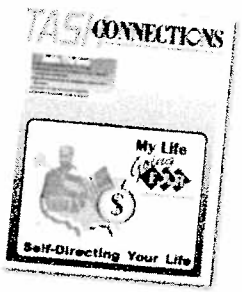
My Life Going F.A.R.
Freedom ' Authority ' Responsibility

Supporting Individuals and Families to Self Direct Their Lives Through the Maryland New Directions Medicaid Waiver



Inside the March - April 2005 Issue of TASH Connections: Self-Directing Your Life (.pdf file)

My Life: Going FAR is a project of TASH.

This project is funded by the Maryland Developmental Disabilities Council, in cooperation with the Maryland Developmental Disabilities Administration.

What is a Medicaid Waiver?

This information is based on a Policy Brief of the National Center for Family Support. The entire brief can be found at www.familysupport-HSRI.org

The Medicaid program is an enormously important source of money to pay for services and supports for people with developmental disabilities. About $3 of every $4 that states spend for developmental disabilities services comes by way of Medicaid. Once, Medicaid dollars only paid for institutional services. Today, Medicaid allows more diverse services and supports for individuals in the community, by "waiving" the need to get those same services in an institution.

Why is it important to learn all about Medicaid?

Advocates need to keep in mind that states have the ability to decide who gets funded for what services (criteria for eligibility and coverage). To realize many of the opportunities afforded by federal policy, a state must elect to include an "option" or change its current policies. Medicaid policy change at the state level means convincing policy makers (governors and legislators) to take advantage of key options if they have not done so already. This is why it is important for individuals, families and other stakeholders to be "at the table" when Medicaid policy is discussed.

The Way Medicaid Works

Federal law (Title XIX of the Social Security Act) and regulations spell out the requirements that a state must meet in operating its Medicaid program. If a state meets these requirements, then the federal government pays a percentage of money (called the Federal Medical Assistance Percentage (FMAP)) of the amount of money that the state spends for services to people who are eligible for Medicaid. The FMAP rate varies, depending on income levels in each state. The lowest FMAP for high-income states is 50%; the maximum rate allowed is 83%. The highest rate currently being paid is about 77% (Mississippi).

States must use their own or local tax dollars (called "matching dollars") to meet their share of Medicaid costs. In order to expand Medicaid services, a state must provide more of their own tax dollars to get more money from the federal government. In the federal budget, Medicaid is an "open-ended entitlement" program. This means that the federal government is required by law to pay its share of state Medicaid costs regardless of the total amount. Each state spells out what is available under its Medicaid program in a document called the "state plan." The state plan describes the groups of individuals who can receive Medicaid services and the services that the state will make available to them. A state can amend its plan to change its program. State plan amendments are subject to federal review and approval. Each state must designate one of its agencies (called the "single state Medicaid agency") to administer its Medicaid program. The Medicaid

Sign up for the My Life: Going FAR email discussion group. This group is for sharing questions, ideas, and sucess stories related to self-directing support services and for supporting people to self-direct and use the Maryland New Directions Medicaid Waiver.

Individuals with developmental disabilities, families, and interested advocates or supporters are welcome and encouraged to participate.

If you or someone you know is interested in the information, but does not have regular access to email or the internet, please call us at 410-828-8274 x109 and we will add you to our regular mailing list.

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agency may enter into agreements with other state agencies (e.g., the state developmental disabilities agency) to administer specific services.

The federal agency responsible for the Medicaid program is the Center for Medicaid and State Operations (CMSO), a branch of the Health Care Financing Administration (HCFA) in the Federal Department of Health and Human Services. HCFA issues regulations and other policy guidance concerning Medicaid. It also oversees state Medicaid program operations. There are ten HCFA Regional Offices located around the country that work with individual states concerning the operation of their Medicaid programs.

Key Requirements For States

There are key requirements with which a state's Medicaid program must comply. These basic requirements govern Medicaid programs nationwide. They include:

- A state must make services available to individuals on a *comparable* basis. With some exceptions, a state may not provide services that differ in amount or type to one group of beneficiaries than others.
- A state must guarantee that recipients have *free choice* in selecting from among qualified service providers when obtaining Medicaid services. That is, a state cannot require a person to obtain services from a specific provider to the exclusion of others.
- A state must make Medicaid services are available *statewide* and provide that individuals have ready *access* to them.
- A state must accept and make a *prompt decision* concerning a person's application for Medicaid services.
- A state may not limit or ration services due to a funding shortfall. A state is obligated to provide services in its state plan to all eligible persons. If a state cannot afford to provide the services, it must change its state plan.
- A state also must permit individuals to appeal adverse decisions concerning their eligibility or the authorization of services. This is called the Fair Hearing process.

In some cases, a state may request *waivers* of some of these requirements. Medicaid home and community-based service waiver programs operate under such waivers. The HCBS waiver program will be discussed in more detail below. When a state decides to use a managed care arrangement to obtain services for individuals (thereby limit their freedom of choice), there are federal laws and regulations concerning how such arrangements must be set up in order to safeguard their interests. Medicaid services must be obtained from "qualified providers." A state must spell out the qualifications that an individual or agency must meet in order to furnish services. States have considerable latitude in specifying these qualifications. At a minimum, providers must meet requirements spelled out in state law. In addition, each provider must enter into a contract (called a "provider agreement") with the state in order to be paid for services it provides to beneficiaries.

Medicaid is a "vendor payment" program. Typically, states pay providers directly on a fee-for-service basis once the provider has furnished a service. Subject to federal requirements, a state may pay for Medicaid services through prepayment ("capitation") arrangements when services are provided by health maintenance organizations (HMOs) or similar organizations. States have broad discretion in determining the amount of payments for services. Federal law requires that payment rates must be

sufficient to attract enough providers so that recipients can access needed services.

Eligibility: The Portal to Medicaid Services

Medicaid services are available only to individuals determined eligible for a state's program. Eligibility is the "portal" through which people must pass in order to obtain Medicaid services. On the other side of this portal lie services that people can obtain.

There are two parts to Medicaid eligibility. One is *financial eligibility*. Medicaid is a *means-tested* program. To qualify for Medicaid, a person cannot have income or assets that exceed the amounts that the state has specified. *The second leg of eligibility is whether a person is a member of a "group" that recognized in federal law* (e.g., people with disabilities who receive federal Supplemental Security Income (SSI) benefits). In order to receive Medicaid services, a person has to meet both tests. "Mandatory" groups (e.g., individuals that all states must serve) essentially include SSI recipients and children who live in very low-income households. But, there are many options or "doors" available to states to widen Medicaid eligibility beyond the mandatory groups. People with developmental disabilities qualify for Medicaid by meeting financial eligibility tests and being members of recognized but broader groups (e.g., individuals with disabilities). It is important to understand that over the past fifteen years, federal Medicaid policy has changed to permit states to offer Medicaid services to more groups of individuals who do not actually receive public assistance payments. Medicaid no longer is closely tied to "welfare." Even though the program is still means-tested, new mandates and options have been added so that individuals and families who have income above the poverty line can pass through the portal.

There are certain eligibility options that can play an important role in enabling people with developmental disabilities to qualify for Medicaid services, even though these options are not reserved exclusively for such individuals. These options revolve around children and adults who do not qualify as members of a mandatory group, generally because their or the family's income prevents them from being eligible to receive an SSI or other public assistance payment. It is helpful to discuss these options in terms of those that are relevant to children, adults and those that cut across all ages.

- **Children**. Not all children and youth with severe disabilities can qualify for an SSI payment and, thus, Medicaid. In the case of children with severe disabilities who live with their families, SSI rules require that a portion of the family's income be counted as available ("deemed") to the child. Even in the case of low-to-moderate income families, this requirement can result in the child's not qualifying for an SSI payment and, thus, make the child ineligible for Medicaid. However, if the child were placed permanently out of the family home in an institutional setting, the family's income would not be counted and the child would qualify for Medicaid. In order to correct this problem, in 1982 Congress enacted the "Katie Beckett option" (also known as "TEFRA 134"). Under this option, a state can decide not to count the family's income when the child meets SSI disability criteria and would be eligible for Medicaid if s/he were in an institutional setting. Several states have adopted this option. One state where this option is used extensively is Wisconsin. See the _ for how to obtain more information about Wisconsin's Katie Beckett program.

- Children who do not receive SSI also can qualify for Medicaid in a variety of other ways. They can qualify as members of low and moderate income households (needy families). There can be other avenues available, depending on the state. The Vermont Parent-to-Parent Network has identified six ways (including the Katie Beckett option) that children with disabilities can obtain Medicaid eligibility in Vermont. See the _ for how to access this information.

- Congress is considering a bill (the Family Opportunity Act) that would give states still another option for extending Medicaid eligibility to children with disabilities who live in higher income households eligible for Medicaid services. We discuss this bill more in the final section.
- **Adults**. Family income does not play a role in Medicaid eligibility for adults with disabilities, including when the person lives with his/her family. Only the adult individual's own income and resources are considered. As noted previously, states must extend Medicaid eligibility to individuals who receive SSI payments. SSI program rules permit individuals to earn income up to a certain level and still qualify for SSI. Recently, these earning limits were raised to $740/month. There also are special rules that continue SSI and Medicaid benefits for a period of time after a person exceeds the earned income ceiling. It is not true that having a job automatically disqualifies a person for Medicaid. But, problems can arise once the person's income climbs above levels that SSI permits.
- Not all adults with severe disabilities qualify for an SSI payment. People who receive "adult disabled child" Social Security benefits or who have other income (including employment income) that exceed SSI maximums can qualify for Medicaid under other options. A state can set higher income thresholds that permit more of these individuals to qualify even though they do not receive SSI. Many states also permit individuals to qualify as "medically needy." In a medically needy program, people who have income above the state's maximum qualify for Medicaid by "spending down" their income on health services until it reaches the state's maximum (e.g., if a state's maximum is $600 per month and a person has income of $800, the person will qualify once he or she spends $200 on health services). Recently, HCFA issued new rules that give states more options to make it easier for people to qualify as medically needy and thus obtain Medicaid eligibility. In addition, starting in 1997, Congress has added more eligibility options that permit states to extend or continue Medicaid eligibility for adults with disabilities whose employment earnings would otherwise disqualify them for Medicaid. See the _ for how to obtain information on this new options (which some states already have adopted). The rules concerning Medicaid eligibility for adults with disabilities differ considerably from state to state with the exception of the requirement that states include SSI recipients. As with children, it is important to have solid information concerning the rules in your state.
- **Long-term Services Eligibility**. In most states, Medicaid financial eligibility rules are more liberal for people who require long-term services. For example, a state may grant Medicaid eligibility to such persons who have incomes as high as three-times the basic grant standard for the SSI program (i.e., as high as $1,590 per month). In operating an HCBS waiver program, a state may employ the same financial rules to determine eligibility as it does for institutional services. For children, this yields the same result as the Katie Beckett option. However, the Katie Beckett option is broader since it

does not hinge on whether the child participates in a waiver program. In the case of adults, using institutional financial eligibility rules can make a big difference in enabling individuals to obtain Medicaid eligibility. But, again, these special provisions apply to people who qualify for long-term services.

Medicaid operates under a simple rule: no Medicaid card, no services. States have many options for widening the eligibility portal for both children and adults with disabilities beyond those who receive an SSI payment. Advocacy with respect to Medicaid eligibility centers on urging states broaden eligibility options to more children with severe disabilities who live with their families and adults who do not qualify for SSI.

Once a person successfully navigates through a Medicaid portal, the next question is what services they can obtain that would be valuable in meeting his or her needs? Answering this question revolves around "coverage" -- the collection of "services" or "benefits" a state offers to Medicaid beneficiaries.

Medicaid coverage also has two parts. Every state must provide all Medicaid recipients with a core set of *mandatory services* (e.g., hospital, physician, nursing facility, home health services). A state also may elect to provide additional *optional services* (e.g., personal assistance, home and community-based waiver services). See the _ for how to locate information about the all the services that a state must or may offer. States can operate Medicaid programs that have either wide or narrow benefits. Usually you can find out about all the services your state offers at the Medicaid agency's website (_). Like other health insurance programs, whether a person requires a service is based on "necessity" (medical or otherwise) criteria (e.g., does a person's condition require a treatment or service that is covered under the state plan?).

State-to-state, the basic services that are available depend on whether the person is a child or adult as well as the decisions that a state has made with respect to the services it offers. Everyone who has a Medicaid card can access the services that a state offers through its Medicaid state plan. Here, we describe some key "regular" Medicaid services (e.g., services that a state can provide without seeking special waivers). In the next section, we will discuss services that a state can over through an HCBS waiver program.

There are differences in the services that a state must or may offer children and adults. In particular:

- **Children**. For more than a decade, Congress has focused on strengthening the role that the Medicaid program plays in ensuring that children (with or without disabilities) have access to health care. In 1989, Congress extensively revamped federal Medicaid law what are labeled "Early and Periodic Screening, Diagnosis and Treatment" (EPSDT) services. States must provide EPSDT services to all children who are eligible for the Medicaid program. It is one of the mandates that states must meet in operating a Medicaid program. Through EPSDT, children must be seen periodically by health care professionals. If the child is identified as having a medical condition, further diagnoses must be performed and a state must follow through to provide all necessary treatment services. However, needed services can be identified at any time by professionals other than the child's own physician. The 1989 law

changes required states to step up their performance in operating EPSDT programs. It also mandated that states furnish any necessary Medicaid service (including dental care) that a child requires – regardless of whether the state specifically covers the service as part of its regular Medicaid program or not. The EPSDT mandate, for example, means that Medicaid eligible children with severe disabilities who require therapeutic services must be provided them. A state cannot restrict the services that it provides under the EPSDT mandate; it must make all types of services available, including the services that children with severe disabilities or special health care needs require. Such services can include home health services and personal assistance. However, EPSDT services do not include services (like respite) that only can be furnished through an HCBS waiver program. It is this EPSDT mandate that potentially makes obtaining Medicaid eligibility so valuable for children with disabilities.

- **Adults**. Except for the mandatory services that all states must include in their Medicaid programs, states have latitude in terms of the types of services that they make available to adults with disabilities. With respect to adults, there is no equivalent to the EPSDT mandate. States vary considerably with respect to the optional services that they make available to adults. For example, states frequently make available only very limited dental services or restrict the provision of therapeutic services only to people who need such services to "restore function," a restriction that frequently results in persons with developmental disabilities not being able to obtain such services. In addition, often states impose restrictions on optional services that can narrow their scope considerably.

There are three "regular" Medicaid services that are especially relevant to meeting the needs of people with developmental disabilities:

- One is home health, which all states must offer in their Medicaid programs. Home health services are provided to individuals at their place of residence. Home health services must include part-time or intermittent nursing services, home health aide services, and certain medical supplies and equipment. Physical, occupational therapy and speech pathology and audiology services also may be provided on an optional basis. In some states, access to home health services has been restricted to "homebound" individuals. But in July 2000, HCFA issued a policy clarification that states cannot restrict the availability of these services to people whose condition prevents them from leaving the home. This is expected to increase access to home health services by individuals who live in the community.
- The second important "regular" Medicaid service coverage is personal care (a.k.a., "personal assistance" or "attendant care"). When this service is offered, workers can provide assistance to people with disabilities in a wide variety of ways (helping with activities of daily living, grocery shopping, or getting about in the community). Once, federal rules limited the provision of these services to the person's home and described them in "medical model" terms. In 1993, Congress changed federal law so that personal assistance could be provided out in the community and "demedicalized" them. In 1999, HCFA issued new guidelines that gave states increased flexibility in providing these services, including sanctioning the use of consumer-directed personal care services (____). A state may provide personal care/assistance services without obtaining a waiver from HCFA and people do not have a

demonstrate a "need for institutional services" in order to obtain these services. Personal care is a potentially very flexible benefit that states can make available to all beneficiaries. However, fewer than 30 states offer personal care under their regular Medicaid programs and many have imposed more stringent restrictions on them than federal policy requires. A few states (e.g., Washington) make personal assistance available relatively widely.

- Another service is "targeted case management." The service is labeled "targeted" because it is one of the few regular Medicaid services that a state can cover but limit to specific groups of individuals. Many states use this coverage to fund their service coordination systems for people with developmental disabilities. States can offer these services to one or many groups of beneficiaries. Targeted case management is designed to help Medicaid beneficiaries access any of a wide range of services -- including social and educational services – not just health care services.

The "regular" services that a state offers through its Medicaid state plan make up a "core" benefit package available to all Medicaid beneficiaries. Federal policy is very liberal with respect to the range of benefits that states may offer. But, many states are reluctant to add more services to their Medicaid programs or loosen up the restrictions that apply to the services that they presently offer. It is not surprising that concerns about increased spending lie behind this reluctance. Once a service is included in the core benefit package, it becomes an entitled service that might be very costly to provide. Nonetheless, advocates should be vigilant for opportunities to urge states to take advantage of opportunities to add services that are important to people with disabilities or remove overly stringent restrictions.

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Waiver Programs

The Medicaid Program is responsible for the implementation and ongoing administration of home and community-based services waivers and targeted case management programs for special population groups. The Program studies, plans, and implement services relating to the needs of special populations such as the elderly, the mentally ill, and the physically and mentally disabled.

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What is a waiver?

Under Section 1915(c) of the Social Security Act, Medicaid law authorizes the Secretary of the U.S. Department of Health and Human Services to waive certain Medicaid statutory requirements. These waivers enable States to cover a broad array of home and community-based services (HCBS) for targeted populations as an alternative to institutionalization. Waiver services may be optional State Plan services which either are not covered by a particular State or which enhance the State's coverage. Waivers may also include services not covered through the State Plan such as respite care, environmental modifications, or family training.

The four basic types of 1915(c) HCBS waivers available for states based on the target population's level of alternative long-term institutional care are:

- intermediate care facility-mental retardation (ICF-MR) level of care for mentally retarded and/or developmentally disabled individuals;
- chronic or rehabilitative hospital level of care for individuals who are medically fragile, chronically ill, or severely disabled;
- psychiatric hospital level of care for individuals who are severely or chronically mentally ill; and
- nursing facility level of care for individuals who are elderly, physically disabled, and/or cognitively impaired.

To be a waiver participant, an individual must be medically qualified, certified for the waiver's institutional level of care, choose to enroll in the waiver as an alternative to institutionalization, cost Medicaid no more in the community under the waiver than he or she would have cost Medicaid in an institution, and be financially eligible based on their income and assets.

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