HEALTH CARE

"The reality is that for too long we provided lesser care to people with disabilities. Today, we must redouble our efforts so that people with disabilities achieve full access to disease prevention and health promotion services."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) maintains a primary goal for 2007-2011: People are healthy and benefit from the full range of needed health care services. The MPC has supported, and continues to support training to increase knowledge about DD among health care professionals.[2]

MPC Beliefs

- ***People with DD, family members and others are confident that publicly-funded services assure and promote good health and individual well-being.***
- ***The system is responsive to individual needs, providing help when and in the manner that people need assistance.***

What the Research Says

Health care "means that persons with disabilities can access appropriate, integrated, culturally sensitive and respectful health care that meets the needs of a whole person, not just a disability."[3] People with disabilities in general often have poorer health care outcomes. People with DD report higher levels of unmet health care and mental health care needs than people without functional limitations.[4]

Uninsured. The number of uninsured persons has risen to 46 million Americans,[5] greater than the combined population of Missouri plus the eight states that surround it. Approximately 11-12% of persons with intellectual or developmental disabilities do not have insurance according to a national health survey.[6] People without health insurance receive about half as much medical care as the insured.[7] Therefore, they use less preventive care, are diagnosed at more advanced disease stages, tend to receive less care once diagnosed, and have higher mortality rates than insured individuals.[8]

Access. The health care rights of people with DD, and protection from discrimination in health care, are ensured in the Americans with Disabilities Act of 1990 (ADA) and Section 504 of the Rehabilitation Act of 1973.[10] However, it is often difficult for persons with DD to find specialized medical care. To facilitate access to specialists, people need to have the continuity of a primary care physician, choice of doctors, and access to out-of-plan care. People with disabilities and their families often feel that doctors and hospital staff are uneducated about disabilities and therefore may not be reliable or respectful. People with disabilities may also have difficulty finding physically accessible health care facilities.[11] Finding dentists for persons with DD is recognized as a serious problem nationwide, particularly for persons who have an intellectual component to their disability, in part due to difficulty finding dental providers who accept public dental coverage.[12] In 2002, 36% of children and adults with disabilities had annual dental visits, compared to 46% of persons without disabilities.[13]

The Surgeon General outlined the following Call to Action Goals in 2005:[14]
1) People nationwide understand that persons with disabilities can lead long, healthy, productive lives.
2) Health care providers have the knowledge and tools to screen, diagnose, and treat the whole person with a disability with dignity.
3) Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
4) Accessible health care and support services promote independence for persons with disabilities.

Costs. Medicaid is a primary source of health care for many persons with disabilities, often providing

What Missourians with DD and Their Families Are Saying[9]

Statewide Needs Assessment Results
Respondents thought people with DD were *most likely* to get health care services through:
- **Doctor's office (62%)**
- **Hospitals/emergency rooms (22%)**

Respondents thought people with DD were *least likely* to get health care through:
- **Residential health care center (42%)**
- **Local health departments (21%)**
- **Community health clinics (16%)**

Health Care Help/Support
Respondents most frequently reported receiving supports from doctors and other medical professionals, and some reported no problem finding medical and/or dental care.

Adequacy of Health Care
Respondents rated the health care options that they were *most likely* to use as *inadequate/fair,* and the ones they were *least likely* to use as *good/excellent.*
(70%) Hospital/emergency room rated *inadequate/fair*
(67%) Doctor's office rated *inadequate/fair*
(51%) Residential health care center rated *good/excellent*
(43%) Community health clinics rated *good/excellent*
(41%) Local health department rated *good/excellent*

Availability of Health Care
(75%) of respondents viewed health care as *only somewhat/not available*
(73%) rated dental services as *only somewhat/not available*

Top Challenges in Health Care
- **Public health insurance program issues**
- **Lack of nearby dental service**
- **Lack of nearby medical resources**

insurance for those who otherwise would be uninsured. A national health care survey revealed that 43-60% of persons with intellectual and/or developmental disabilities utilize public health care plans.[15] As Medicaid costs continue to increase, states have implemented cost containment measures typically focused on reducing eligibility, resulting in loss of health coverage for many Americans.[16] Yet, Medicaid spending per person grew more slowly than spending under Medicare and private insurance between 2000-2003.[17] Medicaid also has a significant positive effect on state economies because it brings in matching federal funds.[18]

Since 2000, health insurance premiums have grown 78%, while wages have only grown by 20%. Health insurance for individuals now averages $4,242 yearly, and $11,480 for family coverage.[19] Only a little over half of employers now offer health insurance,[20] as jobs have shifted towards the service sector and part-time jobs, which both offer less benefits. Yet, data shows that 2/3 of children with special health care needs rely on insurance through the parent's employer, which often doesn't cover the mental health care and physical therapy sometimes needed by children with DD.[21]

"[My] employer discontinued [insurance plan] because of increase in premiums when employee had child with Down Syndrome."[22]

Health care through private insurance has become more inaccessible for individuals with DD due to higher premiums, deductibles, and co-pays. In the absence of a national health care policy, states will be forced to choose between continuing coverage using limited funds, further impacting state revenue; or continuing to reduce coverage for low-income families, further impacting the numbers of uninsured and generating poorer health outcomes.[23]

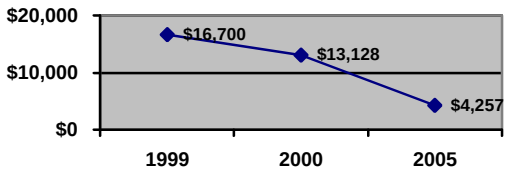
The State of the State in Health Care

Medicaid in Missouri plays a primary role in providing insurance for the poor, and long-term care for the elderly and persons with disabilities.[24] In 2005, the legislature in Missouri enacted changes to the number of persons eligible for the Missouri Medicaid program, and specified sunset dates for the Missouri Medicaid and the State Children's Health Insurance Programs (SCHIP) of June 2008. Coverage of many of the optional Medicaid services for states were also eliminated by the Missouri legislature[25] --services such as dental care, dentures, podiatry, orthopedic devices, hearing aids, eyeglasses and comprehensive day rehabilitation services,[26] which are vital to the independence and productivity of Missourians with disabilities.[27] Approximately 115,000 Missourians lost coverage, or one in every eight persons insured by Medicaid.[28]

In addition, the income limit to qualify for Medicaid was reduced from 100% of the federal poverty level to 85% resulting in larger "spend downs" to be eligible for Medicaid. The number of persons in the "spend down" program doubled between 2005-2006.[29] This keeps people from moving toward economical self-sufficiency. Many others who are still eligible for Medicaid must pay large monthly "spend downs" in order to remain eligible. Federal policy allows individuals to have up to $2,000 in assets (e.g., money in a savings account, SSI, earned income, etc.). However, in Missouri the limit is only $999. Therefore, people who earn money that would take them over the $999 amount are required to spend their "excess" income to avoid losing Medicaid benefits.[30]

Missouri has also made considerable, detrimental eligibility changes since 2000 to Medicaid for working parents, as shown below.[31] Of all states making Medicaid changes for cost containment reasons, Missouri removed the most working parents from the program at 68,000.[32] These changes affect children with developmental delays that might not be caught early due to lack of doctor's visits.

Decreasing Eligibility of Low-Income, Working Parents for Medicaid[33]



Allowable Annual Income for 4-Person Family

In 2008, Missouri will need to either move to extend the sunset dates, or reform the current system, opening the door to consideration of sweeping reform such as the universal health insurance coverage recently enacted in Massachusetts.[34]

Among the Medicaid changes was elimination of the Missouri Aid to Workers with Disabilities (MAWD) program, which enabled people with disabilities to work, yet still be able to purchase affordable health care and personal assistance services on a sliding fee scale. The total number of individuals who lost coverage under MAWD is 18,000. 9,529 persons with DD were left completely uninsured. Despite their lack of insurance, most respondents indicated that they wanted to remain working, but 8% indicated they would need to quit in order to re-qualify for Medicaid. No measures were instituted to track the effects of these decisions on those that lost insurance coverage.[35]

The number of adults and children with DD in Missouri who go without dental services is unknown. For every dentist that accepts Medicaid/SCHIP, there are more than 1,000 children enrolled in the program in the St. Louis area alone. Reimbursement rates are so low that there is no incentive for dentists and doctors to accept these patients.[36]

There is an economic impact from lack of insurance in lost earnings due to fewer years of healthy life and lower productivity while at work. "These economic costs are substantial and represent a hidden cost of uninsurance, over and above the cost of the medical care used by the uninsured."[37]

What We Recommend

Accessible, Affordable, Quality Health Care

- Expand home and community-based services and cover and equipment and services needed for independence. Currently, individuals in need of some services or medical equipment can only receive them in an institutional setting. The need for a single piece of equipment or service could force an individual into a facility, when they could otherwise remain in their home if that same service or equipment were covered in the community.
- Cover dental, personal care, podiatry, rehabilitation, specialty care including durable medical equipment and other services identified as optional by the Centers for Medicaid and Medicare. Denying these essential services moves people toward costly and unnecessary institutional care.
- Offer qualified workers with disabilities the opportunity to buy into a state sponsored health insurance plan. The buy-in rate should be reasonable for the cost of the plan to provide a clear incentive to work. This moves people towards independence, productivity and fulfillment and carves a path out of poverty.
- Reform the spend-down policy to avoid forcing people into poverty, and change to a premium-based approach to encourage productivity and growth. An individual or family should not have to choose between health care and other basic necessities. Expenditures for health insurance should be affordable and premium based depending on income.
- Change asset limits to at least $2,500 for an individual and $5,000 for a couple. This would allow individuals with disabilities to be able to cope with an unexpected emergency, bill, necessary purchase or to save for a home or car down payment.
- Increase the amount of state-funding that is matched with federal Medicaid funds. Missouri has the 10th highest percentage of unmatched MR/DD state funds.[38]
- Increase funding for medical services for people with DD who do not have access to affordable health insurance and do not qualify for Medicaid.
- Improve physical accessibility of health services and medical equipment so that individuals with DD obtain quality assessment and treatment. People currently have to be assessed and treated in wheelchairs.
- Work with other states in developing standards for medical equipment accessibility under ADA.

Professional Education

- Increase training for health care professionals so they are knowledgeable about working with persons with disabilities, reduce stereotypes, and improve communication between health professionals and persons with DD.[39]
- Partner with state departments, legislators and advocates should partner to do the following:

  1) Identify health care gaps and barriers. Develop and implement specific strategies to address the needs of people with DD.

  2) Recruit professionals to underserved areas to increase access.
- Partner with health care professionals and medical schools and utilize the Missouri Developmental Disability Resource Center to develop resource fact sheets for health professionals, with tips for working with persons with disabilities in health care settings.
- Recruit doctors with experience in working with people with disabilities to train other doctors about health care for persons with DD. They should be educated on ways to deliver quality healthcare to persons with DD in partnership with the individual and people who know them best.

Health Care Advocacy

- Include persons with disabilities in public health advisory groups, as is currently being implemented in Montana.[40]

HEALTH CARE ENDNOTES

"The Surgeon General's Call to Action, To Improve the Health and Wellness of Persons with Disabilities". (2005). U.S. Department of Health and Human services, Office of the Surveon General. Retrieved on 2/4/07 at http://www.surgeongeneral.gov/library/disabilities/calltoaction/calltoaction.pdf
[2] "FY 2002-2006 Developmental Disabilities State Plan Goals & Objectives". Missouri Planning Council for Developmental Disabilities. Retrieved 1/07 from www.mpcdd.com
[3] "The Surgeon General's Call to Action, To Improve the Health and Wellness of Persons with Disabilities". (2005). U.S. Department of Health and Human services, Office of the Surveon General. Retrieved on 2/4/07 at http://www.surgeongeneral.gov/library/disabilities/calltoaction/calltoaction.pdf
[4] Anderson, L., Larson, S., Lakin, C., and Kwak, N. (2003) Health insurance coverage and health care experiences of persons with disabilities in the NHIS-D. *DD Data Brief* (University of Minnesota: Minneapolis, Institute on Community Integration), 5(1).
[5] "Health Insurance Coverage". (no date). Washington, D.C.: National Coalition on Health Care. Retrieved on 2/4/07 from http://www.nchc.org/facts/coverage.shtml
[6] Anderson, L., Larson, S., Lakin, C., and Kwak, N. (2003).
[7] Kayani, N.A. and Homan, S.G. (2005). *Report on the Health Care Safety Net in Missouri*. Jefferson City, MO: Missouri Department of Health and Senior Services, Division of Community and Public Health.
[8] "Health Insurance Coverage". (no date).
[9] Rinck, C., Graybill, T., Berg, R., Horn, W. (2006). "The Missouri Planning Council for Developmental Disabilities Statewide Needs Assessment".
[10] "The Surgeon General's Call to Action, To Improve the Health and Wellness of Persons with Disabilities". (2005).
[11] Anderson, L., Larson, S., Lakin, C., and Kwak, N. (2003).
[12] Ibid.
[13] "Disability and Health in 2005: Promoting the Health and Well-Being of People with Disabilities". (2005). Atlanta, GA: Department of Health and Human Services, Centers for Disease Control and Prevention.
[14] "The Surgeon General's Call to Action, To Improve the Health and Wellness of Persons with Disabilities". (2005).
[15] Anderson, L., Larson, S., Lakin, C., and Kwak, N. (2003).
[16] "The Impact of Rising Health Care Costs on the Economy: Effects on the State Budgets". (2006). Washington, D.C.: National Coalition on Health Care. Retrieved on 2/4/07 from http://www.nchc.org/Costs%20on%20Economy/Index.html
[17] "Mental Health Association Medicaid Facts and Fiction". (September 2006). Mental Health Association of Greater St. Louis.
[18] Barker, M.R. (Winter 2006). "Missouri Medicaid Basics". Missouri Health Foundation. Accessed at www.mffh.org
[19] "Health Insurance Jumps Twice Inflation Rate". (September 26, 2006). Associated Press. Accessed at http://www.msnbc.msn.com/id/15014332/
[20] "Health Insurance Coverage". (no date). Washington, D.C.: National Coalition on Health Care. Retrieved on 2/4/07 from http://www.nchc.org/facts/coverage.shtml
[21] Nyman, R. & Ireys, H. (November 2004). "Children with Special Health Care Needs: Building a Quality-of-Care Initiative". Mathematica Policy Reasearch, Inc.: Issue Brief (1).
[22] Rinck, C., Graybill, T., Berg, R., Horn, W. (2006).
[23] "The Impact of Rising Health Care Costs on the Economy: Effects on the State Budgets". (2006).
[24] Ferber, J. (2004). "Medicaid is *Still* Good Medicine for Missouri". St. Louis: Legal Services of Eastern Missouri, Inc.
[25] Barker, M.R. (Winter 2006).
[26] "Missouri Medicaid Program Changes". (Updated July 11, 2005). Missouri Department of Social Services, Division of Medical Services. http://www.dss.mo.gov/dms/providers/pages/msreduct.htm
[27] "2005 White Paper Regarding Public Policy Priorities and Positions". (2005). Missouri Congress on Disability Policy.
[28] Ehresman, R. (2006). "Clock Ticks on Medicaid: Reform Must 'First Do No Harm'". St. Louis: The Missouri Budget Project. Retrieved on 2/3/07 from http://www.mobudget.org/newhealthcarereports.htm
[29] Ibid.
[30] The Missouri Customer Leadership Initiative. (1998). *Show Me Change: Building a Participant-Driven System for Missourians with Developmental Disabilities.* Retrieved 01/07, from http://www.mpcdd.com/pdfs/LeadershipInitiativeFinalReport.pdf
[31] Ferber, J. (2004).
[32] Ehresman, R. (2006).
[33] Ibid.
[34] McBride, T., et al. (2006). "The Massachusetts Plan: A Model for Missouri?". St. Louis: The Missouri Foundation for Health. Retrieved on 2/4/07 from http://www.mffh.org/MassachusettsPlanModelMissouri.pdf
[35] Feltman, S., Hill, J., and McBride, T. (2006). "Losing Health Care in Missouri, Survey Results: Impact of 2005 Medicaid Cuts". The Missouri Association for Social Welfare and the Missouri Budget Project.
[36] "Children's Health Care: The Missouri Perspective". (September 2004). St. Louis, MO: Citizens for Missouri's Children.
[37] Hadly, J. "Consequences of the Lack of Health Insurance on Health and Earnings, Cover Missouri Project (Report 1)". (2006). The Urban Institute. Retrieved on 2/3/07 from http://www.urban.org/UploadedPDF/1001001_CoverMo1.pdf
[38] Braddock, D., et al. (2005). The State of the States in Developmental Disabilities Preliminary Report. Department of Psychiatry and Coleman Institute for Cognitive Disabilities: University of Colorado, Boulder.
[39] "Exploring Environmental and Behavioral Interventions in Health Promotion Programs for People with Disabilities". (2004). Washington, DC: State Grantee Conference of the American Association on Health and Disability. Accessed at www.aahd.us
[40] Ibid.