

PUBLIC HEALTH PAYMENT SYSTEMS ***Medicaid and Related Programs***

The Medicaid program was first enacted in 1965. It was intended to assist those who were uninsured gain access to a medical payment program. Many young people were returning from work in the Peace Corps or the VISTA program and were in need of medical coverage. Few restrictions were placed on the program initially. The federal government was overwhelmed with thousands of people who needed access to medical care and had no source of payment during the first year of the program. Because it was a joint state and federal matching fund program the cost had skyrocketed to the federal government as well as to the states. In 1966, Congress revisited the issue and decided only the poor needed this kind of protection.

Medicaid was designed as an entitlement program for payment of medical services at no cost to those eligible. In recent years, under 1115 waivers some recipients pay a portion of the cost of services. This will be discussed in depth below. The Medicaid program has broad federal requirements that were designed for its original implementation.

Eligibility is determined by the federal poverty level with states determining the extent of coverage for recipients. The state match needed for federal funds is based on the number of individuals in the state who meet the federal poverty limit. No state receives less than 50% of their program money from the federal government. When a state agrees to take this money, they agree to abide by the requirements of the federal Medicaid program. Included in these requirements, the state must file a plan to:

- *meet the federal match;*
- *define the services that will be made available to recipients including amount, duration, and scope of those services; as well as,*
- *an assurance that the state will not discriminate between recipients; and,*
- *a plan to make the Medicaid program available statewide.*

Providers eligible to serve Medicaid clients must be available to all recipients and recipients must have a reasonable choice of providers. The federal government requires seven mandated services and provides a list of optional services that states may choose from to complete their Medicaid service plan. (See chart)

EARLY PERIODIC SCREENING AND DIAGNOSIS (EPSDT)

Early Periodic Screening, Diagnosis and Treatment is among the mandated services. Added in 1967, EPSDT required screening for children under the age of 21 using a periodicity schedule to assure their health and development meet certain goals. If those goals were not met, a diagnosis would be made and treatments would be provided to assist in their growth and development. In 1989, after a recognition that states were not always in compliance with the full implementation of this requirement, the law was strengthened to assure that the treatment portion of the program was implemented to the

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full extent necessary. If a child was screened and diagnosed and a treatment plan was developed; and it was demonstrated that the services required were medically necessary, a state was then obligated to pay for the treatment required under the plan. It was also required that a yearly report detailing the impact of EPSDT on the states population under age 21 be submitted to the Department of Health and Human Services.

TEMPORARY ASSISTANCE TO NEEDY FAMILIES (TANF)

The 1990's brought tremendous change to programs that provide access to Medicaid. Under both statute and regulation, many adjustments have been made causing great turmoil in human service program delivery. The greatest change came with the enactment of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193-PRWORA). This welfare reform legislation ended the federal entitlement to cash and child care assistance that had been available under the Aid to Families with Dependent Children program and replaced it with the Temporary Assistance to Needy Families block grant to the states. This new approach offered time-limited assistance to those eligible with strict work-related requirements. Under this block grant, states were guaranteed a fixed grant amount of funding from the federal government for six years. States were required to maintain state spending or face significant penalties. States were allowed flexibility in the design of their TANF programs hoping that they could streamline their systems based on the individual needs of the states population and its diversity. TANF programs in the state provide a variety of services beyond the cash payment program. These services include employment and training opportunities, child care, transportation, education and family and parental training.

A majority of states have extended benefits to those above the federal poverty level who are moving in the direction of self-sufficiency. States have expanded "disregard" policies and allowed some families to keep more earned income. One of the most sought after benefits to continue has been Medicaid. However, even with these changes, the needs required by these new eligibles are significant. Adequate and appropriate child care has been lacking for many working families. Single mothers have had a very difficult time maintaining good child care and the assistance promised has fallen short of the need in most instances. TANF funding comes up for reauthorization in 2002.

SOCIAL SERVICES BLOCK GRANT (SSBG)

The Social Services Block Grant funds programs for domestic violence, meals-on-wheels programs, child welfare services, services for disabled children and adults, child care, long-term care, and a host of other locally delivered services. In the welfare reform law, the SSBG was set at level funding for the years 1997-2002 with an increase to occur in 2003 from 2.38 billion to 2.8 billion. Congress however, in 1997, reduced the level of funding to 1.7 billion to pay for other programs they wish to fund, mainly transportation.

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TANF funding was allowed to be transferred to the SSBG (10%) to maintain helpful community programs but Congress reduced that transfer authority to 4.25% beginning in 2002. Consequently, many strong community services have been thwarted by a reduction in available funds. Without these services the many eligibles under the TANF legislation have been negatively impacted. While states still report success in their welfare reform programs a review of the SSBG funding levels show that most welfare reform clients are falling through the cracks.

TITLE IV-E OF THE SOCIAL SECURITY ACT -FOSTER CARE AND ADOPTION ASSISTANCE

Established in 1980, the Foster Care and Adoption Assistance provides matching funds to states to cover the cost of room and board for foster care, subsidizes adoptions of children with special needs, trains public agency staff and foster and adoptive parents, administration funds for the program and provides the statutory protections assured for all children particularly for case planning or permanency hearings. These matching funds are only available for low-income children. Their eligibility is based on the pre-welfare reform standards and are applied to the biological family. The state must incur the total costs for those not eligible under this standard. Title IV-B provides discretionary funding for child welfare and provides a capped entitlement for funding family preservation services, family support services, reunification services and adoption promotion and support services. In addition, the Child Abuse Prevention and Treatment Act of 1974, provides state grants with minimal monies to improve prevention, investigation and treatment of child abuse and neglect. The Chafee Foster Care Independence Program provides funding for support services, job training, housing and other skills needed for older youths moving from the foster care system into independent living. Title XIX (Medicaid) has increasingly been used as a source of funding for child welfare services particularly under targeted case management and utilizing the rehab option.

OTHER PROGRAMS IMPACTING CHILDREN WITH SPECIAL HEALTH CARE NEEDS:

MEDICAID FOR SUPPLEMENTAL SECURITY INCOME (SSI) BENEFICIARIES

The Supplemental Security Income program was established for persons who had become disabled and therefore could no longer work. It is a cash assistance program for persons who meet both an income and disability requirement. Part B is a program designed to grant access to children with disabilities to this same cash assistance. The SSI program for children has seen significant changes in the 1990's. The SSI program was difficult to implement for children because it was based on the premises of and ability to work. A great deal of interpretation went on throughout the states that led to multiple disparities in the program impacting eligibles. While a list of conditions was created and

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used for disability determination, many children with disabilities were rejected for eligibility even when they were clearly disabled. Often it is the combination of conditions that restricts a child from the ability to perform tasks of daily living.

Such was the case with Melissa Detzel whose case brought to light the discrimination between adults and children in this program. The courts ruled that because the program was based on the premises of ability to work, the standard for eligibility was clearly discriminatory in its approach to applying that same ethic to children. What followed was a unique revamping of the SSI program focusing on outreach to children who may be eligible. Further education was required for those who made the decisions about eligibility.

Unfortunately in 1997, Congress, hearing concerns that some children were faking disability revisited the program and went back defining eligibility based on a list of disabling conditions. While this was devastating to some advocates, the process that the Social Security Administration had gone through had changed the environment. The people making disability determinations learned how to look at disabling conditions in children. Many states still rely on the Children with Special Health Care Needs programs in their states to assist in determining disability including the use of pediatricians to review charts and make recommendations. The Children with Special Health Care Needs program will be reviewed in more depth later.

Now, Social Security, who is required by law, to refer any child refused eligibility for SSI to the Children with Special Health Care Need program in the state has become a close working ally benefiting from the knowledge and expertise of these programs. Notwithstanding, the SSI program ensures a national uniform income floor for persons who are elderly, blind or disabled. Both income and assets(countable resources) must be low in order to qualify.

For children it is their parents' income and resources that falls under scrutiny. A portion of the household income, including any from children currently working outside the home, is deemed eligible for the child with a disability. Countable income includes cash income plus certain in-kind goods or services a person receives in a given month. Certain items are exempt from this calculation including current basic needs for everyday living. Individuals with up to \$2000 worth of countable resources can be eligible. For couples, it is \$3000 worth of countable resources. Countable resources are defined as cash or property that were acquired sometime in the past; the individual has a right to access and could be converted into cash to cover basic living expenses. Insurance policies where the applicant is a beneficiary is a good example of a countable resource. Please note that federal law imposes a penalty on persons who try to give away or transfer assets to qualify for federal programs such as SSI. Some property is allowed transfer and you can establish a trust for individuals under the age of 65 who are disabled using special needs trust guidelines.

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1915(b) & (c) Waivers and TEFRA

In 1981, a waiver program was established that allowed individuals who were forced to live in an institutional setting to be eligible to live in their homes and communities by waiving the income and resources of the family who would be caring for them. As previously discussed a portion of the families household income was deemed eligible for the person with a disability even though they did not contribute to that income, often making them ineligible for programs such as Medicaid or SSI. Persons who lived in institutions were considered independent of household income and so eligible for institutional care paid for by Medicaid. Prior to 1981, Medicaid did not pay for home care. Three criteria were used to determine if a person was a good candidate. First, the person with a disability or chronic illness had to be able to be cared for at home. Services had to be available to meet the needs of the individual. Second, the family that would become the primary caregivers had to want them to come home. Finally, the home and community based setting could not cost the Medicaid program more than the program had been paying in the institution.

From 1981-1982 a Board was established within the Department of Health and Human Services to help determine who might be eligible for such waivers. These individual waivers were discontinued in 1984 when the Health Care Financing Administrator announced that states themselves could apply to serve a number of citizens they deemed eligible for waiver services in their states. Two types of waivers were established: Model waivers which were restricted to fifty individuals or regular home and community based waivers which allowed the state to determine what types of individuals they wish to serve and how many persons may be eligible. Regular waivers were to describe a category of disability such as Mental Retardation/Developmental Disability, Physically Disabled or Chronically Ill, Mentally Ill or Frail Elderly. Waivers for the HIV/Aids populations were established a few years later.

Whether a state was applying for the model or regular waiver, they still needed to match the use of federal dollars to implement such a waiver. This often limited the number of individuals a state would like to serve. Medicaid programs would have to apply for a certificate of need to serve individuals in institutions or nursing homes. States often limited the number of skilled care beds leading to a discrepancy in the number of beds available for home and community-based waivers. The number of persons eligible for a model waiver soon rose to 200 per waiver and states were not limited to the number of waivers they could apply for. Often a state had a model waiver and several regular waivers. Services under waiver programs were different from the traditional Medicaid program in that states could enhance services currently in their state plans to meet the needs of these individuals being served at home. In addition, states could ask for two services that were not part of the mandated or optional services package available under their state plan. Those services were respite and home renovation. A state could allow reimbursement by Medicaid for these services by detailing the criteria for their use within the waiver application. Waivers must be reapplied for every three to five years.

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TEFRA: Tax Equity and Fiscal Responsibility Act of 1982

States found that developing waivers were time-consuming, primarily because of the cost analysis documentation required. So HCFA developed a state plan amendment option allowing states to serve children with disabilities under the age of 18 who would fit the criteria for institutional care by simply checking a box on their state plan and including them as a population served under the states traditional Medicaid program. These state plan amendment options allow states to provide all the traditional services provided to all clients under the Medicaid program currently being served within the state. States could not enhance those services without providing them to all Medicaid eligible clients. Several states whose benefits under traditional Medicaid were very rich and could meet the needs of children needing to be served at home opted for this less intrusive option. Currently 19 states have used the TEFRA state plan amendment option.

1115 Waivers

To enhance the ability of states to better serve their Medicaid populations, the Department of Health and Human Services developed 1115 waiver demonstrations.

This option allowed states to redesign how they wish to deliver their Medicaid services to eligible individuals. Most 1115 programs contracted with private managed care companies to expand delivery of health services. Some states allowed individuals to choose their own providers but many assigned clients to providers who would limit the amount of cost charged to the state for services rendered. This moved Medicaid from a traditional fee-for service program to a more aggressive managed care approach. The verdict is still out on the success of these programs but several delivery approaches have been tried by the states.

Primary Care Case Management (PCCM) is one of these delivery approaches. In this case, a physician is assigned as the primary care provider to the Medicaid client. In order for the physician to be paid they must see the patient which has resulted in a more aggressive approach by providers to establish regular visits for Medicaid clients. Other states have contracted directly with a managed care company that assigns a client to a primary physician who is under contract to them to see those assigned to his/her care. If a physician under contract cannot treat the client and must refer to a specialist, the primary care provider is often not paid by the managed care company for their time and effort to meet the patient's needs. There is a built in incentive not to refer to more expensive specialists by the managed care company. Often Medicaid clients have difficulty in negotiating the appeals process when something of this nature occurs.

The states have recognized this as a concern and have built in several quality assurance

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mechanisms including paying for out of contract services through the traditional fee-for-service mechanism. This often results in the state paying more than it had intended on a per client basis so much of the cost savings is not recognized. These 1115 waivers are demonstration and so states must reapply every three to five years.

STATE SUPPLEMENTAL ASSISTANCE PROGRAM

Many states supplement the basic SSI payments through a variety of program options. This allows individuals who cannot live entirely on their own to receive the services they need to stay in a community. These programs are state specific and are paid for by state dollars only. In most states a cash payment is provided beyond the SSI limit to supplement programs not paid for under traditional Medicaid. Respite is often one of these programs allowed.

MEDICALLY NEEDY PROGRAM

States can cover people with too much income to qualify under any other eligibility category under a medically needy option. This allows an individual with high medical bills to apply those to their income to bring their income down to a level where they can then qualify for Medicaid. An individual must meet the Social Security disability determination to be eligible for this option. There is also a resource limit similar to SSI. This program works best for those who are close to the poverty level (SSI) with few resources available to them. The medical bills that are applied to bring a families income below the poverty level are not paid by Medicaid.

STATE SYSTEMS ADVOCACY

State Budget Process

As an advocate for persons with disabilities needing health care access, it will be extremely important for you to follow how your state intends to spend the money it has allocated for health care. The Governor develops a budget for the state usually by having the various state government departments submit their individual budgets and seeking out their priorities. Those priorities face certain federal criteria i.e. Medicaid must having state matching funds to draw down there federal dollars. When Congress gives an option to a state to engage in a certain program often there are goals that the state must meet to qualify. It is important for advocates to know what those goals are so that they may monitor the states performance in meeting those goals.

The Governor must submit his budget to the state legislature for their approval. This process involves committee assignments based on the jurisdiction for committees. With

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regards to health care both the committee on health and the committee on human services must agree on how monies will be spent. Sometimes there are two separate committees and sometimes there is a joint committee. The Speaker of the House assigns jurisdiction to the committees in the house. In the Senate it is the majority leader who is responsible for that action. The exception to this is Nebraska which has a unicameral legislature.

When the committees have taken action on the Governors budget they then send the measure to the floor for all members of the house or Senate to vote on the matter. Both Houses of the state legislature must agree or a compromise is drawn up by a bipartisan, bicameral committee. If the measure is the same in both versions of the House and the Senate then the final approval goes directly to the Governor. If there are discrepancies in the various measures those must be agreed upon and the measure again has to pass both Houses of the state legislature. It will be important for advocates to be prepared to provide input at anytime in the process. Within the Department, the Governor's office, the Committee's of jurisdiction and to individual members including the leadership of both the majority and the minority parties. Any data, personal stories and reports will be vital to making your points be heard.

Medicaid Advisory Councils

By federal mandate a state must conduct open forums about what it intends to do with the States budget with regard to Medicaid and Human Services programs. An advisory council of citizens of the state is required. These members are often appointed by the Governor and sometimes by the state legislature or with the legislature approval. It is important to make these committee members aware of the issues of concern that face people with disabilities in accessing health care and other needed services. Often testimony is collected to assure that adequate public input has been provided. Be prepared to testify with documentation to support the issues most concerning you and families like you. Join together with a coalition of others with similar concerns. While one voice is important and can make a difference, several voices from various sectors of the state and With a variety of backgrounds i.e. providers, advocates, families etc. make a bureaucrats pay more attention. Speak up and be heard, provide letter writing campaigns and visit with legislators in their home districts. Involve the media by developing a personal story that would be of interest to the rest of the state's population or impact a legislators decision in his district.

Medicaid State Plan

The Medicaid agency is required by the federal government to submit a plan for how they will use Medicaid money. Part four of the Medicaid plan describes the benefits which will be provided to eligible groups. A review of this section for amount, duration and scope of services is important. The state must also describe how providers will be

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reimbursed and how much that reimbursement will be. Review this to see if it is adequate to engage enough providers to serve persons with disabilities covered by Medicaid. Another area to review is any managed care contracts that the state is willing to enter into. Are there protections for people with disabilities? Quality assurance and access guarantees? Is there a process in place for appeals and how do those being served know of this process? What you do not know or have not reviewed can hurt the people you wish to help.