



**HFS**

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**Report of Medicaid Services for  
Persons who are Medically Fragile, Technology Dependent  
Public Act 95-0622  
January 2024**

**Reporting Period: State Fiscal Year 2021 (July 1, 2020 – June 30, 2021)  
and  
State Fiscal Year 2022 (July 1, 2021 – June 30, 2022)**

**INTRODUCTION**

Effective September 17, 2007, [Public Act 95-0622](#) amended the Illinois Public Aid Code to require the Department of Healthcare and Family Services (HFS) to submit this bi-annual report to the Governor and the General Assembly outlining Medicaid services offered to children and young adults with disabilities who are medically fragile and technology dependent (MFTD).

Under section 5/5-2b of the Public Aid Code, the Department is required to ensure that medical assistance 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 statute requires that eligible children be afforded medical assistance under Article V of the Public Aid Code in the community. The Department administers medical assistance to this population through a home and community-based Medicaid waiver authorized under section 1915(c) of the Social Security Act. Through the MFTD Waiver, and with the involvement of the University of Illinois at Chicago, Division of Specialized Care for Children (DSCC), Illinois provides care coordination, Medicaid State Plan services, and additional waiver-only services to the MFTD population as required under the Public Aid Code. The MFTD waiver was last renewed effective September 1, 2022, and the most current amendment was approved by the Centers for Medicare and Medicaid (CMS) on December 19, 2023, with an effective date of January 1, 2024.

In compliance with Public Act 095-0622, this report includes the following information concerning the MFTD waiver program:

1. The number of customers who currently receive waiver 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 aged out of waiver services.

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

The number of customers served in the MFTD Waiver fluctuates regularly. At the beginning of State Fiscal Year 2021, which began on July 1, 2020, there were 1,327 customers for the MFTD waiver. At the beginning of State Fiscal Year 2022, which began on July 1, 2021, there were 1,525 eligible customers. This reporting period occurred during the COVID-19 public health emergency (PHE). During the PHE, Federal rules did not allow customers to be disenrolled from Medicaid, any 1915c waiver, or to have a reduction in waiver services, unless requested or approved by the customer.

**2. The nature, scope, and cost of services**

Figures 1-a and 2-a detail the number of MFTD Waiver customers and the State Plan Medicaid services they received. A small upward trend of customers receiving services and total expenditures occurred as a result of the PHE as detailed above.

**Figure 1-a**

<b>Medicaid State Plan Services Provided to MFTD Waiver Customers State Fiscal Year 2021 Total Waiver Customers: 1,327</b>			
<b>Basic Medicaid Service</b>	<b>Unduplicated Customers Receiving Service</b>	<b>Total Service Expenditures</b>	<b>Average Service Expenditures Per Customer</b>
Nursing Services	467	\$26,001,491	\$55,678
Inpatient Hospital Care	472	\$46,246,071	\$97,979
Prescription Drugs	1,121	\$15,929,783	\$14,210
Medical Supplies	1,188	\$10,371,674	\$8,730
Medical Equipment	979	\$5,885,716	\$6,012

**Figure 1-b**

<b>Medicaid State Plan Services Provided to MFTD Waiver Customers</b> <b>State Fiscal Year 2022</b> <b>Total Waiver Customers: 1,525</b>			
<b>Basic Medicaid Service</b>	<b>Unduplicated Customers Receiving Service</b>	<b>Total Service Expenditures</b>	<b>Average Service Expenditures Per Customer</b>
Nursing Services	679	\$41,363,658	\$60,918
Inpatient Hospital Care	544	\$52,937,322	\$97,311
Prescription Drugs	1,174	\$17,364,050	\$14,791
Medical Supplies	1,250	\$10,559,647	\$8,478
Medical Equipment	1,039	\$5,933,901	\$5,711

**Figures 2-a and 2-b**

Expenditures for waiver services are significantly lower than costs for the State Plan Medicaid services. Fiscal Year 2021 expenditures for waiver-only service for MFTD Waiver customers are shown in Figure 2-a below and expenditures for State Fiscal Year 2022 are shown in Figure 2-b.

**Figure 2-a**

<b>MFTD Waiver Services only</b> <b>State Fiscal Year 2021</b> <b>Total Waiver Customers: 1,327</b>			
<b>Waiver Service</b>	<b>Unduplicated Customers Receiving Service</b>	<b>Total Service Expenditures</b>	<b>Average Service Expenditures Per Customer</b>
Respite/Nursing hours	295	\$16,533,668	\$56,046
Environmental Modification	192	\$863,256	\$4,496
Special Equipment	0	\$0	NA
Nurse Training	13	\$1,420.79	\$109
Placement Counseling	0	\$0	NA
Family Training	0	\$0	NA

**Figure 2-b**

<b>MFTD Waiver Services only                      State Fiscal Year 2022                      Total Waiver Customers: 1,525</b>			
<b>Waiver Service</b>	<b>Unduplicated Customers Receiving Service</b>	<b>Total Service Expenditures</b>	<b>Average Service Expenditures Per Customer</b>
Respite/Nursing hours	229	\$6,053,499	\$26,434
Environmental Modification	264	\$896,188	\$3,395
Special Equipment	0	\$0	NA
Nurse Training	5	\$561	\$112
Placement Counseling	0	\$0	NA
Family Training	0	\$0	NA

Figure 3-a below details the Medicaid State Plan services provided to MFTD waiver customers, and other expenditures, by cost and percent of total costs in State Fiscal Year 2021. Figure 3-b details these expenditures for State Fiscal Year 2022.

**Figure 3-a**

<b>MFTD Basic Medicaid Services Detailed Expenditures                      State Fiscal Year 2021                      Total Customer: 1,327</b>		
<b>Service Breakdown</b>	<b>Total Cost</b>	<b>Percent</b>
Nursing	\$26,001,491	12.3%
Inpatient Hospital	\$46,246,071	21.8%
Prescription Drugs	\$15,929,783	7.5%
Medical Supplies	\$10,371,674	4.9%
Medical Equipment	\$5,885,716	2.8%
All Other Services Total ( <i>Breakdown below</i> )	\$107,620,150	50.7%
<b>Total Expenditures</b>	<b>\$212,054,884</b>	<b>100%</b>
<b><i>Breakdown of All Other Services</i></b>		
<i>Physician Services</i>	\$3,984,481	1.9%
<i>Outpatient Services</i>	\$3,867,755	1.8%
<i>Therapies (physical, occupation, speech)</i>	\$511,986	0.2%

<i>Early Intervention Services</i>	\$314,724	0.1%
<i>Home Health Services</i>	\$96,221,682	45.4%
<i>All other Medical Services (lab, x-ray, optical, dental, audiology, podiatry, healthy kids services, mental health, transportation, and others including school based)</i>	\$2,719,524	1.3%
<b>Total</b>	<b>\$107,620,150</b>	<b>50.7%</b>

**Figure 3-b**

<b>MFTD Basic Medicaid Services Detailed Expenditures State Fiscal Year 2022 Total Customers: 1,525</b>		
<b>Service Breakdown</b>	<b>Total Cost</b>	<b>Percent</b>
Nursing	\$41,363,658	18.8%
Inpatient Hospital	\$52,937,322	24%
Prescription Drugs	\$17,364,050	7.9%
Medical Supplies	\$10,559,647	4.7%
Medical Equipment	\$5,933,901	2.7%
All Other Services Total ( <i>Breakdown below</i> )	\$92,237,364	41.8%
<b>Total Expenditures</b>	<b>\$220,395,941</b>	<b>100%</b>
<b>Breakdown of All Other Services</b>		
<i>Physician Services</i>	\$4,377,509	2%
<i>Outpatient Services</i>	\$4,595,474	2.1%
<i>Therapies (physical, occupation, speech)</i>	\$523,712	0.2%
<i>Early Intervention Services</i>	\$277,352	0.1%
<i>Home Health Services</i>	\$79,184,886	35.9%
<i>All other Medical Services (lab, x-ray, optical, dental, audiology, podiatry, healthy kids services, mental health, transportation, and others including school based)</i>	\$3,278,430	1.5%
<b>Total</b>	<b>\$92,237,364</b>	<b>41.8%</b>

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

Figures 4-a and 4-b compare the service costs for MFTD Waiver customers to average annual costs, including ancillary costs, of providing services to a similar population in an institution such as a hospital or nursing facility.

**Figure 4-a**

<b>Comparison of Costs Per Customer for Services Provided in the MFTD Waiver and Services Provided in an Institution State Fiscal Year 2021</b>				
<b>Level of Care</b>	<b>Number of MFTD Waiver Customers</b>	<b>Total MFTD Waiver Expenditures</b>	<b>Average Expenditure per Waiver Customer</b>	<b>Average Expenditure per Institutional Customer</b>
Hospital/Nursing Facility	1,327	\$212,054,884	\$159,800	\$281,881

**Figure 4-b**

<b>Comparison of Costs Per Customer for Services Provided in the MFTD Waiver and Services Provided in an Institution State Fiscal Year 2022</b>				
<b>Level of Care</b>	<b>Number of MFTD Waiver Customers</b>	<b>Total MFTD Waiver Expenditures</b>	<b>Average Expenditure per Waiver Customer</b>	<b>Average Expenditure per Institutional Customer</b>
Hospital/Nursing Facility	1,525	\$220,395,941	\$144,522	\$299,754

**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. Through an interagency agreement, the DSCC has authority to pay home health 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.

Illinois submits its claim expenditures to the federal government, which reimburses the state for a portion of those costs. During this reporting period of State Fiscal Years 2021 and 2022, the state received reimbursement from the federal government at a rate of 51.31%.

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

### Home Health Agencies

Although Illinois has 406 Medicaid home health agencies, only a specialized group of 84 nursing agencies serve the technology-dependent pediatric population with in-home shift nursing care. There are also five alternative childcare models enrolled with HFS and approved by DSCC to provide respite and transitional care 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 program requirements, including qualifications, experience, and training for administrative and nursing staff.

Appropriately qualified staff comprised of registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs), all of whom are licensed or certified in Illinois, provide respite care services for children in the MFTD Waiver. The same qualifications apply to State Plan private duty nursing services. Nurses and CNAs must be employed by a DSCC-approved nursing agency unless they provide services in a children's community-based health center and are employed directly by the health center. DSCC has difficulty finding nurses or nursing agencies to serve some areas of the State. However, through various outreach activities, five new nursing agencies have enrolled with DSCC in the past two years and have begun providing shift-nursing services to this population.

During this reporting period, the COVID-19 PHE occurred. As a result, legally responsible individuals (LRIs) who were a licensed RN or LPN were allowed to provide skilled nursing care to their child. As the nursing shortage continues, an amendment to the MFTD waiver was submitted requesting this flexibility to be made permanent. Federal CMS approved the amendment to the MFTD waiver with an effective date of January 1, 2024. In addition, the nurse training hours from a maximum of 4 hours to a maximum of 32 hours in order to help recruit new nurses and ensure appropriate specialized training is available for nurses serving this medically fragile population.

### Environmental Modifications and Specialized Medical Equipment and Supplies

Providers of environmental modifications and specialized medical equipment and supplies, like all Medicaid waiver providers, are subject to applicable requirements regarding licensure, qualifications, and experience. In addition to HFS enrollment requirements, DSCC approves MFTD Waiver home medical equipment and infusion providers and requires annual signed agreements. There are 948 home medical equipment providers enrolled in the Medicaid Medical Assistance Program. Of that

number, 23 meet the additional DSCC requirements for services to waiver children. One new home medical equipment provider has enrolled with DSCC and begun providing services to this population.

#### Placement Maintenance Counseling

Placement maintenance counseling 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 Department of Human Services (DHS), Division of Mental Health (DMH), or Department of Children and Family Services (DCFS) to provide clinical or rehabilitation services. To receive payment for these services, medical providers must be enrolled with HFS.

#### **6. Number of Children who Aged Out of Services**

Children no longer age out of the MFTD waiver. Customers may continue to receive waiver services for as long as they so choose. This change to the waiver was effective in 2017.