

**IN THE UNITED STATES DISTRICT COURT
FOR THE NORTHERN DISTRICT OF ILLINOIS
EASTERN DIVISION**

T.B. by and through his parents THOMAS
BOYCE and MARGARET BOYCE, **Q.G.**
by and through his parents MICHAEL
GOLDBERG and MAYUMI GOLDBERG,
M.K. by and through her parents BRADLEY
KISH and MARY KISH, **X.N.** by and through
his parents FRANCISCO NEVAREZ and
LISETTE NEVAREZ, **S.P.** by and through her
parents FRANK PETERSON and CORELYN
PETERSON, **O.W.** by and through his parents,
JEFFREY WELLMAN and AMY WELLMAN,
individually and on behalf of a class,

Plaintiffs,

vs.

JULIE HAMOS, in her official capacity as
Director of the Illinois Department of
Healthcare and Family Services,

Defendant.

No. 12-5356

Judge: Robert W. Gettleman

Magistrate: Sidney I. Schenkier

**COMPLAINT FOR
DECLARATORY AND INJUNCTIVE RELIEF**

Now come the Plaintiffs, by and through their attorneys, Robert H. Farley, Jr., Ltd., and Cahill & Associates and Michelle N. Schneiderheinze and files the following Complaint against the Defendant as follows:

I. INTRODUCTION

1. The Plaintiffs and Class, consist of approximately 1,050 medically fragile disabled children who currently receive funding from the Defendant for skilled nursing services at their home at an average monthly cost between \$11,000 to \$16,000, 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. The Plaintiffs' funding from the Defendant comes from the State of Illinois "Medicaid Home and Community-Based Services (HCBS) Waiver for Children that are Medically Fragile, Technology Dependent" program (MF/TD) and Medicaid.

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, 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."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.²

¹ MF/TD Waiver at page 3, Sec. 2. The development of community based services for medically fragile children, also known as the "Katie Beckett Waiver" was championed by President Ronald Reagan in 1981. Katie Beckett was 3 years old at that time and had been hospitalized almost since birth and qualified for Medicaid. Katie's parents wanted to manage her care at home with a ventilator, but under existing Medicaid rules, if she had been taken home, her parents' income would have counted against her, and would have lost eligibility for Medicaid. Her hospital care was costing six times as much as home care would have cost. President Reagan cited Katie's case as an example of irrational federal regulation that caused "tremendous expense to the taxpayers." The rules, he said, forced her to stay in the hospital even though she would be better off at home. In 1982, Medicaid policy fundamentally shifted to allow people with significant health care needs and disabilities to receive care at home. See www.nytimes.com/2012/05/23/us/katie-beckett-who-inspired-health-reform-dies-at-34.html. See also, www.hhs.gov/news/press/2012pres/05/20120519a.html.

² 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)

3. Ninety-nine percent (99%) of the children currently 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.³ "[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."⁴ The average monthly cost to serve each child in the MF/TD waiver is approximately \$15,666 per month.⁵ The average monthly cost to serve the other approximately 500 children under Medicaid, under the program known as Private Duty Nursing ("PDN") is approximately \$11,166 per month.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 putative 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

³ See "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)

⁴ Illinois Healthcare and Family Services Annual Report, April 2011 at page 6. (See: www2.illinois.gov/hfs/agency/Documents/2011annualreport.pdf)

⁵ 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)

⁶ 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)

“[t]he Medicaid program is on the brink of collapse.”⁷ The net effect of these changes is to place 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 Medical 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 Service And Other Services Which Will Force The Child To Be Institutionalized At A Yearly Cost Of \$660,000 Per Child.
- 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.

Hospital Level Of Care Is Reduced To A Nursing Facility Level Of Care.

7. Medically fragile children are now limited to a nursing facility level of care as opposed

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.”

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)

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 State of Illinois is arbitrarily reducing the level of care needed for the medically fragile children in the MF/TD Waiver from a hospital level of care to a nursing facility level of care without any corresponding change in the child's medical condition.

9. In the current MF/TD Waiver, the State of Illinois is required to show that the cost of providing home and community based services is less (or at least cost neutral) than the cost of providing those services in an institution (hospital). The hospital level of care is approximately \$55,000 per month and the current cost of providing community based services (Skilled Nursing and Medicaid) is about 1/3rd the hospital level of care so cost neutrality is satisfied.

10. 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. The average monthly cost for the approximately 550 children in the MF/TD is \$15,166 while the average monthly cost for the other approximately 500 children not in the MF/TD but receiving PDN is \$11,166 per month.

11. 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 putative Class at risk of institutionalization.

Current & Prior Litigation Prevents The State From Reducing The Level Of Funding For Medically Fragile Children From A Hospital Level Of Care To A Nursing Facility Level Of Care.

12. 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.⁸ In those 5 cases, when the medically fragile person turned 21, he 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).

13. The United States Department of Justice has filed a Statement of Interest in *Hampe*, supporting the plaintiffs and class and asserts as follows: (*Hampe*, at Doc. 26)

⁸ 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).

[T]his litigation implicates the proper interpretation and application of the integration mandate of title II of the Americans with Disabilities Act (cites omitted).

* * *

This litigation involves the defendant's systematic failure to modify its current policies and practices of providing insufficient home-based medical care for Medicaid-eligible adults to prevent institutionalization. Children and young adults in the State of Illinois who have exceptional medical needs are eligible to receive home-based Medicaid services to avoid institutionalization under the State's Medically Fragile/Technology Dependent ("MF/TD") waiver program. Under defendant's regulatory scheme, however, once these individuals reach the age of 21, they are ineligible for the MF/TD waiver. Because the adult waiver program to which a majority of people transition does not provide community-based services at the same level, these individuals may be forced to enter an institution in order to receive the medical services they need to survive. These institutional placements are often more costly to the State. (Doc. 26 at 1-2)

* * *

Defendant's policy of providing inadequate home and community-based services for the proposed class solely because they reach the age of 21 places them at risk of institutionalization and therefore violates the integration mandate of title II. (Id at 7)

14. 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.

Illinois Excludes All Medical 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.

15. 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%."

16. A medically 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).⁹ 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.

Cost Sharing Is Prohibited For Children Under Federal Law. Moreover, Illinois Promotes Institutional Care As Cost Sharing Is Not Imposed On Persons Residing In Institutions.

17. 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.”¹⁰ “Private duty nursing, [is] the most widely used service by technology dependent children and those children who use the MFTD Waiver.”¹¹

⁹ 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.

¹⁰ HFS - “New Medicaid Program for Technology Dependent Children Fact Sheet” at page 2 - Section Co-Payments. (See: www2.illinois.gov/hfs/sitecollectiondocuments/mftdfactsheet.pdf)

¹¹ 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)

18. 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).

19. 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.

20. This class action lawsuit is necessary in order to stop the Defendant from violating the Americans with Disabilities Act and the Rehabilitation Act and Medicaid for the two groups of children who are medically fragile who are either in the MF/TD waiver or who are not in the MF/TD waiver but receiving Private Duty Nursing (PDN). These 1,000 plus medically fragile children are facing either significant reductions in their funding / benefits or elimination of their funding / benefits which places them at risk of either becoming institutionalized (hospitalized) or if they remain in their family home without sufficient skilled nursing care, then they face a strong possibility of imminent death.

II. JURISDICTION & VENUE

21. This is an action for declaratory and injunctive relief to enforce the rights of the Plaintiffs and the class they seek to represent under 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.

22. This Court has jurisdiction over Plaintiffs federal law claims pursuant to 28 U.S.C. Sections 1331 and 1343. Plaintiffs claim for declaratory and injunctive relief are authorized under 28 U.S.C. Sec. 2201-02 and 42 U.S.C. Sec. 1983.

23. Venue is proper in the Northern District of Illinois under 28 U.S.C. Sec. 1391(b).

III. PARTIES

Plaintiff T.B.

24(a). The Plaintiff, T.B. is a five year old boy and is medically fragile and currently receives funding from the Defendant for approximately 14 hours a day of skilled nursing services at his home (99 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

24(b). T.B. has diagnoses of congenital high airway obstruction syndrome (CHAOS), bronchomalacia, tracheomalacia, horseshoe kidney, hypospadias with bilateral cryptorchidism, and vertebral anomalies of the thoracic spine. He has a tracheostomy and is vent dependent when sleeping. He is monitored during the awake hours for the need for intermittent use of the vent.

24(c). T.B. requires a hospital level of care as opposed to a nursing facility level of care.

24(d). The alternative to T.B.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

24(e) T.B. resides with his parents and brother in Oak Forest, Illinois. T.B. receives home based educational services for one hour 3 days a week and 2.5 hours 2 days a week. T.B.

is functioning above grade level and doing some reading.

24(f) T.B. brings this action through his parents, Thomas Boyce and Margaret Boyce.

Plaintiff Q.G.

25(a). The Plaintiff, Q.G. is a one year old boy and is medically fragile and currently receives funding from the Defendant for approximately 16 hours a day of skilled nursing services at his home (112 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

25(b). Q.G. has multiple medical diagnoses including: 24 week gestation/prematurity, chronic lung diseases, ROP, ASD, pulmonary hypertension, g-tube, s/p tracheostomy, 24 hour ventilator dependence and GERD. He requires care to monitor his respiratory status, ventilator and tracheostomy. He also requires administration of g-tube feeds every four hours.

25(c). Q.G. requires a hospital level of care as opposed to a nursing facility level of care.

25(d). The alternative to Q.G.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

25(e) Q.G. resides with his parents in Chicago, Illinois. Q.G. is a very friendly baby. He smiles and enjoys playing with his toys and engaging with others.

25(f) Q.G. brings this action through his parents, Michael Goldberg and Mayumi Goldberg.

Plaintiff M.K.

26(a). The Plaintiff, M.K. is a fifteen year old girl and is medically fragile and currently receives funding from the Defendant for approximately 18 hours a day of skilled nursing services

at her home (126 hours per week) plus she is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

26(b). M.K. is diagnosed with Hallerman Strieff Syndrome, Growth Disorder, Short Statute, Chronic Respiratory Failure, Chronic Lung Disease, Sleep Apnea, Choanal Stenosis (narrowing of the nostrils), Bilateral Cataracts, Glaucoma, Small Eyes, Seizure Disorder, Gastroesophageal Reflux, Microgastria, Conductive Hearing Loss, Cholesteatoma, Mitral Regurgitation, Mitral Value Prolapse, Mild Cardiomyopathy, High Blood Pressure, Developmental Delay, Alopecia, and Atopic Dermatitis.

26(c). M.K. requires intensive vigilant nursing care that consists of: tracheostomy care, monitoring of respiratory and cardiac status, suctioning, monitoring of fragile status of g-button and trach, meticulous skin care including many topical creams/ointments that are applied daily, and several medications that are administered on a daily basis via g-tube. M.K. uses the ventilator for approximately 10 hours per night and 1-3 hours during the day upon her return from school.

26(d). M.K. requires a hospital level of care as opposed to a nursing facility level of care.

26(e). The alternative to M.K.'s skilled nursing care at her residence is inpatient hospitalization at Children's Memorial Hospital. Dr. Gregory A. Summers, Michelle's treating physician has stated that Michelle's alternative to medical home care is admission to Children's Memorial Hospital.

26(f) The family income of M.K. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 229,000 to provide community based medical /

nursing care in her home.

26(g) M.K. resides with her parents and sister in Bartlett, Illinois. She is in Junior High and enjoys attending school. She enjoys piano lessons, listening to Eargon audio books and is interested in dating.

26(h) M.K. brings this action through her parents, Bradley Kish and Mary Kish.

Plaintiff X.N.

27(a). The Plaintiff, X.N.. is a three year old boy and is medically fragile and currently receives funding from the Defendant for approximately 16 hours a day of skilled nursing services at his home (112 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

27(b). X.N. was born premature with chronic lung diseases (BPD/bronchopulmonary dysplasia) and grade III IVH. He is ventilator dependent 24 hours per day. He has static encephalopathy and stable crowding of his postier fossa.

27(c). X.N. requires daily tracheal, oral and nasal suctioning. He has pulmonary hypertension. X.N. requires close monitoring of his respiratory, neurological and hemodynamic status. His vitals are assessed every 4 hours during shift nursing care. He has aspiration precautions (head of bed elevated), vented G-tube and Farrell bag). He receives bolus, G-tube feedings every 4 hours and baby foods via G-tube, one hour prior to scheduled formula feedings. Medications are administered via G-tube.

27(d). X.N. is completely dependent in all activities of daily living. He has quadriplegia, spasticity (extremities), muscle weakness, hypotonia (trunk) and poor head control. X.N. has

diffuse osteopenia (fragile bones) and a history of leg fractures due to bone demineralization. He is non-ambulatory and is non-verbal.

27(e). X.N. requires a hospital level of care as opposed to a nursing facility level of care.

27(f). The alternative to X.N.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

27(g) The family income of X.N. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 276,000 to provide community based medical / nursing care in his home.

27(h) X.N. resides with his parents in Berwyn, Illinois. X.N. is alert and is becoming more aware of his surroundings. He loves to be held and he responds to touch and play.

27(i) X.N. brings this action through his parents, Franciso Nevarez and Lisette Nevarez.

Plaintiff S.P.

28(a). The Plaintiff, S.P. is a five year old girl and is medically fragile and currently receives funding from the Defendant for approximately 18 hours a day of skilled nursing services at her home (127 hours per week) plus she is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

28(b). S.P. has multiple diagnoses including congenital central hypoventilation syndrome, chronic respiratory failure, laryngeal stenosis, pituitary cyst, 24 hour ventilator dependence, hyperglycemia, seizure disorder and gastroesophageal reflux.

28(c). S.P. requires intensive vigilant nursing care. Skilled shift nursing is prescribed for close monitoring of oxygen saturations and end tidal carbon dioxide levels as well as

interventions based upon these levels according to an intricate ventilator “ladder.” Due to her history of frequent episodes of hypercarbia, she must constantly be monitored. Additionally, since she is a very active child, she must also be continually monitored to ensure a patent airway and to ensure that she does not disconnect herself from her ventilator. Skilled shift nursing is also prescribed for tracheostomy care, gastrostomy tube care, and administration of medications. The ventilator ladder has allowed S.P. to be cared for at home when she has had respiratory symptoms.

28(d). S.P. requires a hospital level of care as opposed to a nursing facility level of care.

28(e). The alternative to S.P.’s skilled nursing care at her residence is inpatient hospitalization at Children’s Memorial Hospital.

28(f) The family income of S.P. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 276,000 to provide community based medical / nursing care in her home.

28(g) S.P. resides with her parents and two brothers in Lisle, Illinois.

28(h) S.P. brings this action through her parents, Frank Peterson and Corelyn Peterson.

Plaintiff O.W.

29(a). The Plaintiff, O.W. is a two year old boy and is medically fragile and currently receives funding from the Defendant for approximately 12 hours a day of skilled nursing services at his home (84 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

29(b). O.W. has a history of intra-ventricular hemorrhage/IVH (grade 1) and ROP (stage

1). He has Hirschprung's Disease, bronchopulmonary dysplasia *BPD and laryngotracheal/stomal/subglottic/trachea stenosis. He has been tracheostomy and gastrostomy dependent since 8/6/10.

29(c). O.W. utilizes a 4.0 NEO Bivona trach tube. He has a productive cough but also requires daily suctioning, the frequency of which varies greatly. Bronchoscopy revealed laryngotracheal stenosis, laryngopharyngeal reflux, limited vocal fold motion, stomal/subglottic/tracheal stenosis. O.W. requires high humidity via trach collar or humidvent. He requires continuous pulse oximetry monitoring while sleeping. Oxygen is utilized as needed to maintain saturations greater than 90%. O.W. has reflux and receives bolus G-tube feedings 4 times per day.

29(d). O.W. requires a hospital level of care as opposed to a nursing facility level of care.

29(e). The alternative to O.W.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

29(f) The family income of O.W. is greater than 500%. The family income is unable to pay the approximate annual cost of \$ 144,000 to provide community based medical / nursing care to O.W.

29(g) O.W. resides with his parents in Chicago, Illinois. O.W. is an alert, active toddler and is ambulatory.

29(h) O.W. brings this action through his parents, Jeffrey Wellman and Amy Wellman.

Defendant

30. The Defendant, Julie Hamos, is the Director of the Illinois Department of Healthcare and Family Services (HFS) and is being sued in her official capacity.

IV. CLASS ACTION ALLEGATIONS

31. Plaintiffs bring this action on behalf of themselves and as a class action pursuant to Rule 23(b)(2) of the Federal Rules of Civil Procedure.

32. The Class consists of the following:

All medically fragile and technology dependent children who are either enrolled or seek enrollment in either the State of Illinois' Medically Fragile, Technology Dependent Medicaid Waiver (MF/TD) or who are either enrolled or seek enrollment under the State of Illinois Medicaid (Private Duty Nursing - "PDN") Services for children, who receive in-home services but do not meet the institutional level of care to qualify for services under the MF/TD Waiver.

33. The Class is so numerous that joinder of all persons is impracticable. The Defendant, the Illinois Department of Healthcare and Family Services has stated in June, 2012, the following:

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.¹²

The Defendant has also prepared a "Fact Sheet" for both programs for fiscal year 2010 which reflects that 622 were enrolled in the MF/TD Waiver and 527 persons were enrolled in the Private Duty Nursing (PDN) Services for Children. See:

www.hfs.illinois.gov/assets/ccmn_mftd_hcbs_factsheet.pdf and

www.hfs.illinois.gov/assets/ccmn_pdnfactsheet.pdf

¹² 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)

34. The claims of the class members raise common questions of law and fact. These include:

(a) Whether the Defendant violated the ADA and Rehabilitation Act for medically fragile and technology dependent children by reducing the level of funding to a nursing facility level of care as opposed to a hospital level of care rate which places the Plaintiffs and Class at risk of institutionalization.

(b) Whether the Defendant violated the ADA and Rehabilitation Act for medically fragile and technology dependent children by reducing the level of funding to a nursing facility level of care as opposed to a hospital level of care rate and whether the reduction results in the denial of medically necessary services and a risk of institutionalization.

(c) Whether the Defendant violated the ADA and Rehabilitation Act for medically fragile and technology dependent children by excluding all medical fragile children with parental incomes exceeding 500% of the federal poverty rate for home and community-based services.

(d) Whether the ADA and Rehabilitation Act permits the Defendant to reduce the level of funding to a nursing facility level of care as opposed to a hospital level of care which results in a reduction of medical services for disabled persons even though there has been no change in their medical needs.

(e) Whether a fundamental alteration of the Illinois disability programs would occur if the Defendant provided funding to continue the same level of services for the Plaintiffs and the putative class.

(f) Whether the Illinois disability programs can reasonable accommodate a modification to their existing programs to allow the Plaintiff and putative class to continue to

receive the same level of care in the community.

(g) Whether the Medicaid Act permits Illinois to impose cost sharing or co pays on children with parental incomes exceeding 150% of the federal poverty rate for home and community-based services.

(h) Whether the Early and Periodic Screening, Diagnostic, and Treatment Services (EPSDT) provisions are mandated by a person's enrollment in the MF/TD Waiver and whether the EPSDT provisions require the furnishing of all medically necessary skilled nursing services irrespective of whether there is a cap or limit on skilled nursing services based on a nursing facility level of care.

The common questions of fact and law predominate over questions affecting only individual class members.

35. The Plaintiffs' claims are typical of the class members' claims because they are based on the same factual, legal and remedial theories as the claims of the Plaintiff Class. The Plaintiffs' and Class members are qualified persons with a disability under the ADA and Section 504 of the Rehabilitation Act.

36. The Plaintiffs' are adequate representatives of the class because they suffer from deprivations identical to those of the class members and has been denied the same federal rights that they seek to enforce on behalf of the other class members. The Plaintiffs' will fairly and adequately represent the interests of the other class members, many of whom are unable to pursue claims on their own behalf as the result of their disabilities. Plaintiffs' interest in obtaining injunctive relief for the violations of federal law are consistent with and not antagonistic to those of any person within the class. Plaintiffs' counsel are qualified, experienced

and able to conduct the proposed litigation.

37. A class action is superior to other available methods for the fair and efficient adjudication of the controversy in that:

- (i) A multiplicity of suits with consequent burden on the courts and defendants should be avoided.
- (ii) It would be virtually impossible for all class members to intervene as parties-plaintiffs in this action.

38. The Defendant has acted or refused to act on grounds applicable to the Class, thereby making appropriate final injunctive and declaratory relief with respect to the Class as a whole.

V. STATEMENT OF FACTS

A. Plaintiff T.B.

39(a). The Plaintiff, T.B. is a five year old boy and is medically fragile and currently receives funding from the Defendant for approximately 14 hours a day of skilled nursing services at his home (99 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

39(b). T.B. has diagnoses of congenital high airway obstruction syndrome (CHAOS), bronchomalacia, tracheomalacia, horseshoe kidney, hypospadias with bilateral cryptorchidism, and vertebral anomalies of the thoracic spine. He has a tracheostomy and is vent dependent when sleeping. He is monitored during the awake hours for the need for intermittent use of the vent.

39(c). T.B. requires a hospital level of care as opposed to a nursing facility level of care.

39(d). The alternative to T.B.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

39(e) T.B. resides with his parents and brother in Oak Forest, Illinois. T.B. receives home based educational services for one hour 3 days a week and 2.5 hours 2 days a week. T.B. is functioning above grade level and doing some reading.

40. T.B.'s funding from the State of Illinois is approximately \$228,000 per year (\$19,000 per month), so that he does not have to be institutionalized or hospitalized his entire life at a rate of approximately \$672,000 per year (\$ 56,000 per month). At the time of the filing of this lawsuit, T.B' funding came 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.

41. T.B. currently needs, 14 or more hours of skilled nursing services per day and funding for this skilled nursing level of care in order that he may remain in the community and not be institutionalized in a hospital.

42. If T.B. does not maintain at a minimum the same level of nursing and home health care services which he currently receives, then T.B. will be forced to either be institutionalized in a hospital to receive the necessary services or if he remains living at home with reduced services then he faces a strong possibility of imminent death.

43. T.B. is requesting injunctive relief to require the Defendant to provide funding to maintain the same level of skilled nursing care and Medicaid benefits which he received prior to the passage of the SMART Act and prior to the recent State's efforts to amend the State Medicaid Plan and renew the MF/TD Waiver in order that he may remain in the community and

not be institutionalized or hospitalized for his entire life. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and violates the Medicaid Act.

44. T.B. is an individual with a disability.

45. T.B. is a recipient of Medical Assistance, commonly known as Medicaid.

B. Plaintiff Q.G.

46(a). The Plaintiff, Q.G. is a one year old boy and is medically fragile and currently receives funding from the Defendant for approximately 16 hours a day of skilled nursing services at his home (112 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

46(b). Q.G. has multiple medical diagnoses including: 24 week gestation/prematurity, chronic lung diseases, ROP, ASD, pulmonary hypertension, g-tube, s/p tracheostomy, 24 hour ventilator dependence and GERD. He requires care to monitor his Re: respiratory status, ventilator and tracheostomy. He also requires administration of g-tube feeds every four hours.

46(c). Q.G. requires a hospital level of care as opposed to a nursing facility level of care.

46(d). The alternative to Q.G.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

46(e) Q.G. resides with his parents in Chicago, Illinois. Q.G. is a very friendly baby. He smiles and enjoys playing with his toys and engaging with others.

47. Q.G.'s funding from the State of Illinois is approximately \$276,000 per year

(\$23,000 per month), so that he does not have to be institutionalized or hospitalized his entire life at a rate of approximately \$672,000 per year (\$ 56,000 per month). At the time of the filing of this lawsuit, Q.G.'s funding came 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.

48. Q.G. currently needs, 16 hours of skilled nursing services per day and funding for this skilled nursing level of care in order that he may remain in the community and not be institutionalized in a hospital.

49. If Q.G. does not maintain at a minimum the same level of nursing and home health care services which he currently receives, then Q.G. will be forced to either be institutionalized in a hospital to receive the necessary services or if he remains living at home with reduced services then he faces a strong possibility of imminent death.

50. Q.G. is requesting injunctive relief to require the Defendant to provide funding to maintain the same level of skilled nursing care and Medicaid benefits which he received prior to the passage of the SMART Act and prior to the recent State's efforts to amend the State Medicaid Plan and renew the MFTD Waiver in order that he may remain in the community and not be institutionalized or hospitalized for his entire life. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and violates the Medicaid Act.

51. Q.G. is an individual with a disability.

52. Q.G. is a recipient of Medical Assistance, commonly known as Medicaid.

C. Plaintiff M.K.

53(a). The Plaintiff, M.K. is a fifteen year old girl and is medically fragile and currently receives funding from the Defendant for approximately 18 hours a day of skilled nursing services at her home (126 hours per week) plus she is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

53(b). M.K. is diagnosed with Hallerman Strieff Syndrome, Growth Disorder, Short Statute, Chronic Respiratory Failure, Chronic Lung Disease, Sleep Apnea, Choanal Stenosis (narrowing of the nostrils), Bilateral Cataracts, Glaucoma, Small Eyes, Seizure Disorder, Gastroesophageal Reflux, Microgastria, Conductive Hearing Loss, Cholesteatoma, Mitral Regurgitation, Mitral Value Prolapse, Mild Cardiomyopathy, High Blood Pressure, Developmental Delay, Alopecia, and Atopic Dermatitis.

53(c). M.K. requires intensive vigilant nursing care that consists of: tracheostomy care, monitoring of respiratory & cardiac status, suctioning, monitoring of fragile status of g-button and trach, meticulous skin care including many tropical creams/ointments that are applied daily, and several medications are administered on a daily basis via g-tube. M.K. uses the ventilator for approximately 10 hours per night and 1-3 hours during the day upon her return from school.

53(d). M.K. requires a hospital level of care as opposed to a nursing facility level of care.

53(e). The alternative to M.K.'s skilled nursing care at her residence is inpatient hospitalization at Children's Memorial Hospital. Dr. Gregory A. Summers, Michelle's treating physician has stated that Michelle's alternative to medical home care is admission to Children's Memorial Hospital.

53(f) The family income of M.K. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 229,000 to provide community based medical / nursing care in her home.

53(g) M.K. resides with her parents and sister in Bartlett, Illinois. She is in Junior High and enjoys attending school. She enjoys piano lessons, listening to Eargon audio books and is interested in dating.

54. M.K.'s funding from the State of Illinois is approximately \$229,000 per year (\$19,000 per month), so that she does not have to be institutionalized or hospitalized her entire life at a rate of approximately \$660,000 per year (\$ 55,000 per month). At the time of the filing of this lawsuit, M.K.'s funding came 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.

55. With the passage of the Illinois "Save Medicaid Access and Resources Together (SMART) Act," effective September 1, 2012, medically fragile and technology dependent children, such as M.K., will no longer be eligible for funding and services if her family income exceeds 500% of the federal poverty level.

56. The family income of M.K. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 229,000 to provide community based medical / nursing care in her home.

57. Without continued funding from the MF/TD waiver and Medicaid, her parents will be unable to pay for M.K.'s in home medical / nursing care which she requires.

58 Without continued funding from the MF/TD waiver and Medicaid, her parents will be

unable to pay for M.K.'s in home medical / nursing care and she faces a risk of institutionalization because her parents cannot provide the nursing care which she medically requires.

59. M.K. currently needs, 18 hours of skilled nursing services per day and funding for this skilled nursing level of care in order that she may remain in the community and not be institutionalized in a hospital.

60. If M.K. does not maintain at a minimum the same level of nursing and home health care services which she currently receives, then M.K. will be forced to either be institutionalized in a hospital to receive the necessary services or if she remains living at home with reduced services then she faces a strong possibility of imminent death.

61. M.K. is requesting injunctive relief to require the Defendant to provide funding to maintain the same level of skilled nursing care and Medicaid benefits which she received prior to the passage of the SMART Act and prior to the recent State's efforts to amend the State Medicaid Plan and renew the MF/TD Waiver in order that she may remain in the community and not be institutionalized or hospitalized for her entire life. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and violates the Medicaid Act.

62. M.K. is an individual with a disability.

63. M.K. is a recipient of Medical Assistance, commonly known as Medicaid.

D. Plaintiff X.N.

64(a). The Plaintiff, X.N. is a three year old boy and is medically fragile and currently

receives funding from the Defendant for approximately 16 hours a day of skilled nursing services at his home (112 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

64(b). X.N. was born premature with chronic lung diseases (BPD/bronchopulmonary dysplasia) and grade III IVH. He is ventilator dependent 24 hours per day. He has static encephalopathy and stable crowding of his posterior fossa.

64(c). X.N. requires daily tracheal, oral and nasal suctioning. He has pulmonary hypertension. X.N. requires close monitoring of his respiratory, neurological and hemodynamic status. His vitals are assessed every 4 hours during shift nursing care. He has aspiration precautions (head of bed elevated), vented G-tube and Farrell bag. He receives bolus, G-tube feedings every 4 hours and baby foods via G-tube, one hour prior to schedule formula feedings. Medications are administered via G-tube.

64(d). X.N. is completely dependent in all activities of daily living. He has quadriplegia, spasticity (extremities), muscle weakness, hypotonia (trunk) and poor head control. X.N. has diffuse osteopenia (fragile bones) and a history of leg fractures due to bone demineralization. He is non-ambulatory and is non-verbal.

64(e). X.N. requires a hospital level of care as opposed to a nursing facility level of care.

64(f). The alternative to X.N.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

64(g) The family income of X.N. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 276,000 to provide community based medical /

nursing care in his home.

64(h) X.N. resides with his parents in Berwyn, Illinois. X.N. is alert and is becoming more aware of his surroundings. He loves to be held and he responds to touch and play.

65. X.N.'s funding from the State of Illinois is approximately \$276,000 per year (\$23,000 per month), so that he does not have to be institutionalized or hospitalized his entire life at a rate of approximately \$672,000 per year (\$ 56,000 per month). At the time of the filing of this lawsuit, X.N.'s funding came 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.

66. With the passage of the Illinois "Save Medicaid Access and Resources Together (SMART) Act," effective September 1, 2012, medically fragile and technology dependent children, such as X.N., will no longer be eligible for funding and services if his family income exceeds 500% of the federal poverty level.

67. The family income of X.N. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 276,000 to provide community based medical / nursing care in his home.

68. Without continued funding from the MF/TD waiver and Medicaid, his parents will be unable to pay for X.N.'s in home medical / nursing care which she requires.

69 Without continued funding from the MF/TD waiver and Medicaid, his parents will be unable to pay for X.N.'s in home medical / nursing care and he faces a risk of institutionalization because his parents cannot provide the nursing care which he medically requires.

70. X.N. currently needs, 16 hours of skilled nursing services per day and funding for this

skilled nursing level of care in order that he may remain in the community and not be institutionalized in a hospital.

71. If X.N. does not maintain at a minimum the same level of nursing and home health care services which he currently receives, then X.N. will be forced to either be institutionalized in a hospital to receive the necessary services or if he remains living at home with reduced services then he faces a strong possibility of imminent death.

72. X.N. is requesting injunctive relief to require the Defendant to provide funding to maintain the same level of skilled nursing care and Medicaid benefits which he received prior to the passage of the SMART Act and prior to the recent State's efforts to amend the State Medicaid Plan and renew the MFTD Waiver in order that he may remain in the community and not be institutionalized or hospitalized for his entire life. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and violates the Medicaid Act.

73. X.N. is an individual with a disability.

74. X.N. is a recipient of Medical Assistance, commonly known as Medicaid.

E. Plaintiff S.P.

75(a). The Plaintiff, S.P. is a five year old girl and is medically fragile and currently receives funding from the Defendant for approximately 18 hours a day of skilled nursing services at her home (127 hours per week) plus she is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

75(b). S.P. has multiple diagnoses including congenital central hypoventilation syndrome, chronic respiratory failure, laryngeal stenosis, pituitary cyst, 24 hour ventilator dependence, hyperglycemia, seizure disorder and gastroesophageal reflux.

75(c). S.P. requires intensive vigilant nursing care. Skilled shift nursing is prescribed for close monitoring of oxygen saturations and end tidal carbon dioxide levels as well as interventions based upon these levels according to an intricate ventilator “ladder.” Due to her history of frequent episodes of hypercarbia, she must constantly be monitored. Additionally, since she is a very active child, she must also be continually monitored to ensure a patent airway and to ensure that she does not disconnect herself from her ventilator. Skilled shift nursing is also prescribed for tracheostomy care, gastrostomy tube care, and administration of medications. The ventilator ladder has allowed S.P. to be cared for at home when she has had respiratory symptoms.

75(d). S.P. requires a hospital level of care as opposed to a nursing facility level of care.

75(e). The alternative to S.P.’s skilled nursing care at her residence is inpatient hospitalization at Children’s Memorial Hospital.

75(f) The family income of S.P. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 276,000 to provide community based medical / nursing care in her home.

75(g) S.P. resides with her parents and two brothers in Lisle, Illinois.

76. S.P.’s funding from the State of Illinois is approximately \$276,000 per year (\$23,000 per month), so that she does not have to be institutionalized or hospitalized her entire life at a rate of approximately \$672,000 per year (\$ 56,000 per month). At the time of the filing of this

lawsuit, S.P.'s funding came 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.

77. With the passage of the Illinois "Save Medicaid Access and Resources Together (SMART) Act," effective September 1, 2012, medically fragile and technology dependent children, such as S.P. will no longer be eligible for funding and services if her family income exceeds 500% of the federal poverty level.

78. The family income of S.P. is greater than 500% of the federal poverty level and is less than the approximate annual cost of \$ 276,000 to provide community based medical / nursing care in her home.

79. Without continued funding from the MF/TD waiver and Medicaid, her parents will be unable to pay for S.P.'s in home medical / nursing care which she requires.

80. Without continued funding from the MF/TD waiver and Medicaid, her parents will be unable to pay for S.P.'s in home medical / nursing care and she faces a risk of institutionalization because her parents cannot provide the nursing care which she medically requires.

81. S.P. currently needs, at a minimum, approximately 18 hours of skilled nursing services per day and funding for this skilled nursing level of care in order that she may remain in the community and not be institutionalized in a hospital.

82. If S.P. does not maintain at a minimum the same level of nursing and home health care services which she currently receives, then X.N. will be forced to either be institutionalized in a hospital to receive the necessary services or if she remains living at home with reduced

services then she faces a strong possibility of imminent death.

83. S.P. is requesting injunctive relief to require the Defendant to provide funding to maintain the same level of skilled nursing care and Medicaid benefits which she received prior to the passage of the SMART Act and prior to the recent State's efforts to amend the State Medicaid Plan and renew the MF/TD Waiver in order that she may remain in the community and not be institutionalized or hospitalized for her entire life. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and violates the Medicaid Act.

84. S.P. is an individual with a disability.

85. S.P. is a recipient of Medical Assistance, commonly known as Medicaid.

F. Plaintiff O.W.

86(a). The Plaintiff, O.W. is a two year old boy and is medically fragile and currently receives funding from the Defendant for approximately 12 hours a day of skilled nursing services at his home (84 hours per week) plus he is eligible for 336 respite skilled nursing hours per year. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

86(b). O.W. has a history of intra-ventricular hemorrhage/IVH (grade 1) and ROP (stage 1). He has Hirschprung's Disease, bronchopulmonary dysplasia *BPD) and laryngotracheal/stomal/subglottic/trachea stenosis. He has been tracheostomy and gastrostomy dependent since 8/6/10.

86(c). O.W. utilizes a 4.0 NEO Bivona trach tube. He has a productive cough but also

requires daily suctioning, the frequency of which varies greatly. Bronchoscopy revealed laryngotracheal stenosis, laryngopharyngeal reflux, limited vocal fold motion, stomal/subglottic/tracheal stenosis. O.W. requires high humidity via trach collar or humidvent. He requires continuous pulse oximetry monitoring while sleeping. Oxygen is utilized as needed to maintain saturations greater than 90%. O.W. has reflux and receives bolus G-tube feedings 4 times per day.

86(d). O.W. requires a hospital level of care as opposed to a nursing facility level of care.

86(e). The alternative to O.W.'s skilled nursing care at his residence is inpatient hospitalization at Children's Memorial Hospital.

86(f). The family income of O.W. is greater than 500%. The family income is unable to pay the approximate annual cost of \$ 144,000 to provide community based medical / nursing care to O.W.

86(g). O.W. resides with his parents in Chicago, Illinois. O.W. is an alert, active toddler and is ambulatory.

87. O.W.'s funding from the State of Illinois is approximately \$144,000 per year (\$12,000 per month), so that he does not have to be institutionalized or hospitalized his entire life at a rate of approximately \$504,000 per year (\$ 42,000 per month). At the time of the filing of this lawsuit, O.W.'s funding came 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.

88. With the passage of the Illinois "Save Medicaid Access and Resources Together (SMART) Act," effective September 1, 2012, medically fragile and technology dependent

children, such as O.W. will no longer be eligible for funding and services if his family income exceeds 500% of the federal poverty level.

89. The family income of O.W. is greater than 500% of the federal poverty level and the family income is unable to pay the approximate annual cost of \$ 144,000 to provide community based medical / nursing care to O.W.

90. Without continued funding from the MF/TD waiver and Medicaid, his parents will be unable to pay for O.W.'s in home medical / nursing care which she requires.

91. Without continued funding from the MF/TD waiver and Medicaid, his parents will be unable to pay for O.W.'s in home medical / nursing care and he faces a risk of institutionalization because his parents cannot provide the nursing care which he medically requires.

92. O.W. currently needs, 12 hours of skilled nursing services per day and funding for this skilled nursing level of care in order that he may remain in the community and not be institutionalized in a hospital.

93. If O.W. does not maintain at a minimum the same level of nursing and home health care services which he currently receives, then O.W. will be forced to either be institutionalized in a hospital to receive the necessary services or if he remains living at home with reduced services then he faces a strong possibility of imminent death.

94. O.W. is requesting injunctive relief to require the Defendant to provide funding to maintain the same level of skilled nursing care and Medicaid benefits which he received prior to the passage of the SMART Act and prior to the recent State's efforts to amend the State Medicaid Plan and renew the MFTD Waiver in order that he may remain in the community and

not be institutionalized or hospitalized for his entire life. The actions of the Defendant constitute unlawful discrimination under Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132, and Section 504 of the Rehabilitation Act, 29 U.S.C. Sec. 794(a) and violates the Medicaid Act.

95. O.W. is an individual with a disability.

96. O.W. is a recipient of Medical Assistance, commonly known as Medicaid.

G. The Federal/State Medical Assistance Program

97. Medical Assistance, commonly known as Medicaid, is a joint federal and state funded program enacted to provide necessary medical assistance to needy aged or disabled persons and families with dependent children, whose income and resources are insufficient to meet the cost of care. 42 U.S.C. Sec. 1396. States choosing to participate in the Medicaid program must operate the program in conformity with federal statutory and regulatory requirements. 42 U.S.C. Sec. 1396a.

98. Each State participating in the Medicaid program must submit a Medicaid plan to the Secretary of Health and Human Services (HHS) for approval. 42 U.S.C. Sec. 1396.

99. Each State must designate a single state agency to administer and / or supervise the administration of the state's Medicaid plan. 42 U.S.C. Sec. 1396a(a)(5).

100. In Illinois, the Department of Healthcare and Family Services (HFS) is the single state agency responsible for administering the Medicaid program.

101. States have the option of covering persons needing home-and-community-based services, if these persons would otherwise require institutional care that would be paid for by Medicaid. 42 U.S.C. Sec. 1396n(c)(1). Under this waiver authority, the Secretary of HHS may

grant waivers of specified requirements like service limitations that are otherwise applicable to the State's Medicaid plan. 42 U.S.C. Sec. 1396n(c)(3). Waiver programs must be cost-neutral in that the average cost of providing care for program participants in the home or community based setting must not exceed the estimated average cost of providing care in the institutional setting they would require. 42 U.S.C. Sec. 1396n(c)(2)(D); 42 C.F.R. Sec. 441.302(e).

102. Illinois has implemented a total of nine (9) federally approved home-and-community-based care waiver programs in its Medicaid program which were approved by the Secretary of Health & Human Services (HHS). One of the nine waiver programs is the following:

- Children that are Technology Dependent / Medically Fragile (MF/TD)

H. Medically Fragile / Technology Dependent Program (MF/TD).

103. Under the waiver for Medically Fragile, Technology Dependent Children, Illinois pays for home-based care for children under age 21 who have exceptional medical needs. The Illinois Department of Healthcare and Family Services (HFS) administers this waiver program with participation of the University of Illinois' Division of Specialized Services for Children (DSCC) under an agreement with HFS.

104. The Illinois Medicaid Home and Community-Based Services ("HCBS") waives, which includes the MF/TD waiver, allows the State of Illinois to provide services to persons, like the Plaintiffs and putative class, in an individual's home or community as long as those services prevent the individual from being institutionalized or hospitalized.

105. The MF/TD waiver for children serves persons under 21 years of age who would require institutional care in a hospital or nursing facility, if nursing and waiver services were not

provided in the home. Cost-effectiveness for eligibility is compared to service costs in a hospital or nursing facility. The primary expenditure for children in the MF/TD waiver is skilled nursing.

I. Illinois Seeks To Renew MF/TD Waiver & Seeks To Amend the Illinois State Medicaid Plan With Significant Adverse Changes To Medically Fragile Children.

106. The current MF/TD Waiver expires on August 31, 2012.

107. The State of Illinois seeks to renew the MF/TD Waiver and seeks to amend the Illinois State Medicaid Plan which will eliminate or reduce the medically necessary home and community-based services to medically fragile children which existed prior to June 1, 2012. The Defendant proposes to make the following changes to the MF/TD Waiver and/or State Medicaid Plan:

- a) Medically Fragile Children Are Now Limited To A Nursing Facility Level Of Care Rate As Opposed To A Hospital Level of Care Rate.
- b) Illinois Excludes All Medical 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.
- 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.

J. EPSDT Program

108. Federal law requires States to fully implement the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) program of Medicaid. 42 U.S.C. Sec. 1396a(a)(43); 43 U.S.C. Sec. 1396d(a)(4)(B); 42 U.S.C. Sec. 1396d(r). The purpose of the ESPDT program is to

ascertain children’s physical and mental health conditions and ensure children receive needed services “to correct or ameliorate defects and physical and mental illnesses and conditions . . .” 42 U.S.C. Sec. 1396d(r)(5). Under EPSDT, States are required to provide screening services to identify health and mental health conditions and illness. 42 U.S.C. Sec. 1396d(r)(1). States must also provide needed diagnostic and treatment services to correct or ameliorate health or mental health conditions. 42 U.S.C. Sec. 1396a(a)(43)(C); 42 U.S.C. Sec. 1396d(r)(5). Needed services must be provided whether or not such services are included in the state plan. 42 U.S.C. Sec. 1396d(r)(5); 42 C.F.R. Sec. 441.56(c).

109. EPSDT requires the State of Illinois to provide or arrange for the provision of covered EPSDT services. Subsection (B) of 42 U.S.C. Sec. 1396a(a)(43) states that a state plan must “provide for . . . providing or arranging for the provision of such screening services in all cases where they are requested[.]” 42 U.S.C. Sec. 1396a(a)(43)(B). Subsection (C) states that a state plan for medical assistance must “provide for . . . arranging for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment the need for which is disclosed by such child health screening services.” 42 U.S.C. Sec. 1396a(a)(43)(C). The ESPDT provisions obligates the State of Illinois to ensure that medically necessary services are available, accessible and provided, either by providing them directly or by arranging for them through “appropriate agencies, organizations, or individuals[.]” 42 U.S.C. Sec. 1396a(a)(43).

110. The State of Illinois has an obligation to ensure that all services required by the ESPDT provisions are being provided to Medicaid-eligible children effectively.

111. Illinois has chosen to participate in the Medicaid program; and therefore must provide EPSDT services to eligible children under the age of 21.

112. For children who have been determined to have extensive medical needs, requiring ongoing skilled nursing in the home setting, they are entitled to EPSDT services if they meet Medicaid eligibility.

113. A child found eligible for the MF/TD Waiver is eligible for EPSDT services.

114. The State of Illinois is attempting to cap or limit the level of EPSDT services for medically fragile children by limiting the services at a nursing facility rate as opposed to a hospital level of care.

115. EPSDT services for medically fragile children who qualify for Medicaid cannot be limited or capped if the services are medically necessary for the child.

116. That upon information and belief, the highest nursing facility rate is approximately \$9,400 per month, which means that funding for skilled nursing for medically fragile children could not be in excess of \$9,400 per month.

117. For fiscal year 2010, the average cost per person in the MF/TD Waiver was \$188,210 per year which equals an average monthly rate of \$15,684.

See: www.hfs.illinois.gov/assets/ccmn_mftd_hcbs_factsheet.pdf

118. For fiscal year 2010, the average cost per person receiving Private Duty Nursing (PDN) Services for children under the age of 21 was \$133,899 per year which equals an average monthly rate of \$11,158. See: www.hfs.illinois.gov/assets/ccmn_pdnfactsheet.pdf.

K. T.B.'s Current Medical Plan

119. Currently, HFS provides a medical plan for T.B that is medically necessary and a cost-effective alternative to care in the institutional setting that HFS determined T.B. would otherwise require.

120. HFS has determined that T.B. has a hospital need for care.

121 Through the MF/TD waiver and Medicaid, HFS pays for skilled nursing care which T.B. needs in his home.

122. HFS approved and pays for approximately \$19,000.00 of monthly in home medical services for T.B., which includes services provided by a registered nurse and a licensed practical nurse.

123. T.B.'s current level of services is based upon a determination made by DSCC, after a full evaluation of T.B., that he needed that level of care to avoid institutionalization (hospitalization). DSCC concluded that T.B. would require hospitalization at an annual cost that would far exceed the amount he was awarded.

124. The alternative to T.B.' skilled nursing care at his residence is admission to Children's Memorial Hospital.

125. T.B.'s current plan of medical care provides for in- home skilled nursing services of 99 hours per week plus 336 hours of home nursing care annually for respite services. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

126. With no modifications in its regulations, and little modifications in its practices, HFS could continue to fund the level of nursing care that T.B. requires in order to remain at home at a cost that is less than would be required to serve him in an appropriate institutional setting for the care he needs.

127. If allowed to go into effect, the proposed reduction in funding for T.B's medical care will ultimately force T.B. into an institutional setting (hospital), isolating him from home

and community, or alternatively, will likely result in his imminent death if he remains in his home without sufficient funding.

L. Q.G.'s Current Medical Plan

128. Currently, HFS provides a medical plan for Q.G. that is medically necessary and a cost-effective alternative to care in the institutional setting that HFS determined Q.G. would otherwise require.

129. HFS has determined that Q.G. has a hospital need for care.

130. Through the MF/TD waiver and Medicaid, HFS pays for skilled nursing care which Q.G. needs in his home.

131. HFS approved and pays for approximately \$23,000.00 of monthly in-home medical services for Q.G., which includes services provided by a registered nurse and a licensed practical nurse.

132. Q.G.'s current level of services is based upon a determination made by DSCC, after a full evaluation of Q.G., that he needed that level of care to avoid institutionalization (hospitalization). DSCC concluded that Q.G. would require hospitalization at an annual cost that would far exceed the amount he was awarded.

133. The alternative to Q.G.'s skilled nursing care at his residence is admission to Children's Memorial Hospital.

134. Q.G.'s current plan of medical care provides for in-home skilled nursing services of 112 hours per week plus 336 hours of home nursing care annually for respite services.

135. With no modifications in its regulations, and little modifications in its practices, HFS could continue to fund the level of nursing care that Q.G. requires in order to remain at

home at a cost that is less than would be required to serve him in an appropriate institutional setting for the care he needs.

136. If allowed to go into effect, the proposed reduction in funding for Q.G.'s medical care will ultimately force Q.G. into an institutional setting (hospital), isolating him from home and community, or alternatively, will likely result in his imminent death if he remains in his home without sufficient funding.

M. M.K.'s Current Medical Plan

137. Currently, HFS provides a medical plan for M.K. that is medically necessary and a cost-effective alternative to care in the institutional setting that HFS determined M.K. would otherwise require.

138. HFS has determined that M.K. has a hospital need for care.

139. Through the MF/TD waiver and Medicaid, HFS pays for skilled nursing care which M.K. needs in her home.

140. HFS approved and pays for approximately \$19,000.00 of monthly in-home medical services for M.K., which includes services provided by a registered nurse and a licensed practical nurse.

141. M.K.'s current level of services is based upon a determination made by DSCC, after a full evaluation of M.K., that she needed that level of care to avoid institutionalization (hospitalization). DSCC concluded that M.K. would require hospitalization at an annual cost that would far exceed the amount she was awarded.

142. The alternative to M.K.'s skilled nursing care at her residence is admission to Children's Memorial Hospital.

143. M.K.'s current plan of medical care provides for in-home skilled nursing services of 126 hours per week plus 336 hours of home nursing care annually for respite services.

144. With no modifications in its regulations, and little modifications in its practices, HFS could continue to fund the level of nursing care that M.K. requires in order to remain at home at a cost that is less than would be required to serve her in an appropriate institutional setting for the care she needs.

145. If allowed to go into effect, the proposed reduction in funding for M.K.'s medical care will ultimately force M.K. into an institutional setting (hospital), isolating her from home and community, or alternatively, will likely result in her imminent death if she remains in her home without sufficient funding.

N. X.N.'s Current Medical Plan

146. Currently, HFS provides a medical plan for X.N. that is medically necessary and a cost-effective alternative to care in the institutional setting that HFS determined X.N. would otherwise require.

147. HFS has determined that X.N. has a hospital need for care.

148. Through the MF/TD waiver and Medicaid, HFS pays for skilled nursing care which X.N. needs in his home.

149. HFS approved and pays for approximately \$23,000.00 of monthly in-home medical services for X.N., which includes services provided by a registered nurse and a licensed practical nurse.

150. X.N.'s current level of services is based upon a determination made by DSCC, after a full evaluation of X.N., that he needed that level of care to avoid institutionalization

(hospitalization). DSCC concluded that X.N. would require hospitalization at an annual cost that would far exceed the amount he was awarded.

151. The alternative to X.N.'s skilled nursing care at his residence is admission to Children's Memorial Hospital.

152. X.N.'s current plan of medical care provides for in-home skilled nursing services of 112 hours per week plus 336 hours of home nursing care annually for respite services. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

153. With no modifications in its regulations, and little modifications in its practices, HFS could continue to fund the level of nursing care that X.N. requires in order to remain at home at a cost that is less than would be required to serve him in an appropriate institutional setting for the care he needs.

154. If allowed to go into effect, the proposed reduction in funding for X.N.'s medical care will ultimately force X.N. into an institutional setting (hospital), isolating him from home and community, or alternatively, will likely result in his imminent death if he remains in his home without sufficient funding.

O. S.P.'s Current Medical Plan

155. Currently, HFS provides a medical plan for S.P. that is medically necessary and a cost-effective alternative to care in the institutional setting that HFS determined S.P. would otherwise require.

156. HFS has determined that S.P. has a hospital need for care.

157 Through the MF/TD waiver and Medicaid, HFS pays for skilled nursing care which

S.P. needs in her home.

158. HFS approved and pays for approximately \$23,000.00 of monthly in-home medical services for S.P., which includes services provided by a registered nurse and a licensed practical nurse.

159. S.P.'s current level of services is based upon a determination made by DSCC, after a full evaluation of S.P., that she needed that level of care to avoid institutionalization (hospitalization). DSCC concluded that S.P. would require hospitalization at an annual cost that would far exceed the amount she was awarded.

160. The alternative to S.P.'s skilled nursing care at her residence is admission to Children's Memorial Hospital.

161. S.P.'s current plan of medical care provides for in home skilled nursing services of 127 hours per week plus 336 hours of home nursing care annually for respite services.

162. With no modifications in its regulations, and little modifications in its practices, HFS could continue to fund the level of nursing care that S.P. requires in order to remain at home at a cost that is less than would be required to serve her in an appropriate institutional setting for the care she needs.

163. If allowed to go into effect, the proposed reduction in funding for S.P.'s medical care will ultimately force S.P. into an institutional setting (hospital), isolating her from home and community, or alternatively, will likely result in her imminent death if she remains in her home without sufficient funding.

P. O.W's Current Medical Plan

164. Currently, HFS provides a medical plan for O.W. that is medically necessary and a cost-

effective alternative to care in the institutional setting that HFS determined O.W. would otherwise require.

165. HFS has determined that O.W. has a hospital need for care.

166. Through the MF/TD waiver and Medicaid, HFS pays for skilled nursing care which O.W. needs in his home.

167. HFS approved and pays for approximately \$12,000.00 of monthly in-home medical services for O.W., which includes services provided by a registered nurse and a licensed practical nurse.

168. O.W.'s current level of services is based upon a determination made by DSCC, after a full evaluation of O.W., that he needed that level of care to avoid institutionalization (hospitalization). DSCC concluded that O.W. would require hospitalization at an annual cost that would far exceed the amount he was awarded.

169. The alternative to O.W.'s skilled nursing care at his residence is admission to Children's Memorial Hospital.

170. O.W.'s current plan of medical care provides for in home skilled nursing services of 84 hours per week plus 336 hours of home nursing care annually for respite services. These nursing services are either provided by a registered nurse (RN) or a licensed practical nurse (LPN).

171. With no modifications in its regulations, and little modifications in its practices, HFS could continue to fund the level of nursing care that O.W. requires in order to remain at home at a cost that is less than would be required to serve him in an appropriate institutional setting for the care he needs.

172. If allowed to go into effect, the proposed reduction in funding for O.W.'s medical care

will ultimately force O.W. into an institutional setting (hospital), isolating him from home and community, or alternatively, will likely result in his imminent death if he remains in his home without sufficient funding.

COUNT I

**VIOLATION OF AMERICAN WITH DISABILITIES ACT (ADA)
AND 42 U.S.C SECTION 1983**

173. The Plaintiffs repeats and incorporates by reference as though fully set forth here the facts contained in paragraphs 1 through 172 above.

174. Title II of the American with Disabilities Act (ADA) provides that no qualified person with a disability shall be subjected to discrimination by a public entity. 42 U.S.C. Sec. 42 U.S.C. Sec. 12132. A public entitle shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R. Sec. 35.130(d) (1998). Policies and practices that have the effects of unjustifiably segregating persons with disabilities in institutions constitute prohibited discrimination under the ADA.

175. The Plaintiffs are qualified individuals with disabilities within the meaning of Title II of the ADA.

176. The Illinois Department of Healthcare and Family Services of which Defendant Hamos is Director is a “public entity” within the meaning of Title II of the ADA.

177. The actions by HFS constitute unlawful discrimination under 42 U.S.C. Sec. 12132 and violate the integration mandate of the regulations implementing this statutory prohibitions. 28 C.F.R. Sec. 35.130(d).

178. The Defendant’s planned reduced funding or actual reduced funding of the home

nursing and other services which the Plaintiffs need in order to avoid institutionalization, violates Title II of the ADA, 42 U.S.C. Sec. 12132 and its implementing regulation. 28 C.F.R. Sec. 35.130(d).

179. The Defendant has discriminated against the Plaintiffs and Class members in violation of the ADA on the basis of their disabilities by the plan reduction or denying the Plaintiffs and Class members medically necessary services in the community as a reasonable accommodation, resulting in the Plaintiffs and Class members being at risk of unnecessary institutionalization.

180. The Defendant has discriminated against the Plaintiffs and the Class members in violation of the ADA on the basis of their disability by:

- a. Placing the Plaintiffs and Class members at risk of institutionalization by failing to provide Plaintiffs and Class members with appropriate community based services.
- b. Denying the Plaintiffs and Class members medically necessary services resulting in the Plaintiffs and Class members being placed at risk of institutionalization.
- c. Denying the Plaintiffs and Class members access to existing community programs by excluding children with families who have incomes in excess of 500% of the federal poverty rate and placing them at risk of institutionalization.
- d. Placing the Plaintiffs and Class members at risk of institutionalization by imposing cost sharing and co pays on them.

These violations entitle the Plaintiffs and Class members to injunctive and declaratory relief under the ADA.

181. The Plaintiffs and the Class members will suffer irreparable injury if the Defendant is not enjoined from reducing or denying the Plaintiffs and Class Members from their existing benefits of the MF/TD waiver and Medicaid which existed prior to July 1, 2012, as the reductions or planned

reductions will force the Plaintiffs and the Class members into an institution, where they will not receive the most integrated setting appropriate to their needs, or alternatively, the reduced level of funding and remaining at home may lead to their death or serious injury.

182. The Plaintiffs and putative class have no adequate remedy at law.

183. The Plaintiffs are indigent and unable to post bond.

COUNT II

VIOLATION OF REHABILITATION ACT AND 42 U.S.C SECTION 1983

184. The Plaintiffs repeat and incorporate by reference as though fully set forth here the facts contained in paragraphs 1 through 183 above.

185. The Rehabilitation Act, 29 U.S.C. Sec. 794, prohibits public entities and recipients of federal funds from discriminating against any individual by reason of disability. The implementing regulation for the statute requires that public and federally-funded entities provide programs and activities “in the most integrated setting appropriate to the needs of the qualified individual with a disability.” 28 C.F.R. Section 41.51(d). Policies and practices that have the effects of unjustifiably segregating persons with disabilities in institutions constitute prohibited discrimination under the R.A.

186. The Illinois Department of Healthcare and Family Services is a recipient of federal funds under the Rehabilitation Act.

187. The Plaintiffs are qualified individuals with a disability under Section 504 of the Rehabilitation Act.

188. The actions by HFS constitute unlawful discrimination under 29 U.S.C. Sec. 794(a) and violate the integration mandate of the regulations implementing this statutory prohibition. 28 C.F.R.

Sec. 41.51(d).

189. The Defendant's planned reduced funding or actual reduced funding of the home nursing and other services which the Plaintiffs need in order to avoid institutionalization, violates Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. Sec. 794(a) and its implementing regulation. 28 C.F.R. Sec. 41.51(d).

190. The Defendant has discriminated against the Plaintiffs and Class members in violation of Section 504 of the Rehabilitation Act on the basis of their disabilities by the plan reduction or denying the Plaintiffs and Class members medically necessary services in the community as a reasonable accommodation, resulting in the Plaintiffs and Class members being at risk of unnecessary institutionalization.

191. The Defendant has discriminated against the Plaintiffs and the Class members in violation of the ADA on the basis of their disability by:

- a. Placing the Plaintiffs and Class members at risk of institutionalization by failing to provide Plaintiffs and Class members with appropriate community based services.
- b. Denying the Plaintiffs and Class members medically necessary services resulting in the Plaintiffs and Class members being placed at risk of institutionalization.
- c. Denying the Plaintiffs and Class members access to existing community programs by excluding children with families who have incomes in excess of 500% of the federal poverty rate and placing them at risk of institutionalization.
- d. Placing the Plaintiffs and Class members are risk of institutionalization by imposing cost sharing and co pays on them.

These violations entitle the Plaintiffs and Class members to injunctive and declaratory relief under Section 504 of the Rehabilitation Act.

192. The Plaintiffs and the Class members will suffer irreparable injury if the Defendant is not enjoined from reducing or denying the Plaintiffs and Class Members from their existing benefits of the MF/TD waiver and Medicaid which existed prior to July 1, 2012, as the reductions or planned reductions will force the Plaintiffs and the Class members into an institution, where they will not receive the most integrated setting appropriate to their needs, or alternatively, the reduced level of funding and remaining at home may lead to their death or serious injury.

193. The Plaintiffs and putative class have no adequate remedy at law.

194. The Plaintiffs are indigent and unable to post bond.

COUNT III

VIOLATION OF EPSDT AND 42 U.S.C SECTION 1983

195. The Plaintiffs repeat and incorporate by reference as though fully set forth here the facts contained in paragraphs 1 through 194 above.

196. The Defendant's planned reduction or reduction for providing private duty nursing, below the level that is medically necessary, violates the EPSDT provisions of the federal Medicaid statute at 42 U.S.C. Section 1396a(a)(43); 42 U.S.C. Section 1396d(a)(4)(B); and 42 U.S.C. Section 1396d(r). This violation entitles the Plaintiffs and Class members to relief under 42 U.S.C. Section 1983.

197. The Defendant's regulations, rules, policies, procedures, customs and practices for providing private duty nursing, below the level that is medically necessary, violates the EPSDT provisions of the federal Medicaid statute at 42 U.S.C. Section 1396a(a)(43); 42 U.S.C. Section 1396d(a)(4)(B); and 42 U.S.C. Section 1396d(r). This violation entitles the Plaintiffs and Class

members to relief under 42 U.S.C. Section 1983.

198. As a result of the Defendants' violations, the Plaintiffs and Class members have been damaged.

199. The Plaintiffs and the Class members will suffer irreparable injury if the Defendant is not enjoined from reducing or denying the Plaintiffs and Class Members from their existing benefits of the MF/TD waiver and Medicaid which existed prior to July 1, 2012, as the reductions or planned reductions will force the Plaintiffs and the Class members into an institution, where they will not receive the most integrated setting appropriate to their needs, or alternatively, the reduced level of funding and remaining at home may lead to their death or serious injury.

200. The Plaintiffs and putative class have no adequate remedy at law.

201. The Plaintiffs are indigent and unable to post bond.

COUNT IV
VIOLATION OF MEDICAID ACT
AND 42 U.S.C SECTION 1983

202. The Plaintiffs repeat and incorporate by reference as though fully set forth here the facts contained in paragraphs 1 through 201 above.

203. The Defendant's planned reduction or reduction for providing private duty nursing, below the level that is medically necessary, violates the Reasonable Promptness provision of the Medicaid Act, 42 U.S.C. Section 1396a(a)(8). This violation entitles the Plaintiffs and Class members to relief under 42 U.S.C. Section 1983.

204. The Defendant's regulations, rules, policies, procedures, customs and practices which limit the provision of medically necessary community-based services and supports, as well as medically necessary specialized services, results in outright denials of medically necessary care to

the Plaintiffs and Class members. This violation entitles the Plaintiffs and Class members to relief under 42 U.S.C. Section 1983.

205. As a result of the Defendants' violations, the Plaintiffs and Class members have been damaged.

206. The Plaintiffs and the Class members will suffer irreparable injury if the Defendant is not enjoined from reducing or denying the Plaintiffs and Class Members from their existing benefits of the MF/TD waiver and Medicaid which existed prior to July 1, 2012, as the reductions or planned reductions will force the Plaintiffs and the Class members into an institution, where they will not receive the most integrated setting appropriate to their needs, or alternatively, the reduced level of funding and remaining at home may lead to their death or serious injury.

207. The Plaintiffs and putative class have no adequate remedy at law.

208. The Plaintiffs are indigent and unable to post bond.

V. REQUEST FOR RELIEF

WHEREFORE, the Plaintiffs respectfully request that this Court:

(a) Certify this case to proceed as a class action.

(b) Issue a Declaratory Judgment in favor of the Plaintiffs and the Class and that the Defendant's planned reduction or reduction or denying the Plaintiffs and Class members from their existing benefits of the MF/TD waiver and Medicaid 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); Title XIX of the Social Security Act ("Medicaid Act") 42 U.S.C. Sec. 1396 *et. seq*; Early and Periodic Screening, Disagnostic, and Treatment Services, 42 U.S.C. Sec. 1396d(r) ("EPSDT Provisions"); and 42 U.S.C. Section 1983.

(c) Issue Preliminary and Permanent Injunctive relief requiring the Defendant to restore the level of Medicaid funding to maintain the existing medical services for the Plaintiffs and Class members in the MF/TD Waiver and Medicaid. That the Defendant, Julie Hamos, be enjoined from reducing or denying the Plaintiffs and Class their existing benefits of the MF/TD Waiver and Medicaid.

(d) Award Plaintiffs and the Class the costs of this action, including reasonable attorneys fees, pursuant to 42 U.S.C. Section 12205; Section 504 of the Rehabilitation Act, and 42 U.S.C. Section 1988; and

(e) Award such other relief as the Court deems just and appropriate.

Respectfully submitted,

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

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