

 <p style="text-align: center;"><b>Mohawk Council of Akwesasne</b></p> <p style="text-align: center;"><b>POLICY: Special Needs</b></p>	<p><b>Subject:</b> MCA Special Needs Fund: Policy, Definitions, Scope, Committee, Appeals, Access &amp; Privacy Protection for Personal Information</p>
	<p><b>Effective Date:</b> June 5, 2023</p>
<p><b>Approval Date &amp; MCR#:</b> May 29, 2023– MCR # 2023/2024 #103</p>	<p><b>Replaces:</b> MCR#: 2019/2020 # 152</p>
<p><b>Applicable to:</b> Executive Director or designee; Directors or alternates for Depts of Health, Community &amp; Social Services, Ahkwasasne Mohawk Board of Education; Community Representative with alternate; one MCA Chief with alternate (and or other Department Representatives of MCA , as needed)</p>	<p><b>Distribution:</b> Mohawk Council; Executive Services; Depts of Health, Community &amp; Social Services; Ahkwasasne Mohawk Board of Education; Community Representative with alternate; one MCA Chief with alternate</p>
<p><b>References:</b> Akwesasne Membership Code; Access to Information &amp; Protection of Personal Privacy Regulation; AMBE Post-Secondary Education Assistance Policy; Akwesasne Child &amp; Family Services Policy; Finance Policy; Department of Health Consent to Release and Disclosure of Personal Health Information;</p>	

**BACKGROUND:**

The Mohawk Council of Akwesasne (MCA) established a Special Needs Fund (Fund) in response to a growing demand from community members who have family members with special needs. Implemented by MCR # 2005/06-223 (January 10, 2006), the MCA resolved to accept the Finance Committee recommendation and apply Casino Rama reserves into a long-term investment, using the interest from this investment to create a ‘Special Needs Fund’.

A working Committee was established. The Committee drafted a mandate, an application form, and a procedure for accepting, reviewing and making decisions on Fund requests. The Fund was initially used for financial assistance to purchase special needs devices. These devices were not covered by existing funding sources. Examples of special needs clients were those who had congenital birth defects, acquired disabilities and people who needed adaptive living devices.

On February 12, 2008, Council ratified MCR#2007/08-303, appointing membership of the Special Needs Committee, their mandate, and a process for individuals and families to apply for funding.

By April 2009, the limit on contribution for any one individual increased from \$5,000.00 to \$75,000.00 due to the nature and costs of devices and services.

By February 2010, the number and reasons for funding requests had become more than what the funding was able to cover. The Committee decided to review these requests and re-consider the process.

Since the fund was established, it was assumed and expected that all other sources of funding for special needs had been exhausted. However, a consulting report<sup>1</sup> showed that families did not know where else to go for funding. Furthermore, MCA employees were not aware of all the sources available.

In an effort to improve the situation and increase support to individuals with special needs, the Committee adapted the following recommendations:

- A Special Needs Facilitator(s) would be identified within the Departments of Health, Community & Social Services and the Ahkwesahsne Mohawk Board of Education. The Facilitators would be of assistance to families from birth to old age and they would be able to offer a continuum of care and support to individuals and their families;
- A Manual of Resources would be developed with the intent that, once an individual was identified as having a Special Need, the Facilitators would be aware of the needs and be better able to make proper referrals and also assist in the application process for all other funding available;
- Once all other sources of funding and support were exhausted, the individuals would then be able to request funding from the Special Needs Fund as a final resort for assistance.

During March 2011 – April 2012, Committee members reviewed the Special Needs Policy.

**POLICY STATEMENT:**

The Special Needs Fund is not an entitlement program but rather it is a fund distributed on a case-by-case basis until the annual funding is exhausted. The Mohawk Council of Akwesasne is committed to securing assistive devices and/or services to meet the needs of the Mohawks of Akwesasne identified with congenital, acquired, or developmental disabilities.

Special needs support shall be provided:

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- in a family-focused, integrated and coordinated manner that is consistent with, and reinforces the traditional, informal patterns of sharing, caring and healing in the extended family and community;
- in a manner that is least-intrusive, non-judgmental and respectful of the individual and family in need;
- to support the healing and strengthening of individuals and families and avoids the creation of dependencies on MCA.

**SCOPE:**

MCA recognizes that children and their families sometimes experience difficulties that cannot be dealt with alone or with the level of support that can be expected from and provided by the extended family and friends. Children may have special physical, emotional, mental, behavioral or developmental needs that call for special skills and other resources not available within the family. Families may, for any number of reasons, lack some of the basic abilities and resources needed to ensure – in terms of community standards – an adequate level of care and a normal process of development for their children.

The composition, roles and responsibilities of the Special Needs Committee are found in the Terms of Reference – Special Needs Fund Committee. The Committee’s primary role and responsibility is to monitor and manage the Special Needs Fund.

Funds may be used for assessment, educational devices, day or respite services, and/or transitional services to foster independence for an individual. Caregivers of Special Needs Youth may access these funds to attend training regarding the disability. Funds are available for assistive technology (devices, equipment) or services from people (training, counseling, assessment, trainers, and/or respite for families) all of which are supported by assessments completed by professionals in the relevant field.

The Fund may not be used for Capital purchases (ex: vehicle, home construction) but may be used for alterations to Capital items purchased by the applicant. In the interest of meeting essential human needs, applications are exempt from the MCA Good Standing Policy.

Special Needs funding does not include provision for, conditions or physical limitations or challenges an individual faces related to chronic disease. This funding is payer of last resort to insurance, provincial, or organizational resources available to the applicant. Applicants must explore all other potential revenue sources. All applicants 0-18 years of age must consent to a Jordan’s Principle Application where it was not completed in order to ensure that all resources were explored. Due to the long wait times of Jordan’s Principle, the Special Needs Fund can be used to make an immediate purchase upon approval of the Special Needs Committee in order to ensure the needs of the applicant are met and it is the Mohawk Council of Akwesasne awaits the reimbursement from Jordan’s Principle. Should

we receive a denial from Jordan's Principle than it would have resulted in the funding being expensed from the Special Needs Fund regardless.

Eligible recipients are:

1. Children/youth ages (0- Deceased), and their families and/or caregivers requiring assistance and/or supports to address their child/youth's needs due to child/youth's limitation(s).
2. Enrolled Members, as defined in the Akwesasne Membership Code. This does not include AANDC (formerly *INAC*, *DIAND*) registry. This is confirmed by the MCA Office of Vital Statistics.
3. Resident within the Territory under jurisdiction of MCA. The applicant must provide proof of residency (i.e., telephone bill, utility bill, signed declaration from parents that minor is residing at home).

**DEFINITIONS:**

Acquired disabilities arise from events occurring after birth and are usually classified as severe, profound, moderate or mild as assessed by the individual's need for devices or services which may be life-long.

Congenital disabilities are conditions existing at birth and often before birth, or that develop during the first month of life (neonatal disease), regardless of causation. Of these disabilities, those characterized by structural deformities are termed "congenital anomalies"; that is a different concept which involves defects in or damage to a developing fetus.

Developmental disabilities are present at birth and are usually classified as severe, profound, moderate or mild cognitive disability, as assessed by the individual's need for devices or services which may be life-long.

Facilitator: Special Needs Facilitators are staff members of various departments i.e.: Health, Community & Social Services, or Education (AMBE) whose normal work duties include interaction with Special Needs individuals or their families. Their training may include knowledge of case management and organizational/ community/ external resources; their role could be expanded with staffing of a Special Needs Coordinator whose job would be dedicated to this work.

Mohawks of Akwesasne: refers to a person who is enrolled, or is entitled to become enrolled, in the Akwesasne Membership List as confirmed by the MCA Office of Vital Statistics.

MCA: Mohawk Council of Akwesasne.

Respite: Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility; provides short-term breaks that can relieve stress, restore energy, and promote balance in the caregiver's life.

Special Needs refers to acquired or developmental intellectual or physical conditions that significantly affect a person's daily functions in any of the following areas: capacity for independent living, economic self sufficiency, learning, mobility, receptive and expressive language, self-care and self-direction. In all cases, funded needs are not normally covered by MCA services or alternate organizations.

Specialized devices and/or services are individualized and based on assessed need.

**FINANCIAL ASSISTANCE AVAILABLE**

ALL FUNDS WILL BE PROVIDED OR PAID IN CANADIAN CURRENCY.

Financial assistance for an individual is available for new or expanding needs from one or all categories up to a maximum of \$25,000 throughout the fiscal year. Maximum allowable funding an applicant may receive:

Costs	Annual Maximum Allowable, Pending Fund Availability
<u>Assistive Devices</u>	
Equipment/Repair	100% to a maximum of \$15,000
<u>Services</u>	
Therapeutic Education (O/T, P/T)	100% to a maximum of \$5,000
Assessment	100% to a maximum of \$5,000
Respite Care	100% of costs up to a maximum of \$20,000
Training for Caregivers	90% of Registration Cost up to a maximum of \$1,000
Support in the home	Not covered
Drug & Alcohol Rehabilitation	Not covered
<u>Supports</u>	
Travel (hotel, mileage)	Reimbursement of original receipts
Meals	Not covered
Medications	Not covered
Special Diet	Not covered
<u>Special Circumstances</u>	
* Home Adaptation	75% of costs up to a maximum of \$25,000

* Vehicle Adaptation	75% of costs up to a maximum of \$10,000
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**SPECIAL CIRCUMSTANCES**

**\*HOME ADAPTATION**

- Special Needs funds may be used to adapt homes for accessibility and safety. This includes, but is not limited to, ramps, bathroom fixtures, doorways, alert systems, specialized door locks, or safety fences.
- All costs must be reasonable and cost-shared.
- Collaboration with appropriate MCA Departments must occur.
- Where an applicant reports that he/she is not financially able to cover the 25% cost-share, then the Committee will approach Council with recommendation for funding decision.

**\*VEHICLE ADAPTATION**

Special Needs funds may be used to adapt family-owned vehicles for accessibility and safety.

**PROCEDURE**

**HOW TO APPLY**

Members may receive the Special Needs Policy, Application, and Appeal documents from the Department of Community & Social Services (DCSS) Executive Assistant (EA), the Kanonhkwatsheri:io Receptionist, or Facilitators. All forms are stored on the MCA Intranet.

Members complete the Application Form attaching all necessary documentation (ex: prescription for special devices) and submit all documents, to the EA, DCSS.

**APPLICATION REVIEW PROCESS**

The EA, DCSS will electronically transmit applications to the Special Needs Committee members for their review.

- Review and date the application to ensure the application is complete before accepting.

**DECISION**

Some requests can be easily approved; others may require open discussion at the next scheduled Special Needs meeting unless request is of an urgent nature and requires immediate discussion of the Special Needs Committee.

Approval of a request is made by a majority of the committee. DCSS will inform the applicant of the Committee’s decision.

Assuming the request is approved:

Where the expense is less than \$5,000.00, the applicant can forward the invoice for direct payment by MCA.

Where the expense is partially paid by the applicant and partially paid by MCA, the applicant can forward a copy of the invoice to the DCSS Director, and MCA will remit their share directly to the vendor.

Assuming the request is denied:

The applicant may appeal the denial to the Akwesasne Health Board. The Appeal will be presented on the MCA form (*SN Appeal-2011*). **All decisions of the Akwesasne Health Board are final.**

## APPEALS

The Special Needs Committee denies requests based on policy or lack of funds. Appeals challenge the denial of benefits based on the applicant's belief that they, or the recipient they represent, require Special Needs benefits not covered.

Appeals will be received in the following areas:

Assistive Devices

Services

Supports

## FUND APPEAL PROCEDURE

Note: This procedure is also available as its own hand-out

1. The applicant completes form (*SN Appeal-2011*). All other necessary documentation should be in order and attached with the appeal.
2. Appeal form (*SN02-2011*) is available through the Kanonhkwatsheri:io Receptionist or through the Department of Health (DOH) Administration Receptionist. The applicant completes (*SN02-2011*) (Special Needs Appeal form) and submits it, with any documents, to the attention of either:
  - DCSS Administration, or
  - Director, Department of Community and Social Services

**By hand:** to DCSS Administration or to the DCSS Director at Kanonhkwatsheri:io, Kanatakon

**By mail:** addressed to DCSS Administration OR DCSS Director, PO Box 90, Akwesasne, QC H0M 1A0; the envelope should be marked as "**Personal and Confidential**"

3. DCSS Administration will prepare Appeal package and forward to DOH to present to Health Board for review and decision.
4. The Department of Health will contact the applicant and Health Board members, by e-mail, to arrange a meeting date. Privacy protection of records is the responsibility of the Director, Department of Health.

5. DOH will inform the applicant and the Special Needs Committee of the Appeal Board's decision.

Assuming the request is approved:

- Where the expense is less than \$5,000.00, the applicant can forward the invoice for direct payment by MCA.
  - Where the request is approved and the expense is partially paid by the applicant and partially paid by MCA, the applicant can forward a copy of the invoice to the DCSS Director and MCA will remit their share directly to the vendor.
6. The decision of the Appeal Board is final and conclusive.
  7. All discussions and facts relevant to the case will be documented and placed in the case files in the DCSS office. All correspondence to the parties in the Appeal will be kept on record.