## Part C – Decision Under Appeal

The decision under appeal is the Ministry of Social Development and Poverty Reduction's (the "Ministry") reconsideration decision of January 2, 2024. In the reconsideration decision the Ministry determined that the Appellant was not eligible for Masimo LNCS Neo/Adult sensors for oximeter or Coban Wrap.

The panel notes that the reconsideration decision states, "After reviewing all documentation provided, the Ministry is unable to approve your request for funding for Masimo LNCS Neo/Adult sensors for oximeter (160/year) and Coban Wrap (60 rolls per year)." However, the initial request also included a Masimo Oximeter and cable. The parties confirmed that the oximeter and cable were also rejected and should be part of this appeal.

## Part D - Relevant Legislation

Employment and Assistance for Persons with Disabilities Regulation sections 57, 62-70, and Schedule C (the "Regulation")

Relevant sections of the legislation can be found in the Schedule of Legislation at the end of this decision.

## Part E – Summary of Facts

[An in-person hearing was held on February 22, 2024. The panel, the Appellant, and the Appellant's father [as advocate] attended the hearing in-person. A representative of the Ministry joined the hearing via telephone. The appellant's doctor attended briefly via telephone.]

#### **Background**

- The Appellant is an 18-year-old woman with a progressive disease. She has severe
  hypotonia and chronic respiratory failure requiring non-invasive ventilation for 1620 hours a day. Given the fragility of her respiratory status, it is imperative for
  caregivers to monitor oxygen levels continuously and respond accordingly. As such,
  she requires an oximeter and related supplies including, but not limited to, a
  Masimo Oximeter and cable (previously provided by the At-Home Program),
  Masimo LNCS Neo/Adult sensors for oximeter (160/year), and Coban Wrap (20
  rolls/year).
- The Appellant is remarkable in that she has progressed to adulthood with her medical condition. The Appellant is transitioning from coverage for medical supplies and equipment provided by the Ministry of Children and Family Development's At-Home program to coverage provided by the Ministry of Social Development and Poverty Reduction.
- She is in receipt of disability assistance.

The information before the Ministry at the time of reconsideration included the following:

- Letter of Justification for an oximeter and supplies, dated Sept. 21, 2023, from Appellant's doctor at a respiratory clinic. This letter:
  - o Summarizes patient's medical status, and
  - States: "imperative for caregivers to monitor oxygen levels continuously and respond accordingly."
- Prescriptions from doctor for oximeter and supplies, dated Sept. 21, 2023
- Reasons for Request for Reconsideration dated Dec. 17, 2023, in which the Appellant's father provides more specificity concerning the need for, and benefits of, the oximeter. He indicates:
  - The Appellant is the first person to live past 3 months of age in her community, according to geneticist (retired).

- Monitoring on the foot using sensors allows us to monitor during normal daily activities safely. We have used this system for 17.5 years.
- Oximetry imperative to alert caregivers of extreme bradycardia events, track recovery from such events, and alarm if a desaturation occurs or if hospitalization is required.
- Frequency of hospitalization has been greatly reduced because of monitoring.

Information submitted after the Reconsideration Decision

# 1. Notice of Appeal

In the Reason for Appeal dated Jan 8, 2024, the Appellant stated that she is non-verbal, and an oximeter is the only way to know if she is crashing or recovering.

## 2. Appellant Submission, submitted Jan. 26, 2024, containing:

- A description of what an Oximeter is.
- Copy of pages 170 176 of Non-invasive Mechanical Ventilation, by John R. Bach MD.
- Copy of a Science Direct article, entitled Diagnosis and Management of spinal muscular atrophy Part 2: Pulmonary and acute care; medications, supplements, and immunizations; other organ systems; and ethics.
- Copy of an article from the Pediatrics (Official Journal of the American Academy of Pediatrics), entitled Special Considerations in the Respiratory Management of Spinal Muscular Atrophy.
- Nursing Support Services Child Assessment Reports for several years between 2005 and 2018.

# 3. Appellant Submission II, submitted at the hearing:

- The document was e-mailed to Ministry representative who had no objection to it being admitted.
- It contained photographs and narrative illustrating the requested items and explaining how they were used in different situations.

## 4. <u>Testimony at the hearing</u>

- The Appellant's doctor:
  - Confirmed he was the same doctor who wrote the letter of justification dated
     Sept. 21, 2023.
  - o Stated he has treated the Appellant since she was only months old.
  - When asked to address the importance of oximetry, responded simply, "She doesn't have it, she crashes." "It's life saving".
  - o When asked to compare Apnea and Oximetry devices, the doctor stated:
    - They are completely different functions.
    - The oximeter is not attached to a breathing monitor in any way; it is attached directly to the patient.
    - An oximeter monitors oxygen levels and an apnea monitor checks for breathing cessation.

## The Ministry

- When asked if the Appellant had any other options for acquiring the items, the Ministry representative said:
  - The reconsideration and appeal process were all that were available through the Ministry.
  - Legislative change would be required before the Ministry could provide funding for the items.
  - They were unaware of community groups providing funding for the items.

# Admissibility of New Information

The Ministry did not object to the new evidence provided by the Appellant.

The panel finds that the information provided in the submissions from the Appellant and by the doctor at the hearing is reasonably required for a full and fair disclosure of all matters related to the decision under appeal. It contributes to the panel's understanding of the circumstances surrounding the Appellant's request for oxygen monitoring equipment and supplies. Other oral testimony at the hearing also clarifies issues related to this appeal. The panel admits this information as evidence pursuant to section 22(4) of the *Employment and Assistance Act*.

#### Part F - Reasons for Panel Decision

The issue in this appeal is whether the Ministry's decision that the Appellant was not eligible for a Masimo Oximeter and cable, Masimo LNCS Neo/Adult sensors, or Coban Wrap was reasonably supported by the evidence or was a reasonable application of the legislation in the circumstances of the Appellant.

## **Ministry's Position**

The Ministry acknowledges the need for the items but maintains that it has no choice but to reject the request. The legislation is very specific about the medical equipment and devices that can be provided. If it is not on the list of allowed equipment and devices, the Ministry has no discretion that would allow it to be provided. The items requested are not on the list.

#### **Appellant's Position**

The oximeter, cable, and supplies have been provided for the past 18 years under the government's At Home care program for minors, through the Ministry of Children and Family Development's At-Home program. They are needed for survival and to prevent hospitalization. It is unreasonable that these costs would no longer be covered simply because the Appellant has become an adult and is transitioning to coverage under a different ministry. During the time leading up to the transition, there was no warning that these costs would not be covered, and no advice or direction has been given as to how to get funding for the costs. The use of an oximeter has resulted in the Appellant not being hospitalized due to desaturation for the past eight years. To deny the supplies and just leave the alternative of going to the hospital when the Appellant crashes, is not good management of government funds. The Appellant recognizes there is a list in the legislation and the oximeter and supplies are not included in it. However, she doesn't understand why the Ministry would not be more adaptive to her need supported by medical evidence, for an oximeter and supplies.

## **Panel Findings**

The panel finds from the evidence that the requested oximeter and supplies are medically essential health items and have prolonged the Appellant's life. The Appellant would be in imminent danger without the items. The intent of the Regulation is, in part, to provide such items to those in receipt of disability assistance.

Sections 62 through 70 of the Regulations address the health supplements that are available to recipients. The only two of these that are applicable are Section 62 General Health Supplements, and Section 69 Health supplement for persons facing direct and imminent life-threatening health need. Both provide the health supplements as directed by Sections 2 and 3 of Schedule C.

In Section 2, it says, "The following are the health supplements that may be paid for by the minister...". Section 3 says, "the medical equipment and devices described in sections 3.1 to 3.12 of this Schedule are the health supplements that may be provided by the minister...". In both cases, unless a supplement is specifically listed, the Ministry is not authorized to approve it.

The panel reviewed Section 2 of Schedule C and found the Ministry was reasonable in determining that the request was not for any of the purposes specified in this section.

The panel considered whether Section 3.9(b) of the Regulation might apply because it deals with items medically essential to monitor breathing. However, the only items allowed under this section are an apnea monitor, and accessories and supplies required to operate an apnea monitor. The panel accepts the doctor's view that an oximeter is a different device than an apnea monitor. There were no other applicable sections in the Regulation which is prescriptive and does not allow the Ministry, or the panel, to react to individual situations, regardless of need for life-saving equipment. This means that the Panel has no alternative but to find that the Ministry was reasonable in their decision that the Appellant was not eligible for a health supplement for the device and supplies requested.

The panel finds the Appellant's argument compelling that it is illogical that a medical device and the associated supplies that have been provided throughout the lifetime of the Appellant suddenly are not eligible because she has had a birthday and must transition from dealing with one ministry to dealing with another. The fact that there was no warning that these items would not be provided any longer, nor any information or advice provided as to alternative sources of funding aggravated the situation.

The panel shares the Appellant's concern about the inequity of the Regulation. If the Appellant's need was to have her breathing monitored, under Section 3.9(1)(b) she would be eligible for an apnea machine and the supplies required for its operation. But, in her case it is the oxygen level that must be monitored. Probably because of the rarity of a person with this disease reaching the age where she must transition to a different

program, this need has not been included in the list of devices and supplies provided. The needs are very similar, but the outcome is drastically different.

The panel also understands the Appellant's concern that the Ministry's decision will result in poor management of government funds. Without this device and supplies, the Appellant can reasonably be expected to spend more time in the hospital, assuming she reaches a facility in time. With the close monitoring enabled by the Oximeter, she has avoided this for eight years. Although the funds for hospitalization may come from a different account, the result is a much higher cost, both in terms of funding and in quality of life for the Appellant.

In summary, while the Appellant raises several valid concerns, the legislation does not allow the Ministry to provide any health supplements that are not listed in Schedule C. The items requested are not listed in Schedule C and, therefore, cannot be provided.

#### Conclusion

The Panel has no authority to go beyond the legislation. Our role is to ensure the Ministry's decision is a reasonable interpretation of the existing legislation. Therefore, the panel finds that the Ministry was reasonable in their decision that the Appellant was not eligible for a health supplement for the device and supplies requested.

The Panel confirms the reconsideration decision and the Appellant's appeal is unsuccessful.

# **APPENDIX - Schedule of Legislation**

#### **General health supplements**

- **62** The minister may provide any health supplement set out in section 2 *[general health supplements]* or 3 *[medical equipment and devices]* of Schedule C to or for
  - (a)a family unit in receipt of disability assistance,
  - (b) a family unit in receipt of hardship assistance, if the health supplement is provided to or for a person in the family unit who is under 19 years of age, or (c) a family unit, if the health supplement is provided to or for a person in the family unit who is a continued person.

#### Health supplement for persons facing direct and imminent life threatening health need

- (1) The minister may provide to a family unit any health supplement set out in sections 2 (1) (a) and (f) [general health supplements] and 3 [medical equipment and devices] of Schedule C, if the health supplement is provided to or for a person in the family unit who is otherwise not eligible for the health supplement under this regulation, and if the minister is satisfied that
  - (a) the person faces a direct and imminent life threatening need and there are no resources available to the person's family unit with which to meet that need, (b) the health supplement is necessary to meet that need,
  - (c) the adjusted net income of any person in the family unit, other than a dependent child, does not exceed the amount set out in section 11 (3) of the Medical and Health Care Services Regulation, and
  - (d)the requirements specified in the following provisions of Schedule C, as applicable, are met:
    - (a) paragraph (a) or (f) of section (2) (1);
    - (ii)sections 3 to 3.12, other than paragraph (a) of section 3 (1).
  - (2) For the purposes of subsection (1) (c),
    - (a)"adjusted net income" has the same meaning as in section 7.6 of the Medical and Health Care Services Regulation, and
    - (b) a reference in section 7.6 of the Medical and Health Care Services Regulation to an "eligible person" is to be read as a reference to a person in the family unit, other than a dependent child.

#### Schedule C

## **General health supplements**

- **2** (1)The following are the health supplements that may be paid for by the minister if provided to a family unit that is eligible under section 62 [general health supplements] of this regulation:
  - (a)medical or surgical supplies that are, at the minister's discretion, either disposable or reusable, if the minister is satisfied that all of the following requirements are met:
    - (in)the supplies are required for one of the following purposes:
      - (A)wound care;
      - (B)ongoing bowel care required due to loss of muscle function;
      - (C)catheterization;
      - (D)incontinence;
      - (E)skin parasite care;
      - (F)limb circulation care;
    - (ii)the supplies are
      - (A)prescribed by a medical practitioner or nurse practitioner,
      - (B) the least expensive supplies appropriate for the purpose, and
      - (C)necessary to avoid an imminent and substantial danger to health;
    - (iii) there are no resources available to the family unit to pay the cost of or obtain the supplies;

#### Medical equipment and devices

**3** (1)Subject to subsections (2) to (5) of this section, the medical equipment and devices described in sections 3.1 to 3.12 of this Schedule are the health supplements that may be provided by the minister if

••

Medical equipment and devices — canes, crutches and walkers

3.1 ...

Medical equipment and devices — wheelchairs

3.2 ...

Medical equipment and devices — wheelchair seating systems

3.3 ...

Medical equipment and devices — scooters

3.4 ...

Medical equipment and devices — toileting, transfers and positioning aids

3.5 ...

Medical equipment and devices — hospital bed

3.6 ...

Medical equipment and devices — pressure relief mattresses

3.7 ...

Medical equipment and devices — floor or ceiling lift devices

3.8 ...

#### Medical equipment and devices — breathing devices

- **3.9** (1) Subject to subsection (4) of this section, the following items are health supplements for the purposes of section 3 of this Schedule:
  - (a) if all of the requirements set out in subsection (2) of this section are met,
    - (in)a positive airway pressure device,
    - (ii)an accessory that is required to operate a positive airway pressure device. or
    - (iii) a supply that is required to operate a positive airway pressure device;
  - (b) if the minister is satisfied that the item is medically essential to monitor breathing,
    - (i)an apnea monitor,
    - (ii)an accessory that is required to operate an apnea monitor, or
    - (iii) a supply that is required to operate an apnea monitor;
  - (c) if the minister is satisfied that the item is medically essential for clearing respiratory airways,
    - (i) a suction unit,
    - (ii)an accessory that is required to operate a suction unit, or

- (iii) a supply that is required to operate a suction unit;
- (d) if the minister is satisfied that the item is medically essential for clearing respiratory airways,
  - (i)a percussor,
  - (ii)an accessory that is required to operate a percussor, or
  - (iii) a supply that is required to operate a percussor;
- (e) if the minister is satisfied that the item is medically essential to avoid an imminent and substantial danger to health,
  - (i)a nebulizer,
  - (ii)an accessory that is required to operate a nebulizer, or
  - (iii) a supply that is required to operate a nebulizer;
- (f) if the minister is satisfied that the item is medically essential to moisturize air in order to allow a tracheostomy patient to breathe,
  - (i) a medical humidifier,
  - (ii)an accessory that is required to operate a medical humidifier, or
  - (iii) a supply that is required to operate a medical humidifier;
- (g) if the minister is satisfied that the item is medically essential to deliver medication,
  - (i)an inhaler accessory device,
  - (ii)an accessory that is required to operate an inhaler accessory device, or
  - (iii) a supply that is required to operate an inhaler accessory device.

#### Medical equipment and devices — orthoses

3.10 ...

Medical equipment and devices — hearing instruments

3.11 ...

Medical equipment and devices — non-conventional glucose meters

3.12 ...

	APPEAL NUMBER 2024-0004
Part G – Order	
The panel decision is: (Check one) 🛛 🖾 U	nanimous    By Majority
The Panel	Decision □Rescinds the Ministry Decision
If the ministry decision is rescinded, is the panel decision referred back to the Minister for a decision as to amount? Yes□ No□	
Legislative Authority for the Decision:	
Employment and Assistance Act	
Section 24(1)(a) $\square$ or Section 24(1)(b) $\boxtimes$ Section 24(2)(a) $\boxtimes$ or Section 24(2)(b) $\square$	
Part H – Signatures	
Print Name	
Wes Nelson	
Signature of Chair	Date (Year/Month/Day)
	2024/02/24
Print Name	
Jan Broocke	
Signature of Member	Date (Year/Month/Day) 2024/02/25
Print Name	•
Margarita Papenbrock	
Signature of Member	Date (Year/Month/Day) 2024/02/25

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