two years after Lyndon Baines Johnson signed the federal Medicaid law. Services provided in the early days of Missouri Medicaid included outpatient hospital care, physician services, and professional nursing home care. Since 1967, the program has been greatly expanded to provide health insurance to a great many of the most vulnerable populations in this state. Because states are allowed flexibility under Medicaid, there are many “optional” services provided.

Moreover, flexibility is also expressed by the states in the way they design Medicaid to meet the state’s budgetary and programmatic needs. Missouri has created a variety of waiver programs to meet the diverse needs of our population. These waivers have been set up under either section 1115 or 1915 (c) of the Social Security Act as amended. Home & Community Based Waiver programs illustrate that Missouri Medicaid is a flexible program, designed to meet the unique needs of its citizens. The state has developed these waivers because they are jointly funded through state and federal government and are cost effective.

Position #1: Medicaid is good for Missouri’s economy, Health care system and citizens.

One of the arguments for restricting Medicaid is that it is taking a larger portion of state funding than ever before. The truth is that this program has been quite steady in the last 14 years in terms of state General Revenue (GR) funds. By comparing the Medicaid GR budget, as a percent of the Department of Social Services budget (Medicaid is appropriated through this Department) it has increased from 16.3% to 17.8% from FY 1990 to FY 2004. However, the overall budget (all funds, including federal) indicates that social services spending rose from 20.4% to 31.1% of the budget (Source: Missouri Hospital Association). The reason for this increase relates to the fact that the budget consists of both state and non-state funding. In fact, about two-thirds of the Missouri budget consists of non-state dollars. Thus, the reason that social services spending has increased in the overall state budget is that federal match money has increased in the last 14

years. The Congress on Disability Policy believes that this is a positive aspect of the program because more individuals are being served, largely because of the ability to draw down federal funds. (Source: Missouri Hospital Association)

Medicaid allows Missouri to leverage federal dollars to meet the medical needs of its most vulnerable citizens. Without utilizing the federal match features, Missouri would be forced to meet rising medical costs on its own. This would have a negative impact on our entire health care system. Medicaid dollars flow into the state as “match” money. In other words, state Medicaid allocations “draw down” federal dollars. Last year alone, Missouri received approximately \$4 billion in federal Medicaid dollars to support the health care needs of Missouri’s citizens. In Missouri, the match is approximately 40% state and 60% federal (72% federal funds for MC + program). Thus, the economic impact can be seen on both a direct and indirect level in Missouri simply because of the significant federal match. Naturally, the state has to allocate GR funds in order to get the federal dollars, but we believe this investment is very much worth it.

While Medicaid is a known quantity in assisting low-income, disabled and elderly citizens of Missouri, the program itself is also very good for the economy of Missouri. Medicaid is a state-federal program, contingent on both state and federal funding. Without state appropriations, these federal dollars simply would not come to Missouri. When these funds come into Missouri,

economic activity in the form of jobs, state and local sales tax, etc. grow the Missouri economy. In fact, the “multiplier” effect is responsible for bringing in over \$8B worth of new business activity for the nearly \$2.8B spent in GR funds on Medicaid. In other words, Missouri reaps \$3.39 in new business activity for \$1 spent on the program (source: Families USA).

Additional Facts

- Medicaid costs are lower than private insurance – 30% less for adults, and 10% less for children
- Medicaid costs per enrollee are growing from 5% - 7% each year while private insurance premiums are growing from 11% to 13% per

Further, the number of new jobs created due to Medicaid in Missouri in FY 2005 is estimated to be 71,538, with about \$ 2.6B in total wages accompanying these newly created jobs. Without this program or if the program were significantly reduced, the number of new jobs would be less, the tax base would, of course, be less and the economy would not be as robust (source: Families USA)

Position #2: People with disabilities in Missouri should continue to access needed Medicaid services.

During past legislative sessions, reductions in Medicaid optional services have been considered. The Congress on Disability Policy sees legislation to cut funding of the optional services as extremely problematic. The term optional is quite misleading because these are not optional services to the individuals who need them, but are considered optional in that the federal

government gives states the opportunity to offer them (versus the federally required “mandatory” services). For example, prescription drugs are hardly “optional” for the elderly and Missourians with disabilities who rely on Medicaid coverage for their medications (Joel Ferber, March 2004). The following is a partial list of other optional services under Missouri Medicaid:

- optical
- dental
- in-home services (Personal Care, respite, Homemaker Chore, etc.)
- dentures and prosthetic devices
- rehabilitation services
- hospice
- audiology services
- podiatry
- mental health services provided by community mental health clinics for children and adults

Any proposed changes that would impact the services and eligibility of persons with disabilities would have alarming negative long-term ramifications for those that utilize this program.

Position #3: To encourage people with disabilities to go to work by maintaining access to the Medical Assistance for Workers with Disability (MA-WD) program.

Many people with disabilities are reluctant to go back to work because their earnings might push them out of the income bracket for Medicaid eligibility. The MA-WD (pronounced “maud”) program has been very beneficial for many who want to work, but cannot due to restrictive eligibility requirements. The MA-WD program allows people with disabilities to return to work, earn a higher income, and purchase affordable health care and personal assistance services on a sliding fee scale. Medicaid and other social welfare policies historically have forced people to remain in poverty in order to have access to necessary health care. The MA-WD program, enacted in Missouri after the passage of the federal Ticket to Work and Work Incentive Improvement Act, invests in people with disabilities by helping them return to work. There are over 6,000 participants in this program and many must pay a premium ranging from \$0 a month to \$129 a month, depending on their income. The Congress on Disability Policy strongly supports MA-WD because for many people it removes the “disincentive” to work.

79% of people with significant disabilities are unemployed
(2004 N.O.D./Harris Survey)

As the individual’s income increases, the state collects premiums for services. Thus, people with disabilities are contributing to the cost of their health care. Without MA-WD, more people with disabilities will be unable to work and will return to the regular Medicaid program, which will cost the state.

MA-WD enables Jefferson City Woman to Work

Prior to the implementation of the Ticket to Work and MA-WD programs, Stephanie was unemployed and receiving SSI benefits due to a medical condition. Standing in the way of a job was the risk of losing cash and medical benefits. Her family and others advised her to play it safe and remain unemployed. Determined to become a productive member of her community, she took advantage of the medical coverage provided by MA-WD and obtained employment after receiving job training. Stephanie has been working for over one and a half years and recently received a job promotion. She has been able to keep her Medicaid health coverage as she transitions into a taxpayer. Without the prospect of a continuation of health care coverage under MA-WD, she most likely would have remained another statistic on the burgeoning SSI roles.

Many persons with disabilities do not work for fear of losing their health coverage. The majority of these individuals want to return to work but cannot afford to lose the health benefits and personal assistance services that they need. Many employers do not offer health insurance or the benefits are inadequate or too costly. The MA-WD program removed one of the biggest disincentives to work. The program must remain intact or people with disabilities will not be able to pursue their employment goals.

Employing more people with disabilities is good for the economy. As the income for working people with disabilities rises, they move off of Social Security benefits,

contribute to their health care costs, and become tax payers. This ultimately saves the state of Missouri money. It is estimated that if 75,000 people, just one percent of the 7.5 million people with disabilities nationwide receiving public benefits, became successfully employed, savings in cash assistance would total \$3.5 billion over the work life of the individuals (Source: Paraquad).

Position #4: The Medicaid asset limit should be raised to \$2,000 per individual and \$3,000 per couple.

Another issue that is of vital importance is the asset limits for Medicaid recipients in Missouri. In order to be eligible for Medicaid in Missouri, a participant must “spend down” their assets so that individuals have no more than \$999.99 in assets and couples have no more than \$2,000. Missouri has held to this asset limit since 1971. In fact, Missouri is one of eleven states that have more restrictive requirements than Supplemental Security Income (SSI) rules for Medicaid eligibility. As a 209(b) state, Missouri historically has had a lower asset level than the federal asset level of \$ 2,000 for individuals and \$3,000 for couples. The Congress on Disability Policy agrees that it is time to eliminate this rule, suggesting that Missouri accept federal SSI Income rules. This rule would need to be changed through legislative action. We believe there are three major reasons for this change.

1. It is antiquated. The asset limit in Missouri has been \$999.99 and \$2,000 since at least 1971. We believe that the asset limit needs to be adjusted. At the time, this was significant money for the individual or couple to use in an emergency. This is not the

case today, where a broken furnace or car repairs can easily wipe out the remaining assets of a Medicaid participant.

2. The Congress on Disability Policy believes that changing the asset limit will actually save the state money because by using the SSI limit, the cost and personnel used to investigate actual asset limits will decrease. In other words, if one is eligible for SSI, then there is no need to research the individual's or couple's asset limit because of the federally approved asset limit of \$2,000 and \$3,000.
3. By changing the asset limit, this would bring Missouri in line with most of the other states in the country.

COMMUNITY RESOURCES AND SUPPORTS

All people, regardless of disability, deserve the opportunity for a full life in their community where they can live, learn, work, and play alongside each other through all stages of life (Arc of the U.S.). People with disabilities need varying degrees of support to reach personal goals and establish a sense of satisfaction with their lives. Community resources and supports enable people with disabilities to participate in their communities in much the same way that people without disabilities live. For children, this usually means living with their family in their own home. For adults, it usually means having opportunities and supports to live and work as independently as possible in their communities. Adequate community resources and supports are critical to assuring the health, safety, and quality of life for Missouri's citizens with disabilities.

Position #1: An annual cost of living adjustment should be provided for community service providers.

Community providers provide vital services to persons with disabilities across the state of Missouri. Incorporated as not for profit organizations and guided by voluntary boards of directors, these agencies offer an array of support services that enable persons with disabilities to live and work in their communities. Community providers offer a cost effective and efficient alternative service delivery model to consumers and their families.

Unfortunately, the viability of community providers is at risk. The quality of services is directly correlated with the qualifications and experience of direct support professionals and other personnel. Increasingly, community providers are unable to compete in the open labor market or recover their operating costs. For the past 15 years, rate increases have been minimal while costs have risen dramatically. Fees for services have not kept pace with expenses such as health insurance coverage, worker's compensation, unemployment insurance, energy and other costs. Without fiscal relief, community agencies are in jeopardy. Since 1991, some providers have received approximately an aggregate total of 11.5 % in rate increases while at the same time, the Midwest Urban Consumer Price Index has risen 42%.

The Congress on Disability Policy advocates an annual cost of living adjustment (COLA) to remedy this situation. The nursing home industry faced a similar dilemma in recent years. Last year SB 1123 was passed to fairly adjust nursing home reimbursement rates. It is recommended that similar legislation be passed to maintain healthy, viable community services for persons with disabilities.

Position #2: The state of Missouri should work toward livable wages and benefits for Direct Support Professionals.

Missouri's Direct Support Professional (DSP) Workforce: One of the biggest challenges to providing community supports for people with disabilities in Missouri is the ability to find, recruit, and retain qualified direct support professionals (DSPs). Individuals identified as DSPs in Missouri are a diverse group who provide support to people with a variety of disabilities including developmental, physical, and psychiatric disabilities of all ages, including the elderly. The roles and functions of DSPs vary greatly and include support for people to live in their homes, support to work in the community, and a variety of other supports that allow individuals with disabilities to be included in their communities. DSPs work for a variety of employers including independent living centers, community provider agencies, mental health centers, and directly for people with disabilities or their families. Their "titles" may vary (child care worker, frontline worker, home health aide, personal care attendant, job coach), but DSPs assume a primary responsibility for meeting the needs of individuals with disabilities who require support or assistance to live in their communities

Missouri DSP Workforce and Recruitment Problems: Five years ago, the Missouri Chapter of the American Network of Community Options and Resources (MOANCOR) issued a paper titled "Crisis in Care Report" which called attention to the growing crisis of availability and competency of DSPs within the state. This report noted that the supply of DSPs to provide supports and services for people with disabilities is below acceptable levels and cited the following barriers: (1) competition for workers across other industries, (2) the low reimbursement for direct service providers and correspondingly (3) high rates of turnover. The MOANCOR report also noted that the competency of DSPs is below desired standards because provider organizations are often forced to hire unskilled, undereducated and inexperienced workers.

**"Missouri's most vulnerable citizens are being cared for by too few direct support workers, who often do not have the necessary education, experience or training, and who are grossly underpaid."
(MOANCOR, 1999)**

Specific to the issues of turnover, a later study by the Missouri Department of Mental Health (DMH) in FY2002 estimated the average annual turnover rate of DSPs who work for community residential contractors within the state to be 70% and the average starting salary to be \$7.16/hour. This study also noted that only 54% of community contract agencies provided access to health care coverage and sick leave for their employees and that less than 25% offered retirement benefits. This study found that higher salaries correlated with lower turnover rates for DSPs.

Turnover also has a negative financial impact on the state as well as community provider agencies. The national average cost per terminating employee is often cited as 25% of the terminating employee's annual salary. For example, if the average employee salary is \$20,000/year, then the average cost to the company per employee would be \$5,000/year. (Source: Retention Management and Metrics, Nobscot Savings Calculator with Nobscot Exit Interviews).

Efforts to Address this Issue: The reality of the DSP workforce shortage has been talked about for many years. Most recently, between 2000 and 2002, at least 27 states undertook or funded

formal analyses of wages of DSPs. Most found that private community agency wages for DSPs equal three-quarters of those of state employees in the same roles and barely half (55%) of the state's average wage. In response, many states undertook modest to major efforts to increase community DSP compensation (AAMR Report).

In Missouri the state legislature appropriated \$1.5 million to provide a 1.5% increase to DSP's in FY 2000, in FY 2001, \$2.7 million dollars was appropriated which provided another 3% wage and benefit increases, and in 2002, \$9.9 million dollars was appropriated for a \$1.00 increase in hourly wage and benefits for community DSPs. These appropriations were a step in the right direction in terms of addressing this issue. However, the realities of state budget cuts of the past

Sara's Story

I came here to work (at Emmanus) in November 1991. Emmaus has been very good to me. In November of 1995 my husband died in a car accident. We had four children, 1 ½, 4 ½, 7 ½ and 13. It was really hard to be a single parent and pay the bills off one salary. Without their Social Security we wouldn't have made it and even then it was tight. Between rent, food and unexpected bills there was very little left over but I did what I could to make sure my kids had good memories. An increase in the pay at Emmaus would help every employee make sure their families are cared for and are optimistic about their futures. The work is fulfilling and I love my job but the pay does not go far enough.

years have impacted funding for provider agencies and with about two-thirds of service provider budgets going to pay staff it has also impacted DSP wages and benefits. With the cost of living and employer costs increasing and reimbursement staying the same, it is difficult to maintain, let alone provide an increase in Direct Support Professional wages.

A stable, competent, and adequately compensated DSP workforce is critical to ensuring the health, safety, and quality of life of people with disabilities in Missouri. The Congress on Disability Policy supports the development of a long-term solution to address this issue. We believe the solution lies in two approaches: First, additional funds (state and federal) need to be appropriated to raise DSP wages to a level

that achieves wage parity between public and private DSP wages. Second, annual cost of living adjustments need to be connected to the reimbursement rates for funded services. As wages are raised to provide parity the annual cost of living increases would assure that this parity is maintained. This was discussed in the previous section of this paper. A competent adequately paid DSP workforce is critical to ensuring the health, safety and quality of life of people with disabilities.

Position #3: The state of Missouri should address and reduce all waiting lists for services for people with disabilities.

The Congress on Disability Policy believes state agencies and service providers must deliver appropriate services and supports when requested and when needed by people with disabilities and their families. We believe that waiting lists must be eliminated or shortened to the greatest extent possible.

Many services for persons with disabilities are provided only if funding is available. Unlike entitlement programs, where services must be provided by law if one meets the eligibility criteria for the program, many disability-related programs have a “waiting list” for services. These waiting lists have grown even in the face of the Olmstead Supreme Court decision, which mandates that states must provide community services under Title II of the Americans with Disabilities Act. In Missouri there are waiting lists for a number of different programs. We believe these waiting lists are a major barrier to living in the community, obtaining jobs with benefits, and ultimately saving the state money.

The following are just several programs that have existing waiting lists. The first is the **Center for Independent Living/Vocational Rehabilitation Personal Attendant Services program** wait list. As of January 7, 2005 the official Non-Medicaid Eligible Personal Attendant services (General Revenue funded) wait list is 62 people. The Independent Living Medicaid Waiver program to provide personal attendant services wait list is 149 people with an average wait time of 881 days. As of January 2005, there were over 200 persons waiting for personal care assistance services.

Department of Mental Health/ Division of Mental Retardation and Developmental Disability (as of 11/30/04). There are 509 people statewide on the “Residential” wait list. The “In-Home” Services waiting list consists of 2,738 individuals with developmental disabilities waiting for services that help them remain at home with their family or live independently in the community.

Vocational Rehabilitation Employment Program lists 4,337 individuals waiting to receive employment support services that would assist them in going to work (as of 1/12/05).

In the 2003 General Assembly session, Senator Charlie Shields sponsored legislation, SB 266, addressing the issue of waiting lists in the Department of Mental Health. His proposal was signed into law by Governor Bob Holden in 2003, and focuses on the “development of plans” for individuals on the Department’s waiting lists. While the Congress on Disability Policy certainly supports such legislation, more needs to be done to impact the growing list of individuals waiting for needed services.

In sum, the Congress on Disability Policy strongly supports addressing and reducing waiting lists through additional appropriations for direct services.

Position #4: The state of Missouri should continue to actively implement the recommendations of the Missouri Home and Community-Based Services and Consumer-Directed Care Commission Report.

In the 1999 *Olmstead v. L.C. and E.W.* decision, the Supreme Court ruled that states are required under the Americans with Disabilities Act to provide services in the “most integrated setting” and that isolating people with disabilities in institutions is discrimination. As the major funding source for long term services, the Medicaid program is essential to *Olmstead* implementation. Medicaid State Plan services such as personal assistance services and Medicaid Home and Community-Based Services Waivers must be available to people with disabilities and families in order to transition people out of institutions and keep people in their own homes and communities (Paraquad).

The Congress on Disability Policy wants to remind the State of Missouri to implement the many recommendations of the Home and Community-Based Services and Consumer-Directed Care Commission Report published on December 31, 2000. There were many recommendations emerging out of the commission’s report based on input from consumers and their families, state agencies, disability service providers, senior groups, and the Missouri General Assembly.

Home and Community-Based Services and Consumer-Directed Care Commission Report Recommendations*

- Increasing Caregiver Compensation.** The current hourly rate for caregivers is essentially flat. There have been little or no salary or wage increases in the last four years. In addition, most of the caregivers have very few benefits, including access to health insurance.
- Housing.** There is a lack of accessible, affordable, and available housing for many persons with disabilities and elderly citizens of this state. This is both an urban and a rural problem.
- Informed Choice.** There has been progress in this area with the publication of *Missouri's Guide to Home and Community Based Services*, but many individuals still do not know there are community care options available.
- Consumer and Family Directed with Supportive and Flexible Funding.** In terms of long-term care, a vast majority of federal and state appropriations still goes for nursing home care and other forms of institutionalization rather than allowing for consumer choice and community options which often cost less.
- Expanding Opportunities for Support and Employment by Expanding Medicaid Eligibility.** There has been progress made in this arena with the Ticket to Work program and the Medical Assistance for Workers with Disabilities (MA-WD) program. Access to this program needs to be maintained and funding for other employment services needs to be increased to address the unemployment rate of individuals with significant disabilities.
- Identifying and Assessing Waiting Lists and Developing Guidelines for Their Movement in Each Program Area.** Please see position #3.

*These six major recommendations were derived from the original 76 recommendations, for more detailed information, please visit <http://www.gcd.ia.mo.gov/Olmstead/exccsum-final.shtml>

SUMMARY

There are nearly a million Missourians with disabilities. The ability of many of our citizens to learn, work, and be involved in their communities is impacted by their disabilities. They require access to appropriate health care, education, employment, transportation, housing, and other services that support them to live as productive citizens. Services provided through the state Medicaid program and other community resources and supports are critically important to their ability to live productive and successful lives. It is crucial that we maintain and enhance access to these programs and services to assure the health, safety, and quality of life for citizens with disabilities in Missouri.