Questions and Answers on the Medicaid Program For Medically Fragile and Technology Dependent Children

We understand you have concerns regarding the restructuring of the program for medically fragile and technology dependent children. We will do our best to answer your questions, but some questions cannot be answered yet as we are still in the process of finalizing the program's restructuring. Please note that the state law and federal parameters under which the program will operate will not take effect until September 1, 2012.

Information is available on the fact sheet and in the question and answers below. The fact sheet can be found at HFS Budget Web site. As more details become final, we will post additional notifications on our Web site.

If you have additional questions, please e-mail them HFS.Director.MFTD@illinois.gov. We will compile these questions and post answers on our Web site to those questions to which we are able to respond. Please know that our staff will not be able to respond to verbal questions on the telephone. We ask for your patience and will make every effort to work with you in transitioning your child if your child will be affected by the restructuring.

Select the Frequently Asked Question to view answer.

1. **Why is this program changing?**
   The Medicaid program is on the brink of collapse. Changes were necessary to save the Medicaid program and these changes can be found in the SMART Act (Public Act 097-0689 pdf). One of the changes in the SMART Act was a modification to the program for medically fragile and technology dependent children, found on Pages 81 and 82. A copy of the SMART Act can be found on the HFS Budget Web site.
2. **Why do you call this a new program?**

   This is not a new program; rather, it is a restructuring of two existing programs.

   Currently, the state serves medically fragile and technology dependent children in two different ways: approximately 550 children are served by the Medically Fragile, Technology Dependent Waiver (“MFTD Waiver”) and there are approximately 500 other medically fragile and technology dependent children under Medicaid who receive in-home services but do not meet the institutional level of care to qualify for services under the MFTD Waiver. The restructured program will use a consistent assessment and care coordination to assist children and their families. The restructured program will also incorporate a philosophy of consumer/family direction and shared financial responsibility, meaning that families will also have more flexibility in accessing and using services.
3. **I would like a copy of the proposed State Plan Amendment.**

   The state has not submitted a draft State Plan Amendment at this time. The state has submitted a

waiver document, but this document is a draft and, therefore, not final. Draft documents are exempt from release under the Freedom of Information Act (5 ILCS 140/7). HFS will release these documents when they are finalized with the federal government. Please note that HFS had months of stakeholder input that we took into account when developing these documents (see #12).

4. **I would like to know the individual Medicaid costs for my client or child.**

   HFS would very much like to give you this. The total cost of Medicaid services is $187 million for both groups of medically fragile and technology dependent children. Individual cost data is protected by privacy laws. HFS wants to assure that these laws are followed when sharing protected health information. HFS will publicize the process to request this information on our Web site.

5. **How is the change of level of care to nursing facility in the waiver going to affect my child?**
   The change to nursing facility level of care in the waiver will not affect your child's eligibility for the program. Under a waiver, states are required to demonstrate cost-neutrality on an aggregate basis, not for each individual child. To establish the cost neutrality of the MFTD waiver, the costs of home and community-based services will be compared to the costs of nursing facility services for a population with similar needs as the MFTD population. Individual eligibility and the available services under the restructured MFTD program will be assessed individually, based on medical need, as described in #6 and #7 below.

6. **What is the Level of Care Tool for the restructured MFTD program?**

   The level of care tool will be the standardized assessment tool that determines eligibility and medical necessity for services available under the restructured MFTD program. The "level of care" in this context should not be confused with the level of care required by the federal government in waivers.

7. **How are the services changing?**

   Services provided through the program will continue to be based on medical necessity, which will be determined consistently through the level of care tool described above. In the context of this standardized assessment tool, "level of care" means the amounts and types of services necessary to meet the varied medical needs of individual children.

   Private duty nursing, the most widely used service by medically fragile and technology dependent children, including those children who currently use the MFTD Waiver, will continue to be available to all eligible children, when medically necessary, under the Early Periodic Screening, Diagnosis & Treatment (EPSDT) requirements.

   In fact, most of the medically necessary services to be provided by the restructured program will be available as a result of the State Plan and EPSDT requirements, not the MFTD Waiver. The only services remaining under the MFTD Waiver in its current draft form are home modifications, specialized medical equipment, nurse training, family training, placement maintenance counseling, and medically supervised

day care. The most used of these services are the Environmental Accessibility Adaptations (EAA) and Specialized Medical Equipment and Supplies (SMES). These services will continue as waiver services, with limits. The total cost for purchase of all EAA and SMES purchases, rental, and repairs may not exceed $25,000 over five years. Respite has been eliminated as a waiver service, as families will have more flexible use of nursing hours based on a monthly service allocation and creation of a flexible account that allows families to bank up to a week's worth of unused hours to be used for respite.

8. **What are my co-pays going to be?**

   The proposal is for families with income at or over 150% Federal Poverty Level to pay co-pays. The co-pays will be the maximum allowed by federal law, as required by the SMART Act. The amount of co-pay has not yet been finalized. Cost-sharing is an essential component in the SMART Act. With the Medicaid program on the brink of collapse, the legislature imposed co-pays for most, if not all, Medicaid services, to the extent permitted by law.

9. **Why was an income cap of 500% Federal Poverty Level imposed?**
   Because of the budget crisis, the legislature imposed income caps for this program. HFS estimates that 95% of families will continue to be eligible to receive services that are medically necessary. It is possible that there is legislative interest to raise this income cap, if additional revenues are identified. Due to the fiscal resources available to the state at this time, it is unlikely that this program will revert to a program for all families of all incomes.

10. **Will the proposed changes have a transition period for families who will not qualify? What is the transition plan?**
    Transition plans will be developed for children who no longer qualify. HFS will make every effort to work with families to make referrals to other programs and services for which your child may be eligible. If you receive a notification that your child is going to lose eligibility, you will also be informed of your right to request a fair hearing.

11. **Will the children currently in the waiver be eligible until their next renewal date, or are they going to be reevaluated on September 1, 2012?**
    Financial eligibility will be reviewed prior to September 1, 2012. However, a child's level of care eligibility will be determined at the time of the child's annual reassessment.

12. **How did the state include families in the decision-making process?**
    HFS engaged in meetings with families and other stakeholders, including doctors, therapists and other healthcare providers, for many months prior to and during the legislative session to brainstorm about ways to make this program more efficient and responsive to individual children and family needs. Many of the suggestions received by the department were incorporated into the proposed program redesign, including cost sharing, the flexibility to bank unused hours, and the use of paraprofessional staff to deliver care.