

COMMUNITY AND ORGANIZATION PANDEMIC PLANNING GUIDE CONSIDERATIONS FOR INDIGENOUS PERSONS WITH DISABILITIES AND SPECIAL NEEDS



NOVEMBER 2020

**WABANAKI COUNCIL
ON DISABILITY**

MAWITA'MK SOCIETY



mawita'mk



WABANAKI
COUNCIL ON DISABILITY

Introduction/Overview

During the Spring, Summer and Autumn of 2020 the Covid-19 pandemic was being dealt with by government officials, Chiefs and Councils, Indigenous political leadership, Indigenous service organizations, Indigenous and non-Indigenous health systems, health officials, social support workers, education officials and so many others across Canada and the Atlantic region.

During this time the Wabanaki Council on Disability (WCD) created and posted a pandemic impact survey for Indigenous persons with disabilities and special needs. What the WCD, Mawita'mk Society and our partners sought was to obtain information from Indigenous persons with disabilities and those with special needs (living in Atlantic Canada) about how they were coping with and managing their issues, concerns and impacts on them from the pandemic.

The WCD, the Mawita'mk Society and the WCD partnership thanks each and every person that completed the survey and for taking the time to provide the responses that were provided by completing our pandemic survey.

Pandemic Survey 2020

In May 2020, the WCD and Mawita'mk Society with the support of our partners posted an on-line survey through So-Go Survey that contained a series of questions asking for responses from Indigenous persons with disabilities and special needs. The questions included various topics and matters including mental wellness, health services and prescriptions, food and nutrition security, transportation, income related issues and overall health, safety and security.

The survey web link was shared with all of the WCD's regional partnership and posted on social platforms including Facebook and Twitter. In the end, 68 survey responses were received from throughout the region – the survey was available for responses from mid-May to the end of August 2020.

The purpose for posting the survey was to provide the opportunity to hear directly from Indigenous persons with disabilities and special needs about their management of the pandemic and the related stresses associated with it. The objective for this work was for the WCD to utilize the survey responses to produce this Indigenous Pandemic Planning Guide on Persons with Disabilities and Special Needs containing specific ideas and suggestions for Indigenous communities and service organizations to incorporate specific actions, plans and activities into their community or organization pandemic response guides to specifically support persons with disabilities and special needs during pandemics and other emergencies.

Contained in this Indigenous disabilities pandemic planning guide are the results of the survey – we have taken the results of the survey and used them to prepare the suggested actions and activities contained in this document.

The regional focus of the survey provided for an Atlantic perspective about how respondents living in the region were dealing with the pandemic. We heard from Indigenous persons living on and off reserve from each province.

The survey provided participants the opportunity to share their experiences with the WCD and the Mawita'mk Society anonymously. By doing this we assured that individual identities were protected, further to protect respondent's identities they were not asked to provide any names or to identify the community where they live.

In order for this document to assist communities and service organizations to adopt the recommended actions, the recommendations are being presented according to key themes and matters related to protecting the health and safety of persons with disabilities and special needs.

The intent of our survey work and production of this resource guide is not to criticize any efforts provided by any government, community or organization. Rather, the goal is to be supportive of all efforts and to strengthen them even as the current pandemic impacts our lives. The WCD, Mawita'mk Society and our partners want to be constructive support agents that will positively strengthen pandemic plans, programs, services and supports especially to Indigenous persons with disabilities and special needs.

Special Note about the survey/study and this report

It is noted that the geographic area of this study is Atlantic Canada which—due to several mobility policies enacted early on at the onset of the Covid-19 pandemic—had considerable success in lessening the pandemic spread throughout the region. Of course, the closure of the Canada/USA international (land) border (nation-wide) provided serious restrictions and safeguards against those from outside of the region to enter the area and severely reduced the possible infection rates regionally.

Added to this measure was the closure of the provincial land boundaries even within the region however the closure of the land border between New Brunswick and Quebec also provided additional protections and helped to provide reduced infection rates regionally.

The further measure of requiring people—who were allowed to enter the region (and at points in time from province to province within the region)—to quarantine for a 14-day period also assured reduced infections regionally. As the infection rates reduced regionally to zero (0) or near zero the 4 provinces established what became known as the “Atlantic Bubble”. This proved to be an effective decision which provided safe environments for the people living in the region while also providing them the opportunities to travel freely from province to province within the “Bubble” area.

These health and safety measures are being recognized for their effectiveness and those who made these difficult decisions—and those who abided by them—must be applauded for instituting them.

These measures significantly reduced the highly dangerous impacts of the pandemic regionally and reduced the severity of it on the people regionally. As such it is under these reduced conditions that this study was carried out. This has to be noted as these would have impacted the magnitude of the effects of the pandemic

on all people living within the region including persons with disabilities and special needs.

Therefore, the results of the study and the conclusions and recommendations contained in this report are based on these realities. This is to say that the impacts of the pandemic on Indigenous persons with disabilities and special needs in other areas where similar mitigation measures were not enacted could be significantly higher and more strenuous.

In regards to the above we do want to re-state that we strongly encourage all communities, service organizations, service providers and governments to make clear and direct measures to engage directly with Indigenous persons with disabilities and special needs and their families to determine what the best measures are that should be included in their pandemic plans to keep this vulnerable population as safe as possible.

Possible Uses of this Document

What is presented in this document is meant to be a beginning – a beginning of the identification of the needs and supports that persons with disabilities and special needs have during times of emergencies including health pandemics. We encourage communities, organizations and government departments/agencies to see this resource for what it is – a primer and a useful tool.

The WCD and our partners feel that it is very important to engage in dialogue and discussion locally to get the full picture of what the needs and supports are for your local population. We encourage community based political bodies along with health, social and education service providers to have thorough discussions with persons with disabilities and special needs and their families to determine what their needs are during times of emergencies and crisis. The contents of this guide can be considered the starting points for these discussions – we hope that communities and organizations will implement the meaningful step of local dialogue to ensure that local people with disabilities and special needs are heard.

We recognize that more dedicated work is needed to assure that the voices of Indigenous persons with disabilities and special needs are heard and thoroughly considered in pandemic and crisis plans. We support and encourage everyone to do this local work and to ensure that this document is used:

1. As a resource to enhance existing pandemic and crisis plans especially as they pertain to establishing practices that focus specifically on Indigenous persons with disabilities and special needs;
2. As a conversation tool to facilitate dialogue and discussion by community leadership and employees with persons with disabilities and special needs so that local pandemic plans meet and are based on the real needs of the local population;
3. As a resource for governments to use for policy and program development especially in regards to pandemics and other crisis situations;
4. As a resource tool for groups and organizations for persons with disabilities and special needs for further discussions and to add to what is in here based on their personal and professional experiences.

We encourage everyone that has responsibilities for health pandemics and other crisis situations not consider this document as the complete picture of the needs for Indigenous persons with disabilities and special needs. The contents here are the result of an initial survey.

Research limitations

The findings of the 2020 Indigenous Pandemic Survey issued by the Wabanaki Council on Disability and Mawita'mk Society respectfully acknowledge the following and the conclusions are based:

- On a limited reach of persons with disabilities and special needs living in the Atlantic region of Canada primarily via the internet (on-line survey);
- On the limitations resulting from the Covid-19 pandemic prohibiting the utilization of multiple research methods including but not limited to:
 - In-person (one to one and small group interviews); and
 - Direct research in communities;
- The number of respondents could have been higher however with the health crisis complications they likely impacted everyone's priorities and these may have impacted the number of respondents completing the survey.

The intent of the survey was not to be invasive into the lives of Indigenous persons with disabilities and special needs but to provide opportunity for their voices to be heard and for their perspectives to be shared with others having responsibilities for community health, wellness and safety.

Themed Recommendations

In the following sections, we present the findings and recommendations under themed areas. Our objective is to make it easier for the people in charge of developing and modifying pandemic plans to focus on specific issues and matters. Further, as a conversation starter these topics provide initial focal points for local community dialogue.

We re-state that these may not be the totality of issues, needs and matters that Indigenous persons with disabilities and special needs have – we strongly encourage leaders and service providers to engage in conversations with the local population of Indigenous persons with disabilities and special needs to determine what specific needs and supports they require.

We also want to note that persons with disabilities and special needs includes: persons of all age groups including children and youth, young and older adults, seniors and Elders and the families (parents and legal guardians) and personal support workers for persons with disabilities and special needs.

This resource is a starting point for the deeper community level discussions we encourage everyone to hold.

Theme: Community Pandemic/Emergency Plans

Throughout Canada and the Atlantic region communities and organizations may or may not have established pandemic plans or guides that present a series of actions and activities designed to keep the people in their community or service area as safe as possible. These pandemic plans may or may not have specific elements in them that are targeted at persons with disabilities and special needs. In either case this resource document is being presented to all Indigenous communities and service organizations as a means of assisting them to incorporate specific plans that support Indigenous persons with disabilities and special needs.

The goal of our work as contained in this document is to effectively support those who have responsibilities to provide support and assistance during times of health crisis such as pandemics as well as during other times of crisis including emergencies of any kind.

The WCD and its partnership hope that the information presented in this resource is received positively by the people in leadership of communities and service organizations. While Indigenous communities and service organizations are the primary audience for this resource, we realize that there will be secondary audiences including governments at all levels as well as health, social and education officials.

Theme: Communications

Communities and organizations must be able to provide reliable information about the pandemic to all persons with disabilities and special needs. Communities and organizations must be supported in meeting this objective by governments that issue the information.

Governments have the primary responsibilities to provide reliable information via their leadership and their established professional health agencies. All information must be based on science and approved for public awareness by the medical officials in charge of the information.

As such the information should be available in all communications mediums including: in written format in regular and large fonts; written in plain language; available in braille and ASL (sign language) and in audio formats.

Communities and service organizations must have the capacity(ies) to provide any and all relevant information about to the pandemic to persons with disabilities and special needs living in their areas. They need to make sure that they have reliable communications mediums and resources. There are many ways of assuring that any and all relevant pandemic information is made available in various communications mediums including the internet, in community newsletters or bulletins, through word of mouth via phone or web casts and by visits to people at their homes (as possible) assuring that health protocols are followed.

Further, communities and service organizations need to make sure that they know what communications mediums are needed by the persons with disabilities and special needs. Communities and organizations should have information that identifies what communications types are needed in their communities.

Communities and organizations should also try as best as they can to make sure that Indigenous persons with disabilities and special needs have communications equipment they need to receive and understand what is being said about the pandemic and the virus.

Some considerations for inclusion into pandemic guides for communications are:

We recognize that more dedicated work is needed to assure that the voices of Indigenous persons with disabilities and special needs are heard and thoroughly considered in pandemic and crisis plans. We support and encourage everyone to do this local work and to ensure that this document is used:

1. Establish a communications plan that includes regularly scheduled team meetings within your community services or organization. Use the meetings to discuss news, updates, government announcements, community feedback, media briefing notes and public relations plans. Decide who is responsible to deliver updated messages and information to the public.
2. Communication plans should include, where possible, multiple forms of delivery: physical (written/paper), web/social media, audio (phone and recordings), and visual (video or picture). It is also important to take into consideration the Indigenous language(s) of the community people served. As stated above this could include plain language, brail, ASL, and large fonts.
3. Plan scheduled communication updates regularly for members of your community. Pandemics are often unpredictable times, so establish a consistent communication plan with multiple forms of delivery as previously stated. Regular updates are recommended.

By providing regularly scheduled updates to community members about the health crisis it will help to ease their tensions and concerns. Informing them about what is happening in the community and in other parts of the region will help them to make plans and adjustments to how they decide on getting foods and other essential goods.

Internet

In today's society the internet has become an important and reliable communications medium. It offers multiple ways of being able to communicate with people to provide them with critical information. Communities and organizations should assure that they have the IT capacity to share information via various ways over the internet. In their pandemic plans, communities and service organizations should include all forms of communications needed and utilized by persons with disabilities and special needs.

1. Offer internet services such as free Wi-Fi for clients to use when attending your community or organization services.
2. Develop online platforms to reach your clientele such as email updates, YouTube video updates, social media updates on all platforms used by your clientele (Facebook, Instagram, Twitter, etc.).
 - a) Implement a regular schedule of updates to publish on all social media platforms.
 - b) Use a social media data tracking app, such as google analytics to determine most active time of day your clients are engaging with your posts.

Cell phone/ House phone

Cell phones are increasingly becoming a basic necessity for information sharing. While cell phones have become an important resource for many people, not everyone has a cell phone and many rely on a house phone for communications. Communities and service organizations should continue to utilize these communication mediums as a method for sharing critical information for persons with disabilities and special needs.

1. Create and implement an emergency text-message and voice-message calling system for your clientele:
 - a. Gather and regularly update contact information from your clientele.
 - b. Develop an emergency protocol contact system, where your service organization can send out text updates and voice-mail updates during times of critical information.
 - c. Provide call-in numbers with automated voice systems that provide voice-updates and TTY.

Theme: Medications/Prescriptions Assistance

Communities need to develop emergency procedures which includes establishing protocols for its health and social program workers to check with all persons with disabilities and special needs to make sure that they have the capacity to get their medications and prescriptions throughout the course of the pandemic. This includes making sure that the person with a disability or special need has either family members, friends or community service providers readily available to provide assistance as required.

Community workers may also be required to provide additional assistance during the pandemic such as helping the person get new glasses, other corrective lenses, or hearing aids and other assistive devices as required.

1. Ask clients to declare (with consideration for privacy, clients can choose to opt out) how they're getting their medications/prescriptions, verify with respect to privacy, if they or someone close to them they know is able to regularly retrieve their medications or prescriptions for them. If not, develop an action plan with weekly, bi-weekly or monthly schedules unique to each client with pick-up runs.
2. Create a team within your organization, whether through current employees or volunteers, to do prescription pickup runs to clients as needed.
 - a) Have your team create a log/list with contact info of clients needing assistance with prescription pickup.
 - b) Schedule weekly runs where clients can pick-up medication/prescription at your service location or delivery.

Theme: Mental Wellness

Communities and service organizations need to make sure that they can assist persons with disabilities and special needs to address their mental wellness during and after the pandemic. As in the case of Covid-19,

people were told to isolate themselves as a measure of health protections against contracting the virus. People have also been told to not visit other family members or friends as a measure to protect themselves from the pandemic.

Being isolated from those you love and those who normally provide support during nonpandemic times causes stresses and changes to lives and what is usually done on a daily basis.

Additional stresses on persons with disabilities and special needs can result in the need for additional supports to be available and utilized as needed. These additional supports will help to provide comfort and relief that supports the well-being of persons with disabilities and special needs.

1. Create a list of local mental health services relevant to your clientele, including helplines to distribute among your clients.
 - a. Include multiple lists specifically targeting First Nations status, non-status, Inuit and Métis, depending on the population your organization serves. (This list may include information like Non-insured health benefits information, Jordan's Principle supports, etc.)
 - b. Create a support/peer group with weekly, bi-weekly and/or monthly meetings for your clientele to meet in-person where safe to do so under pandemic restrictions or online/ phone meet ups.
 - c. Within or separate from the support/peer group, designate an Elder or community leader to help with sending out words of support and positivity during these stressful times.
 - d. Do phone-call or in-person check-ups when safe to do so on your clients.
2. Develop an action plan for individuals expressing mental health concerns.
 - a. This is to include working on referring them to the appropriate mental health supports and professionals where needed.
 - b. This action plan also needs to include follow-ups: weekly, bi-weekly or monthly.
 - c. Implement traditional and spiritual healing modalities in respects to mental health supports.

Theme: Food Security

Community social and health program workers must assure that Indigenous persons with disabilities and special needs have appropriate foods available to them for their proper health and nutrition throughout the pandemic. Special assistance may need to be provided as necessary. Special assistance means the possible purchasing of health foods for the person with a disability or special need.

Community support workers may also be required to assist the person with a disability or special need to properly prepare (cook) their foods so that they are nutritious. Communities and service organizations may need to identify possible ways of helping persons with disabilities and special needs to have properly cooked nutritious meals.

1. Have your community/organization develop a pandemic/emergency foodbank.
 - a. Create a foodbank volunteer team.
 - b. Create daily foodbank hours for clients to pick-up foods and other essentials.
 - c. Create weekly or bi-weekly foodbank drop-off for clients who need it.
2. Create a team or volunteer team to cook healthy meals for your clients daily, weekly and/or bi-weekly – as appropriate and approved by health officials.

Theme: Household Supplies and Personal Security

Communities and service organizations should include in their pandemic plans options and ways to assure that persons with disabilities and special needs have required household items including (but not limited to):

1. Cleaning supplies: disinfectant sprays and wipes, garbage and recycle containers and bags;
2. Bathroom products including toilet paper, soap, body wash, shampoo;
3. Kitchen products: paper towels, dish liquid, spices, cooking oils;
4. Personal items (not limited to): deodorant, powder, sanitary napkins.
 - Create a pandemic/emergency cleaning supplies and essential needs bank.
 - Establish a schedule with daily, weekly or bi-weekly hours for clients to pick up and/or delivery.
 - Supplies need to be distributed based on household and number of dependents.

Communities and organizations should also be aware of the personal safety needs that Indigenous persons with disabilities and special needs require. It is imperative that Personal Protective Equipment (PPE) is made available to Indigenous persons with disabilities and special needs.

The provision of the PPE may require explanations of usage and the protections they provide to persons with disabilities and special needs – it should not be assumed that just by dropping off the PPE the supplies will be properly utilized by individuals.

- Communities and service organizations should establish a PPE supply bank – as possible – to support the health and safety of community residents including persons with disabilities.
- Communities and service organizations should discuss the safety issues and matters with Indigenous persons with disabilities during non-pandemic times as well as (as possible) during pandemic times.

Theme: Education Needs

Communities and service organizations should establish plans and actions that address the ongoing education of children and youth with disabilities and special needs. In many cases these children and youth already have existing challenges to obtain an education. Pandemics and times of crisis can compound and exacerbate these challenges; as such, pandemic plans need to identify options that will support the ongoing education needs of these children and youth are properly addressed.

Children, youth and adult education, special education and education support needs must also be considered in pandemic plans.

Schooling and other education services and supports need to be established. In a pandemic, noncontact and non in-person methods need to be considered. These methods may include computer based processes. There will be particular challenges for children with special needs who normally require and receive one-to-one instruction/support.

School and education supplies should be provided to families and students as required.

Supports and services for parents of children with disabilities and special needs will need to be established. Generally, respite care could or would be provided during non-pandemic times but due to pandemic precautions, alternative support may be required.

1. Have your community/organization create a school supplies bank and donation center.
2. Communities and service organizations should discuss education related issues and matters with Indigenous persons with disabilities during non-pandemic times as well as (as possible) during pandemic times.

Theme: Financial Security

Pandemics and crisis situations can present additional living costs or adversely impact personal and household financial security. It is important for communities and service organizations to establish support options for Indigenous persons with disabilities and special needs and for their families to meet the additional living costs resulting from the pandemic.

Addressing financial insecurity during the stressful times of pandemics can provide much needed relief and sense of support for families of and for persons with disabilities and special needs. As much as possible communities and service organizations should identify how they can address financial insecurity to help ease stresses that can result from pandemic situations. Easing financial stress during these times can be addressed by providing food, household and personal essentials and other goods. Innovative ways of helping families of and persons with disabilities and special needs will allow them to meet other costs with the funds they receive from other sources.

The following recommendations are being provided as considerations for communities and service organizations to include in their pandemic response plans:

1. Create an in-person and online donation fund for emergency financial support, specifically for persons with disabilities and special needs.
 - a. Designate a team and/or manager of this fund bank to monitor.
 - b. Designate a team and/or manager to assess the financial needs of your clients to distribute funds on an on-going individual basis.

2. Create a list of financial resources for your clients and update regularly.
3. Create weekly, bi-weekly or monthly appointments for clients who need assistance with filling out financial resource applications (EI, CERB, etc.)

Theme: Indigenous Elders/Seniors with disabilities and special needs

Indigenous Elders and seniors with disabilities and special needs may have unique needs and types of support and assistance required during times of crisis and pandemic. During these times Indigenous Elders and seniors with disabilities and special needs may be particularly vulnerable meaning that special support and attention may be required to help them and to assure their continued safety. Further, families of Elders and seniors with disabilities and special needs may not have sufficient resources to support their elderly family members therefore requiring additional support to meet the particular needs and assistance of their loved ones.

We urge communities and service organizations to seek information specific for and about Indigenous Elders and seniors with disabilities and special needs living in the community and area. Programming staff with responsibilities for Elders/seniors should make sure that they have reliable information about the needs, supports and assistance Elders and seniors require during times of health crisis including pandemics. Establishing a database of Elders and seniors could help to ensure that programs, services, supports and assistance are included in pandemic plans.

Program staff should obtain this information directly from Elders and seniors and their families. Further, program staff should verify the information regarding Elders/seniors as the pandemic crisis progresses. This step will assure that the supports etc. being provided and made available to Elders/seniors remain viable. If Elders/seniors needs and issues change during the pandemic timeframe then programs should adapt their supports to remain relevant to Elders and seniors.

Theme: Children and Youth with disabilities and special needs

Similar to the needs and supports for Indigenous Elders and seniors with disabilities and special needs, children and youth with disabilities and special needs and their families may require additional assistance, supports and help during times of pandemic and emergencies.

We urge communities and service organization health, social and education staff to seek information from children, youth and their families of persons with disabilities and special needs to find out what their needs, supports and assistance are during normal (non-pandemic) times. Additionally, the staff should find out if children, youth and their families require additional help during the pandemic time period.

The data collected from this information gathering process could be utilized for inclusion as a part of the actions in pandemic guides. This information could help communities and service organizations adapt their pandemic plans to meet the needs, supports and assistance that children, youth with disabilities and special needs and their families require during pandemics.

Summary: key issues brought to our attention through the survey

Presented in this section are some of the key findings of the pandemic survey. These are the words of the respondents and we wanted to provide these here in respect of having their voices heard.

Extra Help:

- Respondents expressed an increased need for help and extra services, especially during the pandemic.
- Respondents pointed out factors such as hindered access to food, medications, doctors, appointments, and the need for help with delivery of food, prescription and transportation to appointments.
- Respondents also identified needing easier access to personal protective wear, in order to safely navigate outside of their homes.
- A major point of feedback was a need for increased funding and emergency money for the disabilities and special needs community, as many mentioned maintaining a livelihood during a pandemic cost more money, as access to various services and maintaining a livelihood became increasingly difficult.
- Having someone or a team reaching out to see what type of help is needed, because as mentioned in feedback, it varies for every person.

Reliable information

- Respondents mentioned the need for reliable and easy access to information regarding the pandemic from service organizations and band councils.
- A website or social media space where information is regularly updated and shared to their members/clients.
- Another suggestion was to have an online place where members and clients can discreetly identify their disability and special needs in order to access help unique to their needs.
- Others suggested better access to devices like phones, tablets and computers needed in order to keep up with information and to maintain community connection and communication.

Mental health:

- Respondents expressed an increased need for mental health services, as the pandemic has heightened stress in their lives.
- Access to mental health services that are not only helplines, like a peer support group, volunteered mental health workers to meet with virtually or safely in-person.
- Information on how to handle mental stress during the pandemic.
- An option for a plus one for emotional and mental support when attending service appointments, etc.

Conclusion

It is the hope of the Wabanaki Council on Disability and our partners that the information presented in the resource document is useful to everyone that has responsibilities for the safety and security of all people during times of pandemics and crisis and in particular Indigenous persons with disabilities and special needs.

As stated earlier the goal is to provide this information in a manner so that is helpful to improve pandemic response plans. The WCD encourages everyone in government, communities and service organizations who determine pandemic responses and supports to have fulsome discussions with Indigenous persons with disabilities and special needs and their families to find out what they need for these times and during these times.

This resource document is proposed to be a tool – a tool for ongoing discussions and dialogue between Indigenous persons with disabilities and special needs and their families with Indigenous leadership, with community programs management and with government representatives.

This document should be used as a resource tool to establish the scope and perspective for ongoing dialogue and discussions. We hope it improves pandemic plans, government response and support as well as community-based response and support to Indigenous persons with disabilities and special needs in times of crisis and pandemics.



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