## STATE OF NEW YORK

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2121--В

Cal. No. 375

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2021-2022 Regular Sessions

## IN SENATE

January 19, 2021

Introduced by Sens. RIVERA, BRESLIN, HARCKHAM, MAYER, SAVINO -- read twice and ordered printed, and when printed to be committed to the Committee on Health -- reported favorably from said committee, ordered to first report, amended on first report, ordered to a second report and ordered reprinted, retaining its place in the order of second report -- reported favorably from said committee, second report, ordered to a third reading, amended and ordered reprinted, retaining its place in the order of third reading

AN ACT to amend the public health law and the insurance law, in relation to enhancing coverage and care for medically fragile children

## The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Subparagraph (iv) of paragraph (a) of subdivision 2 of section 4900 of the public health law, as added by section 42 of subpart A of part BB of chapter 57 of the laws of 2019, is amended and a new subparagraph (v) is added to read as follows:

- 5 (iv) for purposes of a determination involving treatment for a mental 6 health condition:
- 7 (A) a physician who possesses a current and valid non-restricted 8 license to practice medicine and who specializes in behavioral health 9 and has experience in the delivery of mental health courses of treat-10 ment; or
- 11 (B) a health care professional other than a licensed physician who 12 specializes in behavioral health and has experience in the delivery of a 13 mental health courses of treatment and, where applicable, possesses a 14 current and valid non-restricted license, certificate, or registration 15 or, where no provision for a license, certificate or registration 16 exists, is credentialed by the national accrediting body appropriate to 17 the profession; [and] or
- 18 <u>(v) for purposes of a determination involving treatment of a medically</u>
  19 <u>fragile child:</u>

EXPLANATION--Matter in <a href="italics">italics</a> (underscored) is new; matter in brackets [-] is old law to be omitted.

LBD00514-08-1

- (A) a physician who possesses a current and valid non-restricted license to practice medicine and who is board certified or board eligible in pediatric rehabilitation, pediatric critical care, or neonatology; or
- (B) a physician who possesses a current and valid non-restricted license to practice medicine and is board certified in a pediatric subspecialty directly relevant to the patient's medical condition; and
- § 2. Paragraph (b) of subdivision 2 of section 4900 of the public health law, as amended by chapter 586 of the laws of 1998, is amended to read as follows:
  - (b) for purposes of title two of this article:
  - (i) a physician who:

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- (A) possesses a current and valid non-restricted license to practice medicine;
- (B) where applicable, is board certified or board eligible in the same 16 or similar specialty as the health care provider who typically manages the medical condition or disease or provides the health care service or treatment under appeal;
- (C) has been practicing in such area of specialty for a period of at 19 20 least five years; and
  - (D) is knowledgeable about the health care service or treatment under appeal; or
    - (ii) a health care professional other than a licensed physician who:
  - (A) where applicable, possesses a current and valid non-restricted license, certificate or registration;
  - (B) where applicable, is credentialed by the national accrediting body appropriate to the profession in the same profession and same or similar specialty as the health care provider who typically manages the medical condition or disease or provides the health care service or treatment under appeal;
  - (C) has been practicing in such area of specialty for a period of least five years;
  - (D) is knowledgeable about the health care service or treatment under appeal; and
  - (E) where applicable to such health care professional's scope of practice, is clinically supported by a physician who possesses a current and valid non-restricted license to practice medicine; or
  - (iii) for purposes of a determination involving treatment of a medically fragile child:
- 40 (A) a physician who possesses a current and valid non-restricted license to practice medicine and who is board certified or board eligi-41 42 ble in pediatric rehabilitation, pediatric critical care, or neonatolo-43 gy, or
  - (B) a physician who possesses a current and valid non-restricted license to practice medicine and is board certified in a pediatric subspecialty directly relevant to the patient's medical condition.
  - § 3. Subdivision 2-a of section 4900 of the public health law, added by chapter 586 of the laws of 1998, is amended to read as follows:
- 2-a. "Clinical standards" means those guidelines and standards set 49 forth in the utilization review plan by the utilization review agent 50 51 whose adverse determination is under appeal or, in the case of medically fragile children, those quidelines and standards as required by section 52 53 forty-nine hundred three-a of this article.
- 54 § 4. Paragraph (c) of subdivision 10 of section 4900 of the public 55 health law, as added by chapter 705 of the laws of 1996, is amended to read as follows:

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55 56 (c) a description of practice guidelines and standards used by a utilization review agent in carrying out a determination of medical necessity, which in the case of medically fragile children shall incorporate the standards required by section forty-nine hundred three-a of this article;

- § 5. Section 4900 of the public health law is amended by adding a new subdivision 11 to read as follows:
- 8 11. "Medically fragile child" means an individual who is under twen-9 ty-one years of age and has a chronic debilitating condition or condi-10 tions, who may or may not be hospitalized or institutionalized, and 11 meets one or more of the following criteria (a) is technologically dependent for life or health sustaining functions, (b) requires a 12 complex medication regimen or medical interventions to maintain or to 13 14 improve their health status, or (c) is in need of ongoing assessment or intervention to prevent serious deterioration of their health status or 15 16 medical complications that place their life, health or development at risk. Chronic debilitating conditions include, but are not limited to, 17 bronchopulmonary dysplasia, cerebral palsy, congenital heart disease, 18 19 microcephaly, pulmonary hypertension, and muscular dystrophy. The term "medically fragile child" shall also include severe conditions, includ-20 21 ing but not limited to traumatic brain injury, which typically require care in a specialty care center for medically fragile children, even 22 though the child does not have a chronic debilitating condition or also 23 meet one of the three conditions of this subdivision. In order to facil-24 itate the prompt and convenient identification of particular patient 25 26 care situations meeting the definitions of this subdivision, the commis-27 sioner may issue written quidance listing (by diagnosis codes, utilization thresholds, or other available coding or commonly used medical 28 29 classifications) the types of patient care needs which are deemed to 30 meet this definition. Notwithstanding the definitions set forth in this 31 subdivision, any patient which has received prior approval from a utili-32 zation review agent for admission to a specialty care facility for 33 medically fragile children shall be considered a medically fragile child 34 at least until discharge from that facility occurs.
- 35 § 6. The public health law is amended by adding a new section 4903-a 36 to read as follows:
- 37 § 4903-a. Utilization review determinations for medically fragile 38 children. 1. Notwithstanding any inconsistent provision of the utiliza-39 tion review agent's clinical standards, the utilization review agent shall administer and apply the clinical standards (and make determi-40 nations of medical necessity) regarding medically fragile children in 41 42 accordance with the requirements of this section. To the extent any of 43 the requirements of this section impose obligations which extend beyond the contracted role of any independent utilization review agent under 44 45 contract with a health maintenance organization, it shall be the obli-46 gation of the health maintenance organization to comply with all 47 portions of this section which are not administered by the independent 48 utilization review agent.
  - 2. In the case of a medically fragile child, the term "medically necessary" shall mean health care and services that are necessary to promote normal growth and development and prevent, diagnose, treat, ameliorate or palliate the effects of a physical, mental, behavioral, genetic, or congenital condition, injury or disability. When applied to the circumstances of any particular medically fragile child, the term "medically necessary" shall include (a) the care or services that are essential to prevent, diagnose, prevent the worsening of, alleviate or

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ameliorate the effects of an illness, injury, disability, disorder or 1 condition, (b) the care or services that are essential to the overall 3 physical, cognitive and mental growth and developmental needs of the 4 child, and (c) the care or services that will assist the child to 5 achieve or maintain maximum functional capacity in performing daily 6 activities, taking into account both the functional capacity of the child and those functional capacities that are appropriate for individ-7 8 uals of the same age as the child. The utilization review agent shall 9 base its determination on medical and other relevant information 10 provided by the child's primary care provider, other health care provid-11 ers, school, local social services, and/or local public health officials that have evaluated the child, and the utilization review agent will 12 ensure the care and services are provided in sufficient amount, duration 13 14 and scope to reasonably be expected to produce the intended results and to have the expected benefits that outweigh the potential harmful 15 16 17

- 3. Utilization review agents shall undertake the following with respect to medically fragile children:
- (a) Consider as medically necessary all covered services that assist medically fragile children in reaching their maximum functional capacity, taking into account the appropriate functional capacities of children of the same age. Health maintenance organizations must continue to cover services until that child achieves age-appropriate functional capacity. A managed care provider, authorized by section three hundred sixty-four-j of the social services law, shall also be required to make payment for covered services required to comply with federal Early Periodic Screening, Diagnosis, and Treatment ("EPSDT") standards, as specified by the commissioner of health.
- (b) Shall not base determinations solely upon review standards applicable to (or designed for) adults to medically fragile children. Adult standards include, but are not limited to, Medicare rehabilitation standards and the "Medicare 3 hour rule." Determinations have to take into consideration the specific needs of the child and the circumstances pertaining to their growth and development.
- (c) Accommodate unusual stabilization and prolonged discharge plans 35 36 for medically fragile children, as appropriate. Issues utilization 37 review agents must consider when developing and approving discharge 38 plans include, but are not limited to: sudden reversals of condition or progress, which may make discharge decisions uncertain or more prolonged 39 than for other children or adults; necessary training of parents or 40 other adults to care for medically fragile children at home; unusual 41 42 discharge delays encountered if parents or other responsible adults 43 decline or are slow to assume full responsibility for caring for medically fragile children; the need to await an appropriate home or 44 home-like environment rather than discharge to a housing shelter or 45 46 other inappropriate setting for medically fragile children, the need to 47 await construction adaptations to the home (such as the installation of generators or other equipment); and lack of available suitable special-48 ized care (such as unavailability of pediatric nursing home beds, pedia-49 tric ventilator units, pediatric private duty nursing in the home, or 50 51 specialized pediatric home care services). Utilization review agents must develop a person centered discharge plan for the child taking the 52 53 above situations into consideration.
  - (d) It is the utilization review agent's network management responsibility to identify an available provider of needed covered services, as determined through a person centered care plan, to effect safe discharge

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from a hospital or other facility; payments shall not be denied to a discharging hospital or other facility due to lack of an available post-discharge provider as long as they have worked with the utilization review agent to identify an appropriate provider. Utilization review agents are required to approve the use of out-of-network providers if the health maintenance organization does not have a participating provider to address the needs of the child.

- (e) This section does not limit any other rights the medically fragile child may have, including the right to appeal the denial of out of network coverage at in-network cost sharing levels where an appropriate in-network provider is not available pursuant to subdivision one-b of section forty-nine hundred four of this title.
- (f) Utilization review agents must ensure that medically fragile children receive services from appropriate providers that have the expertise to effectively treat the child and must contract with providers with demonstrated expertise in caring for the medically fragile children. Network providers shall refer to appropriate network community and facility providers to meet the needs of the child or seek authorization from the utilization review agent for out-of-network providers when participating providers cannot meet the child's needs. The utilization review agent must authorize services as fast as the enrollee's condition requires and in accordance with established timeframes in the contracts or policy forms.
- 24 4. A health maintenance organization shall have a procedure by which an enrollee who is a medically fragile child who requires specialized 25 26 medical care over a prolonged period of time, may receive a referral to 27 a specialty care center for medically fragile children. If the health maintenance organization, or the primary care provider or the specialist 28 treating the patient, in consultation with a medical director of the 29 30 utilization review agent, determines that the enrollee's care would most 31 appropriately be provided by such a specialty care center, the organiza-32 tion shall refer the enrollee to such center. In no event shall a health 33 maintenance organization be required to permit an enrollee to elect to 34 have a non-participating specialty care center, unless the organization 35 does not have an appropriate specialty care center to treat the 36 enrollee's disease or condition within its network. Such referral shall 37 be pursuant to a treatment plan developed by the specialty care center 38 and approved by the health maintenance organization, in consultation with the primary care provider, if any, or a specialist treating the 39 patient, and the enrollee or the enrollee's designee. If an organization 40 refers an enrollee to a specialty care center that does not participate 41 42 in the organization's network, services provided pursuant to the 43 approved treatment plan shall be provided at no additional cost to the enrollee beyond what the enrollee would otherwise pay for services 44 45 received within the network. For purposes of this section, a specialty 46 care center for medically fragile children shall mean a children's hospital as defined pursuant to subparagraph (iv) of paragraph (e-2) of 47 subdivision four of section twenty-eight hundred seven-c of this chap-48 ter, a residential health care facility affiliated with such a chil-49 dren's hospital, any residential health care facility with a specialty 50 51 pediatric bed average daily census during two thousand seventeen of fifty or more patients, or a facility which satisfies such other crite-52 53 ria as the commissioner may designate.
- 5. When rendering or arranging for care or payment, both the provider
  and the health maintenance organization shall inquire of, and shall
  consider the desires of the family of a medically fragile child includ-

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ing, but not limited to, the availability and capacity of the family, the need for the family to simultaneously care for the family's other children, and the need for parents to continue employment.

4 6. Except in the case of Medicaid managed care, the health maintenance 5 organization must pay at least eighty-five percent (unless a different 6 percentage or method has been mutually agreed to) of the facility's 7 negotiated acute care rate for all days of inpatient hospital care at a 8 participating specialty care center for medically fragile children when 9 the health maintenance organization and the specialty care facility 10 mutually agree the patient is ready for discharge from the specialty 11 care center to the patient's home but requires specialized home services that are not available or in place, or the patient is awaiting discharge 12 13 to a residential health care facility when no residential health care 14 facility bed is available given the specialized needs of the medically fragile child. Medicaid managed care plans shall pay for such additional 15 16 days at a rate negotiated between the Medicaid managed care plan and the 17 hospital. Except in the case of Medicaid managed care, the health maintenance organization must pay at least the facility's Medicaid skilled 18 19 nursing facility rate, unless a different rate has been mutually negoti-20 ated, for all days of residential health care facility care at a partic-21 ipating specialty care center for medically fragile children when the health maintenance organization and the specialty care facility mutually 22 agree the patient is ready for discharge from the specialty care center 23 24 to the patient's home but requires specialized home services that are not available or in place. Medicaid managed care plans shall pay for 25 26 such additional days at a rate negotiated between the Medicaid managed 27 care plan and the residential health care facility. Such requirements shall apply until the health plan can identify and secure admission to 28 an alternate provider rendering the necessary level of services. The 29 30 specialty care center must cooperate with the health maintenance organ-31 ization's placement efforts.

7. In the event a health maintenance organization enters into a participation agreement with a specialty care center for medically fragile children in this state, the requirements of this section shall apply to such participation agreement and to all claims submitted to, or payments made by, any other health maintenance organizations, insurers or payors making payment to the specialty care center pursuant to the provisions of that participation agreement.

8. (a) The commissioner shall designate a single set of clinical standards applicable to all utilization review agents regarding pediatric extended acute care stays (defined for the purposes of this section as discharge from one acute care hospital followed by immediate admission to a second acute care hospital; not including transfers of case payment cases as defined in section twenty-eight hundred seven-c of this chapter). The standards shall be adapted from national long term acute care hospital standards for adults and shall be approved by the commissioner, after consultation with one or more specialty care centers for medically fragile children. The standards shall include, but not be limited to, specifications of the level of care supports in the patient's home, at a skilled nursing facility or other setting, that must be in place in order to safely and adequately care for a medically fragile child before medically complex acute care can be deemed no longer medically necessary. The standards designated by the commissioner shall pre-empt the clinical standards, if any, for pediatric extended acute care set forth

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(b) The commissioner shall designate a single set of supplemental 1 clinical standards (in addition to the clinical standards selected by 2 3 the utilization review agent) applicable to all utilization review agents regarding acute and sub-acute inpatient rehabilitation for medically fragile children. The supplemental standards shall specify the level of care supports in the patient's home, at a skilled nursing facility or other setting, that must be in place in order to safely and adequately care for a medically fragile child before acute or sub-acute inpatient rehabilitation can be deemed no longer medically necessary. The supplemental standards designated by the commissioner shall pre-empt the clinical standards, if any, regarding readiness for discharge of 11 medically fragile children from acute or sub-acute inpatient rehabili-12 13 tation, as set forth in the utilization review plan by the utilization 14 review agent.

- 9. In all instances the utilization review agent shall defer to the recommendations of the referring physician to refer a medically fragile child for care at a particular specialty provider of care to medically fragile children, or the recommended treatment plan by the treating physician at a specialty care center for medically fragile children, except where the utilization review agent has determined, by clear and convincing evidence, that: (a) the recommended provider or proposed treatment plan is not in the best interest of the medically fragile child, or (b) an alternative provider offering substantially the same level of care in accordance with substantially the same treatment plan is available from a lower cost provider.
- § 7. Section 4403 of the public health law is amended by adding a subdivision 9 to read as follows:
- 9. A health maintenance organization shall have procedures for coverage of medically fragile children including, but not limited to, those necessary to implement section forty-nine hundred three-a of this arti-
- § 8. Subparagraph (D) of paragraph 1 of subsection (b) of section 4900 of the insurance law, as added by section 36 of subpart A of part BB of chapter 57 of the laws of 2019, is amended and a new subparagraph (E) is added to read as follows:
- (D) for purposes of a determination involving treatment for a mental health condition:
- (i) a physician who possesses a current and valid non-restricted 38 license to practice medicine and who specializes in behavioral health 39 and has experience in the delivery of mental health courses of treat-40 41 ment; or
  - (ii) a health care professional other than a licensed physician who specializes in behavioral health and has experience in the delivery of mental health courses of treatment and, where applicable, possesses a current and valid non-restricted license, certificate, or registration or, where no provision for a license, certificate or registration exists, is credentialed by the national accrediting body appropriate to the profession; [and] or
- (E) for purposes of a determination involving treatment of a medically 50 fragile child:
- 51 (i) a physician who possesses a current and valid non-restricted 52 license to practice medicine and who is board certified or board eligi-53 ble in pediatric rehabilitation, pediatric critical care, or neonatolo-54 gy; or

- (ii) a physician who possesses a current and valid non-restricted license to practice medicine and is board certified in a pediatric subspecialty directly relevant to the patient's medical condition; and
- § 9. Paragraph 2 of subsection (b) of section 4900 of the insurance law, as amended by chapter 586 of the laws of 1998, is amended to read as follows:
  - (2) for purposes of title two of this article:
  - (A) a physician who:

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- 9 (i) possesses a current and valid non-restricted license to practice 10 medicine;
- (ii) where applicable, is board certified or board eligible in the same or similar specialty as the health care provider who typically manages the medical condition or disease or provides the health care service or treatment under appeal;
  - (iii) has been practicing in such area of specialty for a period of at least five years; and
  - (iv) is knowledgeable about the health care service or treatment under appeal; or
    - (B) a health care professional other than a licensed physician who:
    - (i) where applicable, possesses a current and valid non-restricted license, certificate or registration;
  - (ii) where applicable, is credentialed by the national accrediting body appropriate to the profession in the same profession and same or similar specialty as the health care provider who typically manages the medical condition or disease or provides the health care service or treatment under appeal;
  - (iii) has been practicing in such area of specialty for a period of at least five years;
  - (iv) is knowledgeable about the health care service or treatment under appeal; and
- 31 (v) where applicable to such health care professional's scope of prac-32 tice, is clinically supported by a physician who possesses a current and 33 valid non-restricted license to practice medicine; or
  - (C) for purposes of a determination involving treatment of a medically fragile child:
  - (i) a physician who possesses a current and valid non-restricted license to practice medicine and who is board certified or board eligible in pediatric rehabilitation, pediatric critical care, or neonatology; or
  - (ii) a physician who possesses a current and valid non-restricted license to practice medicine and is board certified in a pediatric subspecialty directly relevant to the patient's medical condition.
  - § 10. Subsection (b-1) of section 4900 of the insurance law, asadded by chapter 586 of the laws of 1998, is amended to read as follows:
  - (b-1) "Clinical standards" means those guidelines and standards set forth in the utilization review plan by the utilization review agent whose adverse determination is under appeal or, in the case of medically fragile children those guidelines and standards as required by section forty-nine hundred three-a of this article.
  - § 11. Subsection (j) of section 4900 of the insurance law, as added by chapter 705 of the laws of 1996, is amended to read as follows:
- 52 (j) "Utilization review plan" means: (1) a description of the process 53 for developing the written clinical review criteria; (2) a description 54 of the types of written clinical information which the plan might 55 consider in its clinical review, including but not limited to, a set of 56 specific written clinical review criteria; (3) a description of practice

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guidelines and standards used by a utilization review agent in carrying out a determination of medical necessity, which, in the case of 3 medically fragile children, shall incorporate the standards required by 4 section forty-nine hundred three-a of this article; (4) the procedures for scheduled review and evaluation of the written clinical review 6 criteria; and (5) a description of the qualifications and experience of 7 the health care professionals who developed the criteria, who are 8 responsible for periodic evaluation of the criteria and of the health 9 care professionals or others who use the written clinical review crite-10 ria in the process of utilization review.

§ 12. Section 4900 of the insurance law is amended by adding a new subsection (k) to read as follows:

(k) "Medically fragile child" means an individual who is under twenty-one years of age and has a chronic debilitating condition or conditions, who may or may not be hospitalized or institutionalized, and meets one or more of the following criteria: (1) is technologically dependent for life or health sustaining functions; (2) requires a complex medication regimen or medical interventions to maintain or to improve their health status; or (3) is in need of ongoing assessment or intervention to prevent serious deterioration of their health status or medical complications that place their life, health or development at risk. Chronic debilitating conditions include, but are not limited to, bronchopulmonary dysplasia, cerebral palsy, congenital heart disease, microcephaly, pulmonary hypertension, and muscular dystrophy. The term "medically fragile child" shall also include severe conditions, including but not limited to traumatic brain injury, which typically require care in a specialty care center for medically fragile children, even though the child does not have a chronic debilitating condition or also meet one of the three conditions of this subsection. In order to facilitate the prompt and convenient identification of particular patient care situations meeting the definitions of this subsection, the superintendent, after consulting with the commissioner of health, may issue written guidance listing (by diagnosis codes, utilization thresholds, or other available coding or commonly used medical classifications) the types of patient care needs which are deemed to meet this definition. Notwithstanding the definitions set forth in this subsection, any patient which has received prior approval from a utilization review agent for admission to a specialty care facility for medically fragile children shall be considered a medically fragile child at least until discharge from that facility occurs.

§ 13. The insurance law is amended by adding a new section 4903-a to read as follows:

§ 4903-a. Utilization review determinations for medically fragile children. (a) Notwithstanding any inconsistent provision of the utilization review agent's clinical standards, the utilization review agent shall administer and apply the clinical standards (and make determinations of medical necessity) regarding medically fragile children in accordance with the requirements of this section. To the extent any of the requirements of this section impose obligations which extend beyond the contracted role of any independent utilization review agent under contract with a health care plan, it shall be the obligation of the health care plan to comply with all portions of this section which are not administered by the independent utilization review agent.

(b) In the case of a medically fragile child, the term "medically necessary" shall mean health care and services that are necessary to promote normal growth and development and prevent, diagnose, treat,

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ameliorate or palliate the effects of a physical, mental, behavioral, 1 genetic, or congenital condition, injury or disability. When applied to 3 the circumstances of any particular medically fragile child, the term 4 "medically necessary" shall include: (1) the care or services that are 5 essential to prevent, diagnose, prevent the worsening of, alleviate or 6 ameliorate the effects of an illness, injury, disability, disorder or 7 condition; (2) the care or services that are essential to the overall 8 physical, cognitive and mental growth and developmental needs of the 9 child; and (3) the care or services that will assist the child to 10 achieve or maintain maximum functional capacity in performing daily 11 activities, taking into account both the functional capacity of the child and those functional capacities that are appropriate for individ-12 uals of the same age as the child. The utilization review agent shall 13 14 base its determination on medical and other relevant information provided by the child's primary care provider, other health care provid-15 16 ers, school, local social services, and/or local public health officials 17 that have evaluated the child, and the utilization review agent will ensure the care and services are provided in sufficient amount, duration 18 19 and scope to reasonably be expected to produce the intended results and 20 to have the expected benefits that outweigh the potential harmful 21 effects.

- (c) Utilization review agents shall undertake the following with respect to medically fragile children:
- (1) Consider as medically necessary all covered services that assist medically fragile children in reaching their maximum functional capacity, taking into account the appropriate functional capacities of children of the same age. Utilization review agents must continue to cover services until that child achieves age-appropriate functional capacity.
- (2) Shall not base determinations solely upon review standards applicable to (or designed for) adults to medically fragile children. Adult standards include, but are not limited to, Medicare rehabilitation standards and the "Medicare 3 hour rule." Determinations have to take into consideration the specific needs of the child and the circumstances pertaining to their growth and development.
- 35 (3) Accommodate unusual stabilization and prolonged discharge plans 36 for medically fragile children, as appropriate. Issues utilization 37 review agents must consider when developing and approving discharge 38 plans include, but are not limited to: sudden reversals of condition or 39 progress, which may make discharge decisions uncertain or more prolonged than for other children or adults; necessary training of parents or 40 41 other adults to care for medically fragile children at home; unusual 42 discharge delays encountered if parents or other responsible adults 43 decline or are slow to assume full responsibility for caring for medically fragile children; the need to await an appropriate home or 44 45 home-like environment rather than discharge to a housing shelter or 46 other inappropriate setting for medically fragile children, the need to 47 await construction adaptations to the home (such as the installation of generators or other equipment); and lack of available suitable special-48 ized care (such as unavailability of pediatric nursing home beds, pedia-49 tric ventilator units, pediatric private duty nursing in the home, or 50 51 specialized pediatric home care services). Utilization review agents must develop a person centered discharge plan for the child taking the 52 53 above situations into consideration.
- (4) It is the utilization review agents network management responsibility to identify an available provider of needed covered services, as 55 determined through a person centered care plan, to effect safe discharge

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from a hospital or other facility; payments shall not be denied to a discharging hospital or other facility due to lack of an available post-discharge provider as long as they have worked with the utilization review agent to identify an appropriate provider. Utilization review agents are required to approve the use of out-of-network providers if they do not have a participating provider to address the needs of the child.

- (5) This section does not limit any other rights a medically fragile child may have, including the right to appeal the denial of out of network coverage at in-network cost sharing levels where an appropriate in-network provider is not available pursuant to subsection a-two of section four thousand nine hundred four of this title.
- (6) Utilization review agents must ensure that medically fragile children receive services from appropriate providers that have the expertise to effectively treat the child and must contract with providers with demonstrated expertise in caring for the medically fragile children. Network providers shall refer to appropriate network community and facility providers to meet the needs of the child or seek authorization from the utilization review agent for out-of-network providers when participating providers cannot meet the child's needs. The utilization review agent must authorize services as fast as the insured's condition requires and in accordance with established timeframes in the contracts or policy forms.
- 24 (d) A utilization review agent shall have a procedure by which an insured who is a medically fragile child who requires specialized 25 26 medical care over a prolonged period of time, may receive a referral to 27 a specialty care center for medically fragile children. If the utilization review agent, or the primary care provider or the specialist treat-28 ing the patient, in consultation with a medical director of the utiliza-29 30 tion review agent, determines that the insured's care would most appropriately be provided by such a specialty care center, the utiliza-31 32 tion review agent shall refer the insured to such center. In no event 33 shall a utilization review agent be required to permit an insured to elect to have a non-participating specialty care center, unless the 34 35 health care plan does not have an appropriate specialty care center to 36 treat the insured's disease or condition within its network. Such refer-37 ral shall be pursuant to a treatment plan developed by the specialty 38 care center and approved by the utilization review agent, in consultation with the primary care provider, if any, or a specialist treating 39 the patient, and the insured or the insured's designee. If a utilization 40 review agent refers an insured to a specialty care center that does not 41 42 participate in the health care plan's network, services provided pursu-43 ant to the approved treatment plan shall be provided at no additional cost to the insured beyond what the insured would otherwise pay for 44 45 services received within the network. For purposes of this section, a 46 specialty care center for medically fragile children shall mean a children's hospital as defined pursuant to subparagraph (iv) of paragraph 47 (e-2) of subdivision four of section two thousand eight hundred seven-c 48 49 of the public health law, a residential health care facility affiliated with such a children's hospital, any residential health care facility 50 51 with a specialty pediatric bed average daily census during two thousand 52 seventeen of fifty or more patients, or a facility which satisfies such 53 other criteria as the commissioner of health may designate.
  - (e) When rendering or arranging for care or payment, both the provider and the health care plan shall inquire of, and shall consider the desires of, the family of a medically fragile child including, but not

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limited to, the availability and capacity of the family, the need for the family to simultaneously care for the family's other children, and the need for parents to continue employment.

(f) The health care plan must pay at least eighty-five percent (unless 4 5 a different percentage or method has been mutually agreed to) of the 6 facility's negotiated acute care rate for all days of inpatient hospital 7 care at a participating specialty care center for medically fragile children when the insurer and the specialty care facility mutually agree 8 the patient is ready for discharge from the specialty care center to the 9 patient's home but requires specialized home services that are not 10 11 available or in place, or the patient is awaiting discharge to a residential health care facility when no residential health care facility 12 bed is available given the specialized needs of the medically fragile 13 14 child. The health care plan must pay at least the facility's skilled 15 nursing Medicaid facility rate, unless a different rate has been mutual-16 ly negotiated, for all days of residential health care facility care at 17 a participating specialty care center for medically fragile children when the insurer and the specialty care facility mutually agree the 18 19 patient is ready for discharge from the specialty care center to the 20 patient's home but requires specialized home services that are not 21 available or in place. Such requirements shall apply until the health 22 care plan can identify and secure admission to an alternate provider rendering the necessary level of services. The specialty care center 23 24 must cooperate with the health care plan's placement efforts.

(g) In the event a health care plan enters into a participation agreement with a specialty care center for medically fragile children in this state, the requirements of this section shall apply to that participation agreement and to all claims submitted to, or payments made by, any other insurers, health maintenance organizations or payors making payment to the specialty care center pursuant to the provisions of that participation agreement.

(h) (1) The superintendent, after consulting with the commissioner of health, shall designate a single set of clinical standards applicable to all utilization review agents regarding pediatric extended acute care stays (defined for the purposes of this section as discharge from one acute care hospital followed by immediate admission to a second acute care hospital; not including transfers of case payment cases as defined in section two thousand eight hundred seven-c of the public health law). The standards shall be adapted from national long term acute care hospital standards for adults and shall be approved by the superintendent, after consultation with one or more specialty care centers for medically fragile children. The standards shall include, but not be limited to, specifications of the level of care supports in the patient's home, at a skilled nursing facility or other setting, that must be in place in order to safely and adequately care for a medically fragile child before medically complex acute care can be deemed no longer medically necessary. The standards designated by the commissioner shall pre-empt the clinical standards, if any, for pediatric extended acute care set forth in the utilization review plan by the utilization review agent.

(2) The superintendent, after consulting with the commissioner of health, shall designate a single set of supplemental clinical standards (in addition to the clinical standards selected by the utilization review agent) applicable to all utilization review agents regarding acute and sub-acute inpatient rehabilitation for medically fragile children. The standards shall specify the level of care supports in the patient's home, at a skilled nursing facility or other setting, that

must be in place in order to safely and adequately care for a medically fragile child before acute or sub-acute inpatient rehabilitation can be deemed no longer medically necessary. The supplemental standards designated by the superintendent shall pre-empt the clinical standards, if any, regarding readiness for discharge of medically fragile children from acute or sub-acute inpatient rehabilitation, as set forth in the utilization review plan by the utilization review agent.

- (i) In all instances the utilization review agent shall defer to the recommendations of the referring physician to refer a medically fragile child for care at a particular specialty provider of care to medically fragile children, or the recommended treatment plan by the treating physician at a specialty care center for medically fragile children, except where the utilization review agent has determined, by clear and convincing evidence, that: (1) the recommended provider or proposed treatment plan is not in the best interest of the medically fragile child; or (2) an alternative provider offering substantially the same level of care in accordance with substantially the same treatment plan is available from a lower cost provider.
- 19 § 14. The insurance law is amended by adding a new section 3217-j to 20 read as follows:
  - § 3217-j. Coverage for medically fragile children. An insurer shall have procedures for coverage of medically fragile children including, but not limited to, those necessary to implement section four thousand nine hundred three-a of this chapter.
  - § 15. The insurance law is amended by adding a new section 4306-i to read as follows:
  - § 4306-i. Coverage for medically fragile children. A corporation that is subject to the provisions of this article shall have procedures for coverage of medically fragile children including, but not limited to, those necessary to implement section four thousand nine hundred three-a of this chapter.
- § 16. Sections three, four, five, six, seven, ten, eleven, twelve, thirteen, fourteen and fifteen of this act shall not apply to any qualified health plans in the individual and small group market on and after the date, if any, when the federal department of health and human services determines in writing that such provisions constitute state-required benefits in addition to essential health benefits, pursuant to the federal Affordable Care Act and regulations promulgated thereunder.
- 39 § 17. This act shall take effect January 1, 2022.