It Takes a Village To Raise a Child

Conducting Anti-Racist and Culturally-Safe Research and Care for Racialized and Disabled Children, Youth, and Families in Canada

Listening TO THE MARGINS

Insights from a National Network of Community Members

01 OUR PROCESS & HISTORY

The Listening to the Margins Conference was held in February 2022 in Toronto, Canada. Due to the COVID-19 pandemic, it was delivered as a virtual conference through video-conferencing (Zoom). Approximately 100-150 people attended over the course of two full days. The conference was dedicated to building and promoting dialogue around the issue of childhood disability and race in Canada. The neglect and omission of discussions related to race and culture occurs within governments and health care organizations and not necessarily between disabled and racialized people themselves. In this way, the conference aimed to increase awareness and discussion about the intersectional experiences of childhood disability and race in Canada. Of note, this document does not present a research study. Rather, it is a knowledge dissemination product that presents key lessons learned via conference dialogue among critical community members, many of whom have disabled and racialized identities themselves, are racialized caregivers, or work with people who identify as members of these marginalized communities.

Our thinking is grounded in an ethos of anti-racism, anti-ableism, and cultural safety. We define anti-racism as the process of working toward the identification and elimination of all levels of race-based discrimination through an examination of the systems and processes that have continued to maintain the centrality of Whiteness in contemporary society (Calgary Anti-Racism Education, 2021). We are also devoted to anti-ableism, defined as identifying and practicing theories and actions that confront normalized, systemic ableism and discrimination based on physical, emotional, developmental, intellectual, and psychiatric differences (CSHA, 2023). Lastly, our thinking is informed by a cultural safety and humility approach, which seeks to address power imbalances in healthcare while promoting respectful engagement with patients and families. An important feature of cultural safety is the commitment to embrace a diversity of global knowledge producing traditions and ways of being and doing that help to de-center the dominant knowledge producing traditions associated with Whiteness. The adoption of cultural humility also means that we recognize that listening and acknowledging the self as a learner is critical to hearing, appreciating, and empathizing with the experiences of the Other (CSHA, 2023).

One of the conference sessions was titled, "Noticing Silences." Moderated by Toronto Metropolitan University's Dr. Fiona J. Moola, this session was specifically devoted toward asking difficult questions and identifying important gaps in intersectional research in childhood disability and race. During this interactive session, critical community members from across Canada came together in dialogue to identify and discuss best-practice recommendations for research in childhood disability and race. Critical community members included clinicians, community-based workers, parents, disabled youth, representatives or individuals from disability community groups, academics, and undergraduate and graduate students. This interactive session was recorded and transcribed verbatim. Additionally, written scripts that participants wrote on a virtual whiteboard were transcribed verbatim. One of the authors of this document (Tharanni) subsequently conducted a thematic/content analysis of the transcribed narratives. In this guide, we present the core best practice recommendations for anti-racist and culturally safe research and care for racialized and disabled children, youth, and families, stemming from insights of our critical community members.

Of note, although the Noticing Silences session was focused on best practice research recommendations, our community also made clinical care recommendations. Thus, we have included both research and care to recognize the ways in which they do not operate as silos. Additionally, in order to avoid conflating different histories of oppression, we have separated our Indigenous-specific research and care recommendations. Unfortunately, we only received one recommendation that was specific to Black disabled youth. For this reason, we were not able to generate recommendations specifically for Black and disabled youth and this continues to be an important area of inquiry for us. Our readers should be aware that Black communities face unique and virulent forms of racism and oppression that can differ in important ways from other racialized people (Della et al., 2021). Whether as a part of a children's hospital, clinic, centre, or community agency, users of this guide can feel free to employ these principles in their research and practice sites. Given distinct and unique histories and experiences of oppression, we have collated separate best practice recommendations for culturally safe and anti-racist research and care in the context of Indigenous childhood disability.

1 Given our alignment with a critical disability studies perspective, we employ identity-first (i.e., disabled person) rather than person-first (i.e., person with a disability) language.

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TABLE - ONE

Best Practice Recommendations for Racialized Disabled Children, Youth, and Families – Anti-Racist and Culturally Safe Research and Care

TABLE - ONE
Best Practice Recommendations

Listening to the Margins:
Insights from a National Network of Community Members

RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
01 1. Researchers must build trust with families and be aware that many racialized families experience fear and betrayal in the context of hospitals.	Researchers must spend ample time building trust with racialized families and be aware of histories of betrayal in research and care. Each family may have different preferences and exposures to different types of treatment based on past experiences. It is crucial for researchers to learn about treatment and research histories to build trust and understanding.	Expect trust-building to be a slow and non-linear process, with the potential for progress and regression. Remember that meaningful trust-building will look different for different racialized people and communities. Consider using open-ended questions to help you understand how best to work with your research partners and tailor your approach (e.g., 'what is one thing I can do, or I can avoid doing, to make our work together as comfortable as possible for you?')
02 2. Researchers must educate themselves on the distinct histories of research and care malpractice experienced by racialized communities, and continuously reflect on their research practice.	Researchers must educate themselves on how research has caused harm to racialized people in the past. Racialized people often feel that they encounter biases and assumptions from researchers. Researchers must learn about microaggressions; that is, subtle and covert racial discrimination. Researchers must avoid making assumptions about racialized communities as well as employing problematic tropes and stereotypes. Assumptions can alienate participants and hinder the research process. They must constantly reflect on assumptions and ask questions, rather than assume.	Microaggressions (e.g., 'where are you from?' or, 'you speak great English!') can be felt as emotionally taxing and exhausting for racialized people. The fields of cell biology and female genital health have made breakthroughs through medical violence and non-consensual experimentation on Black female bodies (e.g., Henrietta Lacks). Each community has its own historical record of medical and research mistreatment. These histories need to be thoroughly researched and understood before engaging with the community in question. We encourage our readers to engage with the EGAP framework that outlines responsible health data collection with Black communities (see link in references)
03 3. Researchers should employ ethical research principles and methods.	Researchers must be aware that certain research traditions, like ethnography, can be traumatizing for racialized people. Other classical research traditions may also not be sensitive to race, culture, and disability. Researchers must seek out and design research methods that are grounded in community-based humanist principles and consider racialized people as experts of their own experiences. Researchers should also seek alternative, culturally-sensitive means for obtaining consent that are attuned to, and informed by the individual's preferences. Researchers must reflect on their research tools and ensure research samples that maximize diversity. Attention should also be given to how the research process itself, as well as an excessive focus on policy, can stifle the growth of equity, diversity, and inclusion.	For example, harmful research practices were carried out several decades ago against marginalized communities. Readers may wish to learn about this by reading about the development of the Nuremberg Code. See https://www.unlv.edu/research/ORI-HSR/history-ethics

RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
04 4. Researchers should urgently address the problem of representation.	There is a need in the field to address problems with representation in research centres and institutes. Researchers should reflect the communities they are researching. Participants in research studies should have direct opportunities to work with researchers who reflect the make-up of their communities, including researchers from racialized and disabled communities.	Black participants should have the opportunity to work with Black researchers and healthcare providers. Resources that enhance representation, such as books and toys that feature disability and race need to be provided to families.
05 5. Personalized care must be delivered in the context of culture and community	Researchers and clinicians must develop reciprocal and collaborative relationships with racialized people in the context of their communities. They must seek to understand the whole person in the context of their culture, community, and belief systems. Researchers should seek to understand the participant's environment, their strengths and resilience, as well as their previous healthcare histories. They should also seek to understand participants' research histories and whether they have encountered any adverse research experiences. Participants must be asked what their needs are with a view to avoiding assumptions about they require (see assumptions, below). Researchers should acknowledge the diversity and uniqueness of participants, and always avoid the use of a deficit perspective. This can help with valuing participants' experiences and ideas and support the creation of participant-informed solutions. Researchers should acknowledge the diversity and uniqueness of participants, and always avoid the use of a deficit perspective. This can help with valuing participants' experiences and ideas and help to support the creation of participant-informed solutions. They should learn more about participants' cultural histories (see education). They should also be aware of the goals of the family and what the family wants from the research.	Sample questions you may want to consider asking partners in care and/or research include: 1.What does meaningful research/care look and feel like for you? 2.What is one of your strengths that you are really proud of, and how might we use it as part of our work together? 3.What is something about you I/we should know when working together? 4.What might you need in order for us to work together effectively? 5.How do you prefer to learn new things?

	RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
06	6. Researchers must be aware of language	Researchers must be aware of participants' language needs and language preferences, including needs for support workers, translation, and interpretation services. Researchers must be patient and seek out the resources needed to develop language-related accommodations for patients and families. They must recognize the importance of language to history and culture, far beyond translation services alone. Researchers should also recognize language preferences, such as how research participants choose to identify (ie, BIPOC, racialized, person with a disability, etc). Finally, it is also important to be aware of language accessibility. It is important to use health literacy that is easily accessible.	Researchers must offer language-based support to participants. It is important to arrange for plain language reviews to be conducted on all distributed written material, so content matches the most accessible health literacy level possible.
07	7. Researchers must be aware of culture and acknowledge that race and culture are not monoliths.	Researchers must educate themselves about the cultural background of the family. If the family is not from Canada or has not resided in Canada for a long time, it is also important for researchers to be aware of the family's cultural story and journey to Canada. There is a need for healthcare institutes to invest in culturally-appropriate healthcare. Researchers should also be aware of how they define culture and environment in the context of health care and research.	
08	8. Awareness of barriers to access	Researchers must be aware of the impact of barriers to accessing research and care, such as long wait times, inappropriate referrals, or lack thereof, criminalization by the health system or academic institutions, few resources for families from rural locations, as well as other negative research and care experiences in the past. Researchers and care providers must ensure that disabled and racialized patients and families have access to meaningful and developmentally appropriate services close to their communities. These services must be accessible. Resources must also be low-cost and affordable (or, even better, free). Lists of accessible resources for families must be provided. Access to child life services should be facilitated given their ability to create fun and joy despite difficult disability experiences. Accessible and welcoming environments for such services must be provided.	Readers can learn about disability-specific barriers by accessing this report by the Accessibility for Ontarians with Disabilities Act. See https://www.aoda.ca/disability-barriers/. Readers can also reference this report on barriers to health services for immigrant families with disabled children - focus on the key messages/takeaways starting on page 4: http://p2pcanada.ca/wp-content/uploads/2011/09/families-with-disabled-child-final-report1.pdf

RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
09 09. Researchers should educate themselves on disability meaning and disability identity	Researchers must be cognizant of the meanings that families ascribe to the idea and experience of disability. Researchers must also be aware of the medical model of disability, the biopsychosocial model of disability, and the social model of disability (as well as how the medical model may have harmed families in the past). Researchers and healthcare providers must also be aware of different disability identities, such as person-first or identity-first orientations. Researchers should have an understanding of ableism. They should also ask participants and patients how they identify and the language they would prefer to use (e.g., person-first or identity-first). Researchers and health care providers should also reflect upon and be aware of how they conceptualize disability and disability identities, and whether their understanding is congruent with those of participants.	Readers may wish to investigate identity issues as they pertain to the autistic community. See https://autisticadvocacy.org/about-asan/identity-first-language/
10 10. Researchers must also be aware that racialized families may not uphold Euro-centric definitions of disability.	Given the histories of trauma among some disabled and racialized participants and their families, researchers and health care practitioners could work toward understanding (inter-generational) trauma experiences among their disabled and racialized participants/patients.	Readers may wish to familiarize themselves with the principles of trauma-informed qualitative research. Please see https://www.urban.org/urban-wire/guidelines-incorporate-trauma-informed-care-strategies-qualitative-research
11 11. Researchers should be aware of participant labour and temporal demands on patients and families	Researchers must be flexible with time and recognize the temporal constraints families face. It is important to recognize the value of participants time in the context of the physical and emotional labour that disabled families soften face.	Adequate participant compensation should be thoughtfully planned, including culturally appropriate compensation for participant labour.

2 Although great strides have been made, the medical model generally attributes disability to an individualized problem that resides in the body. In contrast, the social model of disability regards disability as produced by disabling social environments and societal structures.

Listening

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TABLE - TWO

Best Practice Indigenous-Specific
Recommendations for Culturally
Safe and Anti-Racist
Research and Care

TABLE - TWO
Best Practice Recommendations

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RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
01 1. Researchers should seek to learn about the history of oppressive relationships that Indigenous people have encountered with hospitals and Universities	After a long history of traumatizing and broken relationships laden with betrayal under colonization, Indigenous peoples are starting to re-establish relationships with researchers and care providers. Researchers and care providers must be aware of this history of broken relationships with Indigenous peoples. For example, the Ownership, Control, Access, and Possession (OCAP) course addresses how research has gravely harmed Indigenous communities in the past.	Please see https://fnigc.ca/ocap-training/ for access to the OCAP principles.
02 2. Researchers should seek to educate themselves on histories of trauma and inter-generational trauma	Indigenous peoples have a long history of trauma, including trauma within healthcare and research under colonization and neo-colonization. Researchers and care providers must be aware of this legacy of trauma and understand how it has led to a lack of trust and re-traumatization in health care.	For example, the Union of Ontario Indians, with the support of the Truth and Reconciliation Commission of Canada, has created a document called "How do we Heal?". It outlines intergenerational trauma in the context of Indian residential schools. See https://www.anishinabek.ca/wp-content/uploads/2016/07/How-Do-We-Heal-Booklet.pdf
03 3. Researchers should be aware that Indigenous people may not feeling safe in research environments	Researchers and care providers must be aware that many Indigenous communities do not feel safe in hospitals. When doing research, researchers should attempt to find a space that makes Indigenous research participants feel safe and that is informed by the participant's preference.	Readers may wish to read this report related to culturally safe emergency care for Indigenous communities. https://www.fnha.ca/Documents/FNHA-Paddling-Together-Report.pdf This CBC article and accompanying podcast was aired on "White Coat, Black Art". It featured Dr. Nel Wieman, president of The Indigenous Physicians Association. It explores how racism may deter Indigenous people from seeking health care: https://www.cbc.ca/radio/whitecoat/fear-of-racism-deters-many-indigenous-people-from-seeking-medical-treatment-says-health-care-leader-1.5817730 Researchers should also conduct research in environments that feel safe for participants, such as cultural community centres.

RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
04 4. Researchers must engage in the ongoing process of decolonization.	Researchers should not attempt to fit Indigenous peoples and communities into colonial narratives, nor colonial ways of knowing and being. It is also important not to conflate the oppression experiences of Indigenous peoples with those of Black and racialized people.	We encourage readers to engage with the seminal book "Decolonizing Methodologies" by Linda Tuhiwai Smith.
05 5. Researchers should embrace community and culture as well as foster culturally sensitive health care	Culturally sensitive research and care must be undertaken. Researchers must consider the needs of community members and build upon the expertise and knowledge of Indigenous communities. Where possible, researchers should embrace the agency of Indigenous voices and ways of knowing the world. Researchers and health care providers must undertake culturally-safe health care and research.	Readers can learn more about culturally-sensitive health care by reading this article by the College of Nurses of Ontario. See https://www.cno.org/en/learn-about-standards-guidelines/educational-tools/ask-practice/culturally-sensitive-care/
06 6. Researchers must undertake education and training in Indigenous issues.	Researchers and health care providers in urban centres require training and education to more fully understand the realities facing Northern Indigenous communities. The OCAP and SANYAS courses in particular are excellent forums for education and training for urban dwelling researchers and healthcare providers.	Education and training on colonization and the issues facing Indigenous people can be accessed by taking the SANYAS course. See https://sanyas.ca/
07 7. Researchers must embrace Indigenous worldviews on disability	Researchers must be aware of Indigenous world views and philosophies, including the ways in which Indigenous communities may see the concept of childhood disability.	Readers can learn more about Indigenous perspectives on childhood disability by reading the scholarship of Toronto Metropolitan University professor Nicole Ineese-Nash. See https://c-jds.uwaterloo.ca/index.php/cjds/article/view/645

|	RECOMMENDATION	DESCRIPTION	EXAMPLES AND/OR RESOURCES
08	8. Researchers must undertake ethical research with Indigenous peoples.	In addition to following community-based OCAP principles, researchers must ensure that participants get access to the resources that stem from the research! Researchers must also think about dissemination plans to ensure that the findings from research reach and benefit Indigenous communities. There is also a need to create specific knowledge mobilization products with Indigenous communities.	Researchers should reference TCPS 2 Article 9 and use the guidelines to inform every step of the study (specifically 9.12: Collaborative Research, Article 9.13: Mutual Benefits in Research, Article 9.17: Interpretation and Dissemination of Research Results, Article 9.18: Intellectual Property Related to Research) https://ethics.gc.ca/eng/tcps2-eptc2_2022_chapter9-chapitre9.html
09	9. Researchers should strive to be aware of how politics, power, and policy have impacted Indigenous people	Researchers should strive to understand Jordan's Principal, based on the case of Jordan River Anderson. Researchers must be aware that political votes in Canada determine how much money Indigenous disabled children receive through Jordan's Principle.	Readers who wish to learn more about Jordan's Principle may engage with this reading. See https://www.sac-isc.gc.ca/eng/1568396042341/1568396159824
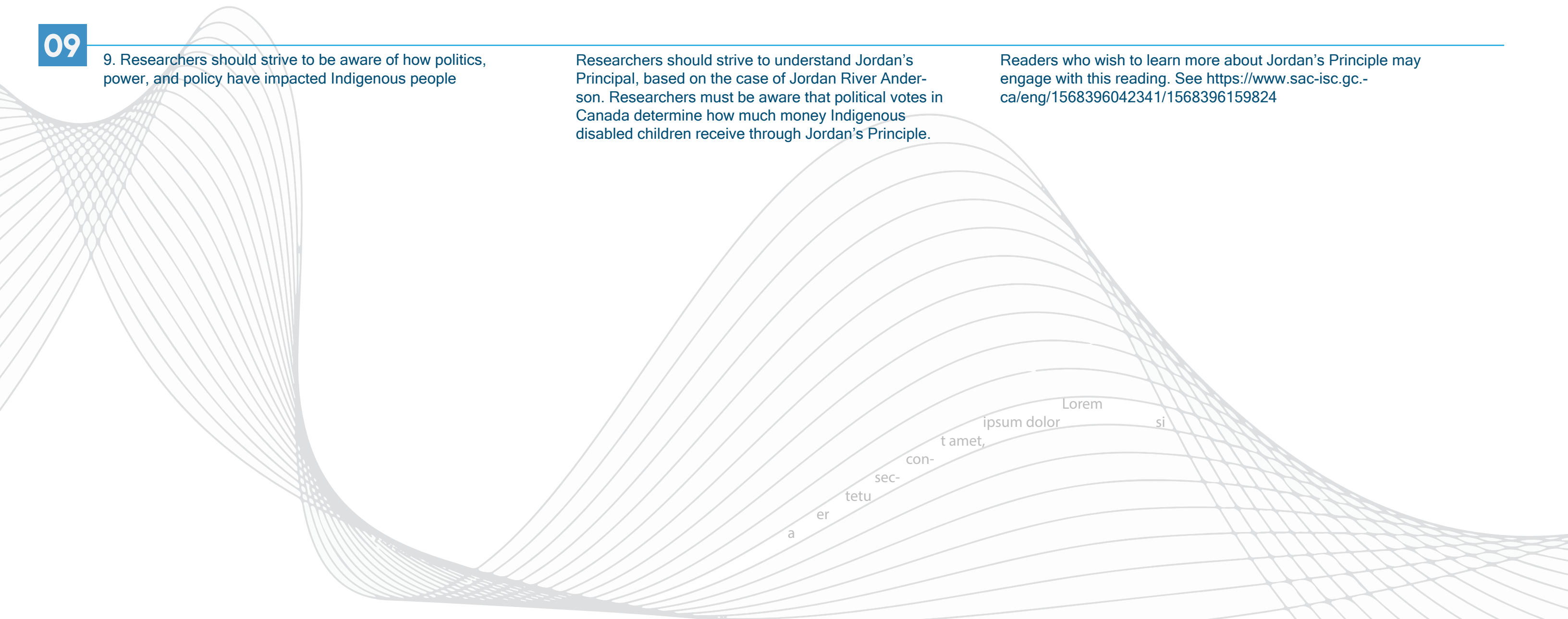
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LISTENING TO THE MARGINS

A TWO-DAY CONFERENCE ON CHILDHOOD DISABILITY AND RACE IN CANADA

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