



2. The Defendant found each of the Plaintiffs and Class eligible for Medicaid-funded in-home shift nursing services, which allow either a nurse (RN), licensed practical nurse (LPN), or a certified nursing assistant (CNA) to provide nursing services in the child's home. However, the Plaintiffs and Class are unable to obtain adequate nursing services due to the Defendant's systemic failure to "arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment [nursing services]", as mandated by the federal Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions of the Medicaid Act. 42 U.S.C. Sec. 1396a(a)(43)(C); 42 U.S.C. Sec. 1396d(r).

3. The Medicaid Act requires the Defendant to proactively arrange for EPSDT services. The Medicaid Act also requires that medically necessary in-home shift nursing services be provided with reasonable promptness. 42 U.S.C. Sec. 1396a(a)(8). However, due to systemic deficiencies in the Defendant's policies, practices, and procedures, the Defendant fails to fulfill these legal obligations and, as result, the Plaintiffs and Class members are going without medically necessary services.

4. The Defendant's deficient systems, policies, practices, and procedures also violate the Americans with Disabilities Act (ADA), the federal Rehabilitation Act and other provisions of the Medicaid Act by failing to arrange for the delivery of in-home shift nursing services, which results in the Plaintiffs and Class members being either institutionalized or facing the serious risk of institutionalization.

5. The Plaintiff O.B. is currently improperly institutionalized (hospitalized) at the Children's Hospital of Illinois (CHOI) in Peoria due to the failure of the Defendant to arrange for adequate in-home shift nursing services. O.B. is enrolled in the Medically Fragile, Technology-Dependent (MFTD) Waiver program, meaning that O.B. requires an institutional level of care.

Upon information and belief from the mother of O.B., there are four other children like O.B. who are currently unable to be discharged from the Children's Hospital of Illinois due to the unavailability of in-home shift nursing services.

- (a) Plaintiff O.B. is 23 months old; he was born prematurely at 34 weeks and has a complex medical history of Down syndrome, pulmonary hypertension, chronic lung disease, patent foramen ovale (PFO), patent ductus arteriosus (PDA), Factor V Leiden-Mutation, and Transient Myeloproliferative disorder. He is tracheostomy- and ventilator-dependent, with a gastrostomy-jejunostomy tube (g-j tube) for nutrition and medication administration.
- (b) O.B. was scheduled to be discharged to his home on March 23, 2015 from the Children's Hospital of Illinois (CHOI) in Peoria, but O.B. has been unable to be discharged from the hospital due to the failure of the Defendant to arrange for the delivery of in-home shift nursing services.
- (c) O.B.'s parents have spent the last nine months searching for adequate in-home nursing services so that O.B. may be safely discharged from CHOI.
- (d) The nursing agency that O.B.'s parents work with has not been able to find nurses to staff O.B.'s case. O.B.'s parents have been unable to find another nursing agency to fully staff the nursing hours that the Defendant approved for O.B.
- (e) In an attempt to find adequate nursing services, O.B.'s mother has also contacted local colleges that have nursing programs. At least three of these colleges sent emails with information about O.B.'s nursing needs to past graduates.

- (f) O.B.'s parents created a Facebook page for O.B. On that Facebook page, O.B.'s parents posted information about O.B.'s need for nursing services, which has been shared widely. That Facebook post has been viewed approximately 42,000 times.
- (g) O.B.'s mother spoke with one nurse who expressed interest in working full-time on O.B.'s case. However, when that nurse found out the pay for O.B.'s care was \$11 less per hour than the hourly pay the nurse received working in a nursing home, the nurse backed out of the position.
- (h) O.B. remains institutionalized (hospitalized) at a cost to the Defendant of approximately \$57,000 per month for just the hospital charges, in contrast to the Defendant's approval for in-home shift nursing services to O.B. at a monthly budget of \$19,718.
- (i) The doctor's charges at the hospital for just the month of May 2015 add an additional \$21,000 to the monthly medical costs for O.B., which means that the approximate hospital and doctor charges during the month of May 2015 was \$78,000 (\$57,000 + \$21,000).
- (j) O.B.'s hospital charges are being paid, at least in part, by a private insurer, as O.B.'s father is an employee of the state of Illinois. However, this private insurer has told O.B.'s parents that they do not cover the long-term private duty nursing services that O.B. requires.
- (k) No nursing agency has been able to provide the approximately 18 hours per day of medically necessary in-home shift nursing services required for the Plaintiff O.B.

6. For months, the Defendant has been aware of O.B.'s inadequate services. The Defendant found in-home shift nursing services to be medically necessary for O.B. in 2014. In the system designed by the Defendant, the University of Illinois Chicago Division of Specialized Care for

Children (DSCC) provides care coordination for O.B.'s in-home skilled nursing services. O.B.'s parents have spoken frequently with their DSCC care coordinator about this issue. On April 7, 2015, DSCC sent a letter to the Defendant regarding O.B. The April 7, 2015 letter stated that no in-home shift nursing services have been provided to O.B. as O.B. remains hospitalized. The April 7, 2015 letter further stated that, "The nursing agency has not been able to fully staff the case, so O.[B.] is still residing at Children's Hospital of Illinois (CHOI) in Peoria. O.[B.] was scheduled to be discharged to home on 3/23/2015. Staffing from the nursing agency was not enough that it was felt to be safe for O.[B.] to go home."

7. The Plaintiff C.F. has been approved for 84 hours per week on in-home shift nursing services and has only been able to obtain approximately 60 hours per week of nursing services. C.F. is at a serious risk of institutionalization because he is not receiving the approved level of in-home shift nursing services. C.F. is enrolled in the Medically Fragile, Technology-Dependent (MFTD) Waiver program, meaning that C.F. requires an institutional level of care.

- (a) During the past three years, it has been extremely difficult for C.F. to receive adequate nursing services. As a result, C.F. has rarely received 84 hours a week of in-home nursing services.
- (b) DSCC care coordinators are aware of C.F.'s inadequate nursing services. However, it remains extremely difficult to staff C.F.'s nursing case.
- (c) The amount of nursing services that C.F. receives changes from week to week or sometimes month to month. At the moment, C.F. receives 60 hours per week of nursing services (40 day shift hours and 20 night shift hours). However, from mid-September 2015 until late October 2015 (approximately September 13 to October 23, 2015), C.F. had 0 hours of nursing services.

(d) When C.F. does not have nursing services, C.F.'s mother and grandmother must provide all of C.F.'s medically necessary care. For example, when he does not have night nursing coverage, C.F.'s mother and grandmother often sleep in two hour shifts to cover all of his night time care.

8. The Plaintiff J.M. has been approved for 120 hours per week of in-home shift nursing services when in school and 112 hours per week when not in school. The Plaintiff J.M. is approved for an additional 8 hours per week when in school. J.M. is enrolled in the Medically Fragile, Technology-Dependent (MFTD) Waiver program, meaning that J.M. requires an institutional level of care.

(a) J.M.'s mother has spoken with at least four nursing agencies that serve the geographical area where J.M. resides. Each has informed J.M.'s mother that they are unable to serve J.M. due to the low nursing rates paid by the Defendant.

(b) Due to the Defendant's failure to arrange for in-home shift nursing, J.M. currently receives only 48 hours per week of in-home shift nursing on a 1:1 basis.

(c) Though approved for individualized nursing services, J.M. received an additional 50 hours per week of nursing which must be shared with his sister, Plaintiff S.M.

(d) The Defendant has found it medically necessary for both J.M. to have individualized nursing services on a 1:1 basis. This need is also supported by J.M.'s treating physician(s).

(e) The Defendant's failure to arrange for medically necessary, individualized nursing services puts J.M. at an unjustifiable risk of experiencing medical complications at home.

(f) The Defendant's failure to arrange for medically necessary, individualized nursing services also puts J.M. at a serious risk of institutionalization.

9. The Plaintiff S.M. is the sister of J.M. Both S.M. and J.M. were adopted by Dan McCullough and Michele McCullough. S.M. has also been approved for 120 hours per week of in-home shift nursing services when in school and 112 hours per week when not in school. The Plaintiff S.M. is approved for an additional 8 hours per week when in school. S.M. is enrolled in the Medically Fragile, Technology-Dependent (MFTD) Waiver program, meaning that S.M. requires an institutional level of care.

- (a) S.M.'s mother has spoken with at least four nursing agencies that serve the geographical area where S.M. resides. Each has informed S.M.'s mother that they are unable to serve S.M. due to the low nursing rates paid by the Defendant.
- (b) Due to the Defendant's failure to arrange for in-home shift nursing, S.M. currently receives only 50 hours per week of in-home shift nursing on a 1:1 basis.
- (c) Though approved for individualized nursing services, S.M. received an additional 50 hours per week of nursing which must be shared with her brother, Plaintiff J.M.
- (d) The Defendant has found it medically necessary for S.M. to have individualized nursing services on a 1:1 basis. This need is also supported by S.M.'s treating physician(s).
- (e) The Defendant's failure to arrange for medically necessary, individualized nursing services puts S.M. at an unjustifiable risk of experiencing medical complications at home.
- (f) The Defendant's failure to arrange for medically necessary, individualized nursing services also puts S.M. at a serious risk of institutionalization.

10. The mother of the Plaintiffs J.M. and S.M. was told by nursing agencies in her geographical area that they are unable to serve J.M. and S.M. due to inability to recruit nurses as a result of the low nursing rates paid by the Defendant.

11. The Plaintiff Sa.S. has been approved for 112 hours per week on in-home shift nursing services and only receives approximately 82 hours per week of nursing services. Sa.S. is enrolled in the Medically Fragile, Technology-Dependent (MFTD) Waiver program, meaning that Sa.S. requires an institutional level of care.

- (a) Sa.S.'s mother has spoken with at least three nursing agencies that serve the geographical area where Sa.S. resides. Each has informed Sa.S.'s mother that they are unable to fully staff Sa.S.'s case.
- (b) Due to the Defendant's failure to arrange for in-home shift nursing, Sa.S. currently receives only 82 hours per week of in-home shift nursing.
- (c) Sa.S.'s mother cannot remember the last time that Sa.S.'s nursing case was fully staffed; she believes it has been about a year and a half since Sa.S.'s nursing case was fully staffed.
- (d) The Defendant's failure to arrange for medically necessary, individualized nursing services puts Sa.S. at an unjustifiable risk of experiencing medical complications at home.

12. The Plaintiff Sh.S. is approved by the Defendant, the Illinois Department of Healthcare and Family Services to receive in-home shift nursing services of 84 hours per week. Sh.S. only receives approximately 65 hours per week of in-home shift nursing services. Sh.S. is enrolled in the Illinois Medicaid program, but is not enrolled in the Medically Fragile, Technology-Dependent (MFTD) Waiver program.

- (a) Sh.S.'s mother has spoken with at least three nursing agencies that serve the geographical area where Sh.S. resides. Each has informed Sh.S.'s mother that they are unable to fully staff Sh.S.'s case.



- (b) Due to the Defendant's failure to arrange for in-home shift nursing, Sh.S. currently receives only 65 hours per week of in-home shift nursing.
- (c) Sh.S.'s mother cannot remember the last time that Sh.S.'s nursing case was fully staffed; she believes it has been at about a year and a half since Sh.S.'s nursing case was fully staffed.
- (d) The Defendant's failure to arrange for medically necessary, individualized nursing services puts Sh.S. at an unjustifiable risk of experiencing medical complications at home.

13. The Defendant failed to provide adequate in-home shift nursing services for the Plaintiffs and Class. Accordingly, the Plaintiff O.B. remains hospitalized (institutionalized); the Plaintiffs C.F., J.M., S.M., Sa.S, and Sh.S. receive inadequate in-home shift nursing services.

The Defendant's system-wide policies, practices, and procedures include a low reimbursement rate for the Plaintiffs' and the Class members' in-home shift nursing services. The Defendant will not pay a nursing agency more than \$35.03 per hour for a RN and \$31.14 per hour for a LPN for in-home shift nursing services for the Plaintiffs and Class members. In contrast, the Defendant will pay \$72.00 per hour for shift nursing services under certain circumstances not applicable to the Plaintiffs, if care is initiated within 14 days from the day of discharge.

(See: [http://www2.illinois.gov/hfs/SiteCollectionDocuments/2015\\_hhfeeschedule.pdf](http://www2.illinois.gov/hfs/SiteCollectionDocuments/2015_hhfeeschedule.pdf))

14. The Defendant compounded the nursing staffing problem in May 2015, when the Defendant imposed a system-wide 16.75% rate cut for the Plaintiffs' and Class members' in-home shift nursing services. As a result, for the months of May 2015 and June 2015, the Defendant reduced RN rates to \$29.16 per hour and LPN rates to \$25.92 per hour, which resulted in a large number of nurses declining to serve the Plaintiffs and Class.

15. Upon information and belief, the Defendant's sister agency, the Illinois Department of Children and Family Services (DCFS) will pay a shift nursing rate of approximately \$45.00 per hour for in-home shift nursing.

16. The Medicaid program is jointly funded by the federal government and the states. In Illinois, the federal government pays approximately 50% of the Illinois's Medicaid costs. Accordingly, if the state of Illinois increased nursing rates by \$10.00 per hour, the net increase in cost to Illinois would be less than \$10.00 per hour.

17. This class action lawsuit asks this Court to order the Defendant to take all immediate and affirmative steps necessary to correct her system-wide policies, practices, and procedures in order to arrange for adequate levels of previously-approved, medically necessary in-home shift nursing services to the Plaintiffs and Class. It will be up to the Defendant to determine the manner in which to implement the Order.

## **II. JURISDICTION & VENUE**

18. This is an action for declaratory and injunctive relief to enforce the rights of the Plaintiffs and the Class under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) and reasonable promptness mandate of Title XIX of the Social Security Act (Medicaid Act); the Americans with Disabilities Act (ADA), 42 U.S.C. Sec. 12132; and Section 504 of the Rehabilitation Act (Rehabilitation Act), 29 U.S.C. Sec. 794(a).

19. This Court has jurisdiction over Plaintiffs' federal law claims pursuant to 28 U.S.C. Sections 1331 and 1343, which grant this Court original jurisdiction in all actions authorized by 42 U.S.C. Sec. 1983 to redress the deprivation under color of state law any rights, privileges, or immunities guaranteed by the United States Constitution and Acts of Congress. The Plaintiffs

and Class' claims for declaratory and injunctive relief are authorized under 28 U.S.C. Secs. 2201-2202, 42 U.S.C. Sec. 1983, and Fed. R. Civ. P. 65.

20. Venue is proper in the Northern District of Illinois under 28 U.S.C. Sec. 1391(b) because a substantial part of the events or omissions giving rise to Plaintiffs' claims occurred here and because Defendant Norwood may be found here.

### **III. PARTIES**

#### **A. The Named Plaintiffs**

21. **Plaintiff O.B.** is 23 months old. O.B. was born prematurely at 34 weeks. He has several complex medical diagnoses, including Down syndrome, pulmonary hypertension, chronic lung disease, PFO, PDA, Factor V Leiden-Mutation, and Transient Myeloproliferative disorder. He is tracheostomy-dependent and ventilator-dependent; he receives nutrition and medication through a g-j tube. As a result of these conditions, O.B. cannot breathe, eat, or take medication without assistance and/or medical equipment. The Defendant has approved a monthly budget of \$19,718 for in-home shift nursing services, equivalent to approximately 126 hours per week (18 hours per day) of in-home shift nursing services. However, O.B. remains institutionalized (hospitalized) due to the Defendant's failure to arrange for the delivery of in-home shift nursing services. Pursuant to Fed. R. Civ. P. 17(c), O.B. brings this action through his parents and next friends, Garland Burt and Julie Burt.

22. **Plaintiff C.F.** is almost 9 years old. C.F. is diagnosed with specified congenital anomalies, reduction deformity brain, laryngotracheal anomaly, and great vein anomaly. C.F. also has cortical visual impairment, congenital bilateral leg contractures (non-ambulatory without medical equipment), tracheostomy dependence, gastrostomy tube for feedings and medications, neurogenic bladder that requires catheterization multiple times a day and indwelling

catheter at night, and dysautonomia. This means that C.F. is blind, non-verbal, and is primarily fed through a g-tube. Additionally, C.F. cannot clearly communicate his needs nor can he control his bladder. The Defendant has approved C.F. for 84 hours per week of in-home shift nursing services, based on medical necessity. However, C.F. has been only able to obtain approximately 60 hours per week of nursing services. Pursuant to Fed. R. Civ. P. 17(c), C.F. brings this action through his mother and next friend, Kristen Fisher.

23. **Plaintiff J.M.** is 16 years old. J.M. is diagnosed with congenital cytomegalovirus (CMV), microcephaly, developmental delay, and a seizure disorder. He is g-tube dependent and is tracheostomy dependent due to dependence on nightly ventilation due to central alveolar hypoventilation. Bolus feeds are given three times a day, with continuous feeding at night. J.M. receives oral suctioning an average of four times per nursing shift, with oxygen saturations normally between 93-100% on room air. J.M. requires total assistance for all activities of daily living. He is wheelchair bound and dependent for mobility and transfers. J.M. is nonverbal, but he is able to communicate through blinking. The Defendant has approved J.M. to receive 120 hours per week of in-home shift nursing services when in school; 112 hours per week when not in school. Due to the unavailability of in-home shift nursing, J.M. is receiving only 48 hours per week of in-home shift nursing on a 1:1 basis. J.M. receives an additional 50 hours per week of nursing, however he shares the same nurse with his sister, S.M., due to the lack of nurse staffing. Pursuant to Fed. R. Civ. P. 17(c), J.M. brings this action through his parents and next friends, Dan McCullough and Michele McCullough.

24. **Plaintiff S.M.** is 14 years old. S.M. was born at 26 weeks premature with sub-glottic stenosis. At five months she sustained a non-accidental traumatic brain injury (Shaken Baby Syndrome). S.M. was later adopted by her current parents, Dan and Michelle McCullough.

S.M. has spastic quadriplegia, microcephaly, a global developmental delay, a seizure disorder, g-tube dependence, tracheostomy dependence due to obstructive breathing problems, and a right-sided cerebrovascular accident (CVA). S.M. has autonomic storms which cause tachycardia, increased temperature, clonus, and agitation. S.M. requires total assistance for all activities of daily living. She is unable to sit up independently. She is nonverbal, has cortical blindness, and moves only the left arm purposefully. The Defendant has approved S.M. to receive 120 hours per week of in-home shift nursing services when in school; 112 hours per week when not in school. Due to the unavailability of in-home shift nursing, S.M. is receiving only 50 hours per week of in-home shift nursing on a 1:1 basis. S.M. receives an additional 50 hours per week of nursing, however she shares the same nurse with her brother, J.M., due to the lack of nurse staffing. Pursuant to Fed. R. Civ. P. 17(c), S.M. brings this action through her parents and next friends, Dan McCullough and Michele McCullough.

25. **Plaintiff Sa.S.** is 3 years old. Plaintiff Sa.S. is the twin brother of Plaintiff Sa.S. Sa.S. was born prematurely, at approximately 27 weeks. Sa.S. remained hospitalized for about nine months after his birth. Sa.S. was discharged in June 2013 for about three days, until he experienced respiratory failure at home. Sa.S. was re-admitted to the hospital where he received a tracheostomy. Sa.S. was discharged again in late December 2013. He was approved for the Medically Fragile and Technology Dependent (MFTD) waiver program around that same time. Sa.S. has been diagnosed with chronic respiratory failure. He had a tracheostomy, and he is ventilator-dependent. He requires a gastrostomy tube (g-tube) for all of his feedings and medications. He receives nebulizer treatments as needed to assist his breathing. Pursuant to Fed. R. Civ. P. 17(c), Sa.S. brings this action through his mother and next friend, Sheila Scaro.

26. **Plaintiff Sh.S.** is 3 years old. Plaintiff Sh.S. is the twin sister of Plaintiff Sh.S. Sh.S. was born prematurely, at approximately 27 weeks. Sh.S. remained hospitalized for about seven months after her birth. Sh.S. has complex medical conditions including dysphagia and esophageal reflux. She requires a gastrostomy tube (g-tube) for all of her feedings and her medications; she cannot take more than 5 mL of any liquid orally. She receives nebulizer treatments twice per day to help with her breathing. Sh.S.'s g-tube feedings are very complex. She receives bolus feeds four times a day. Because of her dysphagia and reflux, she often throws up and gags during feedings. About two to three times a week, Sh.S. aspirates during feedings, requiring use of a Smartvest to help prevent pneumonia. Pursuant to Fed. R. Civ. P. 17(c), Sh.S. brings this action through his mother and next friend, Sheila Scaro.

**B. The Defendant**

27. The Defendant, Felicia F. Norwood, is the Director of the Illinois Department of Healthcare and Family Services (HFS). As such she is responsible for the supervision and oversight of HFS medical programs and contractual arrangements. Her responsibilities in this role include the responsibility to ensure compliance with federal law. She is being sued in her official capacity.

**IV. CLASS ACTION ALLEGATIONS**

28. The Plaintiffs bring this action as a statewide class action pursuant to Fed. R. Civ. P. 23(a) and (b)(2) on behalf of:

All Medicaid-eligible children under the age of 21 in the State of Illinois who have been approved for in-home shift nursing services by the Defendant, but who are not receiving in-home shift nursing services at the level approved by the Defendant, including children who are enrolled in a Medicaid waiver program, such as the Medically Fragile Technology Dependent (MFTD) Waiver program, and children enrolled in the non-waiver Medicaid program, commonly known as the Nursing and Personal Care Services (NPCS) program.

29. The Class is so numerous that joinder of all persons is impracticable. There are approximately 1,200 children eligible to receive in-home shift nursing services through the Defendant's Medicaid programs. The Defendant administers EPSDT-mandated in-home shift nursing services for eligible children under the age of 21.

30. As of January 1, 2015, approximately 535 children under the age of 21 with extensive medical needs were eligible for in-home shift nursing services. The approximately 535 children referenced in this paragraph are not enrolled in a Medicaid waiver program.

31. As of March 13, 2015, approximately 686 additional children were enrolled in a Medicaid waiver program, the Medically Fragile Technology Dependent (MFTD) waiver program. The approximately 686 children referenced here are also eligible to receive the full range of standard Medicaid services, including in-home shift nursing services.

32. The Plaintiffs and Class have severe disabilities and limited financial resources, as Medicaid recipients. They are unlikely to institute individual actions.

33. The claims of the Class members raise common questions of law and fact. The factual questions common to the entire Class include what system-wide policies, practices, and procedures were instituted or permitted by the Defendant and resulted in her failure to arrange for Medicaid-covered, medically necessary in-home nursing services. These legal questions are common to both non-waiver and waiver enrollees in the Medicaid program. The legal questions common to the Plaintiffs and all Class members include:

- (a) Whether the defendant has failed to "arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment [in-home shift nursing services]" to the Plaintiffs and Class as mandated by the

federal Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions of the Medicaid Act pursuant to 42 U.S.C. Sec. 1396a(a)(43)(C) and 42 U.S.C. Sec. 1396d(r)(5);

- (b) Whether the Defendant has failed to furnish medical assistance with reasonable promptness to the Plaintiffs and Class, who are eligible children with disabilities, pursuant to 42 U.S.C. Sec. 1396a(a)(8);
- (c) Whether the Defendant violated the ADA and/or Rehabilitation Act when the Defendant failed to arrange for Medicaid-covered, medically necessary in-home nursing services;
- (d) Whether the Defendant violated the ADA and/or the Rehabilitation Act by failing to assure that in-home shift nursing services are administered to the Plaintiffs and Class in the most integrated setting appropriate to their needs; and
- (e) Whether the Defendant violated the ADA and/or the Rehabilitation Act when the Defendant failed to make reasonable modifications to the existing Medicaid benefit which would result in the availability of in-home shift nursing services.

34. The Plaintiffs' claims are typical of the Class members' claims. None of the Plaintiffs and Class members are receiving in-home shift nursing services at the level that the Defendant found to be necessary to correct or ameliorate their conditions.

35. The Plaintiffs are adequate representatives of the class because they suffer from the same deprivations of the other Class members and have been denied the same federal rights that they seek to enforce on behalf of the other Class members.



36. The Plaintiffs will fairly and adequately represent the interests of the absent Class members, many of whom are unable to pursue claims on their own behalf as the result of their disabilities.

37. The Plaintiffs' interest in obtaining injunctive relief for the violations of their rights and privileges are consistent with and not antagonistic to those of any person within the Class.

38. The Plaintiffs' counsel are qualified, experienced and able to conduct the proposed litigation.

39. Prosecution of separate actions by individual Class members would create a risk of inconsistent or varying adjudication with respect to individual Class members, which would establish incompatible standards of conduct for the party opposing the Class or could be dispositive of the interests of the other members or substantially impair or impede the ability to protect their interests.

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

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

41. The Defendant has, with knowledge of the requirements of the EPSDT mandate, the Medicaid Act, the ADA, the Rehabilitation Act and implementing regulations, acted or refused to act, and continues to act or refuse 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. STATUTORY AND REGULATORY FRAMEWORK**

### **A. The Medicaid Act and Implementing Regulations**

42. The Medicaid Act, Title XIX of the Social Security Act, 42 U.S.C. Secs. 1396-1396w-5, establishes a medical assistance program cooperatively funded by the federal and state governments. Medicaid is designed to “enabl[e] each State, as far as practicable . . . to furnish (1) medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence and self-care . . . ” 42 U.S.C. Sec. 1396-1.

43. The Medicaid program typically does not directly provide health care services to eligible individuals, nor does it provide beneficiaries with money to purchase health care directly. Rather, Medicaid is a vendor payment program, wherein Medicaid-participating providers—including in-home shift nursing providers — are reimbursed by the program for the services they provide to recipients.

44. The Centers for Medicare & Medicaid Services (CMS) of the United States Department of Health and Human Services is the agency that administers Medicaid at the federal level, including publishing rules and guidelines. These rules and regulations are set forth in 42 C.F.R. Secs 430.0-483.480, and in the CMS *State Medicaid Manual*. These rules and regulations are binding on all states that participate in Medicaid.

45. The state must adopt a plan that meets the requirements of the Medicaid Act. 42 U.S.C. Sec. 1396; 42 C.F.R. Sec. 430.12. States can make changes to their Medicaid programs by

submitting state plan amendments for CMS's approval. 42 U.S.C. Sec. 1396; 42 C.F.R. Sec. 430.12.

46. Certain services, such as hospital services, are mandatory under Medicaid and must be covered for all beneficiaries. 42 U.S.C. Secs. 1396a(a)(10)(A), 1396d(a)(7). 42 C.F.R. Secs. 440.210, 440.220. Other services are optional for adults, including in-home shift nursing services. 42 U.S.C. Secs. 1396a(a)(10)(A), 1396d(a)(8).

47. One mandatory category of Medicaid services is the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. The federal EPSDT benefit requires that any of the mandatory or optional services that are coverable under 42 U.S.C. Sec. 1396d(a) must be provided if they are "necessary ... to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening process, regardless of whether or not such services are covered" for adults. 42 U.S.C. Sec. 1396d(r)(5). Included in the list of services under Section 1396d(a) are home health services and private duty nursing services. *See* 42 U.S.C. Secs. 1396d(a)(7), 1396d(a)(8). Accordingly, the EPSDT benefit includes in-home shift nursing services that are necessary to ameliorate, correct, or maintain a child's condition(s).

48. The federal EPSDT mandate requires the Defendant to provide or arrange for the provision of covered services. 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 . . . child health screening services." 42 U.S.C. Sec. 1396a(a)(43)(C). The Defendant must 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).

Accordingly, the Defendant must either provide in-home shift nursing directly or coordinate with others to do so. Furthermore, the Defendant must implement and maintain system-wide policies, practices, and procedures that proactively arrange for the delivery of medically necessary, EPSDT-mandated services.

49. The state Medicaid agency must furnish services with “reasonable promptness to all eligibility individuals.” 42 U.S.C. Sec. 1396a(a)(8). This must happen “without any delay caused by the agency’s administrative procedures.” 42 C.F.R. Sec. 435.930.

**B. The Americans with Disabilities Act (ADA) and Implementing Regulations**

50. In enacting the Americans With Disabilities Act, Congress found that “[individuals with disabilities continually encounter various forms of discrimination, including...segregation....” 42 U.S.C. Sec. 12101(a)(5).

51. Title II of the Americans with Disabilities Act provides that “no qualified individual with a disability shall, by reason of disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity or be subjected to discrimination by such entity.” 42 U.S.C. Sec. 12132.

52. Regulations implementing Title II of the ADA make clear that the ADA requires that: “A public entity 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).

53. Regulations implementing Title II of the ADA provide: “A public entity may not, directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; [or] (ii) that have the purpose or effect of defeating or

substantially impairing accomplishment of the objectives of the entity's program with respect to individuals with disabilities. . . ." 28 C.F.R. Sec. 35.130(b)(3).

54. The United States Supreme Court in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), held that the unnecessary institutionalization of individuals with disabilities is a form of discrimination under Title II of the ADA. In doing so, the Supreme Court interpreted the ADA's "integration mandate" to require that persons with disabilities be served in the community when: (1) the state determines that community-based treatment is appropriate; (2) the individual does not oppose community placement; and (3) community placement can be reasonably accommodated. *Id.* at 607.

### **C. The Section 504 of the Rehabilitation Act and Implementing Regulations**

55. Section 504 of the Rehabilitation Act of 1973 (Rehabilitation Act), on which the ADA is modeled, sets forth similar protections against discrimination by recipients of federal funds, such as the Defendant. 29 U.S.C. Secs. 794-794a. These protections include the prohibition against unnecessary segregation of people with disabilities. Regulations implementing the Rehabilitation Act require that a public entity administer its services, programs and activities in "the most integrated setting appropriate" to the needs of qualified individuals with disabilities. 28 C.F.R. Sec. 41.51(d).

## **VI. STATEMENT OF FACTS**

### **A. The Federal Medicaid Act's Mandate to Provide In-Home Shift Nursing Services to Children Enrolled in the Medicaid Program**

56. The federal EPSDT benefit requires the Defendant to provide the services listed in 42 U.S.C. Sec. 1396d(a) to Medicaid-enrolled children under the age of 21 that are "necessary ... to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the

screening process, regardless of whether or not such services are covered”. 42 U.S.C. Sec. 1396d(r)(5).

57. The services listed in 42 U.S.C. Sec. 1396d(a) include home health services and private duty nursing services. *See* 42 U.S.C. Secs. 1396d(a)(7), 1396d(a)(8). Accordingly, the EPSDT benefit of the federal Medicaid Act requires the Defendant to provide and arrange for in-home shift nursing services (i.e., private duty nursing) to Medicaid-enrolled children under 21 in Illinois. The Defendant refers to private duty nursing as in-home shift nursing services.

58. States may also include home and community-based “waivers” as part of their Medicaid programs. These programs provide Medicaid services to individuals in their homes who would otherwise need the level of care provided in an institution, including nursing homes and hospitals. 42 U.S.C. Sec. 1396n(c)(1). Thus, waiver enrollees have very high medical needs and, in most cases, serious disabilities.

59. These programs are called waivers because they allow states to waive certain Medicaid requirements that may otherwise apply. This includes certain financial eligibility requirements. Thus, in contrast to regular Medicaid rules, income and resources of a child’s family are not taken into account when determining eligibility for a waiver.

60. In Illinois, children be found eligible for Medicaid in one of two ways:

- (a) First, they can found eligible because of their parent(s)/guardian(s)’ limited financial resources. (In this lawsuit, individuals eligible for Medicaid based on financial resources are referred to as “non-waiver enrollees”); or
- (b) Alternatively, children can qualify for a Medicaid waiver program based on their extensive medical needs, regardless of their family’s financial resources. (In this lawsuit, individuals eligible for Medicaid waiver program are referred to as “waiver enrollees.”)

61. Children are eligible for the MFTD Waiver program if the Defendant makes a determination that “except for the provision of in-home care, these individuals would require the level of care provided in a hospital or a skilled nursing facility.” 89 Ill. Admin. Code 120.530(b).

62. The estimated cost of in-home services provided to a waiver enrollee cannot exceed the cost of institutional level of care appropriate to the individual's medical needs (hospital or skilled nursing facility), as determined by the Defendant. 89 Ill. Admin. Code 120.530(e)(4).

63. Non-waiver enrollees in the Illinois Medicaid program are entitled to receive any Medicaid-covered service when medically necessary. 89 Ill. Admin. Code 140.3(a). Under the Medicaid Act, non-waiver enrollees in Illinois Medicaid are entitled to receive the federal EPSDT benefit, which includes in-home shift nursing services when medically necessary. This federal requirement is also codified in 89 Ill. Admin. Code Sec. 140.3(b)(13).

64. Waiver enrollees, meaning children enrolled in the Medically Fragile and Technology-Dependent waiver program, are also entitled to receive the EPSDT benefit, which includes in-home shift nursing services. This requirement is codified in 89 Ill. Admin. Code Secs. 140.3(a)(5), 120.530.

65. A child enrolled in the Medically Fragile and Technology-Dependent waiver program may also be eligible for additional, non-EPSDT services, including:

- i. Respite care;
- ii. Environmental modifications (e.g., home renovation to accommodate a disability);
- iii. Special medical supplies and equipment;
- iv. Medically supervised day care;
- v. Family and nurse training; and
- vi. Maintenance counseling.

Those additional services available to waiver enrollees are not at issue in this case.

66. Non-waiver enrollees in the Illinois Medicaid program can apply for the MFTD waiver program. If a non-waiver enrollee meets the medical requirements of the MFTD waiver program, they can participate in the MFTD waiver program. As participants in the MFTD program, they are still entitled to the full range of EPSDT services, including in-home shift nursing services. Additionally, they may receive the additional waiver services listed in the preceding paragraph.

67. In-home shift services are non-waiver services. Accordingly when medically necessary, in-home shift services must be provided to both waiver enrollees and non-waiver enrollees because of the federal Medicaid Act's EPSDT mandate.

**D. The Defendant's Administration of Federally Mandated In-Home Shift Nursing Services**

68. The Defendant's systems, policies and procedures must comply with the Medicaid Act and associated regulations, including the systems, policies and procedures for administering in-home shift nursing services to both waiver enrollees and non-waiver enrollees.

69. The Defendant sometimes refers to the administration of in-home shift nursing services to non-waiver enrollees as the Nursing and Personal Care Services (NCPS) program.

70. Children approved for in-home services have extensive and complex medical needs. However, waiver enrollees must also be technology-dependent. Though non-waiver enrollees have extensive and complex medical needs, they do not meet the technology-dependent requirements of the waiver program.

71. The Defendant's administration of in-home shift nursing to non-waiver enrollees must comply with federal requirements of the EPSDT mandate, the Medicaid Act, the ADA, the Rehabilitation Act, and implementing regulations.



72. Similarly, the Defendant's administration of in-home shift nursing services to waiver enrollees must also comply with federal requirements of the EPSDT mandate, the Medicaid Act, the ADA, the Rehabilitation Act, and implementing regulations.

73. The Defendant has approved all Plaintiffs and Class members for in-home shift nursing services based on medical necessity. All Plaintiffs and Class members have extensive medical needs. The Plaintiffs and Class members consist of both non-waiver enrollees and waiver enrollees.

#### **E. Defendant's Prior Approval For In-Home Shift Nursing Services**

74. Pursuant to the Illinois Administrative Code, the Defendant requires prior approval for all in-home shift nursing services for children under 21 years of age. 89 Ill. Adm. Code Sec. 140.473(d)-(e). This prior authorization is required for both non-waiver enrollees and waiver enrollees.

75. A prior authorization request for in-home shift nursing services requires the support of a treating physician who supports the medical necessity of such services.

76. When the Defendant grants prior approval for in-home shift nursing services for a non-waiver or waiver enrollee, the Defendant sends a written notice to the child stating that either: (1) the child has been approved for a specific number of nursing hours per week; or (2) that the child has been approved for a specific monthly budget for nursing services.

77. The Defendant's written notice for prior approval for in-home shift nursing services sets forth the reimbursement rates that the Defendant will pay to registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs) to perform in-home shift nursing

services. The Defendant reimburses RNs, LPNs, and CNAs at the same rate for in-home nursing services delivered to both non-waiver enrollees and waiver enrollees.

78. Through her business records, the Defendant has actual or constructive knowledge of her failure to arrange adequate in-home shift nursing services for the Plaintiffs and Class members. The Defendant has knowledge of the amount (i.e., weekly hours or monthly budget) of in-home shift nursing services that she found to be medically necessary for each Plaintiff and Class member. Additionally, the Defendant has knowledge of the monthly billing for each Plaintiff's and Class member's in-home shift nursing services. Therefore, the Defendant is or should be aware of her failure to arrange medically necessary services when the Defendant is not billed for the full of amount in-home shift nursing services.

79. Once the Defendant determines that a certain number of in-home skilled nursing services are medically necessary, the Defendant uses to same systems, procedures, and practices to arrange in-home skilled nursing services for the waiver and non-waiver enrollees. This system involves the delegation of care coordination to University of Illinois at Chicago Division of Specialized Care for Children and the delegation of service delivery to licensed nursing agencies in Illinois. The Defendant's system has failed the Plaintiffs and Class.

**F. The Role of the Division of Specialized Care for Children (DSCC) in the Defendant's Administration of In-Home Shift Nursing Services**

80. The University of Illinois at Chicago Division of Specialized Care for Children (DSCC) provides care coordination for children who receive in-home shift nursing care. DSCC provides care coordination to both waiver and non-waiver enrollees.

81. Additionally, DSCC acts as the single point of entry for both waiver and non-waiver enrollees applying for in-home nursing services. However, the Defendant approves all eligibility determinations for in-home shift nursing services.

82. Once the Defendant finds a child eligible for in-home shift nursing services, the Defendant delegates ongoing care coordinate to DSCC's staff members or contractors (registered nurses, social workers, respiratory therapists and speech therapists).

83. The primary care coordination responsibilities that the Defendant delegates to DSCC include, but may not be limited to:

- (a) conducting assessments to determine a child's eligibility for the waiver program;
- (b) developing a service plan for each eligible child;
- (c) overseeing the health and safety of waiver participants; and
- (d) monitoring of care coordination, nursing agencies and home medical providers.

84. Approximately once every sixty days, DSCC receives periodic reports from nursing agency servicing each waiver and non-waiver enrollee. These periodic reports require the nursing agency to provide the following information about each child to DSCC:

- (a) amount of nursing hours/week prescribed for that time period;
- (b) average amount of nursing hours provided per week for that time period;
- (c) usual days and times of service; and
- (d) any reasons for unfilled shifts.

85. DSCC, acting as the agent of the Defendant, is aware that all Plaintiffs and putative Class members are unable to arrange for in-home shift nursing services at the level approved by the Defendant.

86. DSCC does not have the authority to modify the Defendant's policies, practices, or procedures regarding the arrangement of in-home shift nursing services for the Plaintiffs and Class members.

87. DSCC has informed the Defendant that some Plaintiffs and Class members are unable to arrange for in-home shift nursing services at the level approved by the Defendant.

88. In the case of the Plaintiff O.B., an April 7, 2015 letter from DSCC to the Defendant stated that no in-home shift nursing services have been provided to O.B. as O.B. remains hospitalized. The April 7, 2015 letter further stated that, "The nursing agency has not been able to fully staff the case, so O.[B.] is still residing at Children's Hospital of Illinois (CHOI) in Peoria. O.[B.] was scheduled to be discharged to home on 3/23/2015. Staffing from the nursing agency was not enough that it was felt to be safe for O.[B.] to go home."

89. In the case of the Plaintiff Sh.S., Sh.S.'s mother has contacted one of the Defendant's employees, Ms. Shari Bangert, approximately five or six times by phone regarding the inadequate quantity and quality of Sh.S.'s nursing services. Each time, Sh.S.'s mother left a voicemail message for Ms. Bangert. On only one occasion did Ms. Bangert return the call of Sh.S.'s mother. During that return call, Ms. Bangert informed Sh.S.'s mother that she could not assist her; additionally, Ms. Bangert did not refer Sh.S.'s mother to anyone else for assistance. On all other occasions, Ms. Bangert did not respond to the messages left by Sh.S.'s mother. Sh.S.'s mother was told by the nursing agency staffing Sh.S.'s case that Shari Bangert followed up with them, instructing the nursing agency that Sh.S.'s mother was not supposed to contact Ms. Bangert.

90. In the case of Class member G.A., DSCC wrote to the Defendant on January 21, 2015 stating, "The current plan is approved for 105 hours of nursing care per week...The

family...remains frustrated due to the agency being unable to staff all of the allotted hours...the family is using a total of 48-60/hr of nursing per week.”

91. Despite DSCC’s notifications to the Defendant of inadequate nursing services, the Defendant has not arranged for adequate levels of in-home shift nursing services for the Plaintiffs and Class.

92. The Defendant is aware of both the number of monthly hours and the approved monthly budget that the Defendant found to be medically necessary for all Plaintiffs and Class members. The Defendant is also aware of the monthly bills being submitted for all Plaintiffs’ and Class members’ in-home shift nursing services.

93. Through the Defendant’s own knowledge, and the information that DSSC provided to the Defendant, the Defendant is aware or should be aware that all Plaintiffs and Class members are unable to receive in-home shift nursing services at the level approved by the Defendant. However, the Defendant has neither implemented nor maintained system-wide policies, practices, and procedures that proactively ensure that the Plaintiffs and Class receive medically necessary in-home shift nursing services.

**G. The Defendant’s Use of Nursing Agencies and Home Health Agencies to Arrange for In-Home Shift nursing Services**

94. Illinois has an enrollment of 355 licensed home health agencies, but only a specialized group of 34 home health agencies or private duty nursing agencies serves the technology-dependent pediatric population with shift nursing care.

95. DSCC has specific guidelines for approving providers of private duty nursing under the MFTD waiver. Once approved, and annually thereafter, agencies sign an agreement with DSCC

to comply with the requirements of the program. These include qualifications, experience and training for administrative and nursing staff.

96. In-home shift nursing must be provided by appropriately qualified staff – registered nurses (RNs), licensed practical nurses (LPNs) and certified nurse aides (CNAs), who are licensed or certified in Illinois, provide services for both non-waiver and waiver enrollees. Nurses and CNAs must be employed by a DSCC-approved nursing agency or community-based health center.

**H. Plaintiff O.B.**

97. O.B. was born prematurely at 34 weeks. He has several complex medical diagnoses, including Down syndrome, pulmonary hypertension, chronic lung disease, PFO, PDA, Factor V Leiden-Mutation, and Transient Myeloproliferative disorder. He is tracheostomy-dependent and ventilator-dependent; he receives nutrition and medication through a g-tube. As a result of these conditions, O.B. cannot breathe, eat, or take medication without assistance and/or medical equipment.

98. O.B. was schedule to be discharged to his home on March 23, 2015 from the Children's Hospital of Illinois (CHOI) in Peoria, but O.B. has been unable to be discharged from the hospital due to the failure of the Defendant to arrange for the delivery of in-home shift nursing services. O.B. remains institutionalized (hospitalized) at a cost to the Defendant of approximately \$57,000 per month in the hospital charges alone.

99. In contrast, the Defendant has approved an in-home shift nursing services monthly budget of \$19,718 for O.B., equivalent to approximately 126 hours per week (18 hours per day) of in-home shift nursing services. O.B. is a waiver enrollee; he meets the medical and technology-dependent requirements of the MFTD Waiver program.

100. In a letter dated, April 7, 2015, DSCC told the Defendant the following regarding Plaintiff O.B.:

The nursing agency has not been able to fully staff the case, so O[.B.] is still residing at Children's Hospital of Illinois (CHOI) in Peoria. O[.B.] was scheduled to be discharged to home on 3/23/2015. Staffing from the nursing agency was not enough that it was felt to be safe for O[.B.] to go home.

101. There are qualified in-home nursing care providers in O.B.'s geographic area.

102. The parents of O.B. have been unable to find any nursing agency to fully staff the in-home shift nursing services at the level approved by the Defendant.

103. It is medically necessary that O.B. receives in-home shift nursing services of approximately 18 hours per day which has been approved by the Defendant.

104. Dr. Jeffrey Benson, a pulmonologist with the Pediatric Ventilation Clinic at OSF Healthcare, will be managing O.B.'s medical plan for home care. Dr. Benson continues to recommend in-home shift nursing care for O.B. In lieu of in-home nursing care, O.B. would remain in the Pediatric Intensive Care Unit (PICU) at Children's Hospital of Illinois (CHOI) in Peoria, Illinois.

105. O.B. is currently institutionalized (hospitalized) for the sole reason that in-home shift nursing services are unavailable at the level approved by the Defendant. Discharging O.B. without in-home shift nursing services at the level approved by the Defendant creates an unjustifiable level of medical risk that O.B.'s parents are unwilling to accept.

106. If O.B. is discharged from the hospital and receives in-home shift nursing at a level which is substantially less than the approved level by the Defendant, then O.B. faces a serious risk of institutionalization (re-hospitalization). If he remains at home with reduced in-home shift nursing, then he faces a strong possibility of a life threatening episode.

107. O.B. is requesting injunctive relief to require the Defendant to arrange for the delivery of in-home shift nursing services at the level approved by the Defendant in order that he not remain institutionalized or hospitalized.

108. O.B. is enrolled in the MFTD Waiver program.

109. O.B. is a qualified individual with a disability under the ADA and the Rehabilitation Act.

110. The Defendant has regarded Plaintiff O.B. as having a disability within the meaning of the ADA and the Rehabilitation Act.

111. O.B. is a recipient of Medical Assistance, commonly known as Medicaid.

112. O.B. is a resident of Illinois.

**I. Plaintiff C.F.**

113. The Plaintiff C.F. is almost 9 years old. C.F. is diagnosed with specified congenital anomalies, reduction deformity brain, laryngotracheal anomaly, and great vein anomaly. C.F. also has cortical visual impairment, congenital bilateral leg contractures (non-ambulatory without medical equipment), tracheostomy dependence, gastrostomy tube for feedings and medications, neurogenic bladder that requires catheterization multiple times a day and indwelling catheter at night, and dysautonomia. This means that C.F. is blind, non-verbal, and is primarily fed through a g-tube. Additionally, C.F. cannot clearly communicate his needs nor can he control his bladder. The Defendant has approved C.F. for 84 hours per week of in-home shift nursing services, based on medical necessity. C.F.'s care is managed by Dr. Jason Becker, a board certified pediatrician. Dr. Becker recommends 84 hours per week of in-home shift nursing to safely and stably maintain C.F. at home.



114. It is medically necessary that C.F. receives in-home shift nursing services of 84 hours per week which has been approved by the Defendant.

115. C.F. has been only able to receive approximately 60 hours per week of in-home shift nursing services. Kristen Fisher, the mother of C.F. has been unable to find any other nursing agencies to fully staff the nursing hours approved by the Defendant. C.F. is a waiver enrollee; he meets the medical and technology-dependent requirements of the MFTD Waiver program.

116. There are qualified in-home nursing care providers in C.F.'s geographic area.

117. If C.F. cannot obtain in-home shift nursing services at the level approved by the Defendant, then C.F. will be forced to be either institutionalized in a hospital or if he remains at home and receives in-home shift nursing at a level which is substantially less than the approved level by the Defendant, then he faces a strong possibility of a life threatening episode.

118. C.F. is requesting injunctive relief to require the Defendant to arrange for the delivery of in-home shift nursing services in order that he may remain in the community and not be institutionalized or hospitalized.

119. C.F. is a qualified individual with a disability under the ADA and the Rehabilitation Act.

120. The Defendant has regarded Plaintiff C.F. as having a disability within the meaning of the ADA and the Rehabilitation Act.

121. As an enrollee in the MFTD Waiver program, C.F. is by definition at serious risk of institutionalization if he does not receive the Medicaid services he needs.

122. C.F. is a recipient of Medical Assistance, commonly known as Medicaid.

123. C.F. is a resident of Illinois.

**J. Plaintiff J.M.**

124. The Plaintiff J.M. is 16 years old. J.M. is diagnosed with congenital CMV, microcephally, developmental delay, and a seizure disorder. He is g-tube dependent and is tracheostomy dependent due to dependence on nightly ventilation due to central alveolar hypoventilation. Bolus feeds are given 3 times a day, with continuous feeding at night. J.M. gets suctioned an average of 4 times per nursing shift, with oxygen saturations normally between 93-100% on room air. J.M. requires total assistance for all activities of daily living. He is wheelchair bound and dependent for mobility and transfers. J.M. is nonverbal but he is able to communicate through blinking.

125. The Defendant has approved J.M. to receive in-home shift nursing services of 120 hours per week when in school and 112 hours per week when not in school, based on medical necessity. J.M. is a waiver enrollee; he meets the medical and technology-dependent requirements of the MFTD Waiver program.

126. It is medically necessary that J.M. receives in-home shift nursing services of 120 hours per week when in school and 112 hours per week when not in school, which has been approved by the Defendant.

127. Since approximately June 2015, J.M. has been only able to receive approximately 90 hours per week of in-home shift nursing services, including shared night nursing services received by J.M. and S.M. due to the Defendant's failure to arrange for individualized in-home shift nursing at medically necessary, approved levels. As of October 22, 2015, J.M. receives 48 hours per week of in-home shift nursing services on a 1:1 basis and will receive an additional 50 hours per week of nursing. However he shares the same nurse with his sister, S.M., due the Defendant's failure to arrange for individualized in-home shift nursing.

128. There are qualified in-home nursing care providers in J.M.'s geographic area.

129. Nursing agencies in the geographic area of J.M., have informed J.M.'s mother that they are unable to serve J.M. due to their lack of ability to recruit nurses as a result of the low nursing rates paid by the Defendant.

130. J.M.'s care is managed by his primary care physician, Dr. Terry Ho. Dr. Ho recommends shift nursing in the home to keep J.M. safe, the alternative being admission to Children's Hospital of Illinois (CHOI) in Peoria.

131. If J.M. cannot obtain in-home shift nursing services at the level approved by the Defendant, then J.M. will be forced to be either institutionalized in a hospital or if he remains at home and receives in-home shift nursing at a level which is substantially less than the approved level by the Defendant, then he faces a strong possibility of a life threatening episode.

132. J.M. is requesting injunctive relief to require the Defendant to arrange for the delivery of in-home shift nursing services in order that he may remain in the community and not be institutionalized or hospitalized.

133. J.M. is a qualified individual with a disability under the ADA and the Rehabilitation Act.

134. The Defendant has regarded Plaintiff J.M. as having a disability within the meaning of the ADA and the Rehabilitation Act.

135. As an enrollee in the MFTD Waiver program, J.M. is by definition at serious risk of institutionalization if he does not receive the Medicaid services he needs.

136. J.M. is a recipient of Medical Assistance, commonly known as Medicaid.

137. J.M. is a resident of Illinois.

**K. Plaintiff S.M.**

138. The Plaintiff S.M. is 14 years old. S.M. is diagnosed with spastic quadriplegia, microcephaly, a global developmental delay, a seizure disorder, g-tube dependence, tracheostomy dependent due to obstructive breathing problems, and a right-sided CVA. S.M. has autonomic storms which cause tachycardia, increased temperature, clonus, and agitation. S.M. requires total assistance for all activities of daily living. She is unable to sit up independently. She is nonverbal, has cortical blindness, and moves only the left arm purposefully.

139. The Defendant has approved S.M. to receive in-home shift nursing services of 120 hours per week when in school and 112 hours per week when not in school, based on medical necessity. S.M. is a waiver enrollee; she meets the medical and technology-dependent requirements of the MFTD Waiver program.

140. It is medically necessary that S.M. receives in-home shift nursing services of 120 hours per week when in school and 112 hours per week when not in school, which has been approved by the Defendant.

141. Since approximately June 2015, S.M. has been only able to receive approximately 56 hours per week of in-home shift nursing services, including shared night nursing services received by J.M. and S.M. due to the Defendant's failure to arrange for individualized in-home shift nursing at medically necessary, approved levels. As of October 22, 2015, S.M. receives 50 hours per week of in-home shift nursing services on a 1:1 basis and will receive an additional 50 hours per week of shared nursing services. However, she shares the same nurse with her brother, J.M., due the Defendant's failure to arrange for individualized in-home shift nursing.

142. There are qualified in-home nursing care providers in S.M.'s geographic area.

143. Nursing agencies in the geographic area of S.M., have informed S.M.'s mother that they are unable to serve S.M. due to their lack of ability to recruit nurses as a result of the low nursing rates paid by the Defendant.

144. If S.M. cannot arrange for in-home shift nursing services at the level approved by the Defendant, then S.M. will be forced to be either institutionalized in a hospital or if she remains at home and receives in-home shift nursing at a level which is substantially less than the approved level by the Defendant, then she faces a strong possibility of a life threatening episode.

145. S.M. is requesting injunctive relief to require the Defendant to arrange for the delivery of in-home shift nursing services in order that she may remain in the community and not be institutionalized or hospitalized.

146. S.M. is a qualified individual with a disability under the ADA and the Rehabilitation Act.

147. The Defendant has regarded Plaintiff S.M. as having a disability within the meaning of the ADA and the Rehabilitation Act.

148. As an enrollee in the MFTD Waiver program, S.M. is by definition at serious risk of institutionalization if he does not receive the Medicaid services she needs.

149. S.M. is a recipient of Medical Assistance, commonly known as Medicaid.

150. S.M. is a resident of Illinois.

**L. Plaintiff Sa.S.**

151. **Plaintiff Sa.S.** is 3 years old. Plaintiff Sa.S. is the twin brother of Plaintiff Sh.S. Sa.S. was born prematurely, at approximately 27 weeks. Sa.S. remained hospitalized for about nine months after his birth. Sa.S. was discharged in June 2013 for about 3 days, until he experienced respiratory failure at home. Sa.S. was re-admitted to the hospital where he received

a tracheostomy. Sa.S. was discharged again in late December 2013. He was approved for the MFTD waiver program around that same time. Sa.S. has been diagnosed with chronic respiratory failure. He had a tracheostomy, and he is ventilator-dependent. He requires a gastrostomy tube (g-tube) for all of his feedings and medications. He receives nebulizer treatments to help with his breathing at least [ ] times per day.

152. The Defendant has approved Sa.S. to receive in-home shift nursing services of 112 hours per week. Sa.S. is a waiver enrollee; she meets the medical and technology-dependent requirements of the MFTD Waiver program.

153. It is medically necessary that Sa.S. receives in-home shift nursing services of 112 hours per week, which has been approved by the Defendant.

154. Since approximately January 2015, Sa.S. has been only able to receive approximately 82 hours per week of in-home shift nursing services.

155. There are qualified in-home nursing care providers in Sa.S.'s geographic area.

156. Sa.S.'s mother has attempted recruit nurses to staff Sa. S's case, but she has not been successful.

157. Sa.S. is requesting injunctive relief to require the Defendant to arrange for the delivery of in-home shift nursing services in order that he may remain safely in the community.

158. Sa.S. is a qualified individual with a disability under the ADA and the Rehabilitation Act.

159. The Defendant has regarded Plaintiff S. as having a disability within the meaning of the Rehabilitation Act.

160. As an enrollee in the MFTD Waiver program, Sa.S. is by definition at serious risk of institutionalization if he does not receive the Medicaid services he needs.

161. Sa.S. is a recipient of Medical Assistance, commonly known as Medicaid.

162. Sa.S. is a resident of Illinois.

**M. Plaintiff Sh.S.**

163. Plaintiff Sh.S. is 3 years old. Plaintiff Sh.S. is the twin sister of Plaintiff Sh.S. Sh.S. was born prematurely, at approximately 27 weeks. Sh.S. remained hospitalized for about seven months after her birth. Sh.S. has complex medical conditions including dysphagia and esophageal reflux. She requires a gastrostomy tube (g-tube) for all of her feedings and her medications; she cannot take more than 5 mL of any liquid orally. She receives nebulizer treatments twice per day to help with her breathing. Sh.S.'s g-tube feedings are very complex. She receives bolus feeds four times a day. Because of her dysphagia and reflux complicate her feedings, she often throws up and gags during feedings. About two to three times a week, Sh.S. aspirates during feedings, requiring use of a Smartvest to help prevent pneumonia.

164. The Defendant has approved Sh.S. to receive in-home shift nursing services of 84 hours per week. Sh.S. is a non-waiver enrollee; she does not meet the medical and technology-dependent requirements of the MFTD Waiver program.

165. It is medically necessary that Sh.S. receives in-home shift nursing services of 84 hours per week, which has been approved by the Defendant.

166. Since approximately January 2015, Sh.S. has been only able to receive approximately 65 hours per week of in-home shift nursing services.

167. There are qualified in-home nursing care providers in Sh.S.'s geographic area.

168. Sh.S.'s mother has attempted recruit nurses to staff Sh.S.'s case, but she has not been successful.

169. Sh.S. is requesting injunctive relief to require the Defendant to arrange for the delivery of in-home shift nursing services in order that she may remain safely in the community.

170. Sh.S. is a qualified individual with a disability under the ADA and the Rehabilitation Act.

171. The Defendant has regarded Plaintiff Sh.S. as having a disability within the meaning of the Rehabilitation Act.

172. Sa.S. is a recipient of Medical Assistance, commonly known as Medicaid.

173. Sa.S. is a resident of Illinois.



**VI. CAUSES OF ACTION**

**COUNT I**

**VIOLATION OF THE FEDERAL MEDICAID ACT'S  
EARLY AND PERIODIC SCREENING, DIAGNOSTIC AND TREATMENT (EPSDT)  
MANDATE**

174. The Plaintiffs incorporate and re-allege paragraphs 1 through 173 as if fully set forth herein.

175. In violation of the EPSDT provisions of the Medicaid Act, 42 U.S.C. Secs. 1396a(a)(10)(A), 1396d(a)(4)(B), and 1396a(a)(43)(C), the Defendant, while acting under the color of law, has failed to provide the Plaintiffs and Class with in-home shift nursing services necessary to correct or ameliorate their conditions.

176. In violation of the EPSDT provisions of the Medicaid Act, the Defendant, while acting under the color of law, has failed to “arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment [in-home shift nursing services]” to the Plaintiffs and Class pursuant to 42 U.S.C. Sec. 1396a(a)(43)(C).

177. The Defendant’s violations, which have been repeated and knowing, entitle the Plaintiffs and Class to relief under 42 U.S.C. Sec. 1983.

**COUNT II**

**VIOLATION OF THE FEDERAL MEDICAID ACT'S  
REASONABLE PROMPTNESS REQUIREMENT**

178. The Plaintiffs incorporate and re-allege paragraphs 1 through 177 as if fully set forth herein.

179. The named Plaintiffs and the Class they seek to represent are all Medicaid-eligible children with disabilities residing in Illinois.

180. The Defendant is engaged in the repeated, ongoing failure to arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment, despite the Defendant's acknowledgment that in-home shift nursing services are medically necessary for all named Plaintiffs and Class members.

181. In violation of 42 U.S.C. Sec. 1396a(a)(8) of the Federal Medicaid Act, the Defendant, while acting under the color of law, failed to provide services to the Plaintiffs and Class with ". . . reasonable promptness . . .".

182. The Defendant's violations, which have been repeated and knowing, entitle the Plaintiffs and Class to relief under 42 U.S.C. Sec. 1983.

### **COUNT III**

#### **VIOLATION OF AMERICAN WITH DISABILITIES ACT (ADA)**

183. The Plaintiffs incorporates and re-alleges paragraphs 1 through 182 as if fully set forth herein.

184. 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. Secs. 12131-32. It requires public entities to administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. *See* 28 C.F.R. Sec. 35.130(d).

185. The Plaintiffs and Class are qualified individuals with disabilities within the meaning of Title II of the ADA.

186. The Illinois Department of Healthcare and Family Services (HFS) of which Defendant Norwood is Director is a “public entity” within the meaning of Title II of the ADA.

187. The Defendant’s policies, practices, and procedures have the effects of:  
(1) impermissibly segregating the some Plaintiffs and Class members in institutions or hospitals;  
and (2) placing other Plaintiffs and Class members at a serious risk of institutionalization or hospitalization.

188. The actions by HFS constitute unlawful discrimination under the ADA and violate the integration mandate of the implementing regulations

189. The Plaintiffs and Class members require in-home shift nursing services to avoid institutionalization. The Defendant’s failure to arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment (in-home shift nursing services), violates the ADA and its implementing regulations.

190. The Plaintiffs and Class members have no adequate remedy at law.

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

**COUNT IV**  
**VIOLATION OF REHABILITATION ACT**

192. The Plaintiffs incorporates and re-alleges paragraphs 1 through 191 as if fully set forth herein.

193. Section 504 of 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. Public and federally-funded entities must provide programs and activities “in the most integrated setting appropriate to the needs of the qualified individual with a disability.” See 28 C.F.R. Sec. 41.51(d). Policies, practices, and procedures that have the effects of unjustifiably

segregating persons with disabilities in institutions constitute prohibited discrimination under the Rehabilitation Act.

194. The Illinois Department of Healthcare and Family Services is a recipient of federal funds under the Rehabilitation Act. The Plaintiffs and Class members are qualified individuals with a disability under Section 504 of the Rehabilitation Act.

195. 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).

196. The Plaintiffs and Class members require in-home shift nursing services to avoid institutionalization. The Defendant's failure to arrange for (directly or through referral to appropriate agencies, organizations, or individuals) corrective treatment (in-home shift nursing services), violates Section 504 of the Rehabilitation Act of 1973 and its implementing regulations.

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

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

**VII. REQUEST FOR RELIEF**

WHEREFORE, the Plaintiffs respectfully request that this Court:

1. Certify this case to proceed as a class action under Fed. R. Civ. P. 23(b)(2);
2. Issue a Declaratory Judgment in favor of the Plaintiffs and the Class, requiring Defendant to adhere to the requirements of the Medicaid Act, the Americans with Disabilities Act, and the Rehabilitation Act;
3. Declare unlawful the Defendant's failure to arrange directly or through referral to appropriate agencies, organizations, or individuals, corrective treatment (in-home shift nursing services) to the Plaintiffs and Class;
4. Issue Preliminary and Permanent Injunctive relief enjoining the Defendant from subjecting the Plaintiffs and the Class to practices that violate their rights under the Medicaid Act, the Americans with Disabilities Act and the Rehabilitation Act;
5. Issue Preliminary and Permanent Injunctive relief requiring the Defendant to arrange directly or through referral to appropriate agencies, organizations, or individuals, corrective treatment (in-home shift nursing services) to the Plaintiffs and Class;
6. Award Plaintiffs and the Class the costs of this action, including reasonable attorneys' fees, pursuant to 42 U.S.C. Sec. 12205; Sec. 504 of the Rehabilitation Act, and 42 U.S.C. Sec. 1988; and
7. 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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