

<b>PKU Diet – Limited Eligibility Policy</b>		<b>Date Approved</b>	December 13, 2020
<b>Branch/Division</b>	Disability and Specialized Services/ Community Service Delivery	<b>Applicable to</b>	Children’s disABILITY Services/ Disability and Health Supports Unit
<b>Responsible Authority</b>	Assistant Deputy Minister Community Service Delivery	<b>Next Review Date</b>	
<b>Policy Owner</b>	Director, Children’s disABILITY Services	<b>Date Reviewed</b>	
		<b>Date Revised</b>	

### 1.0 Policy Statement

This policy seeks to provide direction for the provision of limited supports to children with specific health conditions requiring access to disability-related supports, but who do not meet the eligibility criteria for enrollment with the Children’s disABILITY Services program.

### 2.0 Background/Context

Children’s disABILITY Services (CDS) supports children with various developmental and physical disabilities, however not all children with disabilities meet the eligibility criteria for the CDS program. While many of those children are supported through community or other government programs, there exists certain situations that CDS may provide limited disability-related supports to children who do not meet CDS eligibility criteria for enrollment onto the program.

Children diagnosed with phenylketonuria (PKU) are at high risk of developmental delay without access to specialized food to manage the metabolic disorder. The Newborn Screening Program in Manitoba screens for PKU and other metabolic diseases in newborn children. Newborns with suspected or confirmed metabolic diseases are referred to the WHRA’s [Metabolic Service](#), which provides service in the assessment, diagnosis, and ongoing management and counselling of children, adults and their families. The WHRA’s Metabolic Food Program and Children’s disABILITY Services provide funding to the Disability and Health Supports Unit to administer the access to specialized food for Manitobans diagnosed with PKU.

Children diagnosed with PKU have limited eligibility for Children’s disABILITY Services so they may access specialized foods needed to manage the disease in order to prevent cognitive impairment and other neurological problems associated with PKU.

### 3.0 Purpose

The purpose of this policy is to define the parameters and standards for providing eligible health supports to children diagnosed with PKU, who do not meet CDS eligibility criteria for enrollment onto the program.

Note that children diagnosed with PKU may qualify for the CDS program if they meet all the criteria set out in the CDS Eligibility Policy.

## 4.0 Definitions

**PKU** – Short for phenylketonuria, PKU is a rare, inherited metabolic disease that results in developmental disability and other neurological problems when treatment is not started within the first two weeks of life.

**Limited Eligibility** – Refers to the CDS status of children opened under this policy, which limits their eligibility for services and supports to only what is defined in this policy.

## 5.0 Policy

### 5.1 Eligibility

To be eligible under this policy, children must:

- be diagnosed with PKU,
- be under the age of 18, and
- be a resident of Manitoba.

### 5.2 Eligible Supports

An eligible child may receive special low-protein foods supplied by an approved vendor (see [Appendix A](#) for list of approved vendors), up to an annual maximum budgeted per child. Funding is allocated by fiscal year.

As children are opened under a limited eligibility status, they are not eligible for additional services or supports from Children's disABILITY Services.

## 6.0 Core Supporting Standards

### 6.1 Referrals

Referrals must originate from the WHRA's [Metabolic Service](#) and are made directly to the designated contact at the DHSU.

### 6.2 Registration on inFACT

All children opened under this policy will be registered on inFACT and assigned to the *DHSU Only – PKU Diet* caseworker profile.

### 6.3 Administration of Supports

The DHSU is responsible for the administration of the supports on behalf of the Metabolic Food Program and Children's disABILITY Services.

The DHSU is responsible to:

- Notify the inFACT Business Analyst to create inFACT profiles for eligible children
- Notify caregivers of approved vendors and procedure to order food
- Notify vendors to set-up account for eligibility child
- Monitor funding allocated to each child and advise vendors on availability of funds to fill orders
- Review invoices and approve payment for eligible items

Vendors will send invoice direct to the DHSU for payment. Payment will be issued adhering to departmental financial processes.

[Appendix B](#) outlines the various roles and responsibilities for the administration of PKU diet supports.

#### 6.4 Primary Caregiver Tax Credit (PCGTC)

Children are not assessed for the PCGTC under this policy, as they do not meet the criteria for enrollment with the Children's disABILITY Services program. Children may always be assessed by a medical doctor or nurse practitioner for the PCGTC.

**Appendix A – Approved Vendors**

**The Speciality Food Shop (Sick Kids Hospital)**

Tel: 1-800-737-7976 or 416-813-5294

Email: [sfs.admin@sickkids.ca](mailto:sfs.admin@sickkids.ca)

[www.specialtyfoodshop.ca/Products/Specialized-Nutritional-Needs/Low-Protein-Metabolic](http://www.specialtyfoodshop.ca/Products/Specialized-Nutritional-Needs/Low-Protein-Metabolic)

**National Food Distributor**

Tel: 1-888-606-6676 ext. 221

Fax: 1-844-395-2396

Email: [info@nfdc.info](mailto:info@nfdc.info)

Order: [order@nfdc.info](mailto:order@nfdc.info)

[www.nfdc.info/home.php](http://www.nfdc.info/home.php)

### Appendix B – Roles and Responsibilities

Responsibilities \ Roles	Family	Metabolic Service	DHSU	inFACT Business Analyst	Approved Vendor
Referral to DHSU		●			
Register child on inFACT				●	
Notify vendor to create account for child/family			●		
Inform family of process to order food			●		
Place order from Vendor	●				
Monitor child budget			●		
Approve order			●		
Supply Food to Client					●
Send invoice for food order					●
Review items on invoice/approve invoice for payment			●		
Issue payment for invoice				●	
Ongoing management and support to child/family		●			