EXHIBIT "1"

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.

EXHIBIT "2"

FACT Sheet
Private Duty Nursing (PDN) Services for Children under Age 21

Program Overview:
Illinois Department of Healthcare and Family Services (HFS) Division of Medical Program provides services to children under age 21 who have been determined to have extensive medical needs, requiring ongoing skilled nursing in the home setting. Children must meet Medicaid eligibility and live in a private home. Children may be wards of the Department of Children and Family Services or served under the Adoption Assistance Program. Children receiving this PDN may not be concurrently served under the Medically Fragile, Technology Dependent (MFTD) Home and Community-Based Services (HCBS) waiver. Services are prior approved initially for 60 days with two 60-day renewal periods. After the first 180 days of service, cases are reviewed on 6-month or annual schedules depending on the medical stability of the child. Services are provided by approved Home Nursing Agencies licensed by the Department of Public Health.

Expenditures for State Fiscal Year 2010:
Medicaid Liability: $70,564,825
Number enrolled: 527
*Ave. cost pmpy**: $ 133,899
*Per Member Per Year

Eligibility Criteria:
- Children under the age of 21 who have extensive medical needs and require ongoing skilled nursing care as determined by the Department's prior approval process.
- U.S. Citizen or legal alien
- Be a resident of the State of Illinois
- Under age 21
- Eligible for the Medical Assistance Program
- Prior approved for services by the Department
- Physician order and justification for services

Services:
- **Skilled Nursing Services –** services are provided in a child's home by licensed nursing personnel (Registered Nurse or Licensed Practical Nurse) employed by an approved Home Nursing Agency. Services include initiation and implementation of restorative/palliative nursing procedures, coordination of plan of care and patient/family instruction.
- **Home Health Aide Services** – services are provided in a child's home by certified nurses' aides. Services include providing or assisting with personal care, bathing, mobility/transfers, and other Activities of Daily Living (ADLs).

Services Setting:
- Individual homes

How to Access Services:
Point of Entry –Physicians, hospital social workers or enrolled Home Nursing agencies may contact HFS at 877-782-5565.

EXHIBIT "3"

FACT SHEET

Medically Fragile, Technology Dependent
Home and Community-Based Services (HCBS) Waiver for children under age 21

Program Overview:

This program helps families care for children (birth up to age 21) who are medically fragile and technology dependent. The program offers care coordination and services to support the family by providing care for their child at home. In-home nursing services are available based on the medical needs of the child or youth. The Division of Specialized Care for Children (DSCC) manages the day to day operations of this program on behalf of the administering agency, Illinois Department of Healthcare and Family Services (HFS). The services are offered through a federal 1915(c) HCBS waiver. A waiver is a federally approved program that allows states the flexibility to design and cover services that may not otherwise be available under the state's Medical Programs to defined disability groups. The services must be designed to assist individuals to remain in their own home or live in a community setting rather than in an institution, such as a nursing facility or hospital. The cost of the services must be cost neutral to the state. The program is similar to the "Katie Beckett" waiver in other states, but this waiver is unique to Illinois.

Expenditures for State Fiscal Year 2010:
Medicaid Liability: $117,066,489
Number enrolled: 622
*Ave. cost pmpy**: $ 188,210
*Per Member Per Year

Eligibility Criteria:

- Children or youth ages birth to 21 years that meet the medical criteria, as determined by their health condition and technology needs, as evaluated by professionals(a minimum score of 50 on level of care screening assessment). The Department's eligibility criteria can be found under 89 Ill. Admin. Code 120.530.
- The family is willing and able to care for the child in their home to the fullest extent possible.
- The family is able to safely care for the child in the family's home.
- A determination is made that without the in-home support services provided through the waiver program, the child would be at risk to be in an institutionalization in a skilled nursing facility or a hospital.
- The estimated cost of the in-home support services is not greater than the cost of the institutional level of care appropriate to the child's medical need.
- Parental income is not considered, but the child's income is considered in the financial income requirements.

Services:

- All Medical services available under the Illinois Medicaid program such as hospitalizations, doctor visits, and medications are covered, unless the services are covered by the child's insurance.

- Services include shift nursing care in the home, provided by registered nurses, licensed practical nurses and certified nurse's aide from an approved nursing agency. The number of hours provided per week is determined by the assessment of the child's medical and nursing care needs.
- Medical equipment and supplies prescribed by the child's physician.
- Minor home modifications needed to provide access, accommodate needed medical equipment, or to assure the child's safe access and safety in the home.
- Family training that includes instruction about treatments and use of equipment as well as Cardiopulmonary Resuscitation (CPR).
- Respite (nursing) care in the child's home or in a designated community-setting to periodically relieve the family of care-giving responsibilities.
- Medically supervised day care offering technological support and nursing care provided in a licensed medical day care setting. (Currently there are no licensed providers in Illinois.)
- Placement maintenance counseling providing short-term, issue-specific family or individual counseling for the purpose of maintaining the child in the home placement.
- Nurse training to provide child specific training for the in-home nurses in the use of new or unique equipment or special needs of the child.

Services Setting:

- Individual homes
- Licensed Children's Community-Based Health Care Center
- Medically Supervised Day Care

How to Access Services:

Point of Entry – University of Illinois at Chicago, Division of Specialized Care for Children (DSCC) 13 Regional Offices or contact DSCC at 1-800-322-3722.

Additional information on this program can be found at http://www.uic.edu/hsc/dscc/ which includes:

- Application forms (print & mail)
- DSCC Regional Office locator (Zip code – maps)
- More information on the home care program

Medicaid Link and program information: **http://www.hfs.illinois.gov/hcbswaivers/tdmfc.html**

Maximum Waiver Capacity:

700

Unduplicated Waiver Recipients:

As of May 1, 2011, 565 children have been served in waiver year beginning 9/1/10 and ending 8/31/11. Of this number 498 are currently active.

Initial Approval Date:

July 1, 1985 Renewed: 09/01/2007–08/31/2012

EXHIBIT “4”

ILLINOIS DEPARTMENT OF HEALTHCARE AND FAMILY SERVICES

ANNUAL REPORT

MEDICAL ASSISTANCE PROGRAM

Fiscal Years 2008, 2009 and 2010

Submitted April 1, 2011

Illinois does not have a cap on the number of nursing hours. With an institutional alternative federally required to show the cost benefit (or at least neutrality) of the waiver services, the medical service limits for most children under the MFTD waiver are compared to *pediatric* hospitals — or up to approximately $55,000 per month in the Chicago area. It is not an entitlement for the participant to receive that level of services. Nursing is provided as an EPSDT service. Illinois uses almost exclusively RNs and LPNs for nursing services under the waiver. Illinois appears to be one of the most generous states in providing nursing services to children in the MFTD waiver.

Iowa uses an interdisciplinary team process to determine Level of Care (LOC) through the state's QIO and state staff determine budgets. The maximum thresholds that may be authorized are up to $904/month for individuals meeting a nursing facility LOC, up to $2,631/month for individuals meeting a skilled nursing facility LOC, and up to $3,203/month for individuals meeting an ICF/MR LOC. The waiver includes a wide range of supports including consumer directed personal attendant services and additional case management for children needing 12 hours or more of supervision per day. Nursing is provided as an EPSDT service, as a waiver service and as a state plan service.

Maryland operates a model waiver limited to serving 200 individuals. Children are compared to hospital LOC because Maryland does not have pediatric nursing facilities. The state's QIO conducts the eligibility assessment and state staff set the budget. Maryland hires a nonprofit agency to conduct case management. A state RN meets weekly with the case management agency to review participants. Nursing is provided as a medically necessary service under EPSDT, as a waiver service and as a state plan service.

Minnesota, another county based state, utilizes county agencies to conduct eligibility and set budgets. Minnesota is in the process of adopting a new universal comprehensive assessment system to all long-term care services including waivers, institutional care and state programs. The state allocates an aggregate budget to the counties and counties authorize services within the global budget and provide care coordination. The service package is quite broad and includes consumer directed services that allow consumers considerable flexibility either to choose traditional services or to purchase alternatives to traditional services or a combination of both. Minnesota assigns parental payment fee schedules based on parental income. Many nursing functions can be delegated to individuals who are not nurses through specific requirements that outline training and oversight. Minnesota allows payment to parents of minors for up to forty hours per week for personal support services which could be a step toward less dependence on skilled nursing. Minnesota was the first state to obtain this authority under its 1915c) waivers. Nursing is provided as a state plan service, with additional hours provided through the waiver.

Oregon uses state employed nurses determine eligibility and budgets. Oregon links level of services via a tool similar to Illinois' LOC tool, using a numeric scale to identify the medical technology needs of the child. A minimum score of 50 is required for waiver eligibility. These levels are also used to serve Medicaid eligible children under EPSDT that are not eligible for the waiver. Oregon was the only state found to use a numeric system and other clinical criteria in determining the monthly service budgets. These were broken down into six service cost maximum levels of care defined by rule. Level I is the highest and Level VI is the lowest. For example, Level I (up to $19,800/month) requires the individual to be ventilator-dependent 24 hours a day for the maximum budget; have a score on the clinical criteria of 75 or greater and require continuous observation. On the

Appendix B - Overview of HCBS Waiver Programs

A description of the Department's nine HCBS waivers is provided below.

Medically Fragile, Technology Dependent (MFTD) Children Waiver

The MFTD waiver for children serves persons, less than 21 years of age, allowing them to remain in their homes rather than being placed in institutional care. Parental income is waived (or not considered) when determining financial eligibility for Medicaid. Cost-effectiveness for eligibility is also compared to service costs in a hospital or a nursing facility. The waiver was initially approved in 1985 for 50 children and is currently approved for the period of September 1, 2007, through August 31, 2012, with a capacity of up to 700 children. During federal fiscal year 2010, 627 unduplicated children, were served under the waiver.

The primary expenditure under the MFTD waiver is for skilled nursing, which is available as a non-waiver service since the children served by the waiver are afforded the same extent of medical coverage provided to children receiving medical assistance. Services available only under the waiver include respite, environmental modifications, nurse training, family training, placement maintenance counseling, and special medical equipment and supplies not covered by the Medicaid program.

The Department maintains the administrative oversight of the waiver program, and the University of Illinois, Division of Specialized Care for Children (DSCC) is responsible for the day-to-day operations. Funding for the waiver is appropriated to the Department which determines waiver eligibility and approves the plans of care prior to the children receiving services. DSCC provides case coordination, processes claims for nursing payments, conducts utilization review, and monitors delivery of the waiver services. Medical eligibility for the waiver is determined by an objective Level of Care screening tool, implemented in March of 2009. To be eligible for the MFTD waiver, the child must have 50 points on the tool. Scoring is based on medical fragility and medical technology. The Department continues to work on a comprehensive assessment and rule changes related to the assessment.

Adults with Developmental Disabilities Waiver

This HCBS waiver serves individuals with developmental disabilities who are 18 years of age or older. The waiver allows participants to receive services and remain in their homes or home-like community residential settings rather than being placed in an ICF/DD. The Department of Human Services, Division of Developmental Disabilities (DHS-DDD) is the operating agency for this waiver. The waiver for adults with developmental disabilities was initially approved in 1983. In July 1999, CMS approved a replacement waiver. The waiver was renewed effective July 1, 2007 through June 30, 2012.

In fiscal year 2010, federal CMS approved the Department's request to amend the waiver to increase the capacity from 15,225 to 15,920, effective July 1, 2009. At the end of 2010, the Department received an announcement from federal CMS regarding the start of the CMS Management Review of the waiver. For this review, CMS requests that the State submit an evidentiary report showing compliance with the six federal assurances. CMS then uses this report to determine compliance and recommend improvements for the upcoming renewal. Many times CMS recommends technical assistance. During federal fiscal year 2010, 15,040 individuals received services under the waiver.

EXHIBIT "5"

Application for a §1915(c) Home and Community-Based Services Waiver

PURPOSE OF THE HCBS WAIVER PROGRAM

The Medicaid Home and Community-Based Services (HCBS) waiver program is authorized in §1915(c) of the Social Security Act. The program permits a State to furnish an array of home and community-based services that assist Medicaid beneficiaries to live in the community and avoid institutionalization. The State has broad discretion to design its waiver program to address the needs of the waiver's target population. Waiver services complement and/or supplement the services that are available to participants through the Medicaid State plan and other federal, state and local public programs as well as the supports that families and communities provide.

The Centers for Medicare & Medicaid Services (CMS) recognizes that the design and operational features of a waiver program will vary depending on the specific needs of the target population, the resources available to the State, service delivery system structure, State goals and objectives, and other factors. A State has the latitude to design a waiver program that is cost-effective and employs a variety of service delivery approaches, including participant direction of services.

Request for a Renewal to a §1915(c) Home and Community-Based Services Waiver

1. Major Changes

Describe any significant changes to the approved waiver that are being made in this renewal application:

Two significant changes have been made in the waiver renewal:

1) Institutional Cost Comparison: The Department of Healthcare and Family Services (HFS) is removing the ICF/MR institutional level of care as a cost comparison for this waiver. Illinois has studied options for cost comparison including skilled nursing facilities and exceptional care, rehabilitation, ventilator, children's and general hospitals. A blend of hospital and skilled nursing facilities has been selected as the cost comparison for the waiver renewal. Historically, Illinois has used a combined cost comparison of an ICF/MR skilled nursing facility for pediatrics (SNF/Ped) and hospital level of care. In recent discussions with CMS, we learned that the ICF/MR cost comparison cannot be combined with hospitals for persons with disabilities with the exception of waivers for individuals with brain injury.

2) Objective Assessment Tool for Waiver Eligibility: HFS has developed, is testing and plans to implement an objective level of care instrument to determine waiver admissions and continued eligibility by September 2007. Historically, HFS has based medical eligibility determinations on medical information, physician recommendations, and clinical information.

Application for a §1915(c) Home and Community-Based Services Waiver

1. Request Information (1 of 3)

A. The **State of Illinois** requests approval for a Medicaid home and community-based services (HCBS) waiver under the authority of §1915(c) of the Social Security Act (the Act).

B. **Program Title** (*optional - this title will be used to locate this waiver in the finder*):

HCBS Waiver for Children that are Medically Fragile, Technology Dependent

C. **Type of Request: renewal**

Migration Waiver - this is an existing approved waiver

Renewal of Waiver:

Provide the information about the original waiver being renewed

submitted or previously approved:

Specify the §1915(b) authorities under which this program operates *(check each that applies):*

§1915(b)(1) (mandated enrollment to managed care)

§1915(b)(2) (central broker)

§1915(b)(3) (employ cost savings to furnish additional services)

§1915(b)(4) (selective contracting/limit number of providers)

A program authorized under §1115 of the Act.

Specify the program:

2. Brief Waiver Description

Brief Waiver Description. *In one page or less*, briefly describe the purpose of the waiver, including its goals, objectives, organizational structure (e.g., the roles of state, local and other entities), and service delivery methods.

The Illinois home and community-based services (HCBS) waiver for children who are medically fragile, technology dependent (MFTD) was created to allow eligible children to remain in their own homes rather than in an institutional setting. The waiver is administered through the Medicaid agency with day to day operations and case management provided by the University of Illinois, Division of Specialized Care for Children at Chicago (DSCC).

DSCC is the Title V CSHCN (Children with Special Health Care Needs) agency for Illinois providing care coordination for families and children with special health care needs. DSCC's experience with children with special health care needs dates back to 1937. DSCC's Home Care program was established in 1985 when the MFTD waiver was initially approved. Services are coordinated by a network of professional staff located in 13 regional offices throughout the state.

Under the HCBS waiver's Home Care Program (HCP), DSCC offers coordination and support for in-home medical care. Nursing is the primary service received by waiver participants, although it is not a waiver service. Waiver services include: respite, specialized medical equipment and supplies, environmental modifications, family training, nurse training, placement maintenance counseling, and medically supervised day care. The child's resources are considered, but parental income is not counted for Medicaid financial eligibility.

DSCC accepts referrals for the development of applications for waiver services. This includes assessing the home and gathering information necessary to prepare a comprehensive individual waiver application and Medical Plan of Care (MPC), including cost comparison with the appropriate institutional setting which demonstrates the cost benefits of home care. DSCC submits the application to HFS on behalf of the child and family. HFS determines the medical eligibility for the waiver, approves the MPC and all redeterminations. DSCC maintains daily contact with HFS regarding changes in each waiver participant's medical condition or other situations that may impact the waiver participant's MPC.

DSCC provides utilization review, care coordination and conducts ongoing quality assurance activities of nursing agency and home medical equipment providers. DSCC utilizes a variety of reports to track timeliness of processing applications and redeterminations, service needs, utilization of services and unusual incidents. DSCC meets quarterly with HFS to discuss quality assurance reports, incidents, abuse, neglect and other policy issues. The waiver program is small, serving approximately 530 children. It is operated with intensive case management and collaborative, on-going communications between DSCC and HFS.

3. Components of the Waiver Request

The waiver application consists of the following components. *Note: Item 3-E must be completed.*

A. **Waiver Administration and Operation. Appendix A** specifies the administrative and operational structure of this waiver.

B. **Participant Access and Eligibility. Appendix B** specifies the target group(s) of individuals who are served in this waiver, the number of participants that the State expects to serve during each year that the waiver is in effect, applicable Medicaid eligibility and post-eligibility (if applicable) requirements, and procedures for the evaluation and