

## **MEDICAID WAIVERS FOR FAMILIES WHO HAVE CHILDREN WITH DISABILITIES OR HIGH MEDICAL NEEDS**

### **WHAT IS MEDICAID?**

Medicaid is a program that is funded by state and federal dollars that allows people who are low-income and/or disabled to access medical care through various Medicaid providers.

### **WHAT IS SUPPLEMENTAL SECURITY INCOME (SSI)?**

SSI is a federally-funded program that provides funding to families of children with disabilities and people with disabilities to help cover the extra costs associated with having a disability. For a family of four with one child with a disability, a family may not make much more than about \$3,000.00 per month in gross income, or have assets over \$2,000.00 with some exclusions, such as a home or a car if it is used to take the child to medical appointments. When a person is eligible for SSI, they automatically become eligible for Medicaid.

### **WHAT IS A MEDICAID WAIVER?**

Medicaid waivers “waive” a family’s income so that their children may access medical care through Medicaid. Under the Medicaid waiver programs, the family’s income is not counted in determining eligibility; the child’s income is used. The child must not have an income over 300% of SSI benefits or assets of more than \$2,000.00. Both waivers are based on the child’s income, not the parent’s income, so they are income based and do need to have income (for the child) verified prior to enrollment or prior to entering the wait list. Only children who need a “level of care” that would “normally” be provided in a hospital, nursing home or institution will qualify. This is determined on a case-by-case basis, so if your child has a severe disability and requires a great deal of medical or behavioral care, you may want to apply. The State of Colorado currently has two Medicaid waiver programs for children who reside with their family. They are:

- The Children’s Home and Community-Based Services Waiver (HCBS)
- The Children’s Extensive Support Waiver (CES)

These waivers were created in response to a family who got the attention of President Reagan when they wanted to bring their medically-involved daughter, Katy Beckett, home from a lengthy stay in the hospital. Their parental income did not “count” while she was out of the home and in the hospital. Therefore, she received extensive medical care through SSI/Medicaid benefits while in the hospital. Upon entering her family home, which was a better place for her, as well as less costly than the hospital, she was going to lose all benefits. The family simply could not afford to keep her at home without Medicaid benefits. The Colorado program began with medically fragile children and expanded to include developmentally disabled or delayed children.

### **WHAT IS THE DIFFERENCE BETWEEN THE TWO MEDICAID WAIVERS?**

The two waivers have different rules as each waiver serves a specific population. The HCBS waiver has space available for 630 children. The HCBS waiver does not require a child to have a developmental disability or delay but does serve children with developmental disabilities or delays and medical conditions. Anyone who qualifies may be on this waiver if there are open slots available. In general, this waiver provides more appropriate services children who are more medically involved or have long-term medical needs rather than behavioral needs. The CES waiver is specifically targeted to children who have a developmental disability and a medical or behavioral condition that requires near 24 hour supervision. The CES waiver started in the summer of 1995 and has an enrollment cap of 152 children. There

is currently a waiting list for these two waivers. Both waivers have a statewide wait list (not one for each county). These waiting lists are currently 2-5 years long. We recommend that families apply for both waivers (if the child is not SSI eligible) at the same time as it may enable them to receive service faster through one or the other waiver. Children who would meet severe health consequences if they could not get immediately on a waiver, and have to stay in a hospital or other institutional setting, might be eligible for an expedited slot.

## **WHAT KIND OF MEDICAL CARE DO THESE WAIVERS COVER?**

These Medicaid waivers only allow children access to Medicaid. Medicaid covers a variety of “medically necessary” services such as doctor visits, dental visits, hospitalization surgery, therapy, nursing care and other medical services. However, there are only certain doctors and therapists who will accept Medicaid. It is very important to find out if what your child needs is a Medicaid provider. Your doctor or therapist may be willing to become a Medicaid provider, but they are not required to accept Medicaid as payment. You may have to change to a doctor and/or therapist who are a Medicaid-certified provider if your child gets on the waiver and you want Medicaid to pay for that service. It can be difficult to find Medicaid providers for nursing or therapy, and in-home therapies will only be paid for by Medicaid if the child is determined to be “medically homebound”.

The CES Waiver is a little different in that it provides the following services in addition to the regular state Medicaid plan benefits: personal assistance services, household modification services, specialized medical equipment and supplies, and professional/community connection services.

Medicaid is the secondary insurance. If the family has private insurance, it will cover co-pays and services which the primary insurance does not cover. This may include such things as diapers for children three years and older, specialized formula, therapies and durable medical equipment such as wheelchairs. Nursing care is one of the less clear services of the program. Generally, the Peer Review Organization (PRO) determines the level of care necessary, from a one-hour visit to 24-hour care, based on clearly defined needs. Many children may benefit from intermittent nursing care, which means a person coming in to perform a specific duty, such as feeding on a regular basis, but not remaining in the home continually.

For children birth to 21 years of age, an Early Periodic Screening Diagnosis and Treatment (EPSDT) screen should be completed after the child is eligible for Medicaid by the child’s doctor. This instrument will assist in documenting and providing access to the appropriate services, even if these services are not normally covered under the Colorado State Medicaid Plan. EPSDT overrides the state plan and may allow children to access more services and supports, based on the federal Medicaid plan, such as hearing aids and eyeglasses.

## **WHO QUALIFIES FOR MEDICAID WAIVER PROGRAMS?**

- Children who have disabilities or illnesses that could require care in a nursing home, hospital or institution.
- Children whose families make too much in income or have too much in assets to qualify for Medicaid in any other way. (If your family can qualify for SSI/Medicaid or regular Medicaid, they cannot access the waivers.) For the CES Waiver, this is not an issue.
- Children who make less than 300% of SSI in income, and have less than \$2,000.00 in assets.

—Children who can receive care at home or in the community safely, and whose cost of care is not more than it would cost to care for them in an institution.

### **HOW DO I APPLY FOR MEDICAID WAIVER PROGRAMS?**

**For the CES Waiver, contact your local Community Centered Board.** The process to get on the CES wait list is: Once a child has been determined to have a developmental disability (or developmental delay if younger than 5) through the Community Centered Board then the staff at the CCB can begin the application for CES. The CCB and family complete the ULTC 100.2, and the CES Application which is a 24 hour log. Once these two documents are completed they are submitted to Dual Diagnosis Management (DDM), Nashville, TN where they are reviewed by a nurse reviewer. If the child is found eligible DDM will notify the family, the CCB that the child is to go on the CES wait list with a wait list date equal to the date DDM received the application. When there is an opening in CES, then the child must have the SSI Disability Determination and financial eligibility determination before he/she can receive CES services.

### **For the CHCBS Waiver:**

First, call the Social Security Administration at 1-800-772-1213, 7:00 a.m. to 7:00 p.m., Monday through Friday, to apply for SSI/Medicaid and obtain a denial based on having too much in income or assets. You should be able to get this denial by giving them information over the telephone. If they say you are over-income for SSI, tell them you need a letter stating the reason for denial. Tell them you need an informal denial letter immediately. This toll-free number may be busy, so you may want to pick a time when you are doing something else and can just hit redial on your phone as many times as it takes to get through. Early in the morning or close to seven in the evening are also good times to get through. You may also go down to see them in person, but allow at least an hour. You may also be able to do this step on-line at [www.ssa.gov](http://www.ssa.gov).

After you get the denial letter from SSA, contact your county department of social services, Medicaid eligibility section. Tell them you would like to apply for the Children's HCBS Waiver as soon as possible and that you have the letter from SSA stating that your family is over-income for SSI. They will tell you what to do next. The CHCBS waiver requires the submission of the ULTC 100.2 to the state Medicaid office. If you have questions about this process you can contact Family Voices CO (1-800-881-8272)

### **SUMMARY:**

To get on the CES wait list;

1. Child is determined to have a developmental delay or disability buy the CCB;
2. The ULTC 100.2 and the CES application-24 hour log are submitted to DDM and approved or denied
3. Once DDM approves the 24 hour log the child is placed on the wait list based on the day the application was received.

To get on the CHCBS wait list;

1. The completed ULTC 100.2 is submitted to the State Medicaid office
2. The family completes the financial information through their local Department of Human Services office.
3. Once this is completed and the child meets financial eligibility the child is placed on the CHCBS wait list.