

If this was your child...



mawita'mk



WABANAKI
COUNCIL ON DISABILITY

A summary document to guide First Nation Chiefs and Indigenous leadership, Health Directors, government officials, Indigenous service organizations and advocates, clients, caregivers, and allies in discussing the challenges and recommendations for improving access to necessary services for Indigenous Persons with Disabilities and Special Needs who are “aging out” of Jordan’s Principle program support.

CALLS TO ACTION

1. Eliminate the Jordan’s Principle “aging out” federal policy requirement for those with intellectual disabilities.

As stated by one interview participant: *“If this was your child, who had a disability living at home with you, would you kick them out and ask them to live on their own?”* If a guardian is required to make decisions on behalf of an individual, the individual is not an adult.

2. Increase services for the adult population.

Adult services for First Nations individuals with disabilities and special needs are chronically underfunded with jurisdictional barriers to access and lengthy waiting lists. One interviewee said, *“We are preparing clients for a system they cannot access; unless you’re self-harming or a threat to others, the wait time is years long”.* We must do better to protect the most vulnerable among us.

3. Create and fund Youth Transition Coordinator Positions.

To enhance access to services, the creation and hiring of Youth Transition Coordinators would support First Nations Youth with Disabilities and Special Needs and their families through the current “aging out” policy requirement.

4. Develop and deliver First Nations led culturally safe programming for all service providers.

After reviewing over 20 organizations offering services for individuals with disabilities and special needs, it was found that there was no information regarding working with First Nations communities and cultures. This demonstrated lack of cultural safety puts our most vulnerable in the most precarious conditions.

“If this was your child, who had a disability living at home with you, would you kick them out and ask them to live on their own? Why are you expecting us to do that same thing with kids in guardianship?”

- JORDAN’S PRINCIPLE CASE COORDINATOR

CONTEXT

Jordan's Principle has been the official policy of the Canadian government for fourteen years, however its implementation for First Nations Children and Youth with Disabilities and Special Needs has been fraught with inadequacies and gaps in services. Nowhere is this more prevalent than when clients reach the age of majority, effectively "aging out"



of coverage.¹ This resource document was created by the Wabanaki Council on Disability (WCD) and the Mawita'mk Society to advocate on behalf of those clients and caregivers who are facing a severe reality while trying to access the adult systems in Atlantic Canada.

The WCD and Mawita'mk undertook a desktop review of the most relevant services for adults with disabilities in the Wabanaki Territory (Atlantic Region) to assess their accessibility and cultural safety for First Nations children and youth. Jordan's Principle Service Coordinators and other support workers were also consulted regarding their experiences of trying to bridge services between Jordan's Principle and the adult systems. This document concludes with recommendations for future programming, while the Calls to Action listed above are intended to guide leadership discussions and support advocacy efforts.

The concept of aging out of a system, due to Western concepts of age of majority which only take into account biological age, is detrimental to First Nations Children and Youth with Disabilities and Special Needs and their families. We recommend eliminating the "aging out" federal policy requirement and extend Jordan's Principle to encompass all First Nation Persons with Disabilities and Special Needs. Aging out is especially problematic for clients with intellectual disabilities who cannot provide informed consent. This, in our opinion, should be the true test of age of majority: If a guardian is required to make decisions on behalf of an individual, the individual is not an adult. This unfair requirement also negatively impacts case workers who are consistently required to transition youth with intellectual disabilities into an underfunded adult system, when they do not have the capacity to make their own decisions.

To ease the transition to adult systems, Youth Transition Coordinator positions should be funded and staffed by central Jordan's Principle Service Provider organizations until the aging out process is eliminated entirely. The Youth Transition Coordinators would cover the Wabanaki territory in Atlantic Canada and be responsible for creating individualized case plans for First Nations Youth with Disabilities and Special Needs and their families to help them navigate through the current aging out process. For First Nations Youth with Disabilities and Special Needs who are not intellectually disabled, these positions should be made permanent to support their transition to the adult systems.

¹ The First Nations Child & Family Caring Society of Canada in partnership with the Wabanaki Council on Disability and Mawita'mk Society. (2021, March). Jordan's Principle and Children with Disabilities and Special Needs: A Resource Guide and Analysis of Canada's Implementation. ILibrary. Retrieved December 13, 2021, www.ilibrary.net/document/y8m2kj0z-jordan-principle-children-disabilities-special-resource-analysis-implementation.html.

There are currently no federal services accessible for First Nations Persons with Disabilities and Special Needs.

In addition to the injustice of “aging out” of a system, adult services are significantly underfunded in the Wabanaki Territory. As explained by a Jordan’s Principle Service Coordinator, “Unless you’re self-harming or a threat to others, the wait time is years long” for adult mental health services. The lack of funding and services for Indigenous adults with disabilities and special needs is a gap that must be addressed by federal, provincial, and Indigenous governments.

There are currently no federal services accessible for First Nations Persons with Disabilities and Special Needs, an issue which is compounded by the fact that those living on-reserve are not eligible for provincial disability support. Most program requirements are so specific that it restricts access to the majority of First Nations applicants. Waitlists are expected to be so long that the Nova Scotia Disability Support Programs states on their website that it has two waitlists, which are separated based on when services are needed: “Service Request List for those who need a service now or soon — within two years; and, Future Planning Registry for those who will need a service in the future — in two years or more”. It is almost impossible to know what type of service an individual will need in two years because conditions advance at unpredictable rates, and in most cases there is absolutely no way of knowing when and if the services will be needed. As best expressed by an interview participant: “We are preparing clients for a system they cannot access”.

In addition to a lack of services and long waiting times, there is an alarming void in culturally safe practices amongst service providers. After reviewing the website of 21 organizations - including four provincial government departments that provide services for individuals with disabilities, there was no mention of services, programs, or partnerships with Indigenous communities or service groups that offer culturally safe practices. These unsafe practices are evident and well known, thus many individuals and/or their caregivers are hesitant to access the few services that exist. It results in individuals not accessing services because they do not feel safe, as stated by a Jordan’s Principle Service Coordinator. This reality exists because the organizations and services available were not developed with an Indigenous cultural lens or considerations.

“We are preparing clients for a system they cannot access”.

- JORDAN’S PRINCIPLE CASE COORDINATOR



PROGRAMMING RECOMMENDATIONS

The Wabanaki Council on Disability and Mawita'mk Society recommend exploring partnerships with existing organizations offering services for individuals with disabilities to create and deliver training workshops on how to best work with First Nations clients within the Wabanaki Territory, and how to make their services welcoming to all.

During our services review process, it was noted there is a serious lack of services and programming related to reproductive health and positive relationships. Due to the vulnerability of First Nations Children and Youth with Disabilities and Special Needs, it is strongly recommended that culturally appropriate programming be created and delivered throughout the Wabanaki Territory addressing this critical topic.

One of the biggest challenges that Jordan's Principle Service Coordinators reportedly face is the lack of tools and resources available to help facilitate the aging out process. When they were asked about what sort of tool could help them in this area, their responses included:

- Somebody who monitors an online database for each of the Atlantic Provinces about where resources are, categorizing specialty resources/specialized skill sets/professionals; developing and maintaining the online tool; need someone with a social work background to facilitate the aging out plan for clients;
- A navigation tool with "how to use" information/education sessions;
- Access to a family navigator to support in this transition - liaison person between [adult programs] and Jordan's Principle programming.

As per the Jordan's Principle Coordinators' suggestions, the Wabanaki Council on Disability and Mawita'mk Society engaged Agape Professional Services to design and develop a region-wide web-based services database with an easy to use interface that makes all adult services and programs easily searchable for First Nations families of Indigenous Children and Youth with Disabilities and Special Needs.

AREAS FOR FUTURE PROGRAM EXPANSION

In addition to the overarching Calls to Action we provide above, the following areas for future program expansion have been identified through this project. These include:

- Expand Jordan's Principle Coverage to extend over the lifetime of individuals with intellectual disabilities;
- Enhance funding and service delivery for adult systems that serve Indigenous Peoples with Disabilities Special Needs;
- Create and fund permanent Youth Transition Coordinators in each province to help clients and caregivers navigate the transition;
- Develop an Indigenous-led process for extending care across the lifespan for persons with disabilities and special needs and their families;
- Partner with the service delivery organizations to create and offer workshops for staff on how to work in a culturally safe way with First Nations Children and Youth with Disabilities and Special Needs;
- Create a web-based database tool which will include all services available for persons with disabilities in the Wabanaki territory;
- Develop and deliver sessions that provide culturally safe information on reproductive health and positive relationships;
- The "aging out" issue for First Nations Children and Youth with Disabilities and Special Needs must be addressed across the entire system, not just within Jordan's Principle.

ACKNOWLEDGEMENTS

This document would not have been possible without the contributions of Jordan's Principle Service Coordinators across the Wabanaki Territory (Atlantic Canada). We would like to thank them for sharing their expertise and lived experiences with the project team. Their tireless efforts in support of Indigenous Children and Youth with Disabilities and Special Needs inspires us all.

about...

WABANAKI COUNCIL ON DISABILITY

The Wabanaki Council on Disability is a recognized Indigenous organization in Atlantic Canada that advances the economic, social and cultural, spiritual, civil and human rights of Mi'kmaq, Wolastoqiyik, Passamaquoddy, Penobscot, Inuit and Innu persons with disabilities. The WCD is a partnership of Indigenous communities, Indigenous service groups and Indigenous service organizations of the Wabanaki ancestral traditional lands. The Wabanaki Council on Disability's commitment is to support and raise the voices of Indigenous persons with disabilities and special needs helping them to move from 'Isolation to Self-Determination'.

Contact: Conrad Saulis, A/Executive Director, Wabanaki Council on Disability
Email: csaulis@wabanakicouncil.com
Web: <https://wabanakicouncil.com/>

MAWITA'MK SOCIETY

Mawita'mk ('Being Together') is a volunteer Mi'kmaq Charitable Society. We value and support the gifts of people with disabilities and our youth. We strive to see that they receive services and supports within their cultural community.

Contact: Rosie Sylliboy, General Manager, Mawita'mk Society
Email: rosie@mawitamk.org
Web: <https://mawitamk.org/>

