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

Public Comments on MFTD Waiver Amendment (IL 0278) on Behalf of MFTD Waiver Families

The following comments on the proposed amendment to the Medically Fragile Technology Dependent (MFTD) Waiver are made on behalf of the more than 300 members of MFTD Waiver Families, a support and advocacy organization of families whose children participate in the MFTD Waiver.

The proposed amendment, in conjunction with the model managed care contract, demonstrate that the Department of Healthcare and Family Services (HFS) has not constructed a safe, effective, and sustainable managed care program for children who are medically fragile and technology dependent. In fact, the Illinois legislature was so appalled by HFS' lack of preparation and the potential disastrous health outcomes of this program that they passed a bill with near unanimous support exempting children in the MFTD waiver from managed care. 6 of the 7 current managed care plans did not oppose the bill. If the governor fails to sign this bill into law, the legislature has both the votes and the will to override a veto.

Illinois has targeted the children in the MFTD Waiver since 2011, simply because the state does not want to pay for their expensive care. After first trying to eliminate the program, the state went on to impose draconian income restrictions, copays, and other measures that were ultimately denied by the Centers for Medicare and Medicaid Services (CMS). When HFS failed at limiting the program, they cut reimbursement rates for home nursing care and durable medical equipment -- rates that had not been raised in decades -- by nearly 3%. In 2015, further temporary reimbursement cuts of 16.75% nearly devastated the program, with numerous nursing agencies and durable medical equipment providers refusing to take children in the MFTD Waiver. Additional nickel and diming on durable medical equipment, either by imposing harsh limits or limiting reimbursement, has continuously occurred.

Forcing children who are medically fragile into managed care is just the next step in a targeted campaign to devastate the care of children who are medically fragile. With unprepared networks, a lack of safety measures, minimal oversight, and the ramifications of a profit-oriented medical system, children will be substantially harmed by the proposed program.

Because of the serious safety concerns with this managed care program, we request the following:

1) **Immediate withdrawal of the proposed amendment and a permanent exemption from managed care for children in the MFTD Waiver and any other children receiving home nursing through the Division of Specialized Care for Children (DSCC).**

2) If immediate withdrawal is not granted, the following changes must be made to the amendment and the managed care program to ensure the safety of children who are medically fragile:

a. Delay the transition of children in the MFTD Waiver to managed care until at least January 1, 2019.
b. Form an Advisory Council to ensure the safety of the managed care program for children who are medically complex. The Advisory Council must include, at minimum, two pediatricians with expertise in complex care, one DSCC representative, one nursing agency representative from a DSCC-approved agency, one durable medical equipment supplier representative from a DSCC-approved agency, one representative of each managed care organization (MCO) or trade organization, one representative from HFS, one advocate, and two family members of children in the MFTD Waiver. This Advisory Council will meet until a safe managed care program and transition plan is developed and approved.
c. Create an Ombudsman office specifically to handle issues that arise for children who are medically fragile in managed care.
d. Extend continuity of care benefits during the transition for a full 12 months.
e. Offer all current nursing agencies and durable medical equipment suppliers on the DSCC-approved lists guaranteed inclusion in all MCO provider networks prior to transition.
f. Resolve all safety issues listed in section 1 below.
g. Resolve all coordination issues between MCOs and DSCC listed in section 2 below.
h. Correct all errors in the proposed amendment.

The following comments detail specific issues with the proposed amendment and managed care program for children who are medically fragile. They are categorized below:

1. Safety Issues in the Managed Care Program for Children who are Medically Fragile
    a. Failure to Obtain Expert Consultation on Safety
    b. Network Adequacy
    c. Special Considerations for Children who are Medically Complex
    d. Capitation and Risk Management
    e. Transition and Continuity of Care
    f. Qualifications of Care Coordinators
    g. Caseloads
    h. Client/Family Contact with Care Coordinator

1. Safety Issues in the Managed Care Program for Children who are Medically Fragile

HFS has failed to construct a safe managed care program for children who are medically fragile and technology dependent. Moreover, HFS has haphazardly thrown together this proposed amendment, cutting and pasting bits and pieces from other waivers into the application, with no regard whatsoever for the fragile nature of this population. A similar disregard for the complex needs of this population was exhibited in the construction of the MCO model contract.

If ever a population is vulnerable to change, it is the children in the MFTD Waiver. Any change, no matter how minute, can have dramatic and life-altering consequences, including significant morbidity and even death. The lack of careful planning and the failure to resolve the small details in both the proposed amendment and model contract demonstrate a callous disregard for the life and safety of this population. Whether this disregard is calculated or due simply to ineptitude, it would be foolhardy for HFS and the state to even consider implementing this program as it currently stands.

Other states, including Texas and Iowa, have attempted to put populations similar to the children in the MFTD Waiver into managed care. In these states, despite significantly greater preplanning in comparison to Illinois, there have been documented deaths, significant medical complications, loss of home care services, loss of life-sustaining medical equipment including ventilators, denials of care, failure to provide services, failure to locate providers, care coordination failures due to coordinator staffing and experience, and similar problems.[1] Both programs are currently in chaos, with hearings that have spanned for days in Texas. Other states, such as North Carolina, realized their mistake in advance and withdrew managed care proposals, thereby exempting children who are medically fragile.

[1] https://interactives.dallasnews.com/2018/pain-and-profit/part5.html; https://interactives.dallasnews.com/2018/pain-and-profit/part2.html; https://www.desmoinesregister.com/story/news/2017/12/05/iowa-medicaid-recipients-mean-more-than-dollar-sign-emotional-crowd-tells-state/905701001/; https://www.desmoinesregister.com/story/news/investigations/2017/10/19/quadriplegic-spends-hours-dirty-diaper-after-his-medicaid-services-cut/602331001/; https://www.desmoinesregister.com/story/news/investigations/2017/08/13/medicaid-patient-lost-care-hed-received-20-years-3-months-later-he-dead/488367001/.

Medical professionals, advocates, legislators, and families have deemed the current managed care plan dangerous.[2] Implementation will lead to dire consequences to the health and safety of children who are medically fragile.

These consequences are currently being documented in Texas, where managed care has devastated the most vulnerable and medically fragile children in the state.[3] A recent news series recounts how cuts to home nursing care, which were vigorously appealed, caused a foster child to code, leaving him in a permanent vegetative state. When the child's nursing agency fought back, they were retaliated against and the MCO attempted to terminate their contract. The MCO featured in this series is owned and operated by the same corporation as Illinois' MCO Illinicare, which is not only one of the currently approved MCOs, but has been exclusively tasked with caring for foster children in Illinois.

Texas acknowledges there have been numerous problems with MCOs leading to significant morbidity and even death among children who are medically fragile, particularly those who receive home nursing care.[4] Moreover, MCO officials were documented intentionally trying to reduce home nursing hours in a variety of ways in attempts to save money.[5] In just the first three months of the program, 730 complaints relating to children who are medically fragile were logged.[6]

Children who are medically complex are only profitable when their care is denied, restricted, or eliminated. In Texas, research has shown that nonprofits providing managed care for children who are medically fragile lost an average of $1800 per child, but for-profit MCOs were able to make a profit by denying care.[7]

Of perhaps greatest concern is the allowance of MCOs to deny care by creating their own definitions of "medically necessary care." Allowing MCOs inexperienced with children who are medically complex to make these decisions, especially when they know that denial of care will increase profits, has the potential to drastically harm children. This harm is not abstract, as it has been apparent throughout the Texas

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[2] See statements from MFTD Waiver Families at mftdwaiver.org; this sign-on letter described at https://www.usnews.com/news/best-states/illinois/articles/2018-04-26/advocates-urge-lawmaker-curb-on-medicaid-managed-care-switch; the testimony of Dr. Matthew Davis presented at 4/5/18 House Committee hearing, available at http://mftdwaiver.org/files/documents/Lurie-Children-s-Testimony-April-5-2018.pdf; and a 2017 statement from ICAAP, available at http://mftdwaiver.org/files/documents/ICAAP-Letter-to-IDHFS-on-RFP-Rebid-of-MCOs-5-18-17.pdf.

[3] https://interactives.dallasnews.com/2018/pain-and-profit/part1.html

[4] https://interactives.dallasnews.com/2018/pain-and-profit/document.html?number=4491548&title=P-amp-P-1-and-2-Responses.html

[5] https://interactives.dallasnews.com/2018/pain-and-profit/part1.html

[6] https://interactives.dallasnews.com/2018/pain-and-profit/part5.html

[7] https://interactives.dallasnews.com/2018/pain-and-profit/part5.html

and Iowa programs, leading to denials in home nursing care, personal assistance, durable medical equipment, and other critical services.[8]

Sadly enough, Illinois' proposed amendment and model contract demonstrate that Illinois is actually significantly less prepared than Texas to safely transition children who are medically fragile into managed care. After such dramatic failures in the Texas program, Illinois legislators, families, advocates, and the media are on watch to ensure that this dangerous managed care program is not inflicted upon Illinois' most vulnerable children.

Here are just a few examples of how HFS failed to construct a safe managed care program:

a. Failure to Obtain Expert Consultation on Safety

States that have moved populations of medically complex children into managed care have typically spent months working with stakeholders and experts to develop safe managed care programs. For example, in Texas, an advisory council including complex care physicians, advocates, and other stakeholders, has met continuously to negotiate safeguards for the Texas program. Their feedback continues to be critical in solving the ongoing problems in the Texas program.

No such consultations have occurred in Illinois, either in creating the model contract or the proposed amendment. In fact, medical professionals, advocates, and stakeholders have been entirely left out of the creation of the managed care program for children who are medically fragile, which has led to many of the problems listed in this document. The only avenue of public input sought out by HFS is feedback from DSCC's Family Advisory Council, a group that has been inconsistent in formation at best and is primarily made up of parents of children in other programs, and not the MFTD Waiver.

b. Network Adequacy

Given that only about 31 DSCC-approved nursing agencies and 25 durable medical equipment suppliers currently care for children statewide in the MFTD Waiver, network adequacy in MCO provider networks is of critical importance.[9] Approximately 16 Illinois counties currently only have one provider prior to managed care, and the vast majority of rural counties have only one or two. Even before managed care, HFS is failing to provide HFS-approved nursing care services

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[8] https://interactives.dallasnews.com/2018/pain-and-profit/part2.html; https://interactives.dallasnews.com/2018/pain-and-profit/part5.html; https://www.desmoinesregister.com/story/news/2017/12/05/iowa-medicaid-recipients-mean-more-than-dollar-sign-emotional-crowd-tells-state/905701001/; https://www.desmoinesregister.com/story/news/investigations/2017/10/19/quadriplegic-spends-hours-dirty-diaper-after-his-medicaid-services-cut/602331001/; https://www.desmoinesregister.com/story/news/investigations/2017/08/13/medicaid-patient-lost-care-hed-received-20-years-3-months-later-he-dead/488367001/.

[9] Agencies with multiple offices are counted as a single agency.

to children in the MFTD waiver.[10] 85% of children are receiving less than 80% of their approved nursing care shifts, and 35% are receiving less than 40% of their approved hours. Nurse staffing problem will increase exponentially if the number of available agencies is reduced to clients through managed care, especially in rural counties.

In addition, many children who are medically complex require pediatric sub-specialists to treat rare diseases and conditions, and often only one or two such specialists are available in the state. The model contract contains no provisions that pediatric subspecialists be available to children in Illinois. Other states, such as Texas, require subspecialists with pediatric experience, as well as pediatric therapists, to be available within a certain distance throughout the entire state.[11]

Dr. Matthew Davis of Lurie Children's Hospital testified to a House committee at length about network adequacy issues that are already being experienced by children with chronic conditions in managed care.[12] He relayed numerous failures in locating nursing agencies, IV medication providers, rehabilitation providers, and similar specialized services within managed care networks in the Chicago area. Children in the MFTD Waiver require these services every single day and cannot live at home or survive without them. Any threats to their availability will mean children will be permanently hospitalized until resolution.

Illinois has already had to sanction one MCO provider, Blue Cross Blue Shield, for failing to create adequate networks.[13] A current overview of the statewide MCO networks demonstrates that most have no DSCC-approved providers for home nursing or complex medical technology in most rural counties, and only a few in the Chicago area. Information from other states demonstrates that MCOs frequently fail to create adequate networks.[14] In Texas, for example, of 377 listed pediatric psychiatrists, only 34 were taking new patients on Medicaid, meaning only 10% of the listed network was actually available. 45% of listings were inaccurate, an additional 14% weren't taking the Medicaid MCO plan, and 9% weren't taking new patients. Another study showed 2 out of 5 specialists on network lists were not taking new Medicaid MCO patients or were inaccurate. Unusual services, like pediatric audiology or ENT, had no specialists at all listed in some counties.

Illinois has included in its model contract a mandate for waiver services that ensures that 80% of waiver participants continue being served immediately in each managed care network. However, most of the critical services in the MFTD Waiver, including home nursing and durable medical equipment, are state plan services and

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[10] Survey of children in the MFTD Waiver performed May 2018 by MFTD Waiver Families. For thorough documentation, see the case *OB v. Norwood*.

[11] Texas Star Kids contract, pp. 8.28-31.

[12] http://mftdwaiver.org/files/documents/Lurie-Children-s-Testimony-April-5-2018.pdf

[13] http://www.chicagotribune.com/business/ct-biz-medicaid-blue-cross-sanctions-0419-story.html

[14] https://interactives.dallasnews.com/2018/pain-and-profit/part3.html

not waiver services, meaning this provision does not apply. In fact, there is no provision whatsoever ensuring that one or more currently DSCC-approved providers will continue to serve these children.

Other states have prepared networks for those with complex conditions in a variety of ways. Iowa, for example, has offered inclusion of all home and community-based services providers into all MCO networks for a period of two years.[15] Texas mandated that MCOs provide evidence of network adequacy specifically for private duty nursing as part of their transition plans.[16] A complete network must be established, at minimum, before moving children in the MFTD Waiver into managed care.

c. Special Considerations for Children who are Medically Complex

Most states have included very specific measures to protect children with complex medical conditions in their MCO contracts.[17] Texas, for example, has an entirely separate contract just for children with disabilities. Illinois has failed to include even ONE such special measure in the contract or proposed amendment. Typical language includes expedited medication authorization, expedited referrals, exclusion from repeated reassessments, mandated pediatric subspecialist networks, mandated access to nursing agencies and DMEs, and other similar measures. Not one of these has been included for children in the MFTD Waiver in the MCO model contract or proposed amendment.

Illinois' model contract includes an entire appendix devoted to specific additional assistance to be provided by MCOs to children with behavioral health needs. This appendix includes such important measures as establishing a family council, creating crisis response protocols, and mandating extensive hospital discharge planning and transition services. The children in the MFTD waiver have equally complex needs, and yet no crisis protocols, discharge planning, transition services, or any other specialized services are included for them in either the model contract or the proposed amendment.

The needs of this population demand specialized assessment and protocols. Without such protocols in place, managed care will be untenable for these children and their providers due to insurmountable bureaucratic hurdles.

d. Capitation and Risk Management

The capitation and risk management strategies outlined in the model contract and described in the proposed amendment are insufficient to cover the costs of this population. First of all, all "Special-Needs Children" are grouped into one capitation category, even though this group contains a wide array of children, from those with

[15] See, for example, the Iowa AmeriGroup contract, p. 212.

[16] See Texas Star Kids contract, pp. 7.7-7.8.

[17] See, for example, Texas Star Kids contract, pp. 8.77-88 and 8:189-97; or Iowa AmeriGroup contract pp. 82-91.

mild disabilities or medical conditions to those with the most severe medical disabilities, such as children on ventilators. Most other states have included specific capitation structures for waiver populations to avoid this underestimation.[18] For example, Texas has 10 different rate cells specifically for people with disabilities in its STAR+PLUS managed care program, including four specifically for those in HCBS waivers.

Risk adjustment is even more problematic. Most concerning is that there will be no risk adjustment for children under the age of 2, who constitute a large percentage of children in the MFTD Waiver. Secondly, children new to Medicaid and the MFTD Waiver will only receive an "average" risk adjustment, which is likely to be insufficient to cover the costs of expensive care, including ventilator management or IV nutrition. Finally, studies have shown that the trajectory of need varies considerably from year to year in children with complex medical conditions, due to episodic exacerbations and hospitalizations.[19] Past history may not reflect future needs, and in many cases may underestimate the costs for these children.

The failure to create an appropriate capitation and risk management structure for children in the MFTD Waiver means that MCOs will be severely underpaid for this population. Underpayment will lead to one of two outcomes: either MCOs will intentionally attempt to exclude children in the MFTD Waiver from their programs, or they will be forced to deny services and provide them with substandard care. In either scenario, children in the MFTD Waiver will be unable to obtain safe, appropriate healthcare services as guaranteed through the Early Periodic Screening, Diagnostic and Treatment (EPSDT) Medicaid mandate.

e. Transition and Continuity of Care

Continuity of care is critical for children who require intensive and extensive services, yet both the proposed amendment and model contract only specify a 90-day transition period. This transition period is insufficient for children who are medically complex. For example, if a child needs to switch nursing agencies and durable medical equipment providers, that process alone can easily take as long as 6 months to find an approved agency, transfer the case, and assign or hire new nurses for the child.

Other states have mandated much longer transition periods. For example, in Texas, the transition period was initially 6 months and was extended to 12 months for children who are medically complex.[20] Continuity of care must be maintained for 12 months at minimum in any managed care program for children in the MFTD Waiver.

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[18] See, for example, Texas Uniform contract, pp. 39-40.

[19] Rishi Agrawal, et al., Trends in Health Care Spending for Children in Medicaid With High Resource Use. Pediatrics Oct 2016, 138 (4) e20160682; **DOI:** 10.1542/peds.2016-0682

[20] See, for example, Texas Star Kids contract, pp. 7.1-12.

f. Qualifications of Care Coordinators
As specified on p. 97 of the amendment, DSCC care coordinators for children remaining in fee-for-service are required to have specific qualifications, such as a nursing degree or a master's degree in social work. While MCOs have similar requirements on the surface, they are not required to be trained in the specific medical technology and nursing care skillset that is currently in place for DSCC care coordinators. Instead, the training is geared more toward children with behavioral or developmental disabilities.

Children in MCOs are likely to receive unqualified care coordinators with limited experience who will be unable to navigate their complicated needs. MCO contracts in other states have included specific requirements to ensure that care coordinators are appropriately skilled and trained to meet the needs of the population they serve. In Texas, case managers must have access to experts in areas including medically complex conditions, DME, palliative care, and assistive technology.[21]

Best practice would be to have all children in the MFTD Waiver remain with DSCC care coordinators on a permanent basis. In lieu of this, guaranteed specialized training will need to be added for care coordinators in order to provide appropriate care coordination for this population.

g. Caseloads
While the model contract specifies a caseload of 75:1 for care management of individuals with complex needs, those with brain injuries or HIV were allotted caseloads that are 30:1 due to their increased needs. The needs of children in the MFTD Waiver are in many instances far greater than those with brain injuries or HIV, and yet HFS neglected to allot this higher level of care management to them. They again had the opportunity to do so within the context of the amendment and chose not to do so.

Other states have stipulated much smaller caseloads for children who are medically complex. For example, in Texas the caseload requirement is 34:1 for the most complex children in their waiver programs.

Caseloads must be reduced for all children in the MFTD Waiver to at least 30:1.

h. Client/Family Contact with Care Coordinator
While the model contract requires contact between care coordinator and client every 90 days for individuals with complex needs, monthly contact is required for those with brain injuries and HIV. The needs of children in the MFTD Waiver require a similar level of contact. In Texas, children who are medically complex receive monthly phone contacts and face-to-face contact four times yearly.[22]

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[21] Texas Star Kids contract, pp. 8.163-4 and 8.168-70.

[22] Texas Star Kids contract, pp. 8.165.

Considering the proposed amendment on p. 102 and p. 105 still mandates monthly contact for fee-for-service participants, the same level of contact, monthly, should be required for children who are medically fragile in managed care.

i. Reimbursement Rates

Two MCOs, Illinicare and Blue Cross Blue Shield, have already announced or implemented rate cuts for durable medical equipment, including 10-50% cuts by Illinicare and 35% minimum cuts by Blue Cross Blue Shield.[23] Similar reimbursement rate cuts could be implemented on home nursing as well. The proposed amendment and model contract fail to protect children who are medically complex from rate cuts that will directly impact their ability to access home nursing care, durable medical equipment, and particularly ventilators and related supplies. It is not even possible for durable medical equipment suppliers who specialize in complex and labor-intensive technologies such as ventilators to survive at the reimbursement rate levels indicated by these two MCOs.[24]

Other states such as Texas require minimum rates for home services, such as personal care.[25] Without requiring at least minimum rates equivalent to those in the current fee schedules, nursing agencies and durable medical equipment suppliers will refuse to care for children in the MFTD Waiver.

Currently, 85% of children in the MFTD Waiver are receiving less than 80% of their HFS-approved nursing care hours, in large part due to already low reimbursement rates that have actually been reduced twice in the past 6 years.[26] This problem will only grow in intensity if rates are reduced even further, meaning children will end up permanently hospitalized because they cannot receive their home nursing care.

In addition, there are only a handful of DMEs that provide complex pediatric services, especially ventilator, tracheostomy, and infusion services. If these companies are unable to stay in business, there will be no available providers for these services.[27] Children will again be forced into hospitals to receive their care.

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[23] http://www.chicagobusiness.com/article/20171116/NEWS03/171119917/illinicare-slashing-rates-to-medicaid-suppliers;
http://www.chicagobusiness.com/article/20180524/NEWS03/180529915/blue-cross-of-illinois-to-pay-medicaid-suppliers-less

[24] To see how similar cuts to pharmacy reimbursements are devastating small pharmacies, see http://www.chicagotribune.com/business/ct-biz-independent-pharmacy-bill-0508-story.html.

[25] See, for example, Texas Star Kids contract, p. 8.155.

[26] Survey of children in the MFTD Waiver performed May 2018 by MFTD Waiver Families.

[27] http://www.chicagobusiness.com/article/20180117/OPINION/180119916/rauners-medicaid-overhaul-will-risk-kids-lives; http://www.sj-r.com/opinion/20180206/guest-view-legislature-should-act-on-rauner-mco-reorganization

j. Improper Monitoring of Care

An audit of managed care in Illinois recently found a disturbing lack of monitoring of current managed care programs.[28] The audit determined the state was unable to determine how often patients actually received care, could not document what MCOs paid doctors and other providers, and failed to track denials. With a population of children as vulnerable as those in the MFTD Waiver, tracking of services and denials is critical to ensure children are receiving the care they need and are legally entitled to.

Moreover, the quality metrics contained in the proposed amendment are insufficient to determine whether children are actually receiving appropriate services. Only one metric, 28D, requires MCOs to document that the care required by care plans is actually provided. No metrics require care plans to be adequate in scope. Moreover, as demonstrated on pp. 130-1, MCOs are only required to internally document critical incidents and report them as part of normal reporting, and can choose to address incidents as they see fit. There is no mechanism to require MCOs to make systemic changes as a result of critical incidents of other substantial deficits.

2. Duplicative and Unclear Coordination between DSCC and MCOs

The MFTD Waiver currently includes approximately 936 children.[29] Of these children, about 46% are covered by third party liability or commercial insurance in addition to Medicaid. These children will be exempt from managed care at this time, which means the state must operate two separate programs for these 936 medically fragile children. This creates a bifurcated service model that is both duplicative in nature, fiscally wasteful, and is unclear in its roles and responsibilities.

Having two separate systems for such a small program seems needlessly complicated. In addition, because the Operating Agency (DSCC) will need to remain in place to administer the waiver and provide care coordination for about half of the children in the program, it will need to retain the vast majority of its staff. Additional staff will need to be paid for the remaining half of children moving to managed care. Thus, the state will likely see an increase in costs in care management and waiver oversight due to duplication.

Evidence of duplication and unclear coordination is present throughout the proposed amendment. In some cases, roles are not defined. In others, they are unclear. In a few cases, they are directly contradictory.

Examples include the following:

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[28] http://www.chicagobusiness.com/article/20180123/NEWS03/180129966/audit-stings-rauners-medicaid-program

[29] Data obtained from HFS and received 5/31/18.

1. On p. 2 of the amendment, MCOs are designated as the responsible party for ALL care management and plan development. No party is designated in this section for the half of children who will be exempt from MCOs. In direct contradiction, on p. 6 the Operating Agency, DSCC, is designated as the responsible party for ALL case management and plan development. It is unclear which agency or combination of agencies will serve in this capacity.
2. Currently, DSCC approves nursing agencies and durable medical equipment providers that have demonstrated the special skills required to care for children who are medically fragile. Typically, only a small percentage of agencies elect to become DSCC-approved. It is unclear in the information on p. 103 of the proposed amendment if MCOs will be required to use DSCC-approved agencies or can send families to any agency in their provider network, no matter how unqualified the agency is to serve complex, pediatric patients.
3. Virtually every section of the document outlines two separate processes, one through the Operating Agency (DSCC) and another through MCOs, to handle each aspect of care provided through the waiver. These are too numerous to even begin to list out. All are unclear in designating which roles belong solely to the Operating Agency (DSCC), which are assigned to both the Operating Agency (DSCC) and MCOs depending on whether or not a child is exempt from managed care, and which are solely the responsibility of the MCOs.
4. The model contract stipulates DSCC will continue care coordination during the first year of managed care. The proposed amendment neither discusses this first year process, nor details how the transition from DSCC to MCO care coordination will occur.

3. Errors in the Proposed Waiver Amendment

The proposed amendment contains numerous errors that demonstrate HFS's lack of commitment to this population and its needs. While many of these errors are small details, together they demonstrate how little thought was put into this amendment and the population of children who are medically fragile as a whole.

The errors specifically related to managed care include:[30]

1. According to the amendment, HFS is proposing to move children in the MFTD Waiver into managed care before obtaining federal approval to do so. The waiver amendment has an effective date of October 1, 2018, but the amendment states these children will be moved into managed care on July 1, 2018.
2. The waiver amendment contains several references to the Integrated Care Program and Integrated Care Program MCOs and how these MCOs will serve children in the MFTD Waiver. This program has never served children in the MFTD waiver and will never do so. In fact, according to p. 2 of the

[30] Additional errors unrelated to managed care are not listed.

amendment, this program no longer exists and has been rolled into the HealthChoice Illinois program. These references likely occurred when HFS pasted parts of other waiver documents into this one, without carefully reading or adapting the material appropriately.

3. The amendment specifically instructs MCOs to review the Determination of Need assessment conducted by the Operating Agency (DSCC) and containing the "member's strengths, needs, levels of functioning and risk factors." DSCC does not and has never administered the Determination of Need assessment to children in the MFTD Waiver. Again, HFS appears to have simply pasted information from other waivers into this document with no regard for the accuracy of these statements.
4. On pp. 5-6 of the proposed amendment, it is stated that this waiver will work in conjunction with both a 1915(b1) waiver and an 1115 waiver. Neither waiver name nor status is specified. It is unclear what waivers these are referencing, or whether they are proposed, in progress, or approved.

4. Conclusion

The managed care program currently proposed by HFS is unsafe for children in the MFTD Waiver. **We urge HFS to immediately withdraw its application for this proposed amendment.** If HFS does submit it, we urge CMS to deny the amendment until HFS has demonstrated it has created a safe and adequate managed care program for children in the MFTD Waiver.

We have seen the horrific failures of this type of program play out in Texas, where children are being harmed on a daily basis, and will not stand by while Illinois attempts to force a similarly dangerous program on its most vulnerable children.