



. . . speaking on behalf of children and youth with special health care needs

Medicaid Policy Recommendations June 2005

Introduction

Family Voices is uniquely qualified and honored to present our recommendations for reforming the Medicaid program. Family Voices speaks on behalf of this country's 9.4 million children and youth with special health care needs and their families. Many organizations represent the concerns of Medicaid stakeholders. However, few organizations represent, as their only constituency, millions of families across the United States who have children and youth with a range of special health care needs. The Family Voices grassroots network includes more than 40,000 families who daily cope with a broad spectrum of medical, financial and social challenges.

It is critical to understand an important fact about children and youth and their use of the Medicaid program: children represent half of all Medicaid enrollees but account for approximately 25% of Medicaid expenditures.¹ In addition, depending on diagnosis, children might use fewer services as they age. However, children and youth with chronic conditions or disabilities cannot thrive without the comprehensive health coverage that Medicaid provides.

Family Voices endorses the concept of a Bipartisan Medicaid Commission to carefully review the Medicaid program. Reflecting the daily experiences and challenges of millions of American families who have children and youth with special health care needs, Family Voices makes the following recommendations to Congress, the governors, other policymakers, future Medicaid commissions, and all those who also care about how Medicaid policy impacts our children:

Key Medicaid Recommendations from the Family Voices Network

- Family Voices recommends that Congress pass legislation to establish a Medicaid buy-in for children with special health care needs. Because private insurance often limits or denies necessary coverage, thousands of families of children and youth with special health care needs should be able to access the Medicaid program as critical supplemental insurance. A Medicaid buy-in will most likely result in long-term cost savings because families contribute to the Medicaid program and in some cases it will prevent institutionalization. A Medicaid buy-in also helps families contribute more fully to society because

¹ Newacheck PW, Kim SE. A National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs. *Archives of Pediatric & Adolescent Medicine.* January 2005;159(1):10-17.

they can accept increases in income without fear of losing Medicaid coverage.

- Family Voices recommends the establishment and maintenance of funding for Family-to-Family Health Information Centers in every state as a cost effective and efficient way to help families and providers find information about necessary services, leading to informed health care decisions. These Centers also help families navigate complex financing systems that often result in delays of care. Medicaid will find the Centers an excellent source of innovative solutions and data for program and policy issues at state and local-levels. These Centers are also potential resources for state Medicaid Advisory Councils.
- Family Voices recommends preserving the essential entitlement nature of the Medicaid program. The entitlement requires access for all eligible children and youth with special health care needs to critical health care services. Additionally, it is important to examine continuous eligibility to improve service delivery to this population.

Recommendations to Improve Medicaid Service Delivery, Transition to Adult Services, and Administrative Processes

Service Delivery

- Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program must be preserved. The EPSDT benefits package provides cost-effective health care that meets the unique needs of children and youth by addressing their ongoing physical and mental development.
- Pediatric and developmental experts strongly support EPSDT. Family Voices highly recommends that the treatment portion of EPSDT be adhered to and its implementation improved.
- Family Voices knows from experience that delaying or denying treatment by delaying or denying payment not only severely impacts the child or youth but is also not cost-effective in either human or financial terms.
- Family Voices recommends that EPSDT be improved through collaboration among state programs that have expertise in children with special health care needs, including state Title V programs (which have a unique responsibility for children and youth with special health care needs), University Centers for Excellence in Developmental Disability and children's hospitals. Collaboration would prevent duplication and improve service delivery.

- Family Voices recommends that every child have a Medical Home that provides consistent and coordinated health care. The American Academy of Pediatrics defines a Medical Home as the provision of care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent. A Medical Home implies joint accountability between the physician and the family. A medical home addresses the medical and non-medical needs of the child and family. For the primary care physician, this role should involve identifying and making referrals to community, state and federally-funded services that will benefit the child and family.
- Family Voices believes strongly in the importance of Early Intervention (EI) services to assure optimal development and prevent complications that often occur with chronic conditions or disability. Family Voices recommends Medicaid reimbursement for EI services.

Transition to Adult Services

- Family Voices recommends careful review of the role of Medicaid during the transition from youth to adult services. Youth with special health care needs often require significant support in order to succeed in home and community-based settings as adults. The Medicaid program can play a critical role by improving the individual coordination of transition to adult services. Medicaid should require a transition plan for every young adult beneficiary that includes specific services and supports needed to work, live independently, and participate in community activities. This transition plan must also identify steps for working with the appropriate agencies.
- Family Voices believes an overall review of Medicaid's approach to health care services for youth is needed. Family Voices' families know that many youth transitioning to adulthood have great difficulty securing the health care services they need in order to continue living in home and community-based settings. The transition plan must identify a source for health insurance (public or private).
- Family Voices recommends a review of the partnerships between Medicaid and other agencies involved with youth transitioning to adulthood at the federal, state and local levels. Medicaid should coordinate partnerships between agencies that work with youth, including transportation, housing and secondary education. At state and federal levels, Medicaid can work with these agencies by identifying barriers to a smooth transition to independent living. Reimbursement for coordination of programs that assist youth transitioning to college or the workforce should be supported through Medicaid funds just as currently occurs when children move from institutions to home and community-based care. Medicaid is currently requesting proposals from states for "system transformation" grants that would improve

coordination among these agencies at the state-level. The work of these grants needs to be sustained in order to ensure continued commitment to these efforts.

Medicaid Administrative Issues

- Family Voices recommends the continuation of the state option to provide “pay and chase” programs under Medicaid. These programs prevent delays in delivery of health services due to financing issues and allow Medicaid to pay for services for any eligible child covered by private insurance. This allows the child to receive health care services without waiting for approval/payment from their private insurance. Medicaid then can bill, or if necessary, sue the private insurance plan for payment.
- Family Voices believes strongly that Medicaid must remove its institutional bias and instead emphasize the more efficient, cost-effective, and family-friendly home and community-based care. The Supreme Court’s Olmstead ruling and the Bush Administration’s New Freedom Initiative reinforce the nation’s commitment to deinstitutionalization. The Real Choice Systems Change Grants, if adequately supported, reinforces the Administration’s commitment to the Olmstead decision. Real Choice Systems Change Grants are awarded by the Centers for Medicare & Medicaid Services (CMS) to state and local-level agencies to improve access and quality in home and community-based care. CMS should work closely with the Maternal and Child Health Bureau, Division for Children with Special Health Care Needs, to collaborate on the New Freedom Initiative in the implementation of a community system of services for children and youth with special health care needs.
- Family Voices recommends identifying and replicating model home and community-based waiver programs that further eliminate the institutional bias within the Medicaid program. CMS should consider ways to help states improve their home and community-based care through grant programs such as Special Programs of Regional and National Significance (SPRANS).
- Family Voices recommends an examination of eligibility guidelines for government programs using the current Supplemental Security Income (SSI) definition and whether this eligibility definition creates barriers to those with severe disabilities who do not qualify for SSI based on their deemed income. Disability determination is so important for persons with disabilities in order to qualify for multiple programs that could assist them in activities of daily living and health care coverage. Often, policymakers make the assumption that having a disability automatically results in SSI, providing access to Medicaid. This is not always true. The income and assets tests often impede those who should qualify. Many times the disability determination is not even addressed because the income and assets criteria have not been met. Family Voices

believes that the disability criteria should be centered around a functional assessment not just the list of disabilities currently used by the Social Security Administration

- Family Voices recommends a review by the General Accounting Office (GAO) to address issues of fraud perpetrated against the Medicaid program both by providers and beneficiaries, Any changes to the Medicaid program, based on the findings of GAO, should first be carefully reviewed to ensure that unnecessary and costly barriers to care are not added to the program.
- Family Voices recommends that federal and state-governments adhere to requirements for universal and transparent public comment on proposed changes to the Medicaid program, especially inviting participation from Medicaid beneficiaries and their families who can provide valuable insights and recommendations regarding more cost-effective practices.

Program Options to Explore

- Family Voices recommends consideration of separate funding for various populations served by Medicaid. For example: Part A, a children's program; Part B, adults in long-term care served in homes and communities; Part C, adults served in long-term care nursing home facilities; and, Part D, adults who qualify based on income.

Conclusion

Family Voices recognizes Medicaid program costs are rapidly increasing. However, the growth rate of Medicaid is actually slower than health care costs overall. There are different challenges facing different populations served by the Medicaid program. For children and youth with special health care needs, the biggest issue is not cost. The issues of greatest concern for children and youth with special health care needs are: the effective implementation of EPSDT; improved coordination of care; effective planning for youth transition to adulthood; active family involvement; and maximum use of home and community-based services.

These recommended Medicaid changes will not be easy to implement. However, careful, objective, deliberate study of these recommendations can assure health care coverage that is equitable and cost-effective for all those who need it, including our sons and daughters. Whether as a primary or supplemental source of health insurance, Medicaid is critical for quality health care for our children and youth.

If you have any questions regarding these recommendations proposed by Family Voices, please contact Julie Beckett, Director of National Policy (319-365-0227; waivermom@earthlink.net).