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

May 15, 2017

Governor Bruce Rauner
Office of the Governor
207 State House
Springfield, IL 62706

Dear Governor Rauner:

We are writing to you regarding your plan to overhaul Medicaid, specifically your plan to move "special needs children" into Medicaid managed care next January. We represent more than 200 families currently participating in the Medically Fragile, Technology Dependent (MFTD) Waiver and other programs who receive Medicaid home nursing care services. We have been informed that these children likely will be moved into managed care under your current proposal.

We request that the approximately 1100 children currently receiving home nursing care through the MFTD waiver and other programs be excluded from managed care.

Children in the MFTD Waiver include many of our state's most medically vulnerable children. The vast majority of children require tracheostomy tubes to help them breathe. Most also have feeding tubes, and many use ventilators or have intravenous lines. All require 24-hour nursing care, and many require intensive care level nursing services. They are extremely complex with profoundly life threatening conditions, and their care must be carefully planned with great consideration.

Moving children in the MFTD Waiver to managed care is extremely risky and unsafe. The current managed care proposal has been created with little thought to the needs of these children. Without careful consideration, these children could suffer severe health issues under the current proposal, including death. Moreover, costs to the state may rise precipitously if children are unable to access appropriate care, which may force them to receive care through emergency rooms or be hospitalized long term.

Here are just a few of the risks:

- The life and safety of children with complex medical conditions will be threatened by Managed Care Organizations (MCOs), who have virtually no experience with this population.

- A lack of continuity of care will result in disrupted care, morbidity, and mortality, because children will no longer be able to see pediatric physicians who have cared for them and their unique needs for years.
- Fractured care coordination systems split between MCOs and Specialized Care for Children (DSCC) will result in critical delays in care, emergency room visits, and hospitalizations.
- Delays in care due to prior authorization requirements will result in costly emergency room visits and hospitalizations.
- Delays in critical life saving medications due to prior authorization requirements will result in emergency room visits and hospitalizations.
- Children will be unable to access critical pediatric subspecialists, resulting in poor or disrupted care, due to network inadequacy.
- Children will be unable to access home nursing care, resulting in forced hospitalization, due to network inadequacy.
- Durable medical equipment such as ventilators will be unavailable due to network inadequacy, resulting in forced hospitalization and emergency room visits.
- Access to pediatric therapists, such as physical therapists, occupational therapists, and speech/language/feeding therapists will be severely limited due to geographical network inadequacy.

The following issues are present in the proposed plan and the current model contract, and need to be resolved:

1. **There has been no consultation with pediatric specialists on the safety of placing this population in managed care, and no forums with families on how the program will safely meet children's needs.** It is extremely risky and life threatening to move children with this level of complex medical needs into managed care. Yet, the state has failed to even consult with pediatric specialists on the risks of such a plan. Nor has the state explained to families how managed care can safely meet their children's needs. To forge ahead without ensuring the safety of these children is foolhardy.
2. **Research on the safety and efficacy of placing extremely medically complex children into managed care has not yet been done, and few states have ever even attempted placing such a population into managed care.** While other states have placed children with chronic medical conditions into managed care successfully, there is a tremendous difference between a child with a simple chronic medical condition and the MFTD population. Children with asthma or diabetes can be safely served by managed care. Children with tracheostomies, ventilators, intravenous lines, and feeding tubes require a wholly different level of care. The two populations are not comparable or exchangeable. In fact, the one state that has placed extremely complex children into managed care, Texas, has proven children will experience tremendous life threatening complications under

managed care. Children have been denied essential care, lost therapists, lost home nursing, and instead ended up hospitalized or in the emergency room.

3. **The transition plan for children with complex medical conditions in inadequate, which could lead to increased hospitalizations, morbidity, and mortality.** While the proposed contract proposes a 90-day transition plan for all members, this plan is not sufficient for children who receive home nursing care, extensive therapies, complex durable medical equipment and supplies, and other complicated services. Gaps in the provision of life support equipment and supplies, as well as gaps in nursing, are extremely life threatening for these children. Children who use ventilators, intravenous pumps, or feeding pumps will require immediate hospitalization if a gap in service occurs. Gaps in nursing care are equally life threatening, and could lead to immediate intensive care hospitalization for children.
4. **There are no contract specifications for the MFTD population, leaving them vulnerable to hospitalization due to life threatening gaps in care.** While "high-needs" children primarily with behavioral problems or mental illness receive 10 full pages of specialized provisions, there have been NO provisions made for the even more vulnerable MFTD population. Specific provisions regarding access to durable medical equipment, home nursing care, expedited authorizations, expedited medication provision, timely access to specialists, and emergency access have not been provided beyond the standard stipulations for individuals with chronic diseases. There are no crisis provisions for this population. Information about how managed care providers will work with DSCC for care coordination has not been provided. A plan for who determines nursing care hours has not been provided. There is no plan for ensuring access to life support equipment and services. Delays in care for this population are not only life threatening, but also typically end up being costly, requiring lengthy intensive care hospitalizations and frequent emergency room usage.
5. **There is no plan for ensuring children receive durable medical equipment, home nursing care, or therapies.** Currently, only a small number of agencies are approved to provide durable medical equipment, such as ventilators, to children. As of 2016 there were only 11 approved pediatric ventilator providers statewide, and only 9 intravenous providers. In addition, as of 2016 there were only 36 nursing agencies approved to care for MFTD children. In rural regions of the state, there may be only one or two available providers, and it is already challenging to find a provider in these areas. While section 5.7.1.4 of the model contract has requirements for continuity of care of those receiving waiver services, these requirements do not apply to children in the MFTD Waiver because their nursing care, equipment, and therapies are part of the federally mandated Early and Periodic Screening, Diagnostic and Treatment (EPSDT) state plan service package. The model contract contains no plan to ensure that children will have access to medical equipment providers and nursing agencies, which could lead to increased hospitalizations and forced institutionalization if children cannot leave hospitals due to a lack of providers.

6. **The model contract does not require pediatric subspecialist access, and children may no longer have access to pediatric subspecialists.** The model contract only specifies that managed care enrollees have access to specialists, but not pediatric subspecialists. Children in the MFTD Waiver require complex pediatric subspecialist services, such as pediatric gastroenterology, pediatric pulmonology, and similar services. Moreover, many of these children have rare conditions that require pediatric super-subspecialists, such as pulmonologists who care for children on ventilators, and gastroenterologists who provide pediatric home-based intravenous infusion care. Managed care would severely limit children's access to these critical services.
7. **Current legal orders in place could affect the state's ability to move children in the MFTD Waiver to managed care.** Two pending lawsuits, *OB v. Norwood* and *MA v. Norwood*, have orders in place mandating the state not reduce nursing hours without a change in medical status and ensure that children receive all state-approved nursing hours. Network inadequacy will likely limit access to nursing agencies, making it considerably less likely children will be able to receive their home nursing care hours. Similarly, alterations in nursing care hours by managed care organizations could run afoul of legal orders.
8. **Managing children in the MFTD Waiver creates a two-tiered system: those with private insurance and those without.** According to the RFP, the state plans to exclude children with third party liability from managed care. Currently, approximately 33% of children in the MFTD waiver have third party liability and would be excluded from managed care. This sets up an unbalanced, two-tiered system, in which care coordination through DSCC for the third party liability group is significantly different than care coordination for the remainder of children without private insurance. It is difficult for such a bifurcated model to serve the needs of all children appropriately.
9. **Duplicative expensive management and care coordination services will increase costs to the state.** Children in the MFTD Waiver are already "managed" by Specialized Care for Children (DSCC). The proposal to roll them into managed care states they will continue to receive care coordination through DSCC, but will also be managed by a managed care organization. Thus, these children will be double managed, creating not only bureaucratic interagency conflicts, but also duplicative high-cost services.
10. **Duplicative services for determining nursing care hours will increase costs to the state.** Currently, physicians evaluate a child and prescribe home nursing care, and the child is referred to and evaluated a second time by a DSCC nurse for home nursing approval. Then, an outside agency, KePro, evaluates the child a third time to determine if the physician's recommended number of nursing care hours is medically necessary. This already represents a duplication of services. Adding a managed care organization on top of this process will not only add yet another layer of costly bureaucracy, but will also create an evaluation process that is repeated four times.

11. **The risk adjustment plan is insufficient for children in the MFTD Waiver.** While risk adjustment will be in place for these children, it fails to consider the typical pattern of an MFTD Waiver child, thereby failing to provide adequate payment for this population. A large number of children in the program are infants, and many are discharged to the program directly from the Neonatal or Pediatric Intensive Care Units. Most do not have a lengthy history of charges to form a basis for risk adjustment, which means they will only receive an "average" risk adjustment. Moreover, all infants under age 2 will not be risk adjusted regardless of condition, and a considerable portion of the most costly MFTD Waiver children are under 2, placing a tremendous burden on insurance companies.
12. **MCOs lack experience with complex care populations such as children in the MFTD Waiver, and many do not want to manage this population.** Since virtually no state manages complex care populations as complex as children on the MFTD Waiver, MCOs do not have experience in this area. Many recognize they are unequipped to handle the care coordination needs of these children, as well as their financial needs.
13. **Federal law does not allow mandatory managed care enrollment for children who are deemed disabled by SSI or participate in Title V programs such as Specialized Care for Children (DSCC).** 42 U.S. Code §1396u-2(2) excludes children in the MFTD Waiver from mandatory managed care enrollment due to their participation in a Title V program, and in some cases due to their participation in SSI. While a waiver of this rule could be requested, Illinois has neither received a waiver nor requested one.

Please fully exempt children in the MFTD Waiver, as well as all children receiving home nursing services through DSCC, from managed care. The consequences of pushing forward with managed care for this population are potentially life threatening and costly, and the current proposal has failed to prioritize the critical needs of these children.

Sincerely,

Susan Agrawal
Founder, MFTD Waiver Families