MFTD Waiver Families
www.SaveMFTDWaiver.com
mftdwaiver@gmail.com

What "Level of Care" Means and Why It is Important

On July 11, 2012, Julie Hamos, the director of Illinois' Department of Healthcare and Family Services (HFS), said the following: "The Hospital level of care is not something that I've ever understood because nobody is actually receiving $650,000 worth of care and nobody is living in a hospital permanently."

Since she is confused about this issue and the state cannot understand why parents feel it is so important, we will make an attempt to explain it.

What is level of care?

Children with disabilities have such high care needs that they are at risk of being institutionalized, and the state is required to pay for their costs in institutions according to Social Security Administration rules. Depending on their level of need, children could end up in an Intermediate Care Facility, Nursing Facility, or Hospital if they cannot be cared for at home. When states offer home and community based services as an alternative to institutionalization, whichever type of facility a child would require if he/she could not receive care at home becomes the "alternate placement" and the designated "level of care."

Level of Care	Where Defined in Federal Code	Type of Care	Cost per Month in Institution	Max Home Nursing Hours to be Cost Neutral[1]
Intermediate Care Facility	42 CFR §440.150	Non-medical care for individuals with cognitive, mental and/or development disabilities	$7880[2]	7.6 hours per day
Nursing Facility	42 CFR §440.155	Care for individuals who require daily medical care but do not need intensive monitoring or constant care	$9406[3]	9.1 hours per day
Hospital	42 CFR §440.10	Care for individuals requiring constant, intensive monitoring and ongoing medical care, such as children with trach, vent, central IV line, or medical instability	$40,000-$56,000	24 hours per day

Director Hamos takes the position that Hospital level of care is inherently inappropriate, that there is no such thing as a child whose needs are too intensive to live in a nursing home.

First, federal law contradicts this position in 42 CFR §441.301, which offers Hospital level of care as an alternate placement to home and community based services. Most states use this level of care for children with medical technology. For example, Minnesota states that a Hospital level of care is defined by the following:[4]

> 1. Need professional nursing assessments and intervention multiple times during a 24-hour period to maintain and prevent deterioration of health status.
> 2. Have both predictable health needs and the potential for status changes that could lead to rapid deterioration or life-threatening episodes due to the person's health condition.

3. Require a 24-hour plan of care, including a back-up plan, to reasonably assure health and safety in the community.
4. Require frequent or continuous care in a hospital without the provision of [Minnesota's] waiver services.

Secondly, this argument ignores the fact that before these waiver programs existed, children *did* live in hospitals. Katie Beckett lived in a hospital for three years until President Ronald Reagan granted her a special Medicaid exception, paving the way for kids like her to live at home. The reason kids rarely live in hospitals these days is *because* of waiver programs. The argument that there is no Hospital level of care because no one lives in a hospital is like saying, "Polio vaccine is not something I've ever understood because no one has Polio anymore."

In Illinois, the Medically Fragile Technology Dependent (MFTD) Waiver currently serves children who were designated as having a Hospital level of care OR a Nursing Facility level of care, though 99% of participants in 2010 had a Hospital level of care. Most children have tracheostomies, ventilators, or central IV lines. All Hospital level of care children need constant monitoring of their life support equipment at all times.

It may be difficult to understand how families can provide Hospital level of care at home. Each one of these families has a mini-hospital unit in their home, filled with equipment normally only seen in hospitals, such as ventilators, IV pumps, and resuscitation equipment. These families can and do provide intensive care 24 hours a day in their homes, but can only achieve this level of care with the assistance of one-on-one nurses. Most of these children need someone to stay up with them all night long to perform various skilled nursing care tasks.

Illinois currently has 10 nursing facilities approved to care for children, but most do not even accept children on ventilators or with central IV lines. The vast majority of children in nursing facilities do not have significant medical technology beyond feeding tubes or oxygen. The few children with trachs or vents in nursing homes tend to be much more stable than the kids in the MFTD Waiver; all children with trachs and vents are not created equal. Some are much more fragile than others. There were so few comparable children in nursing homes that the state is using the costs of 116 *adults up to the age of 60* in nursing homes as a comparison group. Kids have smaller, more fragile airways and lungs, can pull out their own life support if not adequately supervised, and have to attend school. Some adults can self-direct their own care; no child can do so.

In a nursing home, a child rarely sees a registered nurse. Most care is done by a certified nurse assistant, someone who is only required to be 16 years old, have an eighth grade education, and be trained for 75 hours.[5] Not surprisingly, there have been multiple well-publicized deaths of children in Illinois nursing homes.[6] Yet Director Hamos insists that a nursing facility level of care comparison is appropriate for *all* children in the MFTD Waiver, even the ones that every single nursing facility in the state would turn down.

Why is the level of care so important?

The level of care is critical because it essentially sets a cap on the amount of services that can be delivered, either in the aggregate for the whole program or at the individual level. All waiver programs must be cost-neutral, which means it has to cost a state less to keep the children in the program at home than it would cost to keep the children in whatever type of institution--Intermediate Care Facility ($7880/month), Nursing Facility ($9406/month), or Hospital ($40,000-$56,000/month)--the children would require.

The federal government mandates that all waiver programs must be cost-neutral on an aggregate basis, which means that the average cost per child in the program must be less than the average cost of institutionalization.

States are given the **OPTION** of whether they also want to impose an individual cost limit on individual children. In Appendix B-2 of every waiver application, states may choose to have no individual cost limit or an individual cost limit that is based off of institutional care costs. **Illinois has always chosen to include an individual cost limit in the past, and did so in the "draft" application for the proposed MFTD Waiver that was submitted to the federal government on June 5, 2012.**

Illinois completes an individual cost neutrality assessment for all children in the waiver on a regular basis to ensure they are still eligible. Here is an example of one Hospital level of care child's individual cost neutrality statement:[7]

V. Cost Comparison Analysis

Institutional	$ 55,967.13
Home Care	$ 24,925.96
Potential Difference	$ 31,041.17

Take a look at the line labeled "Institutional Care," which in this case lists the cost of a Hospital, $55,967.13. Under the state's proposal to only use a Nursing Facility level of care, that number would be capped at $9406 (and perhaps up to $14,785 to account for other incidental costs) instead of the current figure of $40,000-$56,000, which is the cost of care in the hospital of discharge in most cases.

Currently, this child could receive up to $55,967.13 in home nursing care, which is far more than 24 hours a day (though the state never grants this much care, even when needed), and still be eligible for the program. But if the Institutional facility cost is restricted to $9406, this child could only have a maximum of 9 hours daily of nursing care in order to stay under the $9406 cost limit. If the doctor says the child needs more hours to remain home safely, the state can "refuse entrance" to the waiver, effectively forcing institutionalization on the child.

The state has repeatedly said that the level of care comparison is only being calculated in the aggregate, and not on an individual basis, even though their own federally submitted application contradicts this statement. For the sake of argument, we will hypothesize that the state drops the individual cost neutrality requirement and only looks at the hours in the aggregate. If so, they can give one child 12 hours a day instead of 9 hours. But that means that another child would have to get 6 hours instead of 9 to keep the average at 9 hours a day.

Here's another way to look at it. Let say 10 kids were used to eating three meals a day. But they are then told that their "level of fare" is being reduced to two meals a day, but only calculated in the aggregate, from 30 total meals a day to 20 total meals. So with 20 meals for 10 kids in a day, some could get 3 *if they really need them*, but only if others get 1.

Summary of the Impact of Level of Care

If the level of care is calculated individually, 99% of kids in the program are no longer eligible for the waiver due to the change to a Nursing Facility level of care. Their monthly costs exceed the $9406 monthly facility cost of a Nursing Facility, as shown in the example above.

If it is calculated in aggregate, families would be limited to an average of 9 hours of nursing per day. This is not enough hours for children who require constant monitoring. Most of these children need 24/7 nursing care, but the state already restricts most to 12-16 hours per day, and pays the nurses so little it is hard to even find nurses willing to cover those hours. To reduce hours even further will result in institutionalization or force families to use the "option" of unlicensed personal care attendants who are not qualified to provide a Hospital level of care.

Even after slashing the number of nursing hours available to families, the state is also planning to charge a copayment on every nursing shift, but make the use of personal assistants or nursing homes free. In the federally submitted waiver application, the state even assumes that 75% of families will be using personal assistants by 2014 when making its calculations.

To take the previous analogy further, those 10 kids with 20 meals between them will have to pay a copayment for each meal they eat, but dog food will be completely free. If they are unhappy with eating dog food, they are reminded that it is *only an option*.

Level of care is not just an issue; it is the most important issue. We believe the focus on income caps and cost sharing, which mathematically will not save the state dollars, is a political strategy designed to misrepresent this program as one being abused by wealthy people to legislators and the public. This intellectually dishonest demagoguery is a distraction that allows the state to gut the program under the radar for children of *all* income levels through the level of care change and the use of unsafe unqualified personal assistants.

If this assessment is incorrect, all the state has to do is release the federal waiver application and state plan amendment to set the record straight.

---

[1] Hours were calculated using the following methodology. The total yearly cost (if known or the monthly cost multiplied by 12) was then divided by 365 to determine how much money would be available on a daily basis. This number was then divided by $34, the average hourly cost of nursing care to determine how many hours a child could receive and still cost the same or less than the cost of an institution. Please note that nurses do not earn $34/hour. This is an average of the rate paid to nursing agencies. Their overhead, the nurses liability coverage, and benefits all comes out of this rate, meaning the actual nurses are paid $20-25/hour, which is much less than area hospitals pay.

[2] This figure was determined by using the cost of an Intermediate Care Facility specified for 2012-13 in the Children's Support Waiver, a waiver program for children with developmental disabilities. http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Documents/waiver0473.pdf p. 141, Factor G.

[3] This figure was determined by using the cost of a Nursing Home specified for 2012-13 in the proposed application for the new MFTD Waiver. http://savemftdwaiver.com/MFTD2012application.pdf p. 132, Factor G.

[4] http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=id_000812

[5] Illinois CNA requirements from the Illinois Department of Public Health, http://www.idph.state.il.us/nar/cnafacts.htm.

[6] See http://www.chicagotribune.com/health/neglect/

[7] This example was taken from the class action lawsuit on this matter. To see the complete analysis for several children, see http://savemftdwaiver.com/lawsuit/5-Exh-31-34-.pdf