



MFTD Waiver Families

www.mftdwaiver.org
mftdwaiver@gmail.com

Statement on the MFTD Waiver and Managed Care

Good morning. My name is Susan Agrawal and I represent MFTD Waiver Families, an organization for families of children in the Medically Fragile, Technology Dependent Medicaid Waiver. My daughter, Karuna, was in this waiver for 8 years until her death in 2014. This program serves children with the most extraordinary medical technologies, such as ventilators, tracheostomies, feeding tubes, IV central lines, and oxygen. It also serves a large number of current or former DCFS wards, since many children who are medically fragile are given up to the state due to the complexity of their needs.

About a year ago, we found out that this extremely fragile population of about 1000 children was to be moved into Managed Care. We strongly oppose placing children in the MFTD Waiver into managed care, as it will put their very lives at risk.

Today, I will be reviewing a few of the reasons children who are medically fragile and technology dependent should be excluded from managed care.

1. Managed care is inappropriate and unsafe for children who are medically fragile.

In almost every other state, children who are medically fragile have been excluded from managed care, and it has not gone well in the few states that have attempted it. For example, in Texas, little Luke, who could not breathe on his own, had his ventilator denied. There have been several documented cases of individuals dying after homecare was reduced by MCOs in Iowa.

It's one thing to put people with chronic conditions like asthma or diabetes into managed care. It's another thing entirely to put kids with trachs and ventilators into managed care. Take Alexis, with cerebral palsy, a trach, feeding tube, 8 medical specialists, 12 medications, and four types of daily respiratory therapies. Or Hunter, a little boy with a brain malformation, trach, feeding tube, and seizures. Any interruption in any aspect of their care -- even something as simple as a delay in seizure medication or running out of catheters to suction a trach -- will lead to emergency room visits, hospitalizations, and could even cause their deaths. The hospital or ICU level of care required by these children is far beyond what any standard MCO care coordination program can handle.

2. HFS has failed to create a safe managed care system for children who are medically fragile.

HFS failed to ensure MCO contracts included provisions to prevent bureaucratic delays, unnecessary reevaluations, and inappropriate denials for children who are medically fragile. In fact, HFS included no transition plans or special considerations for this population at all, despite multiple warnings from both our organization and the IL chapter of the American Academy of Pediatrics (ICAAP). HFS has failed to consult with pediatric experts or families on the safety of placing this population into managed care. They have even failed to create a system to effectively monitor MCOs, which is critical for this population.

3. The MCOs are not capable of caring for children who are medically fragile.

Network inadequacy for this population remains a huge, insurmountable hurdle. Currently, there are only 31 nursing agencies and about 25 specialized durable medical equipment suppliers statewide approved to care for children in the MFTD waiver. For Christopher in Vermilion County, there is only one nursing agency and equipment supplier as it is. If these companies are unable to contract with the approved MCOs, children may lose access to nurses and medical equipment. These children will be forced to live in hospitals, at three times the cost, if they cannot receive these life-preserving services and supplies.

MCOs have a financial incentive to minimize care since the only way for MCOs to make money on this expensive population is to reduce services or cut reimbursements. One MCO, Illinicare, has already stated it will cut rates for medical equipment and supplies by up to 50%, definitively affecting all foster kids. Similar cuts to both homecare services and reimbursements are allowable and likely. Cuts like these occurred in Texas and backfired once children started showing up at ERs to get prescription refills and medical supplies, and in some cases, were admitted to hospitals because home nursing was eliminated.

Despite my past testimony to this committee, multiple media reports, and warnings from our community, neither HFS nor the MCOs have made any effort to gain expertise or plan for children who are medically fragile. I guess they have not learned their lessons from Iowa, where the MCO serving the majority of people with disabilities pulled out because they could not make a profit. Or the 15 states where MCOs have been fined or had lawsuits filed against them for failure to provide appropriate care.

In conclusion, managed care is not the right choice for children who are medically fragile. I strongly urge all of you to support Representative Fred Crespo's bill, HB4736, to exclude children in the MFTD Waiver from managed care. We also support SB2262, which would prevent reimbursement cuts for medical equipment. These children's lives are too fragile to be thrown into an ill-conceived, poorly planned, and inexperienced system of MCOs, on the false premise that doing so will save a few pennies.