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STATE OF WISCONSIN
Division of Hearings and Appeals

In the Matter of

██████████ ██████████
c/o ██████████ & ██████████ ██████████ (parents)
██████████
██████████

DECISION
Case #: MKB - 200031

PRELIMINARY RECITALS

Pursuant to a petition filed on September 29, 2020, under Wis. Stat. § 49.45(5), and Wis. Admin. Code § HA 3.03(1), to review a decision by the Bureau of Long-Term Support regarding Medical Assistance (MA), a hearing was held on December 15, 2020, by telephone. Hearings scheduled for October 20, 2020, and November 24, 2020, were rescheduled at the request of petitioner's parents.

The issue for determination is whether petitioner meets the legal standard for disability required to establish eligibility for Medical Assistance benefits through the Katie Beckett program.

There appeared at that time the following persons:

PARTIES IN INTEREST:

Petitioner:

██████████ ██████████
c/o ██████████ & ██████████ ██████████ (parents)
██████████
██████████

Respondent:

Department of Health Services
1 West Wilson Street, Room 651
Madison, WI 53703

By: No Appearance
Bureau of Long-Term Support
PO Box 7851
Madison, WI 53707-7851

ADMINISTRATIVE LAW JUDGE:

Jason M. Grace
Division of Hearings and Appeals

FINDINGS OF FACT

1. Petitioner (CARES #) is a resident of La Crosse County. He turned 12 months of age in December 2020. He participates in the Birth to Three Program, receiving physical therapy and occupational therapy services. He also attends music therapy.
2. Petitioner has Mosaic Down Syndrome with hypotonia.
3. Petitioner had an echocardiogram that was found to be normal. Vision test at 5 months of age was normal other than a mild Ptosis of the right eyelid and astigmatism. Petitioner failed his newborn hearing screen but a reassessment approximately 3 weeks later ruled out any thing greater than slight to mild hearing loss. At a 5 month medical appointment, petitioner passed a hearing exam, with the mother further reporting no significant concerns with his speech or hearing development.
4. A 6 month comprehensive evaluation was conducted using the Bayley Scales of Infant and Toddler Development. It indicated petitioner presented with emerging skills at the 5 month age level on the cognitive subtest and 3 month level in communication. It was indicated that he was demonstrating positive gains overall developmentally but continued to present with significant delays. It was noted that petitioner's cognitive delays would likely become more evident over time.
5. A letter dated July 1, 2020, authored by Dr. [REDACTED] [REDACTED], a clinical geneticist, indicated that although petitioner's Trisomy 21 is mosaic, that did not predict that petitioner's clinical course will be any less severe and that he should be considered exactly the same as other children with non-mosaic Down Syndrome. It was noted petitioner has global developmental delays and significant hypotonia impacting his gross motor development.
6. By a letter dated December 4, 2020, petitioner's physical therapist with Birth to Three indicated that he has low muscle tone (hypotonia) throughout his whole body, impacting his ability to perform gross motor activities that are age appropriate. It was noted that petitioner was just beginning to army crawl to get to caregivers and obtain toys. He was also starting to achieve a sitting position on his own, which is typically seen in children ages 6 to 8 months. His low muscle tone impacted his endurance to explore his environment and placed him at increased risk of respiratory sickness. The low muscle tone also impacted his feeding as he does not consistently bring food to his mouth other than NutriGrain bars. He demonstrated the ability to eat pureed food from a spoon when fed by a caregiver but had some difficulty with transitioning to different food textures. It was noted petitioner functioned at around the 7 – 9 month age range for most areas but was at 10-11 months for social/emotional skills and 9—10 months for language.
7. Petitioner's father indicated that petitioner's hypotonia was the main issue. He noted petitioner was not crawling normal for his age, rolls a little bit, cannot walk, and is unable to pull himself up to stand. Petitioner is showing signs he has or may have issues with gross motor skills. Petitioner picks items up and is able to pass them hand-to-hand but has difficulty holding a drum stick to bang on toys. Petitioner is unable to feed himself, and feedings take an extended period of time. Petitioner is transitioning from a bottle, chews and eats well, but has some issues with food textures. Petitioner is showing delays in movement, speech, and feeding. It was noted that petitioner looks at books but it was not known what he is actually seeing. His vision will be reassessed when petitioner turns two.
8. On January 22, 2020, an application for Katie Becket MA was filed on petitioner's behalf on January 22, 2020. By letter dated June 4, 2020, the DDB found that petitioner was not disabled. Petitioner sought reconsideration, but the DDB affirmed the denial on September 25, 2020.

9. The DDB's assessors (both medical doctors) found that petitioner had less than marked limitations in domains for moving about and manipulating objects and physical health and well-being.
10. On September 24, 2020, the DDB forwarded petitioner's file to the Division of Hearings and Appeals to schedule a hearing.

DISCUSSION

The Katie Beckett Program allows certain children with long-term disabilities who reside at home with their parents to receive Medical Assistance. Wis. Stat. §49.46(1)(d)4; 42 USC 1396a(e)(3); 42 C.F.R. §435.225; *Medicaid Eligibility Handbook (MEH)* §29.1. To qualify for Katie Beckett benefits, a child must be under the age of 19, capable of receiving appropriate care in his or her home, *meet Social Security standards for childhood disability*, require a level of care that is typically provided in a hospital, nursing home, or ICF-MR, and meet certain financial eligibility criteria. See *Id.*

The issue in this case is whether petitioner meets the required legal standard to be considered disabled. The federal regulations provide the following definition of a disabling impairment for children:

(b) If you are a child, a disabling impairment is an impairment (or combination of impairments) that causes marked and severe functional limitations. This means that the impairment or combination of impairments:

- (1) Must meet, medically equal, or functionally equal the [Listing of Impairments in appendix 1 of subpart P of part 404], or
- (2) Would result in a finding that you are disabled under § 416.994a.

20 C.F.R. §416.911(b). §416.994a referenced in number (2) describes disability reviews for children found disabled under the prior law.

The process of determining whether an individual meets this definition is sequential. See 20 C.F.R. §416.924. The first step requires a determination as to whether the claimant is working and performing "substantial gainful activity" (SGA). As petitioner is only 12 months-old, he has not performed SGA. He therefore passes this step.

Second, physical and mental impairments are considered to see if the claimant has an impairment or combination of impairments that is severe. If the impairment is a slight abnormality or a combination of slight abnormalities that causes no more than minimal functional limitations, it will not be found to be severe. 20 C.F.R. §416.924(c). The DDB determined that petitioner met this step.

The third step considers whether the child has an impairment(s) that meets, medically equals, OR functionally equals in severity any impairment that is listed in Appendix 1 of Subpart P of Part 404 of the regulations (Listings). See 20 C.F.R. §416.924(d).

There is a listing for non-mosaic Down Syndrome at 110.06. However, petitioner has mosaic Down Syndrome. For mosaic Down Syndrome, the listing indicates that "... we evaluate the disorder under the appropriate affected body system(s), such as musculoskeletal, special senses and speech, neurological, or mental disorders. Otherwise, we evaluate the specific functional limitations...." 110.00F(3).

Petitioner's parents argued that there is no difference between mosaic and non-mosaic Down Syndrome and the former does not mean an individual will not have significant impairments. That

argument was consistent with the information provided in writing by petitioner's doctors. It was further argued that the DDB's "guidelines" did not correctly account for that fact.

The listings explicitly distinguishes between mosaic and non-mosaic Down Syndrome. The latter automatically meets the listing with appropriate documentation while the former requires further assessment. An administrative law judge with the Division of Hearings and Appeals does not have the authority to act in equity or to depart from the disability analysis set forth in statute and code. As such, I must evaluate mosaic Down Syndrome under the appropriate affected body system to determine if it medically meets a listing. If it does not, the analysis turns to the next step in the process, which is to determine if it is functionally equivalent to the listings. The DDB found that the impairment did not medically meet or equal a listing and proceeded to the next step in the analysis.

The record indicates that petitioner's impairment causes him to have low muscle tone, also known as hypotonia, which has caused delays in meeting developmental milestones. While there is no listing for hypotonia, I did review listings under systems for musculoskeletal (101.00) and neurological (111.00). Those listings require the child's limitation to be extreme, meaning the child's performance is at no more than one-half of his chronological age. While the petitioner has notable delays, the record does not support a finding of extreme, as defined. I also reviewed the listing for mental disorders under 112.00, and specifically, developmental disorder under 112.14, but it requires extreme limitations in one, or marked limitations in two, of four areas. If the child does not meet a listing, the review moves to the next step. I will move there immediately because the next step incorporates the listing areas but adds two additional areas.

If a child does not meet or equal the listings, the last step of the analysis is the assessment of functional limitations as described in sec. 416.926a of the regulations. This means looking at what the child cannot do because of the impairments in order to determine if the impairments functionally equal the listings. The six areas, which are called domains, evaluated are: (1) acquiring and using information; (2) attending and completing tasks; (3) interacting and relating with others; (4) moving about and manipulating objects; (5) caring for yourself; and (6) health and physical well-being. 20 C.F.R. §416.926a(a) and (b)(1). To be found disabled, the child must have marked limitations in two of the six domains, or an extreme limitation in one of the domains. 20 C.F.R. §416.926a(b)(2).

The federal regulations provide the following standards for assessing whether a limitation is marked or extreme:

(2) Marked limitation. (i) We will find that you have a "marked" limitation in a domain when your impairment(s) interferes seriously with your ability to independently initiate, sustain, or complete activities. Your day-to-day functioning may be seriously limited when your impairment(s) limits only one activity or when the interactive and cumulative effects of your impairment(s) limit several activities. "Marked" limitation also means a limitation that is "more than moderate" but "less than extreme." It is the equivalent of the functioning we would expect to find on standardized testing with scores that are at least two, but less than three, standard deviations below the mean.

(ii) If you have not attained age 3, we will generally find that you have a "marked" limitation if you are functioning at a level that is more than one-half but not more than two-thirds of your chronological age when there are no standard scores from standardized tests in your case record.

(iii) If you are a child of any age (birth to the attainment of age 18), we will find that you have a "marked" limitation when you have a valid score that is two standard deviations or more below the mean, but less than three standard deviations, on a comprehensive standardized test designed to measure ability or functioning in that domain, and your day-

to-day functioning in domain-related activities is consistent with that score. (See paragraph (e)(4) of this section.) ...

(3) Extreme limitation. (i) We will find that you have an “extreme” limitation in a domain when your impairment(s) interferes very seriously with your ability to independently initiate, sustain, or complete activities. Your day-to-day functioning may be very seriously limited when your impairment(s) limits only one activity or when the interactive and cumulative effects of your impairment(s) limit several activities. “Extreme” limitation also means a limitation that is “more than marked.” “Extreme” limitation is the rating we give to the worst limitations. However, “extreme limitation” does not necessarily mean a total lack or loss of ability to function. It is the equivalent of the functioning we would expect to find on standardized testing with scores that are at least three standard deviations below the mean.

(ii) If you have not attained age 3, we will generally find that you have an “extreme” limitation if you are functioning at a level that is one-half of your chronological age or less when there are no standard scores from standardized tests in your case record.

(iii) If you are a child of any age (birth to the attainment of age 18), we will find that you have an “extreme” limitation when you have a valid score that is three standard deviations or more below the mean on a comprehensive standardized test designed to measure ability or functioning in that domain, and your day-to-day functioning in domain-related activities is consistent with that score. (See paragraph (e)(4) of this section.) ...

(4) How we will consider your test scores. (i) As indicated in § [416.924a\(a\)\(1\)\(ii\)](#), we will not rely on any test score alone. No single piece of information taken in isolation can establish whether you have a “marked” or an “extreme” limitation in a domain.

(ii) We will consider your test scores together with the other information we have about your functioning, including reports of classroom performance and the observations of school personnel and others.

20 CFR §416.926a(e)(2)-(4).

The federal childhood disability regulations provide detailed instructions regarding how each domain must be evaluated. For reference, portions of these instructions are included below:

(g) Acquiring and using information. In this domain, we consider how well you acquire or learn information, and how well you use the information you have learned. ...

(2) Age group descriptors—(i) Newborns and young infants (birth to attainment of age 1). At this age, you should show interest in, and explore, your environment. At first, your actions are random; for example, when you accidentally touch the mobile over your crib. Eventually, your actions should become deliberate and purposeful, as when you shake noisemaking toys like a bell or rattle. You should begin to recognize, and then anticipate, routine situations and events, as when you grin with expectation at the sight of your stroller. You should also recognize and gradually attach meaning to everyday sounds, as when you hear the telephone or your name. Eventually, you should recognize and respond to familiar words, including family names and what your favorite toys and activities are called.

(ii) Older infants and toddlers (age 1 to attainment of age 3). At this age, you are learning about the world around you. When you play, you should learn how objects go together in different ways. You should learn that by pretending, your actions can represent real things. This helps you understand that words represent things, and that

words are simply symbols or names for toys, people, places, and activities. You should refer to yourself and things around you by pointing and eventually by naming. You should form concepts and solve simple problems through purposeful experimentation (e.g., taking toys apart), imitation, constructive play (e.g., building with blocks), and pretend play activities. You should begin to respond to increasingly complex instructions and questions, and to produce an increasing number of words and grammatically correct simple sentences and questions.

...

(h) ***Attending and completing tasks.*** In this domain, we consider how well you are able to focus and maintain your attention, and how well you begin, carry through, and finish your activities, including the pace at which you perform activities and the ease with which you change them. ...

(2) *Age group descriptors*—(i) *Newborns and young infants (birth to attainment of age 1).* You should begin at birth to show sensitivity to your environment by responding to various stimuli (e.g., light, touch, temperature, movement). Very soon, you should be able to fix your gaze on a human face. You should stop your activity when you hear voices or sounds around you. Next, you should begin to attend to and follow various moving objects with your gaze, including people or toys. You should be listening to your family's conversations for longer and longer periods of time. Eventually, as you are able to move around and explore your environment, you should begin to play with people and toys for longer periods of time. You will still want to change activities frequently, but your interest in continuing interaction or a game should gradually expand.

(ii) *Older infants and toddlers (age 1 to attainment of age 3).* At this age, you should be able to attend to things that interest you and have adequate attention to complete some tasks by yourself. As a toddler, you should demonstrate sustained attention, such as when looking at picture books, listening to stories, or building with blocks, and when helping to put on your clothes.

...

(i) ***Interacting and relating with others.*** In this domain, we consider how well you initiate and sustain emotional connections with others, develop and use the language of your community, cooperate with others, comply with rules, respond to criticism, and respect and take care of the possessions of others. ...

(2) *Age group descriptors*—(i) *Newborns and young infants (birth to attainment of age 1).* You should begin to form intimate relationships at birth by gradually responding visually and vocally to your caregiver(s), through mutual gaze and vocal exchanges, and by physically molding your body to the caregiver's while being held. You should eventually initiate give-and-take games (such as pat-a-cake, peek-a-boo) with your caregivers, and begin to affect others through your own purposeful behavior (e.g., gestures and vocalizations). You should be able to respond to a variety of emotions (e.g., facial expressions and vocal tone changes). You should begin to develop speech by using vowel sounds and later consonants, first alone, and then in babbling.

(ii) *Older infants and toddlers (age 1 to attainment of age 3).* At this age, you are dependent upon your caregivers, but should begin to separate from them. You should be able to express emotions and respond to the feelings of others. You should begin initiating and maintaining interactions with adults, but also show interest in, then play alongside, and eventually interact with other children your age. You should be able to spontaneously communicate your wishes or needs, first by using gestures, and eventually by speaking words clearly enough that people who know you can understand what you say most of the time.

...

(j) ***Moving about and manipulating objects.*** In this domain, we consider how you move your body from one place to another and how you move and manipulate things. These are called gross and fine motor skills. ...

(2) *Age group descriptors*—(i) *Newborns and infants (birth to attainment of age 1).* At birth, you should begin to explore your world by moving your body and by using your limbs. You should learn to hold your head up, sit, crawl, and stand, and sometimes hold onto a stable object and stand actively for brief periods. You should begin to practice your developing eye-hand control by reaching for objects or picking up small objects and dropping them into containers.

(ii) *Older infants and toddlers (age 1 to attainment of age 3).* At this age, you should begin to explore actively a wide area of your physical environment, using your body with steadily increasing control and independence from others. You should begin to walk and run without assistance, and climb with increasing skill. You should frequently try to manipulate small objects and to use your hands to do or get something that you want or need. Your improved motor skills should enable you to play with small blocks, scribble with crayons, and feed yourself.

...

(k) ***Caring for yourself.*** In this domain, we consider how well you maintain a healthy emotional and physical state, including how well you get your physical and emotional wants and needs met in appropriate ways; how you cope with stress and changes in your environment; and whether you take care of your own health, possessions, and living area.

...

(2) *Age group descriptors*—(i) *Newborns and infants (birth to attainment of age 1).* Your sense of independence and competence begins in being able to recognize your body's signals (e.g., hunger, pain, discomfort), to alert your caregiver to your needs (e.g., by crying), and to console yourself (e.g., by sucking on your hand) until help comes. As you mature, your capacity for self-consolation should expand to include rhythmic behaviors (e.g., rocking). Your need for a sense of competence also emerges in things you try to do for yourself, perhaps before you are ready to do them, as when insisting on putting food in your mouth and refusing your caregiver's help.

(ii) *Older infants and toddlers (age 1 to attainment of age 3).* As you grow, you should be trying to do more things for yourself that increase your sense of independence and competence in your environment. You might console yourself by carrying a favorite blanket with you everywhere. You should be learning to cooperate with your caregivers when they take care of your physical needs, but you should also want to show what you can do; e.g., pointing to the bathroom, pulling off your coat. You should be experimenting with your independence by showing some degree of contrariness (e.g., “No! No!”) and identity (e.g., hoarding your toys).

...

(l) ***Health and physical well-being.*** In this domain, we consider the cumulative physical effects of physical or mental impairments and their associated treatments or therapies on your functioning **that we did not consider in paragraph (j) of this section.** When your physical impairment(s), your mental impairment(s), or your combination of physical and mental impairments has physical effects that cause “extreme” limitation in your functioning, you will generally have an impairment(s) that “meets” or “medically equals” a listing. ...

20 C.F.R. §416.926a(g)-(l).

The DDB assessors found no limitations for domains (g) acquiring and using information, (h) attending and completing tasks, (i) interacting and relating to others, and (k) caring for yourself. The parents

expressed concern about the future outlook for their child given the range of possible impairments and medical issues that can develop over time for an individual who has Down Syndrome, but the information provided at the hearing pertained to the domains for (j) moving about and manipulating objects and (l) health and physical well-being.

I would note that a letter by a Birth to Three physical therapist dated December 4, 2020, included the most recent information about petitioner's developmental delays. At the time of the letter petitioner was a week shy of turning 12 months of age. The letter indicated petitioner was functionally at about 10-11 months for social/emotional skills and 9—10 months for language. While this reflects delays, those delays are not presently to the level needed for a finding of marked or extreme. Based on my review of the record, I agree with the DDB that the limitations do not meet marked or extreme for domains (g), (h), (i), and (k).

Domain: (j) Moving about and manipulating objects

The DDB found petitioner has a “less than marked” limitation in the domain of moving about and manipulating objects. Based on the medical documents in the DDB file, credible testimony by petitioner's parents, and the December 4, 2020, letter from petitioner's physical therapist, I find that the limitation rises to the level of marked.

The record indicates that petitioner's hypotonia (low muscle tone) causes severe delays in gross motor development. The resulting impact is that he is not able to walk, pull himself up to stand, feed himself, and is just starting to be able to achieve a sitting position on his own, which typically is seen in children ages 6 to 8 months. Moreover, the hypotonia impedes his ability crawl in an age appropriate manner and impacted his endurance to explore his environment. Furthermore, the December 2020 physical therapy letter places petitioner's functioning approximately between one-half and two-thirds his chronological for all areas other than language and social/emotional.

Domain: (l) Health and Physical well-being

The DDB assessors found petitioner has “less than marked” limitation in the domain for health and physical well-being. It was noted that petitioner's growth, sleep pattern, and elimination were all within the range of normal. It was further noted that hearing loss was slight to minor, heart functioning was normal, and that while petitioner had diagnoses of Downy Syndrome, global developmental delays, and hypotonia, it was not presenting serious delays at the time.

The parents identified issues with feeding and vision. As to vision, it was noted by the father that petitioner had nystagmus. However, as set forth in Finding of Fact #3, the most recent vision test indicated it was normal other than a mild Ptosis of the right eyelid and astigmatism. As to feeding, the parents indicated it was taking an extended period of time and there were some food texture issues. However, the record does not indicate that petitioner is unable to receive appropriate and sufficient nutrition through his feeds or was aspirating. The six month wellness exam, the most recent physical examination by a medical doctor in the record, indicated petitioner was well-developed and well-nourished. The record also indicates that petitioner was starting to transition from liquids to puree foods, which he was eating well. It is my understanding that the parent's will be looking at obtaining a feeding assessment or swallow study in the future. The results of those exams would certainly be considered if they re-apply for Katie Beckett down the road. I would also note that the record reflected some sleep issues. Medical records indicate, however, that those issues were not atypical for children of similar age.

The main argument set forth by the parents was that the severe health issues and associated limitations that can be present for individuals with non-mosaic Down Syndrome can also be present for individuals with mosaic Down Syndrome. Petitioner has mosaic Down Syndrome. This argument was supported by their child's geneticist. My understanding of the information provided by the geneticist is that there was

no guarantee what the health issues will ultimately be for petitioner, nor the degree of any resulting impairment. The functional disability assessment is individualized and evaluates limitations as they currently exist. As found by the DDB, the limitations under the health and physical well-being domain do not support a finding of marked or extreme at this time.

In summary, a finding of disabled for Katie Beckett requires marked limitations in two domains or an extreme limitation in one domain. No domain was found to be extreme and only one domain (moving about and manipulating) supported a finding of marked. As such, the petitioner does not functionally meet the childhood disability listings and does not meet the legal standard to be considered disabled for purposes of attaining Medical Assistance-Katie Beckett benefits.

I understand that petitioner would benefit from more comprehensive health coverage than he currently has and that his parents are working exhaustively and at considerable expense to obtain the best therapeutic care they can find for him. While I have no doubt that petitioner would benefit from the treatment that his parents believe Katie Beckett would make more accessible, as an administrative law judge, I am required to apply the relevant statutes, regulations, and policies as they are written and regrettably have no discretion to grant any type of hardship exception.

Finally, I note that nothing prevents the petitioner's parents from re-applying for Katie Beckett as petitioner's medical conditions change or his functional limitations become more apparent as he ages.

CONCLUSIONS OF LAW

Petitioner does not meet the legal standard for disability required to establish eligibility for Medical Assistance benefits through the Katie Beckett program.

THEREFORE, it is **ORDERED**

That petitioner's appeal is dismissed.

REQUEST FOR A REHEARING

You may request a rehearing if you think this decision is based on a serious mistake in the facts or the law or if you have found new evidence that would change the decision. Your request must be **received within 20 days after the date of this decision**. Late requests cannot be granted.

Send your request for rehearing in writing to the Division of Hearings and Appeals, 4822 Madison Yards Way, 5th Floor North, Madison, WI 53705-5400 **and** to those identified in this decision as "PARTIES IN INTEREST." Your rehearing request must explain what mistake the Administrative Law Judge made and why it is important or you must describe your new evidence and explain why you did not have it at your first hearing. If your request does not explain these things, it will be denied.

The process for requesting a rehearing may be found at Wis. Stat. § 227.49. A copy of the statutes may be found online or at your local library or courthouse.

APPEAL TO COURT

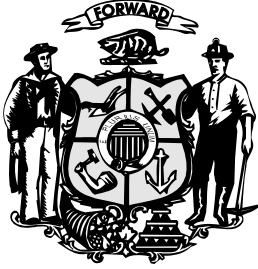
You may also appeal this decision to Circuit Court in the county where you live. Appeals must be filed with the Court **and** served either personally or by certified mail on the Secretary of the Department of Health Services, 1 West Wilson Street, Room 651, **and** on those identified in this decision as "PARTIES

IN INTEREST” **no more than 30 days after the date of this decision** or 30 days after a denial of a timely rehearing (if you request one).

The process for Circuit Court Appeals may be found at Wis. Stat. §§ 227.52 and 227.53. A copy of the statutes may be found online or at your local library or courthouse.

Given under my hand at the City of Madison,
Wisconsin, this 14th day of January, 2021

\s _____
Jason M. Grace
Administrative Law Judge
Division of Hearings and Appeals



State of Wisconsin\DIVISION OF HEARINGS AND APPEALS

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The preceding decision was sent to the following parties on January 14, 2021.

Bureau of Long-Term Support
Division of Health Care Access and Accountability

