From Intention to Impact:

CIHR IRSC
Canadian Institutes of Health Research en santé du Canada

CIHR Anti-Ableism Action Plan





From Intention to Impact: CIHR Anti-Ableism Action Plan

From Intention to Impact: CIHR (Canadian Institutes of Health Research)
Anti-Ableism Action Plan

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Document availability

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Message from the Acting CIHR President

I am pleased to introduce "From Intention to Impact: CIHR Anti-Ableism Action Plan." This plan adds to CIHR's commitments in the <u>CIHR</u>

<u>Accessibility Plan 2023-2026</u> by going beyond accessibility to address ableism at CIHR.

We know that <u>persons with disabilities are disproportionately</u> <u>underrepresented in health research</u>, largely due to barriers to accessibility and issues of ableism. It is our hope and expectation that the actions in this plan will make CIHR programs safer and more welcoming for persons with disabilities. We wish to strengthen momentum in building the disability-focused health research community in Canada, contributing to improved health outcomes for persons with disabilities through inclusive <u>research</u> excellence.

I would like to thank the members of the External Advisory Committee on Accessibility and Systemic Ableism for their work to co-develop the plan with CIHR, noting the leadership of Co-Chair, Dr. Mahadeo Sukhai, whose steadfast commitment informed, challenged and inspired many. I would also like to thank the community members who shared their knowledge and experiences during our engagement activities and the CIHR staff members who provided input throughout the process. I am so proud of this co-development process that brought together diverse backgrounds and experiences, valued each person's voice as equal, and used a consensus-building approach to reach decisions.

As we all know, change takes time. Over the course of this plan, we will continue to learn, grow, and adapt as we remove barriers to participation and work towards eliminating ableism in the health research system. As we begin the work described in this plan, we will continue to collaborate with persons with disabilities to put these actions into place and will hold ourselves accountable by monitoring and publicly reporting on our progress.

Everyone should be included and represented within health research. With the release of this plan, we commit to becoming an actively anti-ableist organization. We hope that our actions in this space will help other organizations to do the same.

Tammy J. Clifford, PhD Acting President, CIHR

Message from the CIHR External Advisory Committee on Accessibility and Systemic Ableism

First, we wish to thank the Canadian Institutes of Health Research (CIHR) for its invitation to serve on this committee. We are incredibly proud of the work we carried out together and in the true spirit of collaboration and power-sharing with CIHR.

Many of our accomplishments can be found on <u>CIHR's webpage</u>. However, during our two years together we did so much more. For example,

- We increased the knowledge and understanding of disability experiences at CIHR.
- We influenced CIHR to change its internal practices by changing the ways in which it developed documents, used accessible technology, delivered presentations, engaged with the community, and incorporated universal design into its governance structures. These changes demonstrate CIHR's willingness to incorporate anti-ableism into its work and sets an example for other organizations.
- We created a safe space in our meetings for members to express themselves openly by respecting each other and learning from one another's expertise. This is not always the case when people come together, and it is something we celebrate.

We were successful, in part, because of our co-chairs. We are grateful for their leadership and commitment. We are also thankful to CIHR for listening and the opportunity to take part in the co-development process and for the CIHR staff who prepared meeting materials and ensured meetings were fully accessible.

This is not to say we did not experience any challenges. However, we are confident that CIHR will integrate our lessons learned as it engages with the community and continues in the implementation and evaluation of this important work.

Importantly, we would like to thank those in the disability community who gave generously their time and knowledge in the development of this plan. Without their wisdom and lived expertise, none of this would have been possible. Finally, we would like to thank each other. Through our

discussions, we have broadened our perspectives. We have built lasting relationships we know will continue beyond this committee's work.

With this plan's release, we are hopeful for the future. We look forward to seeing CIHR implement these actions over time. We are hopeful that our work will be the starting point for CIHR, and others, to integrate antiableism into its work.

Sincerely,

The CIHR External Advisory Committee on Accessibility and Systemic Ableism

Message from the Co-Chairs of the CIHR External Advisory Committee on Accessibility and Systemic Ableism

First, our deepest gratitude to our fellow members of the External Advisory Committee on Accessibility and Systemic Ableism (EAC-ASA). The EAC-ASA was brought together with a mandate to provide CIHR guidance on the identification of barriers and actions to take that will eliminate those barriers. CIHR's anti-ableism action plan represents a tremendous codevelopment effort that evolved through deliberate, meaningful engagement of the Committee membership. During our work together, the Committee modeled the principles of inclusion and anti-ableism reflected in the plan – an approach that required the commitment of everyone at the table.

Second, we'd like to commend the dedicated team in CIHR's Equity Strategy Branch (ESB) for their exceptionally thoughtful inclusive design and care throughout this process. The development of this action plan has been a learning journey for CIHR and the ESB team was highly successful in creating the context for meaningful collaboration.

This action plan is the culmination of deliberations among subject matter experts, including those with lived and living experience of disability, and CIHR staff. It outlines concrete, practical actions that will increase momentum to leverage the practices, tools and resources necessary for increased inclusion of persons with disabilities in CIHR funding programs. We believe that these steps, when taken, will also lead to an increased focus on disability health research.

This action plan recognizes that systemic barriers encountered by persons with disabilities in the health research funding system arise because of ableist assumptions underpinning our current system. Via this plan, the Committee hopes to call attention to, and begin to deconstruct and remove, those ableist assumptions. We recognize that CIHR as an organization has much work ahead to achieve its goals related to anti-ableism. However, for this plan to achieve its goals, all members of the health research funding community must join with CIHR in committing to the principles of fostering a truly anti-ableist and inclusive health research environment.

We look forward to the plan's ongoing implementation and next steps, and to the community's engagement in the work ahead.

Mahadeo Sukhai, PhD (Co-Chair) and Trudy Samuel (Co-Chair)

Executive Summary

Background: The Canadian Institutes of Health Research (CIHR) is committed to address barriers to accessibility and remove ableism in our funding system. That is why, we worked with the External Advisory Committee on Accessibility and Systemic Ableism to co-develop "From Intention to Impact: CIHR Anti-Ableism Action Plan".

We co-developed this action plan using the principles of respect, power-sharing, and collaboration. We also used information from an environmental scan, virtual discussion sessions, surveys, and a review of our policies and practices.

The Action Plan: The goal of this action plan is for CIHR and the health research community to be safer and more welcoming places for persons with disabilities. This plan commits CIHR to actions that address barriers experienced by persons with disabilities who interact with CIHR.

The actions are divided into four sections:

1) Who CIHR funds

- The aim of these actions is to make participation in CIHR funding opportunities equitable for persons with disabilities.
- Actions in this section focus on strengthening our communications, investing in training, and removing barriers when applying to CIHR programs.

2) What CIHR funds

- The aim of these actions is to increase disability-focused research and anti-ableist approaches to research funded by CIHR.
- Actions in this section focus on increasing the capacity of health researchers to conduct disability-focused research.

3) How CIHR funds

 The aim of these actions is to use anti-ableist approaches across all CIHR funding programs. Actions in this section focus on updating CIHR policies and processes to eliminate barriers and ableism.

4) Organizational Culture

- The aim of these actions is to improve knowledge and awareness of disability and ableism at CIHR and beyond.
- Actions in this section focus on training, knowledge sharing, and using practical tools in our day-to-day business and in decisionmaking.

Next steps: CIHR will publish a high-level implementation plan including details related to when the work will be done, how progress will be measured and reported, and how actions will be adjusted, if needed.

1. Background

The Canadian Institutes of Health Research (CIHR) is Canada's federal health research funding agency. For information about what we do, visit our homepage where you will find information on health research and how CIHR funds health research.

This action plan is titled, From Intention to Impact: CIHR Anti-Ableism Action Plan. It was co-developed by the <u>CIHR External Advisory Committee</u> on Accessibility and Systemic Ableism (EAC - ASA) and the CIHR Equity Strategy Team. The actions in this plan are intended to go beyond accessibility-focused commitments within <u>CIHR's Strategic Plan (2021-2031)</u> and <u>CIHR's Accessibility Plan (2023 – 2026)</u> to make CIHR an actively anti-ableist organization.

For CIHR, being actively anti-ableist means acknowledging and actively confronting inequities that inadvertently lead to oppression of persons with disabilities within CIHR's health research funding system¹ and in the broader health research system². It also means that CIHR will continue to learn and change to reflect that the concept of anti-ableism evolves over time. By taking this journey towards anti-ableism, CIHR and the broader health research system will become safer and more welcoming places for persons with disabilities to participate and become agents of change.

The process of co-development for this action plan began in 2021 with a call for expressions of interest for membership on the EAC – ASA. This was the first time CIHR proactively included efforts to acknowledge and remove barriers to interacting with CIHR, such as offering accessible formats of application documents and submission of applications in a non-written form. Since that time, the EAC – ASA has been invaluable to CIHR's learnings about ableism and the ways in which it manifests itself within CIHR's health research funding system and across the broader health research system.

The co-development process was founded on bringing together diverse backgrounds and experiences, treating each person's voice as equal, and taking a deliberate consensus-building approach to decisions. EAC – ASA members have been actively involved in each step of the creation of this plan, from establishing agendas for recurring meetings, to guiding accessible consultations and evidence gathering, to an iterative writing

process of this document. In this context, there was power sharing in deciding the content of this action plan with the EAC – ASA who represent a diversity of disabilities from the across the health research community.

What guided the co-development of this plan?

This plan was co-developed with the following context in mind:

- <u>CIHR's organizational values</u> align with the intent to create an actively anti-ableist organization. CIHR is committed to openness, responsibility, fairness, and mutual respect with all its researchers and partners.
- There are various ways to define words, such as ableism. CIHR has published a <u>glossary of terms</u> to describe how these words are used in the context of this action plan.
- Persons with disabilities experience barriers and ableism that impact their funding success long before interacting with CIHR. This plan intends that the cumulative effects of changes to CIHR's policies, processes and programs will change the culture within and exert influence over other organizations so that anti-ableist approaches are integrated across the broader health research system.
- Disability and impacts of systemic ableism intersect with other factors of identity (e.g., gender) and systems of oppression (e.g., racism). This is called <u>intersectionality</u> and where possible, the actions in this plan align with other work at CIHR (e.g., development of CIHR's anti-racism action plan) to take into account differing lived and living experiences related to ableism.
- Power within the broader health research system, and within CIHR, is not evenly distributed. This means that the people who make decisions about what types of research and what types of researchers are valuable may not include the perspectives of persons impacted by ableism (or other intersecting systems of oppression).
- CIHR's approach to <u>research excellence</u> requires that research be accessible and anti-ableist in its approach. The actions in this plan incorporate an anti-ableist approach into CIHR's ongoing work to redefine and uphold an inclusive concept of <u>research excellence</u>.
- This action plan is complementary to the <u>CIHR Accessibility Plan (2023 2026)</u> and expands on the actions within the "Design and Delivery of Programs and Services" section. Actions related to employment, built

environment, information and communication technology, and procurement of goods and services are covered under the CIHR Accessibility Plan and not repeated here.

What evidence informed the co-development of this plan?

This plan was informed by multiple sources of evidence, consultations, documented experiences, and research, including:

- A <u>survey of persons with a disability or health condition</u> that affects how they interact with the health research system.
- A <u>survey of allies</u>, or those who have helped persons with a disability to navigate the health research system.
- A series of <u>virtual discussion sessions</u> with persons with a disability or health condition that affects how they interact with the health research system.
- A <u>review of policies and practices</u> at CIHR to identify barriers to participation.
- An environmental scan of peer reviewed and non-academic literature.

Implementing the actions in this plan

The timeline of this plan follows that of the <u>CIHR Strategic Plan</u> (2021-2031), meaning that the actions are intended to be put in place over several years up to 2031. This document describes 'what' actions CIHR will take. CIHR will publish a separate document that describes details for putting the actions in place, including when the work will be done, how progress will be measured and reported, and how actions will be adjusted, if needed.

Continued engagement of persons with disability

Actions in the <u>CIHR Accessibility Plan (2023 - 2026)</u> commit to establishing a permanent advisory committee on ableism and accessibility (action 21.1) and to establish a mechanism for continued consultation with persons with a disability (action 21.2) to guide the implementation of actions related to the design and delivery of programs and services. Similarly, under Strategic Priority D of the <u>CIHR Strategic Plan</u>, CIHR has committed to continued engagement of people with lived and living experience of health inequities in the design and delivery of CIHR programs. CIHR is coordinating these

commitments to make sure they are fulfilled in a meaningful, sustainable, and effective way. The engagement mechanism that will be put in place (e.g., an advisory group) will be informed by actions in this plan to make sure that it will be inclusive and welcoming to persons with disabilities. This advisory group will be tasked with providing advice on co-design, how to best carry out the actions in this action plan and ensure persons with disabilities are included throughout their implementation.

2. The Action Plan

This plan aims for a cultural change in which CIHR, and the broader health research system, become safer and more welcoming places for persons with disabilities to participate and become agents of change. Culture change takes a long time and the changes that are expected to happen may not be fully realized in the timeframe of this plan. However, it is intended that the ultimate impacts of this plan are that:

- Persons with disabilities have autonomy to enter, stay, and advance within roles in the health research system.
- The application, utility, and impact of CIHR-funded research is strengthened.
- CIHR is deemed by the health research community to be an actively anti-ableist organization.
- All those involved in the health research system actively work to dismantle and eliminate ableism.

Actions intended to lead to these ultimate impacts are organized into four sub-sections to align with how CIHR supports health researchers and health research.

- Who CIHR funds: This section is related to the people and organizations who apply for, and receive, CIHR funding (e.g., <u>awards</u> or prizes for training or career support and <u>grants</u> for research projects or knowledge mobilization).
- What CIHR funds: This section is related to the type of science and methodologies of research projects that are submitted to, and funded by, CIHR. CIHR funds <u>four themes of health research</u>: biomedical, clinical, health systems and services, and social, cultural, environmental and population health.
- **How CIHR funds**: This section is related to the policies, processes, and procedures that CIHR uses to carry out the day-to-day operations related to designing and delivering health research funding programs.
- **Organizational culture**: This section is related to who informs and makes decisions at CIHR and the knowledge, beliefs and attitudes that shape decision-making.

Each of the four sub-sections will describe:

- Objective: This is the desired change.
- Barriers³: These are the challenges identified that prevent or hinder persons with disabilities from full participation in the health research system. Collected evidence on these barriers can be found on the <u>publications section</u> of the <u>CIHR Accessibility and Systemic Ableism</u> <u>webpage</u>.
- **Actions:** These are the recommended actions that are needed to address the barriers and lead to desired changes.

2.1 Who CIHR funds

This section is related to the people and organizations who apply for, and receive, funding from CIHR.

Objective

To make participation in CIHR funding opportunities equitable for persons with disabilities.

Documented barriers

- Fear of consequences and biases when disclosing having a disability.
- Lack of role models and mentors.
- Lack of awareness of research funding and/or available support by the disability community.
- Lower prioritization of the disability community compared to other equitydenied groups.
- Low application rates by persons with disability.
- Lack of meaningful inclusion of persons with disabilities in all stages of research (e.g., tokenism).

Actions

These are the actions CIHR will take to establish an understanding of the valuable contributions of persons with disabilities in health research and to build capacity for persons with disability to enter and succeed in the health research funding system.

Action 1: Promote the contributions of scholars with disabilities in advancing health research.

Description: Feature health researchers with disabilities in CIHR publications (e.g., website content, researcher profiles, newsletter spotlights) to showcase their work and increase awareness of their contributions to advancing health research.

Action 2: Strengthen communications of CIHR programs, services, and products to reach persons with disabilities.

Description: Expand where and how communication products are distributed to the health research community. This includes expanding intended audiences to reach disability-related organizations that may not typically have received this information and providing information in accessible formats.

Action 3: Invest in training, and mentorship initiatives for persons with disabilities in (or entering) the health research system.

Description: Co-design⁴ and deliver program(s), services, or products that will connect persons with disabilities with suitable mentors, training opportunities, and other supports.

Action 4: Invest in mechanisms to make the application process barrier-free.

Description: Co-design⁴ and pilot processes and tools to remove barriers for participation of persons with disabilities in the application process (i.e., before grant or salary/training funds are awarded). Barriers to be addressed include expenses incurred by researchers to engage persons with disabilities in the development of research proposals and those incurred by the researchers themselves in the preparation of an application (e.g., support workers to assist them in completing application tasks).

Action 5: Review language used across CIHR through an anti-ableist lens to meaningfully include persons with disabilities.

Description: Language used to describe the people who interact with CIHR, who do health research, and who participate in health research needs to better reflect the language used by disability communities and persons with disabilities. This action includes reviewing language that describes the variety of roles of applicants, partners, community members, and peer reviewers.

Action 6: Explore barriers to institutional eligibility so that persons with disabilities who conduct research and are not affiliated with traditional academic institutions are eligible to apply for CIHR funding.

Description: Review and revise based on findings of the review, institutional eligibility criteria to allow persons with disabilities to apply who are affiliated with Canadian non-governmental organizations that have research and/or knowledge translation mandates. These organizations may not be currently eligible to administer CIHR funding.

Action 7: Strengthen the transparency of <u>self-identification data collection</u>, <u>its use</u>, and reporting so that the demographics of CIHR applicants and funded researchers are better understood⁵.

Description: Publicly release data⁶ each year showing trends in applications to CIHR programs (including training and career awards, and research grants) from persons with disabilities and trends in the success of persons with disabilities in receiving CIHR funding. Intersecting factors of identity will be included in data analyses. The findings will be used to inform the co-development or refinement of CIHR programs.

2.2 What CIHR funds

This section is related to the type of science and methodologies of research projects that are funded by CIHR.

Objective

To increase disability-focused research and integrate the consideration of disability and anti-ableism across CIHR-funded research.

Documented barriers

- Limited advancement of research based on social model of disability.
- Low applications received and funded on disability-, accessibility-, or ableism-focused research.

Actions

These are the actions CIHR will take to establish an understanding of the value of disability-focused research and to build capacity of health researchers to conduct disability-focused research.

Action 8: Promote the various types of research that CIHR values and supports.

Description: Feature a variety of CIHR-funded research in CIHR publications (e.g., website content, research profiles, newsletter spotlights) to increase awareness of disability-related research (e.g., how it relates to and/or differs from chronic illness research, the social model of disability, arts-based research on disability).

Action 9: Strengthen the transparency of CIHR data related to disability-focused research, its use, and reporting such that the proportion of applications and funding in these areas is better understood.

Description: Publicly release data each year showing trends in CIHR applications and funding received in relevant disability-focused health research, including research based on the social model of disability. This data will be used to inform the co-development of CIHR programs.

Action 10: Integrate accessibility and anti-ableist considerations into all CIHR-funded health research.

Description: Co-design⁴ mechanisms to ensure an anti-ableist lens is integrated into health research priority areas, investigator-initiated research, and funding program design. This could include tools for applicants and peer reviewers to identify and address ableism in health research (similar to tools produced to integrate sex and gender) and introducing champions with knowledge of inclusive research excellence, including ableism and disability-related issues (similar to sex and gender champions).

Action 11: Invest in funding opportunities for disability-focused health research, including research based on the social model of disability.

Description: Co-design⁴ and deliver funding opportunities (e.g., Institute Priority Announcements) and supplemental funding (e.g., similar to top-up funds for successful applications) with eligibility criteria restricted to disability-focused research⁷. Seek opportunities to partner with disability-focused organizations as funding competition partners.

Action 12: Invest in network development initiatives for researchers to apply best practices in engagement of persons with disabilities in health research.

Description: Co-design⁴ and deliver program(s), services, or products that will connect persons with disabilities and disability-related organizations with researchers conducting, or wanting to conduct, disability-focused health research (i.e., research conducted for, with, and by persons with disabilities) and knowledge mobilization activities. Effective engagement practices focus on research by, and with, persons with disabilities rather than for persons with disabilities.

2.3 How CIHR funds

This section is related to the policies, processes, and procedures that CIHR uses to carry out the day-to-day operations related to designing and delivering health research funding programs.

Objective

To embed anti-ableist approaches across all areas of the design and delivery of all CIHR funding programs⁸.

Documented barriers

- Inaccessible application platforms⁹, funding opportunity advertisements, application formatting, peer review materials and templates.
- Short deadlines do not allow sufficient time for persons with disabilities to complete tasks or arrange for supports.
- Eligibility criteria that penalize or disadvantage persons with disabilities (e.g., academic achievement as measure of success, gaps in CV for disability-related leaves from school or research).
- Perception that applications from persons with disabilities are screened out by institutional gatekeepers, meaning they are not submitted to CIHR.
- Challenges with compensation practices (e.g., inconsistent practices or compensation not offered).
- Accessibility considerations are not mandatory when conducting research, meaning they are often not included (e.g., accessible format of data collection tools or methods).
- Lack of accessibility supports for those applying for or receiving funding (e.g., lack of information or lack of transparency on availability of supports and for whom, lack of coordination within and across organizations).
- Lack of information for supplementary funding related to accessibility supports (e.g., to conduct research, attend knowledge mobilization events).
- Lack of accountability for ableist practices upheld by academic institutions.

Actions

These are the actions CIHR will take to recognize issues of ableism in our operations and apply an anti-ableist lens to the design and delivery of all CIHR programs and services.

Action 13: Promote the accessibility-related supports that are available to anyone interacting with CIHR in any role¹⁰.

Description: Communication activities will be undertaken to increase awareness of available supports among the health research community and CIHR staff.

Action 14: Incorporate operational changes to make the process of completing and submitting a funding application easier for all <u>applicant</u> <u>roles</u> (including nominated principal applicant, collaborators, partners, etc.)¹¹.

Description: Co-design⁴ and pilot test operational changes to help address the diversity and dynamic nature of disabilities and their impacts on applying for grants and awards. For example, increase the time available to prepare applications, harmonize content across funding opportunities and eliminate redundancy of information across forms, or offering alternatives to submitting information in a written form. Learnings from these pilot tests will inform ongoing adjustments to operations of programs.

Action 15: Incorporate operational changes to make the process of participating in peer review easier for all <u>reviewer roles</u> (including researchers, knowledge users, and patient reviewers)¹².

Description: Co-design⁴ and pilot test operational changes to help address the diversity and dynamic nature of disabilities and their impacts on participating in peer review. For example, increase the time available to evaluate applications, availability of learning materials in accessible formats, or offering alternatives to submitting review comments in a written form. Learnings from these pilot tests will inform ongoing adjustments to operations of peer review.

Action 16: Incorporate an anti-ableist approach into CIHR's concept of research excellence¹³.

Description: Co-define⁴ research excellence and develop or refine assessment tools so that accessibility and anti-ableism are embedded, fundamental concepts of excellent research. This builds upon the collaborative work underway via the San Francisco Declaration on Research Assessment.

Action 17: Incorporate a strength-based approach to recognize the full contributions of persons with disabilities when applying for funding and participating in peer review or other advisory groups at CIHR¹⁴.

Description: Co-design⁴ and pilot test changes so that persons with disabilities can describe relevant experiences and contributions in applications for funding or in seeking membership to advisory groups. This means applying an anti-ableist concept of research excellence in the development and assessment of selection criteria. This builds upon collaborative work underway to broaden what is considered valuable contributions and impacts to health research.

Action 18: Update the funding decision process for CIHR's largest grant program (Project Grant program) to ensure equal opportunity for <u>nominated principal investigators</u> who identify as persons with disabilities.

Description: The results of the Project Grant competition will be monitored to make sure that the proportion of persons with disabilities funded is at least equal to the proportion of persons with disabilities who apply to the competition. This process is called <u>equalization</u> and has been successfully used at CIHR for early career researchers, female nominated principal investigators, and French language applications.

Action 19: Establish standard practices to compensate persons with disabilities or representatives from organizations working with persons with disabilities for their time and expertise given to activities related to CIHR business or participation in CIHR-funded research.

Description: Co-design⁴ equitable compensation policies and practices for engagement and apply them consistently. This includes

consideration of participation honoraria for consultations, advisory groups (excluding peer review), or as a participant in a research project.

Action 20: Establish standard practices for reimbursable expenses that a person may incur when participating in activities related to CIHR business or participation in CIHR-funded research.

Description: Co-design⁴ equitable guidelines for reimbursable expenses and apply them consistently. This includes consideration of reimbursement of expenses that are needed to fully participate in consultations, advisory groups (including peer review), or as a participant in a research project. For example, expenses related to accessible transportation or support care worker services when attending meetings.

Action 21: Establish standard practices for accessibility-related expenses in project budgets that a researcher may incur when conducting research¹⁵.

Description: Co-design⁴ equitable guidelines for including accessibility supports expenses to conduct research within research budget proposals (e.g., accessible formats for data collection tools). Educational materials will be produced for both applicants and peer reviewers to consistently apply these guidelines.

Action 22: Establish standard practices for accessibility-related expenses needed by researchers with disabilities themselves to conduct their research⁹.

Description: Co-design⁴ equitable guidelines for supplemental funding (beyond the research budget) for accessibility supports that researchers with disabilities need to conduct their research project. For example, include consideration of travel costs for a support care worker and additional costs of accessible transportation to conduct field work or attend knowledge mobilization events). Educational materials will be produced for both applicants and peer reviewers to consistently apply these guidelines.

Action 23: Incorporate the use of best practices in accessibility for conferences and events that are held using CIHR funding ¹⁶.

Description: Co-design⁴ and apply policy and practical tools to make sure best practices in accessibility for events are communicated to, and applied by, organizers of CIHR-funded events.

Action 24: Explore mechanisms to influence institutions that administer CIHR funding to become actively anti-ableist organizations.

Description: Co-design⁴ practical tools to help institutions identify and address ableist practices. Co-design and apply policy and procedures so that institutions must demonstrate that they are addressing barriers and ableism to be eligible to administer CIHR funding.

2.4 Organizational Culture

This section is related to changing the knowledge, beliefs and attitudes that shape decision-making ¹⁷ and the ways in which CIHR operates ¹⁸. By establishing CIHR as an actively anti-ableist organization and leading by example, the collective effects of changes to CIHR culture, policies, processes, and programs will exert influence over CIHR-funded institutions and the broader health research funding system.

Objective

To build knowledge and awareness across CIHR, and the broader health research community, so that the responsibility and ownership of dismantling systemic ableism is a shared behavioural practice.

Documented barriers

- Underrepresentation and lack of inclusion of persons with disabilities on advisory and decision-making committees at CIHR.
- Knowledge gaps of those on advisory and decision-making committees
 of how disability, accessibility, ableism, and inclusion impact participation
 in the health research system.
- Ableism in peer review and academia (e.g., reviewer bias, inequalities related to narrow measures of research excellence, medical leave, and part-time work).
- Inconsistent, untapped, and misaligned work in accessibility by research institutions and funding agencies (e.g., emphasis on accommodations rather than focusing on accessibility and anti-ableism).

Actions

These are the actions CIHR will take to establish an awareness of ableism and its impacts on persons with disabilities within the health research funding system and to influence other organizations to integrate an antiableist lens to their respective roles in the broader health research funding system.

Action 25: Repackage and promote publicly available education products related to ableism and its impacts on health research.

Description: Co-design⁴ education products (or adapt existing products) to increase awareness of how disability, accessibility, ableism, and inclusion impact participation in the health research system. Target audiences include those who interact directly or indirectly with CIHR, such as applicants, members of CIHR advisory bodies (e.g., peer review committees) or decision-making groups, research administrators, general public, etc. Products will be made available in accessible formats.

Action 26: Integrate anti-ableism training into mandatory learning for members of CIHR advisory and decision-making committees.

Description: Co-design⁴ training (or adapt existing training) to recognize ableism in health research and how to apply anti-ableist considerations when making recommendations and decisions about CIHR and its programs. Target audiences include those nominated to, applying for, or serving as members of CIHR advisory (e.g., peer review committees) and decision-making committees. Training will be offered in accessible formats.

Action 27: Provide publicly available practical tools that help apply an antiableist lens to activities across the health research funding system¹⁹.

Description: Co-design⁴ tools (or adapt existing tools) to help those interacting with CIHR to recognize barriers to accessibility and issues of ableism and apply best practices in accessibility, principles of universal design, and practical anti-ableist actions to their work. Target audiences include those who interact directly or indirectly with CIHR, such as applicants, members of CIHR advisory (e.g., peer review committees) or decision-making groups, research administrators, general public, etc. Products will be made available in accessible formats.

Action 28: Incorporate best practices in accessibility and universal design and anti-ableist approaches in the operations of CIHR advisory or decision-making committees²⁰.

Description: Recruitment activities (e.g., expressions of interest, nomination, or application processes), selection processes (e.g., eligibility criteria and their assessment), and committee management (e.g., availability of accessible format of materials or accessibility services) will not disadvantage persons with disabilities from fully participating on CIHR advisory or decision-making committees.

Action 29: Strengthen the transparency of the demographics of members of CIHR advisory and decision-making committees such that the composition of committees is better understood²¹.

Description: Publicly release data⁶ each year showing trends in nominations or applications, and memberships to CIHR advisory committees (e.g., College of Reviewers and peer review committees) and decision-making committees. Intersecting factors of identity will be included in data analyses. The findings will be used to inform recruitment and selection processes.

Action 30: Coordinate accessibility and anti-ableism actions across federal funding agencies to amplify the influence over research and academic institutions.

Description: Accessibility and anti-ableism will be added as a standing item on the Interagency Committee on Equity, Diversity, and Inclusion (ICEDI). The ICEDI is a group of executive representatives from CIHR, Canada Foundation for Innovation, Natural Sciences and Engineering Research Council, and Social Sciences and Humanities Research Council with a mandate to oversee the implementation of the Tri Agency Equity, Diversity and Inclusion Action Plan.

Action 31: Engage other organizations on an ongoing basis in knowledge-sharing and taking accountability for addressing ableism and barriers to accessibility.

Description: CIHR will use its position at various stakeholder and partner tables to raise awareness of ableism, the ways in which the

health research system perpetuates ableism, and how organizations can work together and support each other in eliminating ableism in the health research funding system.

Action 32: Promote the actions and progress of other health research organizations in their anti-ableism journeys.

Description: Feature institutions and organizations in CIHR publications (e.g., website content, research profiles, newsletter spotlights) that are addressing barriers to participation of persons with disabilities in the health research funding system.

3. Enablers, Assumptions, and Risks

Enablers

Enablers are conditions (internal or external to CIHR) which need to be, or are expected to be, in place for the changes or effects to happen. The following are enablers for this action plan:

- Diverse representation across CIHR and across the broader health research system (e.g., guidance and decision-making committees, mentorship).
- Commitments in the <u>CIHR Accessibility Plan (2023 2026)</u> are achieved as expected.
- CIHR senior leadership continues to champion the work within the CIHR Accessibility Plan (2023 - 2026) and embraces additional actions in this action plan.
- <u>CIHR's 13 Institutes</u> integrate anti-ableism within their respective strategic plans and across their strategic funding opportunities.
- Where relevant, work in this plan is coordinated with the other federal funding agencies (CFI, NSERC, SSHRC) and across the health portfolio and builds upon the <u>Tri-Agency Equity</u>, <u>Diversity and Inclusion Action</u> <u>Plan (2018 – 2025)</u>.
- Research evaluation is carried out through an anti-ableist lens.

Assumptions

Assumptions are the beliefs or expectations about the conditions that will be in place or how something will happen. The following are assumptions for this action plan:

- The people within the health research funding system accept and are willing to follow through with the actions in this action plan.
- CIHR staff and management, and CIHR Institute staff and leadership, are aware of the impacts of ableism. They are appropriately trained to address issues of ableism at CIHR and have the tools to do so, in a variety of ways scaled to available resources.
- Accessibility supports for persons with disabilities are conscious and inclusive, meaning that they are proactive and intentional (instead of reactive or an after-thought).

• Once actions have been implemented, the undue burden for persons with disabilities to carry out anti-ableist work while experiencing ableism (i.e., the equity tax) will decrease.

Risks

Risks are known or unknown elements that may compromise the enablers or assumptions. Plans to mitigate these risks will be included in implementation plans. The following are risks for this action plan:

- At the beginning of this work, the burden on persons with disabilities to inform this work (i.e., the equity tax) will be high.
- Some of the actions in this plan are beyond CIHR's direct control. There may be limitations to CIHR's ability to influence the broader health research system and the organizations within it.
- Putting some of the action in this plan into place may be hampered by limited resources.

4. Next Steps

Implementing the actions in this plan

CIHR will publish a high-level implementation plan including details related to when the work will be done, how progress will be measured and reported, and how actions will be adjusted, if needed.

Implementation of actions in this plan will build on CIHR's experience in transforming its guiding policies and program delivery. Established change management practices will be used to roll-out actions in a manner that will build momentum and acknowledge that culture change will occur from the cumulative, longer-term effects of the actions taken over time and across the organization. Within CIHR, early implementation will focus on establishing an organization-wide understanding of ableism and antiableism and building capacity for staff to recognize issues of ableism through education and training. Subsequently, implementation will move towards developing and using tools and resources to apply an anti-ableist lens to all CIHR operations, monitoring progress and continuous learning/unlearning.

Implementation of actions beyond CIHR will follow a similar approach. Building on a foundation of learning from previous initiatives that created a more equitable and robust health research funding system (e.g., integrating sex- and gender-based analysis into health research), CIHR will use a progressive approach beginning with increasing awareness, knowledge, and skills in the broader health research community of ableism and its detrimental effects on health research and those participating in the health research system. This will be done using communication products, education and training resources, and guidelines and practical tools for applying an anti-ableist lens to health research. This will be followed by changes to policy and processes for applicants, organizations, and peer reviewers to make sure an anti-ableist lens is a mandatory consideration across all CIHR-funded health research. CIHR will make tools, resources, lessons learned and progress available as a support to the broader anti-ableist transformation of the broader health research system.

Acknowledgments

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This plan was written by the CIHR Equity Strategy team and members of the EAC – ASA:

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- Trudy Samuel (Co-Chair), Director General, Equity Strategy Canadian Institutes of Health Research
- Emilio I. Alarcón, Associate Professor, Faculty of Medicine University of Ottawa
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Endnotes

¹ The phrase 'CIHR health research funding system' refers to the policies, processes, and procedures undertaken at CIHR to deliver programs and services that provide funding or other support for health research and health researchers.

² The phrase 'broader health research system' refers to the many institutions involved in health research and health research funding and includes other government or non-government funding agencies, health charities, academic institutions (e.g., universities), and research institutions.

³ Sometimes barriers and subsequent actions are interrelated such that they may cut across multiple sub-sections. In these instances, they are not repeated but are noted in the sub-section deemed to have the best fit.

⁴ Co-design means persons with disabilities will provide guidance to CIHR on specific activities and how this action is put in place (see the 'continued engagement of persons with disability' section of this document for more details).

⁵ This action aligns with Initiative 1.1.1 in the <u>Tri-Agency Equity, Diversity and Inclusion</u> Action Plan (2018 – 2025).

⁶ Self-identification statistics will always be reported in aggregate form to ensure confidentiality. To protect the privacy of individuals, if the number of individuals who selected a specific identity response option is less than five, or if the combination of responses (e.g., intersectional analyses) may compromise the privacy of individuals, the data will not be publicly reported. For more information: Frequently asked questions about the self-identification questionnaire.

⁷ Disability-focused research means research conducted for, with, and by persons with disabilities. It also means prioritizing research topics related to disability, such as social and structural determinants of health for disability populations, use of the <u>social model</u> <u>of disability</u> and research that applies community-informed approaches.

⁸ The design and delivery of CIHR funding programs includes a series of steps from prioritization of funding opportunities, announcing and launching funding opportunities, intake and processing of applications, peer review, release of funding decisions, and program monitoring.

⁹ The <u>CIHR Accessibility Plan (2023 - 2026)</u> (Goals 13 – 16) commits to actions to eliminate barriers to accessibility in information and communication technology (ICT). Actions related to ICT are not repeated in this plan.

¹⁰ This action builds upon Action 1.4 in the CIHR Accessibility Plan (2023 - 2026).

¹¹ This action links to Action 21.5 in the CIHR Accessibility Plan (2023 - 2026).

¹² This action links to Action 21.6 in the CIHR Accessibility Plan (2023 - 2026).

¹³ This action links to <u>Action 21.7 in the CIHR Accessibility Plan (2023 - 2026)</u> and to <u>Initiative 1.4.1 in the Tri-Agency Equity, Diversity and Inclusion Action Plan (2018 – 2025)</u>.

¹⁴ This action links to <u>Actions 21.6 and 21.7 in the CIHR Accessibility Plan (2023 - 2026).</u>

- ¹⁵ This action must take into consideration the policies of the institution administering CIHR funds and/or legislative requirements of the institution as employer (CIHR does not have an employer-employee relationship with funding recipients).
- ¹⁶ This action will build upon Action 18.1 in the CIHR Accessibility Plan (2023 2026).
- ¹⁷ At CIHR, decision-making is carried out by: <u>Governing Council</u> which makes decisions on strategic direction, research priorities, and budget, the CIHR President who makes decisions on funding for research and the <u>Senior Leadership Committee</u> which makes decisions on day-to-day management of CIHR. At CIHR, endorsement and/or guidance on decision-making is provided by: <u>Science Council</u>, Institute Advisory Boards, and Priority Steering Committees which endorse recommendations for research funding, <u>Peer Review Committees</u> which make recommendations for research funding, and various CIHR staff working and advisory groups which give recommendations on day-to-day operations.
- ¹⁸ The <u>CIHR Accessibility Plan (2023 2026)</u> (Goals 1 9) commits to actions related to increasing knowledge of current CIHR staff and on recruiting and retaining persons with disabilities across all levels of the CIHR workforce. Actions related to employment and staff training are not repeated here except where there are potential gaps in actions related specifically to program design and delivery.
- ¹⁹ This action expands upon Action 1.4 in the CIHR Accessibility Plan (2023 2026).
- ²⁰ This action expands upon Actions 21.3 and 21.6 in the <u>CIHR Accessibility Plan (2023</u> 2026).
- ²¹ This action aligns with Initiative 1.1.1 in the <u>Tri-Agency Equity, Diversity and Inclusion Action Plan (2018 2025)</u>.