

# **Report of Medicaid Services for Persons who are Medically Fragile, Technology Dependent**

**Presented Pursuant To  
*Public Act 095-0622***



**Illinois Department of HealthCare and Family Services**

**Pat Quinn, Governor  
Julie Hamos, Director**

**January 2014**

201 South Grand Avenue East  
Springfield, Illinois 62763-0002

Telephone: (217) 782-1200  
TTY: (800) 526-5812

December 31, 2013

Governor Quinn and Honorable Members of the General Assembly:

I am pleased to present this report, in compliance with *Public Act 095-0622*, regarding existing services offered under the Illinois Public Aid Code to persons who are medically fragile, technology dependent. This report provides detailed information on the home and community-based services waiver for children who are medically fragile, technology dependent, including numbers served, expenditures, utilization of waiver and non-waiver services, and the number of children who have aged out of the waiver since July 1, 2011.

The report is a bi-annual report and was prepared in collaboration with the University of Illinois at Chicago, Division of Specialized Care for Children. I will take this opportunity to express my appreciation for their support.

Sincerely,



Julie Hamos  
Director

# TABLE OF CONTENTS

<b>TABLE OF CONTENTS</b> .....	i
<b>INTRODUCTION</b> .....	1
<b>STATUS OF SERVICES UNDER THE <i>PUBLIC AID CODE</i></b> .....	2
Table 1. Basic Medicaid Services Provided to Medically Fragile, Technology Dependent Waiver Children.....	4
Table 2. Waiver Services Provided to Medically Fragile, Technology Dependent Waiver Children.....	4
Table 3. Basic Medicaid Services Expenditures by Cost Comparison Group.....	5
Table 4. Basic Medicaid Services Detailed Expenditures.....	6
Table 5. Comparative Costs – Institutions .....	7
<b>GLOSSARY</b> .....	10
<b>INDEX OF WEB LINKS</b> .....	11
<b>Appendix I Background on Home and Community Based Services Waivers and Medicaid programs and services</b> .....	12

**Report of Medicaid Services for Persons who are  
Medically Fragile, Technology Dependent  
*Public Act 95-0622***

**January 2014**

**INTRODUCTION**

On September 17, 2007, [\*Public Act 95-0622\*](#) was enacted and amended the Illinois Public Aid Code (305 ILCS 5/5-2.05) in provisions concerning services for children under Medicaid. The Act requires the Department of Healthcare and Family Services to make a bi-annual report on even numbered years beginning January 1, 2008. This report outlines Medicaid services offered to children and young adults with disabilities who are medically fragile, technology dependent.

The Act also created reporting requirements under the Department of Human Services Act (20 ILCS 1305/10/55 new) for the Department of Human Services (DHS) to report on the extent to which children with developmental disabilities, mental illness, severe emotional disorders, or more than one of these disabilities who are currently served in institutions could be served in the community or home-based settings for the same or lower cost. The DHS report is also bi-annual and is required on even numbered years beginning March 1, 2008.

Finally, the Act amended the Illinois Public Aid Code (305 ILCS 5/12-4.36) extending the assessment pilot established in Public Act 94-0838 from three to four years; with an annual report requirement in January of each year starting in 2008 with the last report due in January 2011. This Act has been superseded by the reporting requirements of Public Act 95-0622.

This report is being submitted to satisfy the requirements of Public Act 95-0622 related to services for children and young adults with disabilities who are medically fragile, technology dependent in accordance with (305 ILCS 5/5 – 2.05).

## STATUS OF SERVICES UNDER THE *PUBLIC AID CODE*

The *Illinois Public Aid Code* authorizes a home and community based services waiver program for children. Section 5/5-2b of the Public Aid Code provides that medical assistance shall be available to children who qualify as persons with a disability, as defined under the federal Supplemental Security Income program and who are medically fragile and technology dependent. The program allows eligible children to receive medical assistance under Article V of the Public Aid Code in the community and must maximize, to the fullest extent permissible under federal law, federal reimbursement and family-cost sharing.<sup>1</sup> The waiver program for children and young adults who are medically fragile, technology dependent (MFTD) is the only Illinois waiver that operates under this provision.

In compliance with *Public Act 095-0622*,<sup>2</sup> this report includes the following information concerning the MFTD waiver program:

1. The number of persons who currently receive these services.
2. The nature, scope and cost of services.
3. The comparative cost of providing those services in a hospital, skilled nursing facility, or intermediate care facility.
4. The funding source for the provision of services, including federal financial participation.
5. The qualifications, skills, and availability of caregivers for children receiving services.
6. The number of children who have aged out of the services offered under paragraph 7 of the section 5-2 and 5/5-2b during the two years preceding the report (since July 2011).

State fiscal year 2012, data have been used except where otherwise stated. Additionally, hospital and nursing facilities are being used as the cost comparison population. The HCBS waiver was renewed effective September 1, 2007. At that time, the comparable population for cost comparison was changed from hospital and Intermediate Care Facility for the Developmentally Disabled (ICF/DD)-Skilled Nursing Facility for Pediatrics (SNF/Ped) to hospital and nursing facility. The department 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 was ultimately selected as the cost comparison. The waiver is currently operating under an extension and continues to use the same cost comparison group.

---

<sup>1</sup> Effective June 14, 2013, Public Act 97-689 amended the Public Aid Code by deleting 305 ILCS 5/5-2(7) and adding 305 ILCS 5/5-2b. Public Act 98-104 subsequently amended 305 ILCS 5/5-2b effective July 22, 2013.

<sup>2</sup> To the extent Public Act 095-0622 requires this report on services offered under paragraph 7 of 305 ILCS 5/5-2, which was deleted effective June 14, 2012, this report contains information responsive under 5/5-2(7) and 5/5-2b.

## **1. Number of Persons Who Currently Receive Waiver Services.**

As of September 1, 2013, 553 children were eligible to receive services in the MFTD waiver. This number is lower than the 630 referenced in the report's services and expenditure charts, because it is based on a point in time. The 630 figure is based on the total number of unduplicated children served in the waiver from July 1, 2011 through June 30, 2012. This is the most recent year of complete claims data. The State may submit claims for federal match up to two years after the date of payment.

## **2. Nature, Scope, and Cost of Waiver Services.**

Home and community based waiver services are services not otherwise covered under the Medicaid program. Title 1915c allows the State to waive certain requirements in order to provide specialized services, other than room and board to individuals who would otherwise require an institutional level of care. Waivers allow states to cover a wide-range of services to a targeted population as long as services are needed to keep a person from being institutionalized.

Under federal law, all medically necessary services described in Section 1905(a) of the *Social Security Act* must be provided to children. This includes a wide range of preventive and therapeutic services.

Tables one through five provide detailed information regarding waiver and non-waiver services and expenditures.



Nursing services, hospital care, prescription drugs and durable medical equipment and supplies are services most frequently used by children in the MFTD waiver. These services are regular State Plan Medicaid services available to waiver participants, and do not require the child to be in a waiver. Utilization and expenditures for waiver participants are shown in Table 1 below.

<b>Table 1. Basic Medicaid Services Provided to MFTD Waiver Children</b>			
<b>State Fiscal Year 2012</b>			
<b>Total Waiver Children: 630</b>			
<b>Basic Medicaid Service</b>	<b>Unduplicated Participants Receiving Services</b>	<b>Total Expenditures of Service</b>	<b>Average Per Capita Per User of Service</b>
Nursing	573	\$61,110,510.56	\$106,650
Inpatient Hospital	227	\$22,047,776	\$97,127
Prescription Drugs	575	\$6,324,119	\$10,998
Medical Supplies	548	\$4,629,957	\$8,449
Medical Equipment	455	\$3,297,471	\$7,247

Services available only under the waiver include respite care, environmental modifications, and a few other services unique to this waiver population. Waiver service costs are significantly less than Medicaid covered non-waiver service costs. Of the 630 waiver participants, 504 received waiver services. The other 126 participants received case management through the waiver and nursing and other medical services through the State Plan. Table 2 shows the utilization and expenditures for waiver services in FY 2012.

<b>Table 2. MFTD Waiver Services</b>			
<b>State Fiscal Year 2012</b>			
<b>Total Children: 630</b>			
<b>Basic Medicaid Service</b>	<b>Unduplicated Participants Receiving Service</b>	<b>Total Expenditures of Service</b>	<b>Average Per Capita Per User of Service</b>
Respite Care	448	\$2,113,081	\$4,716.70
Environmental Modification	219	\$370,322	\$1,690.97
Special Equipment*	0	\$0.00	\$0.00
Nurse Training	0	\$0.00	\$0.00
Placement Counseling	1	\$600	\$600.00
Family Training	0	\$0.00	\$0.00
Medically Supervised Day Care	0	\$0.00	\$0.00

\* In general, Medicaid covers medical equipment and supplies. This service is included in the waiver for situations where children may need special equipment not otherwise covered by the Medicaid program.

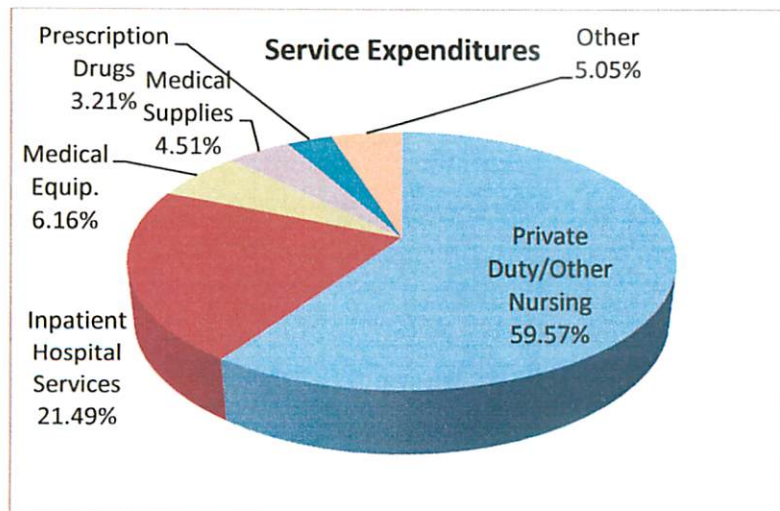
Children enrolled under the MFTD waiver also receive other covered Medicaid services. In Table 3, non-waiver (basic Medicaid) costs of children are shown by cost comparison group; either hospital level of care or nursing facility level of care. Of the 630 waiver participants, 604 received other covered Medicaid services.

Table 3 includes breakdowns of unique users, total costs, and the average cost per child of other Medicaid covered services:

<b>Table 3. Basic Medicaid Services Expenditures by Cost Comparison Group</b>			
<b>State Fiscal Year 2012</b>			
<b>Total Waiver Children: 630</b>			
<b>Level of Care Cost Comparison</b>	<b>Number of Participants</b>	<b>Total Expenditures</b>	<b>Average Per Capita</b>
Hospital	617	\$90,157,265.76	\$146,122
Nursing Facility	13	\$720,170.67	\$55,398

Table 4 details the five largest categories of non-waiver (basic Medicaid) services and all other expenditures by cost and percent of total costs for children enrolled in the MFTD waiver. These categories are: Private Duty Nursing and other Nursing Services, Inpatient Hospital Services, Prescription Drugs, Medical Supplies, and Medical Equipment.

**Table 4. MFTD Basic Medicaid Services Detailed Expenditures**  
**State Fiscal Year 2012**  
**Total Children: 630**





**Table 4. MFTD Basic Medicaid Services Detailed Expenditures (Continued)**  
**State Fiscal Year 2012**  
**Total Children: 630**

<b>Service Breakdown</b>	<b>Total Cost</b>	<b>Percent%</b>
Nursing Services	\$61,110,511	59.57%
Inpatient Hospital Services	\$22,047,776	21.49%
Prescription Drugs	\$6,324,119	6.16%
Medical Supplies	\$4,629,957	4.51%
Medical Equipment/Prosthetic Devices	\$3,297,471	3.21%
All Other Total*	\$5,175,739	5.05%
<b>Total Expenditures</b>	<b>\$102,585,573</b>	<b>100.0%</b>
<b>Breakdown of All Other</b>	\$2,031,903	1.98%
<i>Physician Services</i>		
<i>Therapies (Physical, occupational &amp; speech; includes EI therapies)</i>	\$767,258	0.75%
<i>Home Health Services</i>	\$671,545	0.65%
<i>Outpatient Services</i>	\$577,067	0.56%
<i>Early Intervention Services (Excludes therapies)</i>	\$211,717	0.21%
<i>All Other Medical Services (Lab, x-ray, optical, dental, audiology, podiatry, healthy kids services, mental health, transportation, &amp; others)</i>	\$916,249	0.89%

**Note: The School-Based Health Services expenditures totaling \$1,738,383.06 are included in the nursing, therapies and all other medical service categories identified above.**

**3. Comparative Cost of Providing Those Services in a Hospital, Skilled Nursing Facility, or Intermediate Care Facility.**

In waiver year 2012 hospital and skilled nursing facilities were used as the cost comparison groups. The following table shows the institutional costs for the comparable population. These costs cover both institutional costs and Medicaid ancillary costs for services provided while in the institution, but not covered in the hospital or nursing facility rate.

Level of Care	Average Per Capita Cost
Hospital Comparison Group	\$204,992
Nursing Facility Comparison Group	\$113,814

**4. Funding Sources for the Provision of Services, Including Federal Financial Participation.**

Funding for MFTD waiver services is appropriated to HFS from the General Revenue Fund. Claim expenditures are then submitted to the federal government for federal financial participation. Through an interagency agreement, DSCC has authority to pay home health and nursing agency providers for nursing and waiver services out of the HFS appropriation. Other medical services for children enrolled in the waiver are paid directly by HFS from its appropriations for hospital, physician, home health, and other services, respectively. During the reporting period of July 1, 2011 through June 30, 2013, the state received a federal matching rate of 50.00%.

## **5. Qualifications, Skills and Availability of Caregivers for Children Receiving Services.**

### **Home Health Agencies**

Illinois has an enrollment of 355 home health agencies, but only a specialized group of nursing agencies serves the technology-dependent pediatric population with shift nursing care. There are 34 home health agencies or private duty nursing agencies. There are also two alternative child care models enrolled with HFS and approved by DSCC to provide respite services in the waiver program. These are licensed as community-based health care centers.

DSCC has specific guidelines for approving providers of private duty nursing services under the waiver. Once approved, and annually thereafter, agencies sign an agreement with DSCC to comply with the requirements of the program. These include qualifications, experience and training for administrative and nursing staff.

Appropriately qualified staff—registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs), who are licensed or certified in Illinois, provide respite care services for children in the MFTD HCBS waiver. The same qualifications apply to the State Plan private duty nursing services. Nurses and CNAs must be employed by a DSCC approved nursing agency, except those providing services in a children's community-based health center who are employed directly by the health center.

Agencies providing home-based services must constantly compete with recruitment strategies and wages offered by institutions and the general shortage of available nurses. Due to the changes in the economy, however, more nurses are reentering the workforce or not retiring. DSCC has noticed this shift and has reported that they have been able to staff cases in all areas of the state. There are also no children waiting for discharge from a hospital due to lack of nursing.

### **Medically Supervised Day Care**

Medically supervised day care provides skilled nursing care in a daycare setting as an alternative to in-home nursing care. There is no medically supervised day care provider currently certified in Illinois. However, *Public Act 93-0402* amended the *Alternative Health Care Delivery Act* to include medical day care as a service that may be provided in a children's community-based health center licensed under that act by the Department of Public Health. DCFS certifies medical day care.

### **Environmental Modifications and Specialized Medical Equipment and Supplies**

Providers of waiver services, such as environmental modifications and specialized medical equipment and supplies, are subject to applicable licensure requirements or qualifications and appropriate experience. Environmental modifications and specialized medical equipment and supplies must be prior approved by HFS. In addition to HFS enrollment requirements, DSCC approves home medical equipment and infusion providers serving children approved for waiver services and requires annual signed agreements. The Department of Financial and Professional Regulation must also license home medical equipment providers. There are 1340 home medical equipment providers enrolled in the Medical Assistance Program. Of that number, 79 meet the additional DSCC requirements for serving waiver children.

### **Placement Maintenance Counseling**

This service provides short-term, issue-specific family counseling or individual counseling for the purpose of maintaining the child in the home. Placement maintenance counseling is provided by a licensed social worker, licensed clinical psychologist, or an agency certified by DHS Division of Mental Health (DMH) or DCFS to provide clinical or rehabilitation services. To receive payment for covered services, all medical providers must be enrolled with HFS.

<p><b>6. Number of Children who Aged Out of Services Offered under Paragraph 7 of the Section 5-2 and 5/5-2b During the Two Years Preceding the Report.</b></p>
---

For the period of July 1, 2011 through present, 19 individuals aged out of the waiver. This means that the child has reached his or her 21<sup>st</sup> birthday.

## **GLOSSARY**

<b>CMS</b>	<b>Centers for Medicare and Medicaid Services</b>
<b>CNA</b>	<b>Certified Nurse Aide</b>
<b>DCFS</b>	<b>Department of Children and Family Services</b>
<b>DHHS</b>	<b>Department of Health and Human Services</b>
<b>DHS</b>	<b>Department of Human Services</b>
<b>DRS</b>	<b>Division of Rehabilitation Services, within DHS</b>
<b>DSCC</b>	<b>Division of Specialized Care for Children</b>
<b>FY</b>	<b>Fiscal Year</b>
<b>HCBS</b>	<b>Home and Community-Based Services</b>
<b>HFS</b>	<b>Department of Healthcare and Family Services</b>
<b>HIV/AIDS</b>	<b>Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome</b>
<b>ICF/MR</b>	<b>Intermediate Care Facilities for Persons with Mental Retardation</b>
<b>ILCS</b>	<b>Illinois Compiled Statutes</b>
<b>LPN</b>	<b>Licensed Practical Nurse</b>
<b>MFTD</b>	<b>Medically Fragile, Technology Dependent</b>
<b>RN</b>	<b>Registered Nurse</b>
<b>SLP</b>	<b>Supportive Living Program</b>
<b>SNF/PED</b>	<b>Skilled Nursing Facility for under 22 Years of Age</b>



## INDEX OF WEB LINKS

The following provides a list of links referenced in the report:

*Public Act 95-0622*

<http://www.ilga.gov/legislation/publicacts/fulltext.asp?name=095-0622>

Section 1915(c) of the Social Security Act

[http://www.ssa.gov/OP\\_Home/ssact/title19/1915.htm](http://www.ssa.gov/OP_Home/ssact/title19/1915.htm)

Sections 1905(a) and 1905(r) of the Social Security Act

[http://www.ssa.gov/OP\\_Home/ssact/title19/1905.htm](http://www.ssa.gov/OP_Home/ssact/title19/1905.htm)

Illinois HCBS waivers homepage including links to each operating agency

<http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Pages/default.aspx>

Children with Developmental Disabilities Waivers (DD)

<http://www.dhs.state.il.us/page.aspx?item=32253>

## Appendix I

### BACKGROUND

#### Medicaid Home & Community-Based Services Waivers

Medicaid is the federal program authorized under Title XIX of the *Social Security Act* to reimburse states for providing health benefits to low-income persons. The federal law sets out requirements and limitations that states must follow in operating their programs.

Title XIX limits the kinds of services that states may provide. Generally speaking, eligible services must be of a medical or rehabilitative nature. Certain services needed to allow a child with disabilities to remain at home, for example, environmental modifications, habilitation services, and respite care, are restricted by Title XIX.

The Secretary of (the U.S. Department of) Health and Human Services (DHHS) is authorized to waive certain Title XIX requirements to enable states to receive reimbursement for home and community-based services. Such waivers are generally granted under the authority of [Section 1915\(c\) of the Social Security Act](#) and are referred to as HCBS waivers. Illinois has been granted a total of nine HCBS waivers.

HCBS waivers permit states to provide home and community-based services other than room and board to individuals who would otherwise require an institutional level of care. Essentially, these waivers allow states to cover a wide range of additional services as long as the services are required to keep a person from being institutionalized.

A state may receive federal Medicaid funds only for persons who are eligible for Medicaid. Such persons must meet Medicaid's financial eligibility requirements (income and assets) and non-financial eligibility factors (fit into an eligible group: children, parents, seniors, persons with disabilities; live in Illinois; be a U.S. citizen or a qualified legal alien, for example). Under HCBS waivers, states may choose not to count parents' income and assets when determining whether a child is eligible. Anyone who qualifies for a waiver is also eligible for all other Medicaid services provided by the state. Here in Illinois, the state has chosen to exempt parental income in the HCBS waivers that are targeted toward children only. These include the MFTD children's waiver and the two HCBS waivers for children with developmental disabilities that were implemented July 1, 2007. These programs are known as the Support Waiver for Children with Developmental Disabilities and the Residential Waiver for Children with Developmental Disabilities. <http://www.dhs.state.il.us/page.aspx?item=32253>

The HCBS waivers also allow states flexibility in developing alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities, or intermediate care facilities for persons with mental retardation (ICFs/MR). HCBS waivers allow states flexibility to select a mix of services that best serves the population of individuals covered. HCBS waivers may be limited to persons having a particular disability or who are of a certain age. The waiver program does not have to operate statewide.

The number of participants in an HCBS waiver program may be capped, although once a participant is enrolled, the participant is entitled to all medically necessary services made available to any other participant under that waiver. An individual may participate in only one waiver at a time.

The state must assure the federal Centers for Medicare and Medicaid Services (CMS) that the cost of providing home or community-based services will not exceed the cost of care for an identical population in an institution. In addition, the state must document that safeguards are in place to protect the health, safety, and welfare of those served.

HCBS waivers are initially approved for a three-year period. They may subsequently be renewed for five-year periods as long as federal CMS determines that the waiver is operated within federal guidelines relating to the health, safety, and welfare of the participants, and the total federal spending for participants' support does not exceed the cost of care in an institution. These waiver programs are subjected to much closer federal oversight than a state's base Medicaid program.



## **Illinois HCBS Waiver Programs**

In Illinois, there are nine HCBS waivers. HFS directly administers one of the nine waivers—the Supportive Living Program (SLP). For the other eight, HFS serves as the administrative authority by providing oversight, program monitoring, fiscal monitoring, and administrative coordination to secure federal funding. The programs operated by sister agencies include the HCBS waivers for: persons with HIV/AIDS, brain injury, physical or developmental disabilities (waivers that are operated by the Department of Human Services), the elderly (waiver for whom is operated by the Department on Aging), and MFTD waiver (waiver for whom is case managed by the Division of Specialized Care for Children, University of Illinois at Chicago). HFS is ultimately responsible to the federal government for all the waiver programs.

Six of the nine waivers serve children under 18 years of age. The following waivers serve adults only: waiver for the elderly (60 years of age and older), waiver for adults with developmental disabilities (18 years of age and older) and the Supportive Living Program waiver (for persons with disabilities who are 22 through 64 years of age and for the elderly 65 years of age and older. More information on Illinois HCBS waivers may be found at the following web link: <http://www.hfs.illinois.gov/hcbswaivers/>. This website includes links to the operating agency of each waiver.

### **Illinois HCBS Waiver for Children who are Medically Fragile Technology Dependent**

The MFTD waiver for children serves persons under 21 years of age who would require institutional care in a nursing facility or hospital, if nursing and waiver services were not provided in the home.

The waiver was initially approved in 1985 for a maximum of 50 children annually. During fiscal year 2010 the waiver served 519 children. The waiver may serve up to 700 individuals per year, through 2012. The current waiver effective dates are September 1, 2007, through August 31, 2012.

The primary expenditure for children in the MFTD waiver is in-home shift nursing, a non-waiver service. The children served by the waiver are afforded the same medical coverage provided to children receiving medical assistance. Additional services available only under the waiver include respite care, environmental modifications, nurse training, family training, placement maintenance counseling, and special medical equipment and supplies not covered by the Medicaid program.

In 2009, HFS implemented a standardized level of care screening tool to determine waiver eligibility. This new process, codified in rule on March 1, 2009, provides a more consistent and objective way to determine initial and ongoing eligibility, based on medical and technology needs criteria.