

1. The Plaintiffs and Class, consist of approximately 1,050¹ medically fragile disabled children who currently receive funding from the Defendant for skilled nursing services at their home at an average monthly cost between \$11,000² to \$16,000³, depending upon their medical needs, so that they do not have to be institutionalized or hospitalized for their entire life at a rate of approximately \$55,000 per month.⁴ The Plaintiffs and Class funding comes from the Defendant with some medically fragile children receiving funding from the State of Illinois “Medicaid Home and Community-Based Services (HCBS) Waiver for Children that are Medically Fragile, Technology Dependent” (MF/TD) and Medicaid and some medically fragile children receiving funding from just Medicaid as they do not qualify for the MF/TD waiver.

2. Since 1985 and prior to the passage of the Americans with Disabilities Act (ADA), the State of Illinois has been able to successfully provide through the MF/TD Waiver and Medicaid,

¹ See Exhibit “1” - The Defendant states: “Currently, [Illinois] serves medically fragile and technology dependent children in two different ways: approximately 550 children are served by the Medically Fragile, Technology Dependent Waiver (“MFTD Waiver”) and approximately 500 other technology dependent children under Medicaid, who receive in-home services but do not meet the institutional level of care to qualify for services under the MFTD Waiver.” See: “HFS - Questions and Answers on the Medicaid Program for Medically Fragile and Technology Dependent Children” at No. 2. (See: www2.illinois.gov/hfs/agency/Pages/MFTD.aspx)

² See Exhibit “2” - Fact Sheet - “PDN” Services - Expenditures for State Fiscal Year 2010 - \$134,000 per child equals approx. \$11,166 per month. (See: www.hfs.illinois.gov/assets/ccmn_pdnfactsheet.pdf)

³ See Exhibit “3” - Fact Sheet - “MFTD” Waiver - Expenditures for State Fiscal Year 2010 - \$188,000 per child year equals approx. \$15,666 per month. (See: www.hfs.illinois.gov/assets/ccmn_mftd_hcbs_factsheet.pdf)

⁴ See Exhibit “4” - “[T]he medical service limits for most children under the MF/TD waiver are compared to *pediatric* hospitals - - or up to approximately \$55,000 per month in the Chicago area.” Illinois Healthcare and Family Services Annual Report, April 2011 at page 6. (See: www2.illinois.gov/hfs/agency/Documents/2011annualreport.pdf)

home and community-based services for children who are medically fragile, technology dependent “to allow eligible children to remain in their own homes rather than in an institutional setting.”⁵

3. Ninety-nine percent (99%) of the children in the MF/TD Waiver have been found by the Defendant and by the children’s personal physician to require a hospital level of care.⁶

4. Effective September 1, 2012, the State of Illinois is unraveling 27 years of community based services to medically fragile children by making draconian cuts to Medicaid services to the Plaintiffs and Class which puts them at risk of institutionalization in violation of the Americans with Disabilities Act, Rehabilitation Act and Medicaid.

5. The State of Illinois readily acknowledges that “Illinois is making several significant changes to the state’s Medicaid program for children who are technology dependent” because “[t]he Medicaid program is on the brink of collapse.”⁷ The net effect of these changes is to place

⁵ See Exhibit “5” - MF/TD Waiver at page 3, Sec. 2.

⁶ See Exhibit “6” - “Report of Medicaid Services for Persons who are Medically Fragile, Technology Dependent” by Illinois Department of Healthcare and Family Services, January, 2012 at page 5, Table 3. (See: www2.illinois.gov/hfs/agency/Documents/2101mftd.pdf)

⁷ See Exhibit “7” - On June 14, 2012, Governor Quinn signed into law the “Save Medicaid Access and Resources Together Act” (SMART) (Public Act 097-0689). The Public Act states that the purpose of the SMART Act is “to address the significant spending and liability deficit in the medical assistance program budget of the Department of Healthcare and Family Services.”

See also Exhibit “8” - The MF/TD program has been in place years before Illinois fiscal crisis and the cost of the MF/TD program has been relatively unchanged since 2004 as the average cost per person served in 2004 was \$173,772 and in 2010 was \$188,210. The Total Annual Liability in 2004 was approximately 93 million dollars as compared to 117 million dollars in 2010. With federal financial participation in the program, Illinois is reimbursed one half (1/2th) of the total costs by Medicaid. (See: www.hfs.illinois.gov/assets/ccmn_facesheet_history.pdf)

the medically fragile children at risk of institutionalization.

6. The Plaintiffs' and Class are at risk of institutionalization because of the following changes to both the State Medicaid Plan and MF/TD Waiver.

- A) All Medically Fragile Children Are Now Limited To A Nursing Facility Level Of Care Rate As Opposed To A Hospital Level of Care Rate Which Will Reduce Their Level Of In-Home Funding By Approximately 50% Even Though Their Medical Needs Remain Unchanged Which Will Force The Children To Be Institutionalized At A Yearly Cost To The State Up To \$660,000.
- B) Illinois Excludes All Medically Fragile Children With Parental Incomes Exceeding 500% (\$95,450 for a family of 3) Of The Federal Poverty Rate For Home and Community-Based Services Even Though The Family Will Be Unable To Pay The Average Yearly Cost Of \$188,000 For In-Home Services Which Will Force The Child To Be Institutionalized At A Yearly Cost To The State Of \$660,000.
- C) Illinois Imposes Cost Sharing or Co Pays On Children With Parental Incomes Exceeding 150% (\$28,635 for a family of 3) Of The Federal Poverty Rate For Home and Community-Based Services Which Violates Federal Law and Which Places The Child At Risk of Institutionalization.

7. Medically fragile children will be limited to a nursing facility level of care as opposed to a hospital level of care which will result in approximately a 50% reduction in skilled nursing and medicaid services without any change in the medical condition of the child.

8. The current MF/TD Waiver expires on August 31, 2012 and the Defendant has submitted a renewal of the MF/TD Waiver which eliminates the hospital level of care and substitutes a nursing facility as being the level of care which the medically fragile children require. Accordingly, in order to be cost neutral, the comparable institution (nursing facility) rate

would be used instead of the hospital rate. The nursing facility rate will be approximately \$9,400 per month, which means the State of Illinois will not approve community based skill nursing and Medicaid funding for the medically fragile children which exceeds the sum of \$9,400 per month. A significant number of children in the MF/TD Waiver receive Medicaid services (skilled nursing, medication, equipment, supplies and therapies) which are approximately \$20,000 per month. (See Exhibits 29 - 34 which contain the cost estimates of institutional care compared to home care of the named Plaintiffs).⁸ The average monthly cost for the approximate 550 children in the MF/TD is \$15,166 while the average monthly cost for the other approximate 500 children not in the MF/TD but receiving PDN is \$11,166 per month.

9. By Illinois reclassifying 99% of the persons in the MF/TD Waiver as only needing a nursing facility level of care as opposed to a hospital level care in order to cap or limit the “medical necessity” level of funding, the State is placing the Plaintiffs and Class at risk of institutionalization.

10. Prior to the filing of this lawsuit by the Plaintiffs, the Defendant has been successfully challenged by individual plaintiffs in 5 separate lawsuits over its practice and policy of reducing medical funding which results in a reduction of medical services when the disabled person turns 21 years of age.⁹ In those 5 cases, when the medically fragile person turned 21, he

⁸ The Defendant maintains the administrative oversight of the MF/TD Waiver and the University of Illinois, Division of Specialized Care for Children (DSCC) is responsible for the day-to-day operations. (See Exhibit “2” at page 68).

⁹ See *Radaszewski v. Maram*, 2008 U.S. Dist. LEXIS 24923 (N.D. Ill.)(March 26, 2008); *Grooms v. Maram*, 563 F.Supp.2d 840 (N.D.Ill. 2008); *Jones v. Maram*, 373 Ill.App.3d 184, 867 N.E.2d 563 (3rd Dist. 2007); *Sidell v. Maram*, 2009 U.S. Dist. LEXIS 131324 (C.D. Ill. 2009); and *Fisher v. Maram*, 06 C 4405 (N.D. Ill.)(January 8, 2009).

or she no longer was assigned a hospital level of care and was shifted or transferred to a different program which capped funding based on a nursing facility level of care. Despite these adverse rulings against the Defendant, the Defendant would not change the policy in the MF/TD Waiver and continued to reduce medical funding at age 21. As the result, a class action lawsuit was filed against the Defendant in May, 2010, to prevent the reduction of funding when a medically fragile person turns 21 years of age. See *Hampe, et. al., v. Hamos*, 10-3121 (N.D. Ill.) (J. Castillo). Since the filing of *Hampe*, the District Court has entered Court Orders for approximately 22 plaintiffs and class members to continue the same level of Medicaid and skilled nursing services past their 21st birthday pending the outcome of the case.

11. The Defendant testified before the Illinois House of Representatives Executive Committee that the State estimates that 36 medically fragile children will not qualify for home and community based services as their family income exceeds 500% of the Federal Poverty Rate (“FPR”). She acknowledged that some families “are just over that 500%.”

12. A medical fragile child will be unable to receive in-home medically necessary services when the average cost of those services is \$188,000 from a family that is excluded because they make too much money (in excess of \$95,450 for a family of 3).¹⁰ Excluding families with incomes over 500% of the FPR will place the child at risk of institutionalization in order to receive the medically necessary services which he or she will not be able to receive in the community.

¹⁰ Even a family who earns twice the sum of \$95,450 a year cannot afford to pay \$188,000 a year out-of-pocket for nursing care.

13. The State of Illinois claims:

“[HFS] analysis estimates that approximately 160 of the 650 children served in the Medically Fragile, Technology Dependent (MFTD) home and community based services (HCBS) waiver have incomes over 150 percent FPL. The cost share approach for Medicaid eligible families is unlikely to produce significant revenue, but is a philosophical approach showing an effort for participants to contribute toward care and share in the cost when their incomes are above the Medicaid eligibility limits. (Healthcare and Family Services Annual Report - submitted March, 2012 at page 10)

“Co payments will be established for private duty nursing for all families.”¹¹ “Private duty nursing, [is] the most widely used service by technology dependent children and those children who use the MFTD Waiver.”¹²

14. Federal law and regulation prohibit the use of cost sharing, co-pays, premiums, deductibles, enrollment fees and similar charges for children up to the age of 18. See 42 U.S.C. Sec. 1396o(a)(2)(A); see also 42 C.F.R. Sec. 447.53(b)(1).

15. There is no cost sharing for children residing in institutions in Illinois. Illinois promotes institutional care by imposing cost-sharing on families who choose community care over institutionalization. Additionally, Illinois acknowledges that cost share is not fiscally necessary but serves to promote a “philosophical approach” that people should pay as noted above.

16. The net effect of the State of Illinois changes to Medicaid and the MF/TD Waiver,

¹¹ See Exhibit “9” - “HFS - New Medicaid Program for Technology Dependent Children Fact Sheet” at page 2 - Section Co-Payments. (See: www2.illinois.gov/hfs/sitecollectiondocuments/mftdfactsheet.pdf)

¹² See Exhibit “1”) - “HFS - Questions and Answers on the Medicaid Program for Medically Fragile and Technology Dependent Children” at No. 7. (See: www2.illinois.gov/hfs/agency/Pages/MFTD.aspx)

effective September 1, 2012, is to place the Plaintiffs and Class at a risk of institutionalization. With the Plaintiffs and Class having their Medicaid benefits either reduced or eliminated, without any change in the medical condition, they are at risk of institutionalization (hospitalization) or if they remain in their residence without sufficient skilled nursing care and Medicaid benefits, then they face a strong possibility of imminent death or a life threatening episode.

17. The Plaintiffs and Class' medically fragile condition and needs will remain unchanged on September 1, 2012.

18. The Defendant's planned elimination or reduction in Medicaid benefits will cause grave harm or death to the Plaintiffs and Class if they remain in their home and will force them into an institution to receive the medical care which they need in order to remain alive and maintain their current health.

19. The Plaintiffs and Class are likely to prevail on her claim that the planned reduction in benefits violates the Americans with Disabilities Act, 42 U.S.C. Sec. 12132; Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a); and Title XIX of the Social Security Act ("Medicaid Act") 42 U.S.C. Sec. 1396 *et. seq*; Early and Periodic Screening, Diagnostic, and Treatment Services, 42 U.S.C. Sec. 1396d(r) ("EPSDT Provisions"); and 42 U.S.C. Section 1983.

20. The Plaintiffs have no adequate remedy at law and will suffer irreparable injury if the Defendant's planned reduction or elimination of benefits is not enjoined.

21. The Defendant will not suffer hardship if injunctive relief is issued. The balance of equities between the parties favors issuance of the relief sought.

22. The public interest favors the issuance of a Temporary Restraining Order and a

Preliminary Injunction in this case.

This verified motion is based upon the following documents:

- a) Complaint for Declaratory and Injunctive Relief. (See Exhibit “10”)
- b) Declaration of Margaret Boyce. (See Exhibit “11”)
- c) Declaration of Kimberly Ottis, R.N. (See Exhibit “12”)
- d) Declaration of Dr. Lyna Massih. (See Exhibit “13”)

- e) Declaration of Michael Goldberg. (See Exhibit “14”)
- f) Declaration of Bethany Fonck, R.N. (See Exhibit “15”)
- g) Declaration of Dr. Steven Lestrud. (See Exhibit “16”)

- h) Declaration of Mary Kish. (See Exhibit “17”)
- i) Declaration of Tammy Mouradian, R.N.. (See Exhibit “18”)
- j) Declaration of Dr. Gregory A. Summers. (See Exhibit “19”)

- k) Declaration of Francisco X. Nevarez. (See Exhibit “20”)
- l) Declaration of Stacy Turner, R.N. (See Exhibit “21”)
- m) Declaration of Dr. Hannah Chow (See Exhibit “22”)

- o) Declaration of Corelyn Peterson (See Exhibit “23”)
- p) Declaration of Nurse. (See Exhibit “24”)
- q) Declaration of Dr. Zehava Noah (See Exhibit “25”)

- r) Declaration of Amy Wellman. (See Exhibit “26”)
- s) Declaration of Jen Tufano, R.N. (See Exhibit “27”)
- t) Declaration of Dr. Christopher Donohoe (See Exhibit “28”)

- u) Additional Declarations if obtained will be later filed upon receipt.

- v) Plaintiff’s Memorandum of Law in Support of Plaintiff’s Motion For Temporary Restraining Order and Preliminary Injunction.

The Plaintiffs’ are also prepared to offer testimony in Court to support this Motion.

WHEREFORE, the Plaintiffs’ request that the Court grant the following relief:

- A. Enter a Temporary Restraining Order and/or Preliminary Injunction directing the Defendant, Julie Hamos, to maintain the same level of Medicaid benefits to the Plaintiffs’

and Class and enjoin the Defendant from reducing or denying the Plaintiffs and Class from their existing benefits of the MF/TD waiver and Medicaid, pending final judgment in this action or until further order of Court.

B. That this Court waive or excuse the filing of any security or bond by the Plaintiff.

Respectfully submitted,

/s/ Robert H. Farley, Jr.
One of the Attorneys for
the Plaintiffs'

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VERIFICATION

I, Margaret Boyce, mother and next friend of T.B., being first duly sworn upon oath and under penalties of perjury, do hereby state that the statements contained in the Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction are true and correct to the best of my knowledge and belief as they pertain to T.B.

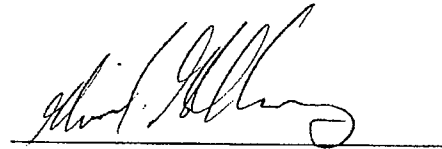
Margaret M Boyce

07/05/12

Date

VERIFICATION

I, Michael Goldberg, father and next friend of Q.G., being first duly sworn upon oath and under penalties of perjury, do hereby state that the statements contained in the Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction are true and correct to the best of my knowledge and belief as they pertain to Q.G.



7/5/12

Date

VERIFICATION

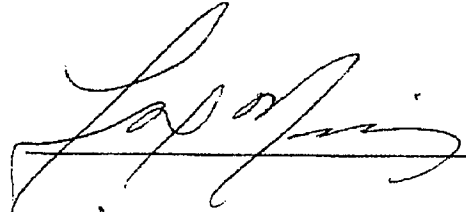
I, Mary Kish, mother and next friend of M.K., being first duly sworn upon oath and under penalties of perjury, do hereby state that the statements contained in the Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction are true and correct to the best of my knowledge and belief as they pertain to M.K.

Mary Kish

7-4-12
Date

VERIFICATION

I, Francisco Nevarez, father and next friend of X.N., being first duly sworn upon oath and under penalties of perjury, do hereby state that the statements contained in the Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction are true and correct to the best of my knowledge and belief as they pertain to X.N.




July 4, 2012
Date

VERIFICATION

I, Corelyn Peterson, mother and next friend of S.P, being first duly sworn upon oath and under penalties of perjury, do hereby state that the statements contained in the Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction are true and correct to the best of my knowledge and belief as they pertain to S.P..





Date

VERIFICATION

I, Amy Wellman, mother and next friend of O.W., being first duly sworn upon oath and under penalties of perjury, do hereby state that the statements contained in the Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction are true and correct to the best of my knowledge and belief as they pertain to O.W.

Amy Wellman
7/5/12
Date

CERTIFICATE OF SERVICE

I, Robert H. Farley, Jr., one of the Attorneys for the Plaintiffs, deposes and states that he caused the foregoing Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction to be served by electronically filing said document with the Clerk of the Court using the CM/ECF system, this 9th day of July, 2012, and will cause the foregoing Plaintiffs' Motion for Temporary Restraining Order and Preliminary Injunction, to be served on the named Defendant, by hand delivering a copy to the office of the Defendant, Julie Hamos at 401 S. Clinton, Chicago, Illinois on July 10, 2012.

/s/ Robert H. Farley, Jr.