A Neurodivergent Lens: Recommended Practices for Neuroinclusivity

Final Research Report

June 2024

Contents

1. Executive Summary

The project *A Neurodivergent Lens: Recommended Practices for Neuroinclusivity* was executed by the Accessibility Institute at Carleton University, with funding from Accessibility Standards Canada (ASC). It is crucial that standards developers consider neurodivergence when creating standards. The principal goal of this project was to, as an initial step, generate a set of recommended practices that will support standards developers in applying a neurodivergent lens to standards development. By promoting neuroinclusivity in both the content of standards and the standards development process itself, we have the opportunity to increase the accessibility of environments, which are typically designed for individuals with neurotypical cognitive styles. Neurodivergence is a descriptive category that recognizes the diversity of cognitive functioning and typically encompasses non-visible disabilities such as, but not limited to, autism, ADHD, and learning disabilities.

The project engaged with members of the neurodivergent community, as well as standards development professionals to carry out the following objectives:

- Identify some of the accessibility barriers and facilitators for neurodivergent Canadians
- Conduct targeted community consultation to find constructive solutions to inform the creation of the recommended practices and supporting toolkit
- Inform and assist standards development agencies to create more robust and inclusive future standards

In order to meet these objectives, the project team conducted literature reviews, environmental scans, as well as community-focused research including focus groups, interviews, and surveys with members of the neurodivergent community, and individuals who work in standards development. In the first phase of this project, neurodivergent individuals were asked to discuss the barriers and facilitators to accessibility that they experience, and standards development professionals were asked about accessibility considerations in the standards development process, knowledge gaps about neurodivergence in the profession, and preferred ways to access information. The preliminary themes found from the focus group data were then shown back to the neurodivergent participants for their feedback. After their feedback was incorporated, we identified the following key themes:

Barriers to Inclusion

- Sensory overload hinders participation in daily activities

- Different communication styles and obscure and complicated systems lead to confusion and cause barriers to access
- Lack of support, flexibility, clarity, and understanding are barriers to access
- Neurotypical privilege, expectations, prejudices, and stigma limit inclusion

Facilitators to Inclusion

- Sensory-friendly environments are more accessible
- Clear communication and directions relieve stress and facilitate understanding
- The availability of choice within environments promotes autonomy, accessibility, and comfort
- Supports (i.e., social support, assistive devices, as well as accommodations and accessible practices) promote inclusivity
- Awareness and education about neurodivergence encourage inclusion
- Freedom and availability to use personalized meaningful strategies promote accessibility

Recommendations for neuroinclusion from the neurodivergent community to standards developers

- Need increased awareness and education about neurodivergence to change attitudes and perceptions
- Create simple, clear standards and easily accessible procedures to advance neuroinclusion
- More diverse and neurodivergent voices need to develop standards and do research

Based on these findings, a draft set of recommended practices to promote neuroinclusivity and accompanying resources were created. In the second phase of this research, both the neurodivergent community and individuals involved in standards development were asked to review and share their feedback on the draft recommended practices and select resources. After their feedback was considered, a set of five key recommended practices to promote neuroinclusivity in the standards development process were created. These recommended practices are broken down into 21 actionable sub-recommendations. The recommended practices are:

1. Use education to improve awareness, reduce stigma, address attitudinal barriers and adjust neurotypical expectations related to neurodivergence to increase neuroinclusivity.
2. Ensure that diverse and neurodivergent voices are involved in research and standards development
3. Reduce ambiguity in communication, processes, and procedures

4. Recognize and accommodate the sensory needs of neurodivergent people
5. Design proactively and be responsive to the needs of neurodivergent people

In addition, this report also includes an implementation guideline which outlines the sub-recommendations as applicable to relevant key stages in the standards development process.

2. Project Overview and background

2.1 Project Mandate and Team

The overarching purpose of the research project entitled *A Neurodivergent Lens: Recommended Practices for Neuroinclusivity* was to generate a targeted yet widely adaptable set of recommended practices to apply a neurodivergent lens to standards development.

This two-year (2022-2024) project, carried out by the Accessibility Institute at Carleton University, was funded by Accessibility Standards Canada (ASC). Key project outputs include:

- A set of bilingual recommended practices to apply a neurodivergent lens to standards development
- A toolkit of resources including a neuroinclusion orientation/training module to support neurodiversity learning and awareness building
- Implementation guidelines to improve future use of the recommended practices

As listed below, the project team included three Principal Investigators (located at Carleton University and the University of Alberta), one Research Lead/Project Manager, one Project Administrator, one Project Coordinator, one Project Officer, two operations managers, one Community Liaison, one Practicum Student, and one Research Assistant. The project also had partnerships with three organizations: 1) The Autism Alliance of Canada, 2) The Conference Board of Canada (CBoC), and 3) the Canadian Accessibility Network (CAN). All stages of this research were reviewed and approved by the Carleton University Research Ethics Board.

a) Principal Investigators

- **Dr. Boris Vukovic**, Director, Accessibility Institute, and Adjunct Research Professor, Carleton University
- **Tara Connolly**, Assistant Director, Research & Development, Accessibility Institute, Carleton University
- **Dr. Heather Brown**, Associate Professor, Faculty of Education, University of Alberta

b) Research Team

- **Dr. Sonia Rahimi**, Research Lead and Project Manager
- **Jasmin Macarios**, Project Administrator
- **Dr. Michael Walker**, Project Coordinator
- **Jessie Gunnell**, Project Officer
- **Erin Feltmate** and **Julie Caldwell**, Operations
- **Jess Rocheleau**, Community Liaison
- **Loraina Marzano**, Practicum Student
- **Carolyn Simon**, Research Assistant

2.2 Project Background

Much of Canadian society is designed based on standards. Standards are documents established by consensus that provide widely agreed-upon guidelines for activities (Standards Council of Canada). Standards ensure that the services and products that people use every day are reliable. They are used everywhere in society – such as workplaces, schools, recreation centers, healthcare settings, and transportation. The important work of standards development requires agencies to take into consideration the perspectives of a wide range of Canadians. Unfortunately, those with non-visible disabilities, such as neurodivergent people, are often excluded. *Neurodivergence* is a descriptive term that recognizes the diversity of cognitive functioning that encompasses non-visible disabilities such as autism, attention-deficit/hyperactivity disorder (ADHD), learning disabilities, and other neurodevelopment differences (with autism most commonly assumed under the term). Neurodivergent Canadians face an array of barriers in education, employment, and day-to-day life. Yet, since neurodivergent differences and identities are largely invisible, these barriers can often go unaddressed. Neurodivergent individuals can face challenges related to the areas of:

- Sensory input (e.g., noises, smells, lighting)
- Communication (e.g., different communication styles)
- Executive functioning (e.g., organization, attention, and focus)

Environments, policies, and practices can be designed with these challenges in mind and made more neuroinclusive, thus creating equitable opportunities for neurodivergent individuals to participate and work to their strengths. Creating inclusive spaces where everyone can flourish does not have to be difficult, resource-heavy, or costly. In fact, up to 95% of possible adjustments are not costly to implement. However, designers and organizations may not be aware of these small changes or may overlook them, even though they can significantly impact the neurodivergent community (Sargent, 2019). By applying a neurodivergent lens to the creation of standards and policies, neurodivergent

people will be included in Canada's built environments, provision of services, workforce, and consumer communities.

If standards that are developed often do not account for the diverse ways that neurodivergent people experience and navigate society, this can create barriers to inclusion and participation. This project strived to take a small step towards addressing this challenge by developing a resource to build the awareness of those involved in developing standards of any kind. This resource includes a set of recommended practices, and corresponding implementation guidelines, as well as a toolkit with neuroinclusion educational materials, that were informed by:

- Literature reviews and environmental scans with a broad scope on:
    - Barriers (obstacles that prevent access) that neurodivergent people experience in everyday life
    - Facilitators (something or someone that makes an action or process easier) that promote neuroinclusivity for neurodivergent people
    - Best practices related to neurodivergent accessibility
- Multiple consultations with neurodivergent Canadians about the barriers and facilitators they experience and their viewpoints on our project outputs
- Multiple consultations with individuals working in standards development, seeking their input on the development of our project outputs

The entire standards development process can take around 2.5 years (sometimes longer, depending on the organization). The process has many steps and includes input from both technical advisors as well as feedback from the public before a standard can be accepted. As an example, the stages involved in the National Standards of Canada (Standards Council of Canada) standards development process include the following:

1. **Evaluate** existing standards and approve the need for a new one
2. **Notify** the public at the project start
3. **Develop content** at committee level
4. **Consult** with the public on the proposed standard
5. **Reach consensus** at committee level
6. **Quality** review and revisions
7. **Approve** the standard
8. **Publish** the standard
9. **Maintain** the standard

The stages outlined above, are similar to those of other organizations in Canada, such as The Health Standards Organization (HSO) and Accessibility Standards Canada (ASC).

Neurodiversity can be considered and integrated at any point or in any aspect of the standards development process but also as part of the content of the standards with direct recommendations for neuroinclusion, regardless of the field, sector, or activity that the

standard is intended to guide. With that lens, this project aimed to promote neuroinclusion within:

1. The *process* of standards development itself
2. The *content* of the standards that are developed and reviewed

2.3 Project Considerations

a) Involvement of the community

In alignment with the principle "nothing about us without us", members of the neurodivergent community took an active and creative role in informing this project at every stage from the research design to the interpretation of study findings and knowledge mobilization of project outputs. Our community engagement endeavoured to draw on the full diversity of the neurodivergent community in two ways:

1. Incorporating the perspectives and opinions of individuals with intersectional identities by strongly encouraging and supporting the involvement of all people, including those who are visible minorities, Indigenous communities, and members of the LGBTQ2+ community
2. Incorporating the perspectives and opinions of people representing the diversity of neurodivergence itself, such as autism, attention-deficit/hyperactivity disorder (ADHD), and different learning disabilities (LD)

b) Quotations

This report includes quotations from neurodivergent people with lived experience and individuals involved in the development of standards. The quotes included in this report are taken from the transcriptions of the focus groups conducted with each group. They are not intended to be demonstrative of the opinions or experiences of a population of people. Instead, they demonstrate the specific experience of a given individual.

c) Our understanding of neurodivergence

It is important to note that *neurodivergence* is an expansive term that continues to evolve and refers to those whose brain processes, learns, and/or behaves in some way that diverges from what is generally considered "typical." Accordingly, neurodivergent individuals are a widely diverse group that can include those with experience or identity of autism, dyslexia, dyscalculia, epilepsy, hyperlexia, dyspraxia, attention-deficit/hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), Tourette's syndrome, among others. Acknowledging the challenges that neurodivergent people can often face in accessing a formalized diagnosis and the barrier this can cause, we included self-identification as one of the participation criteria for our project (for those who were

over the age of 18, please see the data collection section of the report below for more information).

d) Our understanding of individuals involved in standards development

For our project, we defined standards developers as anyone involved in creating standards in Canada. This can include those involved directly in the standards development process such as individuals working in the Standards Council of Canada, Chairs of technical committees, or members of technical committees themselves. Furthermore, this can also extend to others who work in government, policy writers, or educators who are working on the development of policies or guidelines in their respective fields.

e) Language and perspectives

Guided by discussion in our team which is made up of both neurodivergent and non-neurodivergent members, we chose to use person-first language (e.g., person with autism) and identity-first (e.g., autistic person) interchangeably throughout our research project and this report. This project considers accessibility through the social model of disability. We consider barriers to accessibility as found in the *environment*, rather than in the *person*.

f) Indigenous perspectives on neurodivergence

As researchers, we acknowledge our responsibility to conduct inclusive research that recognizes and respects Indigenous knowledges and ways of knowing. We have chosen to educate ourselves as a first step towards this goal. However, we understand and respect that research on Indigenous ways of conceptualizing neurodivergence should be carried out in collaboration with Indigenous communities and led by Indigenous researchers. This approach ensures that the research is grounded in authentic perspectives and aligns with the cultural contexts and values of the many and diverse communities of Indigenous peoples. As is stated in Carleton University's Kinamagawin Report, "Indigenous knowledge belongs to Indigenous people and there are cultural protocols that must be adhered to. Engaging respectfully with Indigenous people takes time in order to build healthy relationships."

We recognize that neurodivergence may be conceptualized differently in Indigenous communities and deserves dedicated focus that is outside this project's scope. This conclusion was based on a preliminary review conducted by an Indigenous team member and an Indigenous external reviewer.

Most of the literature on the definition and conceptualization of neurodivergence among Indigenous people and communities indicates that different communities view disability and neurodivergence, such as ADHD and autism, as differences rather than deficits. In

terms of recommended practices for inclusive research design and outreach to Indigenous communities, research and practice should be designed in ways that both incorporate Indigenous perspectives on neurodivergence and honour Indigenous knowledge production.

Further research is needed on this topic, specifically on the concept of neurodivergence and neuroinclusivity with Indigenous communities, to be led by Indigenous researchers.

2.4 Organization of the Report

The forthcoming sections of this report focus on the data collection and analysis, research findings, recommended practices, implementation guidelines, and knowledge mobilization plan.

- Section 3 will outline our data collection and analysis including our methodological approach, research design, as well as our data collection and data management procedures and research limitations
- Section 4 will focus on our research findings that will be divided into six subsections
  - The first five subsections, informed by the literature and the community consultations, will cover barriers and facilitators that neurodivergent individuals can experience in their daily lives
  - The last subsection will focus on the standards developers' perceptions of neuroinclusivity in standards development, and insights on the potential impact of neurodivergence being considered in standards development, as well as standards developers' suggested formats for resources and toolkit items to encourage uptake
- Section 5 concludes with high-level recommendations, including sub-recommendations for standards developers to consider when reviewing, creating, and implementing Canadian standards
- Section 6 will provide an implementation guide
- Section 7 will outline our knowledge mobilization plan

3. Data Collection and Analysis

3.1 Data Collection and Data Management

All stages of this research were reviewed and approved by the Carleton University Research Ethics Board. The research for this project made up of data gathered, reviewed, and consolidated from:

- Literature reviews and environmental scans on the barriers, facilitators, and current best practices for neuroinclusivity

- Consultations with neurodivergent people who shared their lived experiences navigating the world
- Insights from standards development professionals on the standards development process and our project outputs

This multi-phase research project was community informed at every step. As seen in Table 1 below, in Phase 1 of this project neurodivergent individuals were asked to discuss the barriers and facilitators to accessibility that they experience in general.

Additionally, standards development professionals were asked about accessibility considerations in the standards development process, knowledge gaps about neurodivergence in the profession, and preferred ways to access information. This input was used to guide us in developing a responsive resource geared for uptake by our intended audience.

In Phase 1.1 of our research, neurodivergent participants provided feedback on preliminary themes found in the data, pertaining to the barriers and facilitators they experience. Following analysis of the data from Phase 1, our research team created a set of recommended practices for neuroinclusion in the standards development process.

In Phase 2 of this project, both neurodivergent individuals and standards developers were asked to provide feedback on the recommended practices and a draft of the toolkit (including educational resources) by participating in a webinar.

Table 1 Research Project Phases

	Phase 1: Gathering information	**Phase 1.1: Verifying themes**	**Phase 2: Gathering feedback**
Neurodivergent Community	Focus Groups/Interview, and Demographics Survey	Survey Verifying Themes Found from Phase 1	Webinar
Standards Developers	Focus Groups/Interview, and Demographics Survey	Not applicable	Webinar

a) Focus groups and interviews

Focus groups were conducted with both the neurodivergent community and individuals involved in standards development. Neurodivergent individuals were eligible to participate if they were:

1. Formally diagnosed or self-identify as neurodivergent
2. 18 years of age or older
3. Living in Canada
4. Able to understand and communicate in English, French, ASL, or LSQ, with or without support

Standards developers were eligible to participate if they were:

1. Employed in a profession that involves developing standards in Canada
2. Able to understand and communicate in English, French ASL, or LSQ, with or without support

Focus groups were chosen as the primary method of data collection due to their economical and practical features (Onwuegbuzie et al., 2009). More specifically, focus groups offer a unique opportunity to gather rich data that results from interactions among participants. However, in two of our focus groups, only one French participant signed up, therefore we conducted interviews with each of these participants.

Our focus groups were conducted over Zoom, with the cloud settings disabled. This was to prevent any of the content from being uploaded to Zoom's cloud for storage, and therefore prevent it from being stored on less secure servers. For the same reason, we recorded the focus groups using physical audio devices and transferred them manually to our computers. All materials were uploaded to Citrix to be stored. The focus group recordings were transcribed using Transcribe Me, a human translation and transcription service. The research lead verified all the audio against the transcriptions to ensure accuracy and worked alongside the project administrator to clean and de-identify the data, removing names, places, certain dates, organization names, and other sensitive or identifiable information. All removed data was tracked in an excel file.

b) Surveys

All participants were asked to complete a survey of registration and optional demographic questions (see Appendix B). The neurodivergent community also completed an additional survey in Phase 1.1 of our project about the preliminary themes found from the focus groups, pertaining to the barriers and facilitators that they experience.

Our surveys were hosted on Qualtrics. Qualtrics is a research management product with secure survey tools and hosting capabilities. All survey data was collected anonymously,

and IP addresses were not recorded. All recruitment and participant information were stored on Citrix for the project. Citrix is a secure cloud portal for the transfer and sharing of sensitive material between team members. All computers used to work with the data are password protected and have device encryption enabled.

3.2 Participant Recruitment and Procedures

Research data was collected online by the project research team through pre-screening questions (using a Carleton Webpage form) focus groups/Interviews (using Zoom), and surveys (using Qualtrics). Please see Table 2 below for final participant numbers.

Table 2 Final Participant Numbers

	Phase 1: Gathering information	**Phase 1.1: Verifying themes**	**Phase 2: Gathering feedback**
Neurodivergent Community	31 neurodivergent people	59 neurodivergent people (20 returning and 39 new)	36 neurodivergent people (31 returning and 5 new)
Standards Developers	14 people involved in standards development	Not applicable	7 people involved in standards development (7 returning)

a) Phase 1

Neurodivergent participants were recruited through Canadian organizations that are designed by and/or for neurodivergent people (e.g., non-profits), social media (e.g., social, support, and advocacy groups by and/or for neurodivergent people in Canada), the Accessibility Institute's social media accounts, and partners of the project (Autism Alliance of Canada, Conference Board of Canada, Canadian Accessibility Network). The project team emailed the administrators of the organizations and direct messaged the moderators of the social media groups to ask them to share our recruitment materials with their members (e.g., Autism Ontario, the Centre for ADHD Awareness Canada, CADDRA, Dyslexia Canada, OCD Ottawa, Autism Society of Edmonton, DAWN Canada, the Learning Disabilities and ADHD Network, and the ADHD & Spectrum Centre). Overall, 31 neurodivergent individuals were recruited.

The original intended project plan was to conduct 2 focus groups per year, each with 10 persons with disabilities, for a total of 20 focus group participants per year. In addition, a community consultation survey was planned to be administered to 50 people in year 1 and 10 people in Year 2. The project team decided to increase the number of focus groups from 2 to 8 (recruiting more neurodivergent individuals in the focus groups) to increase the amount of community voices that informed our work (seven English-language focus groups, and one French-language interview). In addition, in Phase 1.1 and 2 of our research, we recruited additional participants, making our total of neurodivergent participants 75.

Standards developers were recruited through standards development organizations (e.g., government agencies, non-profits, businesses, as well as individuals sitting/working on committees, councils, and programs devoted to the development of standards), as well as the Accessibility Institute's social media accounts. LinkedIn ads were also used to garner attention towards our research. Overall, standards developers were recruited for this phase of the project from the Government of Canada, multiple non-profit and consulting contexts, and the Standards Council of Canada (five English-language focus groups, and one French-language interview). Overall, 14 individuals who work in standards development were recruited.

For all participants, the recruitment materials asked participants to visit our webpage if they were interested in registering for this study. Given the prominence of spam/bot accounts infiltrating web-based projects, additional measures were taken to verify participants' identities (please see the research limitations section below for more information). The registration page asked participants to provide their name, preferred name [optional], email address, and Canadian phone number. The phone call served as a form of identity verification and to deter potential imposter participants. Once registered, we called each participant on the phone to verify their identity and asked them why they were interested in participating in our project. For the standards developers, we also requested that they send us examples of their involvement in the development of standards, guidelines, or policies. Afterwards, they were directed to the registration survey and demographics questionnaire which included a question about their availability for the focus group. The research team worked with an external facilitation company to organize and execute the focus groups.

b) Phase 1.1

Members of the neurodivergent community who had participated in the Phase 1 focus groups were invited to participate in Phase 1.1 of our project. In addition, the project team received an influx of interest for Phase 1 of our research but did not have enough space in our focus groups to accept all interested participants. Therefore, these participants were

invited to participate in Phase 1.1 of our research and were informed of this change during the verification phone call or by email. In addition, our project partners – the Autism Alliance of Canada, the Conference Board of Canada, and the Canadian Accessibility Network – shared our posters and links to help our recruitment efforts. The recruitment materials asked participants to visit our webpage if they were interested in registering for this study. Once again, we called each new participant on the phone to verify their identity and asked them why they were interested in participating in our project. Afterwards, they were directed to the survey.

c) Phase 2

The same participants from Phases 1 and 1.1 were recruited in Phase 2. The project team received an influx of interest for Phase 1.1 of our research after the deadline to participate had passed, thus these participants were invited to participate in Phase 2. In Phase 2, both the neurodivergent community and individuals involved in standards development were asked to review and share their feedback on draft recommended practices and some of the resources in our toolkit. The feedback was obtained in a webinar hosted by the research lead (one webinar for neurodivergent participants and one webinar for standards developers).

Participants were also encouraged to provide written feedback (e.g., via email, via additional survey link, and through the chat during the webinar). The project materials were then adjusted and improved based on these consultations. In addition, an extensive list of resources was shared with the Autism Community Partner (autistic members of community or graduate students who are part of the Aidan Lab at the University of Alberta) who gave us some feedback. Based on all the feedback that we obtained, we narrowed down our list of resources for our final toolkit.

The outputs of Phase 2 were based on the results from our consultations and survey responses with the neurodivergent community and individuals who work in standards development. As part of these outputs, we have:

- Drafted recommended practices for neuroinclusivity
- Curated a list of resources that support the implementation of the recommended practices
- Created additional resources and educational materials

3.3 Data Analysis

a) Focus Group and Interview Data

Reflexive Thematic Analysis: Thematic analysis of the focus group and interview data was selected as our analytical approach. Thematic analysis is used to identify, organize, and interpret the commonalities or patterns of meaning across data by making sense of collective experiences (Braun & Clarke, 2012, 2019). Thematic analysis involves six distinct phases:

- Phase 1: Familiarization with the data
- Phase 2: Generating initial codes
- Phase 3: Generating themes
- Phase 4: Reviewing potential themes
- Phase 5: Defining and naming themes
- Phase 6: Producing the report

Phases 1-5 will each be described in more detail below.

Coding and data analysis took place using NVivo (version 14), a software downloaded locally onto password protected computers. The research lead and project administrator both participated in the data analysis. The research lead participated in all steps, whereas the project administrator was given 15% of the data to code, randomly selected by the research lead (using a random number generator to find a random page out of the total pages to start the 15% of data extraction). Each person coded the data independently and then met to compare codes. However, the research lead and the project administrator coded focus group 3 (neurodivergent community) and focus group 5 (standards developers) together (both were interviews with French participants) to ensure a clearer understanding of the French data, and half of focus group 6 (neurodivergent community) together to ensure a similar understanding of what was said because some of the recording was inaudible.

Familiarization with the Data and Generating Initial Codes: The research lead and project administrator independently listened to all the focus group/interview audio to become familiar with the data. This step involved carefully listening to the audio and reading the transcriptions in-depth. The initial codes were generated by tagging meaningful sections of the data with labels (i.e., codes). The coding process was not linear, but instead iterative, where the research lead revisited and revised the codes as needed several times throughout the data analysis. When different participants in the same focus group were discussing the same topic, it was coded as one code (with multiple references). For example, if one participant mentioned the importance of awareness of neuroinclusivity,

and another participant agreed, these were both captured under the code entitled "awareness of neuroinclusivity is important in standards development." However, the same topic was not captured across different focus groups given that the contexts of their discussions may have been different.

b) Neurodivergent community consultations and survey

As the initial codes were generated, the research lead and project administrator organized the data based on the *code's content* and *code's environment*. First, the content of each code was examined and grouped together based on whether participants were referring to a facilitator (something or someone that makes an action or process easier), barrier (an obstacle that prevents access), or recommendation to standards developers. During the focus groups/interview, participants were shown examples of environments to keep in mind in their discussions. Nested within the *code's content* category, codes were grouped together based on the *code's environment*. In addition, instances where participants referred to how barriers/facilitators intersected with other identities that they hold (*intersectionality*) were coded with an additional marker (an "*i" was added* at the beginning of each code).

Examples of environments for focus group discussions:

- Working (employment)/educational environments
- Recreation/leisure environments (including malls/shopping)
- Health care environments
- Transportation
- Home life/other

The research lead and project administrator met several times to discuss interpretations and organization of the codes to clarify different understandings of the data, and to ensure that a neurodivergent perspective was included in the analysis. The research lead also discussed these codes with the focus group facilitator, and project Co-PI's.

Generating Themes: The themes were generated by reviewing the codes and organizing them together into themes. Overlapping themes were merged across the different life areas (e.g., consideration of sensory needs in health care environments and consideration of sensory needs in employment settings were merged into *consideration of sensory needs*). Once again, the research lead discussed these preliminary themes with the focus group facilitator and the Co-PI's on this project. The thematic analysis revealed 14 preliminary themes organized into three categories:

1. Facilitators (6)

2. Barriers (4)[1]
3. Recommendations for standards developers (4)

To ensure that the themes found represented what participants had wanted to share, feedback was obtained from the focus group attendees, as well as new participants in the neurodivergent communities for verification (Phase 1.1).

Phase 1.1 Survey: The preliminary themes were presented to participants in a Qualtrics survey. All themes within each category were presented together (e.g., all six of the themes organized under "facilitators" were placed together in the survey in one block, all four of the themes representing barriers to inclusion were placed together, etc.). For the facilitators and barriers, participants were asked to use a slider (range = 1-10 with .1 intervals between each number) to indicate to what extent each theme resonated with them and their life. For the recommendations, they were asked to use a slider (range = 1-10 with .1 intervals between each number) and indicate to what extent each theme resonated with them and their life and are examples of things they would want a standards developer to know. There was also an open textbox for participants to share feedback with the project team at the end of the survey.

Overall, the results revealed that participants found each of the themes resonated with them. Out of a possible score of 10, all themes received at least a score of 7.7, thus our preliminary themes were verified. Although participants provided high scores for each of the themes presented, they did mention that one of our themes called: "The responsibility for inclusion should not be placed on the neurodivergent community and accommodations should be offered to anyone who needs them" should be divided into two as: "The responsibility for inclusion should not be placed on the neurodivergent community" *and* "accommodations should be offered to anyone who needs them". This code was revisited and subsequently divided and added to other themes within this section. Thus, the thematic analysis revealed 13 final themes organized into three categories:

1. facilitators (6)
2. barriers (4)
3. recommendations for standards developers from the neurodivergent community (3)

Please see Tables 3 and 4.

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[1] There was also a category entitled *other personal challenges also barriers to inclusion*, which included personal challenges, such as home cleaning, sticking to a schedule, and organization. The project team felt that these personal challenges were very personal, and thus, were not considered in the results of the analysis.

The themes that were derived from the Phase 1 focus groups conducted with the neurodivergent community (N = 31) were presented back to the community for feedback. In addition, we recruited others who were not in the initial focus group to provide their feedback as well. In total, we received interest from 20 returning participants (those who participated in Phase 1) and 39 new participants. An independent t-test (using the software SPSS, version 25) was conducted to examine differences between these two groups (returning and new participants) to see if patterns in responses differed between these groups (e.g., testing if the returning participants felt as though the themes resonated with them more than new participants, who are not involved in the initial sets of focus groups). Results revealed no statistical difference between the two groups of participants (p < .001), thus providing some additional validity for our project results. Participants felt as though all of our themes resonated with them. These themes will be presented in the next section.

Table 3 Phase 1.1 Survey Results on the Facilitators and Barriers to Inclusion

To what extent do the following statements resonate with you and your life?		
Barriers to Inclusion	Neurotypical privilege, expectations, prejudices, and stigma limit inclusion.	8.46
	Lack of support, flexibility, clarity, and understanding create barriers to access	8.32
	Different communication styles can cause barriers in communication	7.85
	Sensory overload hinders participation in daily activities	7.72
Facilitators to Inclusion	Clear communication and directions relieve stress and facilitate understanding	9.26
	Support (i.e., social support, assistive devices, as well as accommodations and accessible practices) promote inclusivity	9.25
	Freedom and availability to use personalized meaningful strategies promotes accessibility	9.17
	Awareness and education about neurodivergence encourages inclusion	8.66
	The availability of choices within environments promotes autonomy, accessibility, and comfort	8.64
	Sensory-friendly practices make environments more accessible	8.58

Table 4 Phase 1.1 Survey Results on the Recommendations for Neuroinclusion from The Neurodivergent Community to Standards Developers

To what extent do the following statements resonate with you and your life and are examples of things that you would want a standards developer to know?		
Recommendations for neuroinclusion from the neurodivergent community to standards developers	More diverse and neurodivergent voices need to develop standards and do research	9.29
	Create simple, clear standards and easily accessible procedures to advance neuroinclusion	8.91
	Need increased awareness and education about neurodivergence to change attitudes and perceptions	8.79
	The responsibility for inclusion should not be placed on the neurodivergent community and accommodations should be offered to anyone who needs them.	8.5

Reviewing Potential Themes and Defining and Naming Themes: Once these themes were established, the research lead reviewed the potential themes that emerged across the different categories. To derive the final themes, patterns across the categories (facilitators, barriers, and recommendations for standards developers from the neurodivergent community) were identified.

c) Standards developers' consultations

Familiarization with the Data and Generating Initial Codes: As with the neurodivergent community focus group data, the research lead and project administrator independently listened to all of the standards developers focus group/interview audio to become familiar with the data and create initial codes. Codes were then grouped together according to patterns identified within the data. Initial codes were generated by tagging meaningful sections of the data with labels. Codes were generated based on their content. The research lead and project administrator met several times to discuss interpretations and organization of codes to clarify different understandings of our data.

Generating, Reviewing, Defining, and Naming Themes: The themes were generated by reviewing the codes and organizing them together into themes. Overlapping themes were merged. The research lead discussed these preliminary themes with the Co-PI's on this *project*. The thematic analysis revealed the following categories of data:

- Standards developers' experience in standards development and background information
- Neurodivergent considerations in current standards development
- Potential impact of neurodivergence being considered in standards development
- Best standards development stage to provide standards developers with resources on neuroinclusivity
- Who should be considering neurodivergence in standards development
- Best type of resources and tools to promote neuroinclusivity in standards development

3.4 Research Limitations

Our research project had several limitations that warrant consideration. First, our project was conducted entirely online which meant that participants also registered online. Unfortunately, we received hundreds of bot/spam registrations and had to adapt our registration process to ensure that participants were not fraudulent. This is not uncommon with online research, with some studies reporting upwards of 96% of fraudulent responses (Goodrich et al., 2013).

In order to verify participants and deter potential imposter participants, we asked them to provide us with their name, preferred name [optional], email address, and Canadian phone number. We then proceeded to contact each registrant by phone to verify their identity. For the standards developers, we also requested that they send us examples of their involvement in the development of standards, guidelines, or policies. These additional steps slightly delayed our project and potentially deterred individuals from participating due to the additional steps required to participate (evidence of employment, a phone call, etc.).

The nature of the study being online also contributed to other challenges such as discouraging participation from those who would want to be involved in person or use other forms of communication (other than speaking of writing in the chat). While we were able to successfully recruit members of the neurodivergent community with different neuro-types (e.g., ADHD, Autism), our research was limited in terms of ethnic/cultural diversity. In addition, the transcription company occasionally was unable to tell what participants with accents were saying, which created barriers when coding. Lastly, each French focus group only had one participant; thus, these interviews did not allow for collaboration with others.

4. Research Findings

a) Introduction

The project results are separated into two parts:

1. Findings from consultations with the neurodivergent community
2. Findings from consultations with standards developers

The results will be presented in this order below. For more detailed information on each group's demographics, please see Appendix A.

First, the final themes that emerged from our research with the neurodivergent community (Phases 1 and 1.1) will be discussed below in Sections 4.1 - 4.4. For a summary of the neurodivergent community focus groups and interview themes, please see Sections b (Barriers to Inclusion), and Section c (Facilitators and Recommendations for Inclusion), below.

b) Barriers to Inclusion

"What has been challenging for you and/or stands in the way of your participation?"

Sensory overload hinders participation in daily activities (see subsection 4.1b)

- Lack of sensory input
- Overstimulation with smells, fluorescent lighting, loud noises, crowded spaces, and rapidly changing visuals

Different communication styles and obscure and complicated systems lead to confusion and cause barriers to access (see subsection 4.2b)

- Different communication styles can cause barriers in communication
- Obscure and complicated systems and procedures lead to confusion and limited access

Lack of support, flexibility, clarity, and understanding are barriers to access (see subsection 4.3b)

- A lack of support, understanding, and flexibility at an educational, employment, and healthcare settings creates barriers
- Accessible options and accommodations are not always available or the right fit

Neurotypical privilege, expectations, prejudices, and stigma limit inclusion (see section 4.4b)

- Neurotypical expectations are challenging
- Prejudice and stigma limit inclusion

- Lack of understanding about what inclusivity, and the needs of neurodivergent people are

c) Facilitators and Recommendations for Inclusion

"What has been working well for you and/or facilitated inclusion?"

"If someone were going to create standards of practice or ways of doing things that guide the way we live our lives, what would you want them to know or be thinking about?"

Sensory-friendly environments are more accessible (see subsection 4.1c)

- Environments that have quiet places to sit, are scent-free, with lighting accommodations (e.g., private, sensory-friendly spaces in healthcare settings)
- Sensory-friendly hours and spaces at grocery stores, malls, and museums

Clear communication and directions relieve stress and facilitate understanding (see subsection 4.2c)

- Clear communication and directions facilitate understanding
- Having access to reliable and up-to-date travel information eases stress

Create simple, clear standards, and easily accessible procedures to advance neuroinclusion (see subsection 4.2c)

- Create simple, transparent, and flexible standards, based on universal design
- Clarity in procedures and language is needed
- Make the processes for accessing essential services less challenging

The availability of choice within environments promotes autonomy, accessibility, and comfort (see subsection 4.3c)

- Flexibility and control over work structure and environments promotes autonomy
- Virtual options for engaging in work, education, and healthcare settings can increase accessibility for some
- Alternative methods of shopping (online, pick-up) make shopping and getting medication more accessible

Support (i.e., social support, assistive devices, as well as accommodations and accessible practices) promote inclusivity (see subsection 4.3c)

- External sources of social support are helpful in navigating life
- Accommodations and accessible practices promote inclusivity
- Assistive technologies promote communication and access, as well as facilitate organization

Awareness and education about neurodivergence encourages inclusion (see subsection 4.4c)

- Awareness of neurodivergence in employment settings
- Trained staff facilitates inclusion

Freedom and availability to use personalized meaningful strategies promotes accessibility (see subsection 4.4c)

- Personal strategies are used to self-regulate and reduce sensory overload
- Control and flexibility in work and life environments supports goal accomplishment
- Assistive technologies and tailored physical environments aid organization and communication
- Preparing in advance and staying organized reduces stress

Need increased awareness and education about neurodivergence to change attitudes and perceptions (see subsection 4.4c)

- Increase awareness, understanding, education, and training about neurodivergent people and their needs are needed
- Awareness of specific needs
- Attitudes, perceptions, and stigma need to change
- The responsibility for inclusion should not be placed on the neurodivergent community
- Accommodations should be offered to anyone who needs them

More diverse and neurodivergent voices need to develop standards and do research (see subsection 4.4c)

- Put the people who experience the challenges on the boards, creating the standards, and doing the research
- Increased diversity in research and provide proper payments for neurodivergent participants

Each of the barriers and facilitators outlined above are discussed in the subsections that follow. To derive the final themes, patterns across the categories (barriers, facilitators, and recommendations for standards developers from the neurodivergent community) were reviewed. For example, the barrier called *sensory overload hinders participation in daily activities*, and the facilitator called *sensory-friendly environments are more accessible* were grouped together in a new higher-order theme called "Investigating sensory differences in neurodivergent people" (Section 4.1 below). This was done for all of the remaining data and is outlined below.

Second, the final themes that emerged from our research with standards developers (Phase 1) will be discussed below in section 4.6 and include the following:

- Neuroinclusivity in current standards development

- The potential impact of neurodivergence being considered in standards development
- Recommendations for resources and toolkit

4.1 Investigating sensory differences in neurodivergent people

a) Literature Review: Sensory barriers

Neurodivergent people may experience differences in sensory processing (Clouder et al., 2020; *Cobbaert & Rose, 2023*; *Jameson, 2021*; Kuiper et al., 2019; *Robertson, 2010b;* Sarrett, 2018; Savickaite, 2023; Tomczak, 2022). Some of the sensory systems that can be challenged by surrounding environments are:

- Visual or sight (bright fluorescent lighting, lack of natural lighting)
- Auditory or hearing (loud noises or environments, such as concerts)
- Gustatory (unable to eat certain food textures or flavours, as well as digestion sensitivities)
- Olfactory or smell (strong smells such as perfumes)
- Tactile or touch (certain types of clothing or textures)
- Proprioception or position of body (confusing layouts, crowded visual field, or rapid motion)
- Vestibular or movement of body (balance)

In a case study done with autistic adults, the most disabling sensory environments were supermarkets, eateries, highstreets and city/town centers, public transportation, healthcare settings, and retail shops/malls (MacLennan et al., 2022).

The key features that made these environments disabling were:

- Sensory landscape (including bright unnatural lighting)
- Music and other noises, and smells
- Physical space limitations (crowded and no space to escape)
- Unpredictability (varying layouts)
- Unsupportive people and unsuitable adjustments (lack of support from staff and inflexible communication at checkouts)

Several organizations have started to consider these barriers and have made reasonable adjustments to their built environments to provide a more inclusive experience for all individuals. In a library at the Glasgow School of Art, an autistic librarian initiated a neurodiversity strategy to support neuroinclusivity by offering a neurodiversity guide and color-coded subject area maps to help direct students, providing learning aids, noise-

cancelling headphones, and pen readers, as well as a silent sensory room to relax (*Robertson, 2010b*).

Other public places and environments that have become more aware of sensory needs include:

- Sensory-friendly concerts in Toronto (Xenia Concerts, 2024)
- Sensory rooms and training for all staff at a hotel, as well as quiet time in a barber shop in Channel-Port aux Basques, Newfoundland (Canadian Broadcasting Corporation, 2018)
- Sensory-friendly weekly hour at a grocery store in Darlington, northern Britain, Canadian Broadcasting Corporation, 2018)
- Clonakilty is an autism friendly town in Ireland with designated quiet spaces, quiet hours at venues, and sensory maps at hotels (Medina, 2021)
- In the United States, Philadelphia has become more sensory-friendly by offering quiet spaces, sensory kits, noise-reducing headphones/ear plugs, weighted blankets, sensory-friendly films/performances, unique movie showings where they turn the lights up/sound down, and limited crowds in museums/art centers (*Sensory Friendly Cities, 2020*)
- Sensory-friendly IMAX movies at a science center in Ontario (e.g., Cineplex, 2024)
- Designated times when the music is off and dimmed lights in shopping centers in the UK (*North East Autism Society, 2019*)

b) Focus Group Findings: Sensory overload hinders participation in daily activities

In line with this literature, participants from the focus groups and interview revealed that their sensory needs are often not taken into consideration.

Overstimulation was often reported, with barriers in the environment including:

- Smells
- Poor lighting (e.g., fluorescent, or bright lighting) causing headaches and vertigo
- Loud noises in public spaces such as concerts and shopping malls
- Crowded and small spaces

To combat these challenges one participant wrote that they were living outside of town to reduce the sensory stimuli because the layers of sensory overload happen very quickly when they are in town (e.g., noise pollution, many people, poor lighting):

> *"My child and I are both autistic. So, I have to live outside of town... my child and I both needed to, so we're not exposed to the ongoing ambient noise. As soon as we go in town to do anything—it could be an hour or two in town—we're just baked for the day. We're done. And so that being at home allows—we have chosen this "location for our living for the reason of need, and so that's one of them. The other is lighting. I mean, so it's just all the sensory stuff, really. And the more you're out, the more you have to navigate so many people that you're around as well. So, I mean, just the layers of overload just happen so quickly when you're out from your home. Whereas, when you're in your home, we can be really productive."*
>
> Neurodivergent Focus Group Participant

Other specific examples of sensory overload mentioned by neurodivergent participants came from:

- Drive-thru's due to rapidly changing information, garbled speech, and unexpected questions
- Shopping is challenging because sales associates can be overwhelming
- Social aspects of work and office politics are exhausting and overwhelming
- Social media can be overwhelming due to speed and content of information
- Too many choices when shopping is overwhelming

c) Focus Group Findings: Sensory-friendly environments are more accessible

On the other hand, participants explained how sensory-friendly environments are more accessible such as:

- Environments that have quiet places to sit, are scent-free, with lighting accommodations
- Sensory-friendly hours and spaces at grocery stores, malls, and museums

Participants shared that sensory-friendly environments with places to sit in public. For students, these settings aid learning and make it easier to study or work. Moreover, sensory-friendly hours in public places such as grocery stores, malls, and museums were described as peaceful. One participant wrote:

> *"a good example is when our local grocery store turns off all the lights because they have enough windows for local lighting, and they have two hours of sensory... And they've got enough beautiful front windows, open front windows, so there's natural light. They turn the lights off, so it looks like the store is closed, but it's not. They turn off the audio, so you're not having these horrible pop songs repeating in your head for a month after. It takes the glare away. Not very many people show up to the sensory so you're also—just it's peaceful."*
>
> Neurodivergent Focus Group Participant

d) Section Summary

Our research points to the importance of taking the sensory needs of neurodivergent people, be they for less or more sensory input, into consideration when designing the built environment, as well as standards or policies in a variety of settings (e.g., healthcare, education, employment, recreation, etc.). Several pieces of literature provide guidance on how to reduce sensory barriers. Design features (furniture, layout, decor, lighting, thermal comfort, and acoustics) and inclusion considerations (control, flexibility, education, independence, personalization) are encouraged (Narenthiran et al., 2022).

Within the built environment, designers should consider many factors when designing spaces (Tola et al., 2021). These spatial recommendations include:

1. Sensory quality
   a. Low arousal environments (reducing clutter, providing natural lighting, using simple materials and textures, and ensuring good sound insulation and ventilation).
   b. Transition spaces
   c. Quiet spaces
   d. Clear and simple spatial layouts
2. Intelligibility
   a. Visual relation (clearly delineating between different environments)
   b. Predictability and routine (emphasizing sequences)
   c. Circulation and possibility of choosing
   d. Proportion and proxemics (design spaces with correct proportions)
3. Orientation
   a. Visual supports
   b. Wayfinding (e.g., maps, colours)

Moreover, providing people with flexibility and tools that can support neurodivergent adults when navigating these spaces is also important. Some examples include:

- Noise-cancelling headphones where students can be alone for some time
- Computer monitor settings adjustments and/or blackout covers/filters
- Profiled computer mice
- Silent computer keyboards
- Redesigning workstations to create individual workstations instead of busy spaces such as cubicles (Doyle, 2020; Sarrett, 2018; Tomczak, 2022)

4.2. Examining barriers in communications

a) Literature Review: A lack of clarity in communications leads to confusion and causes barriers to access

Neurodivergent people and neurotypical people can have differing communication styles. A neurotypical individual may use indirect language, filled with coded non-verbal cues, while neurodivergent people use direct language (Clouder et al., 2020). In other cases, some neurodivergent people may use different forms of communication such as sign-language and assistive devices (Saunders, 2023).

These discrepancies in the ways that neurotypical and neurodivergent people communicate cause many challenges for those who identify as neurodivergent. Most environments and systems (work, healthcare, education, community businesses and services) are set up in ways that prioritize and work well for neurotypical styles of conveying and receiving information. This often creates barriers for neurodivergent individuals in getting the information they need to equitably navigate those environments. The challenge of getting key information and/or having to adjust for and interpret neurotypical communications can lead to exhaustion and a barrier to accessing settings and services that could otherwise provide benefits. For instance, autistic adults who experience challenges in social interaction and/or communication and may be less likely to take part in recreational programs due to social demands, leading to isolation (*Robertson, 2010a, b*).

These communication differences can also lead to inaccessibility in the justice system. Gormley & Watson (2021) found that disabled people (including neurodivergent communities) who were accused of a crime received unfair and fragmented support, including racial stigma (Antony et al. 2022; Wilson, 2013), and inaccessible information and communication. At times, information was not provided or communicated in a way that they could understand, forcing them to rely on others (e.g., Clasby et al., 2022).

In addition to communication differences, a lack of clarity in procedures can also negatively affect neurodivergent people. For instance, the layouts of libraries and other public places can be confusing (e.g., Dewey system, *Robertson, 2010b*). The use of vague and imprecise language in recruitment to employment settings can have impact on outcomes for neurodivergent people. For instance, Autistic adults have difficulty securing a job leading to both unemployment and underemployment (underutilizing their skills; *Robertson, 2010a,* Khan et al., 2022). One of the core reasons for this can be attributed to the job application process which has the following barriers:

- Frequently using language that describes social-emotional abilities (e.g., "soft" skills) which can be overwhelming and discouraging for those who do not perceive themselves to have soft skills such as "good teamwork" or "communication skills"
- Complicated application processes
- Ambiguity or over-specificity in writing (e.g., the use of jargon words)
- Workplace culture descriptions lacking information about diversity, inclusion, flexibility, and accommodations (Labour Market Information Council, 2024)

b) Focus Group Findings: Different communication styles and obscure, complicated systems lead to confusion and cause barriers to access

<u>Different Communication Styles</u>: The results of our focus groups and interview showed that differences in communication styles were barriers. This included disconnects between neurotypical and neurodivergent styles of expressing and receiving information. Miscommunications and differing understandings were reported to lead to frustration, confusion, and feelings of being unseen or dismissed. Some examples of communication challenges that participants shared include:

- Communicating in a language that is not your first language
- Communicating as a woman
- Communicating without Augmented and Alternative Communication Devices
- Being forced to communicate or interact in social situations
- Not being told all the options or permissions to use available resources
- Lack of clarity in online communication (i.e., due to meaning and context being lost in messaging, or not being able to see people on camera)
- Autistic communication is on a spectrum which makes communication challenging with other autistic people or neurotypical people

One neurodivergent individual shared the challenges that they experience with respect to communication:

<u>Obscure and complicated systems and procedures:</u> Another point emerging from the focus groups was that lack of clarity with respect to time, roles, and responsibilities created anxiety and impacted participants ability to anticipate and plan in their daily live limits. Some specific examples of such challenges include:

- Lack of clarity in school, work, and transportation schedules creates confusion and stress
- Lack of clarity with respect to roles and responsibilities in the workplace
- Adapting to unfamiliar social and environmental contexts
- Complicated systems (healthcare settings and other governmental buildings) resulting in delaying addressing health concerns and fears of not being believed
- Services with inconsistencies in their procedures were less likely to be accessed
- Open-ended questions are too broad which can be overwhelming
- A lack of clearly communicated expectations and processes of settings, along with the resources that are available in those environments led unmet needs Technology on buses and transportation applications malfunctioning
- There is a lack of consistency in procedures and rules across different organizations
- Wayfinding is challenging in public buildings

Neurodivergent individuals highlighted, the various ways in which complicated systems and procedures can limit their access, including access to medications. One individual wrote:

c) Focus Group Findings: Clear communication and directions facilitate understanding

Participants also revealed how clear communication and directions helped understanding and eased stress. Examples include:

- Clear directions (step-by-step, colour coding, visuals) that are user friendly facilitate understanding
- Clear signs in shopping centers help with wayfinding
- Getting detailed instructions in person is easier than learning new programs alone (for some)
- Having a clear understanding of expected wait times reduces anxiety
- Having clear goals, roles, and responsibilities works well in work settings
- Visuals on screens are helpful when shopping in person
- Having access to reliable and up-to-date travel information eases stress

When asked what they would want standards developers to take into consideration when they are making standards, the community responded with the following actions. Examples include:

- Creating simple (e.g., using plain language), clear, flexible, and transparent standards

- Creating standards that will help a variety of people (with an emphasis on standards that are based on universal design principals)
- Standards need to be considered through an equity lens with empathy in mind
- Standards need to be updated and upheld
- Shifting away from the language of the medical model
- Simplify getting access to services and products
- Ensuring that people are kept informed about important services (e.g., wait times, the layout of public places)

d) Section Summary

These findings highlight the vital role that clear communication and procedures play in accessibility for neurodivergent people. Several examples of guidance on how to improve clarity are found in the literature. In the workplace, suggested communication-based improvements include clarity in each of the following:

- Recruitment (job postings in clear language, layout, basic colours, communicating the nature of the work and work environment in various formats, videos linked to postings or on main website)

- Selection (flexible format for job interviews, verbal and written instructions, detailed questions)
- Onboarding (providing support, encouraging asking for help or scheduling check-ins, reviewing some of the unwritten social norms in the specific workplace)
- Job retention (non-direct, electronic mediated communication, small group meetings, checking in by "neurodiverse-aware managers", Tomczak et al., 2021)

Suggestions for communication and procedures in the workplace include:

- Electronic-mediated forms of communication (emails, chats)
- Flexible forms of contact with teams
- Direct contact limited to one person
- Meetings in small groups
- Written agendas before meetings/minutes after)
- Improving intelligibility of messages
  - Using speech-to-text and text-to-speech applications
  - Verbal instructions followed by written communication
  - Regular feedback (*Robertson, 2010a*, Tomczak, 2022)

Other suggestions include reducing social communication demands, promoting the use of color communication badges, and using plain language in all communications (Autistic Self-Advocacy Network, 2024; Doyle, 2020). Designing, hiring, contracting, training, performance review, and well-being must be altered to account for the principles of Universal Design (Doyle & McDowall, 2021).

4.3 Exploring neuroinclusion supports

a) Literature Review: The importance of supporting neurodivergent people

The literature points to challenges with receiving support in a variety of settings. In higher education settings, students report a lack of support and flexibility (Clouder et al., 2020; *Robertson, 2010a*). Support can come in many different forms (e.g., social support, accommodations, etc.). Students need customized support services to meet their needs, yet the available academic accommodations are often not a fit for the needs of autistic students who can benefit from inclusive teaching practices and student supports (Sarrett, 2018; Wright et al., 2021).

In the literature, neurodivergent students reported significant barriers in post-secondary settings, such as not being provided reasonable accommodations and services, being treated poorly, facing inflexible teaching/learning approaches, and not being offered enough technological supports. This leads to students experiencing frustration when they are unable to get adequate supports (Couzens et al., 2015). On one hand, those who do

not self-disclose their disabilities often experience a lack of support, while on the other, those who choose to disclose experience stigma (Khan et al., 2022).

In terms of employment, barriers for neurodivergent individuals in Alberta include:

- Employers' knowledge, ability, and management practices
- Late start to concept of work and workplace culture education and
- Stigma (Dunn et al., 2018)

b) Focus Group Findings: Lack of support, flexibility, clarity, and understanding are barriers to access

The results of our focus groups and interview showed the key role of support in neurodivergent people's lives. Navigating certain spaces can be challenging for some individuals. Participants shared that a lack of support was found in educational, employment, and healthcare settings. One neurodivergent individual, who was entering university, found it difficult to navigate that space with limited support:

> *"I think this is kind of an intersection with class, but thinking back to university, trying to navigate that process for the first time without having anybody in my family who had been through university before. So I couldn't access that guidance about how to navigate. And then I didn't know where to access that within the university, and universities are set up in a way that it's so much work to find what you need and to figure out what's expected of you. And what class do I need to get to this place? So it would be nice to have, I guess, that peer support worker again or something like that. Someone who can actually walk you through it and explain it to you instead of the onus being on you to understand websites and calendars that are super confusing."*
>
> Neurodivergent Focus Group Participant

The focus group discussions also revealed that there were many challenges with getting access to certain services of environments. Additionally, participants shared that the accommodations process, and sometimes the accommodations themselves, were not always available. This lack of support includes a lack of relevant or readily available accommodations. Even when accommodations were provided, participants felt as though they were challenging to access such as the following specific examples:

- A lack of standardization at a policy level makes getting work accommodations challenging

- Accessible options are not aligned with other values such as being a considerate consumer (e.g., shopping on online platforms such as amazon instead of locally owned small businesses)
- Accommodations are not always properly given (e.g., they do not meet the needs of those who need them)
- Getting accommodations is isolating
- Lack of accessible options in public settings (e.g., bathrooms in shopping malls, shopping options for those living in rural areas)
- Shifting from in-person to virtual work is challenging due to strain on eyes from screens and not being trained on how to use certain programs
- Small communities do not have adequate transportation which limits access
- Accommodations are not offered even when requested
- Finding suitable employment and advancing career
    - Getting a job for those with a physical or cognitive impairments
    - Working online is challenging (e.g., using zoom)
    - Disclosure during the hiring process (participant does not want to be dishonest)
    - Gaps in employment history limit future employment opportunities

c) Focus Group Findings: Support (i.e., social support, assistive devices, as well as accommodations and accessible practices) promote inclusivity

Support can come in different forms and participants discussed how receiving the following types of support promoted inclusivity:

- Social support (romantic relationship, pets, friends, medical community, family members, and others who identify as neurodivergent)
- The use of assistive devices and other technological aids (Augmented and Alternative Communication devices, phone applications, chat features, and online communities)
- Relevant accommodations and support networks (personalized accommodations, access to peer support workers, working in organizations that affirm neurodivergent people who provide resources such as noise-cancelling headphones, blankets, among others to their employees)
- Flexibility to control educational, employment and healthcare environments
    - Flexibility and control over work structure and environments (adjustability of desk, supportive supervisors who let employee work at their own pace, having own office space)
    - Learning, working, or seeing healthcare professionals virtually

- Having the opportunity to shop using different methods (online, pick-up)

Many of the participants shared how challenging it was for them to remember to take their medication on time or visit their doctors when needed. One participant shared with us how pharmacists can support with these challenges:

> *"But this is what my pharmacy uses for me. It's like a blister pack. So I can always see if I've taken my medication. I can always see how much medication I have left to take for the day because I do take three doses a day of ADHD medication, as well as various other medications. And my pharmacy has had no problems packing this up for me in this way and delivering it as well. And I'm not a hundred percent sure if she's supposed to be doing this, but my doctor will fax refill requests to my pharmacy if I ask her to. Recently, she said, "You still have to come in for an appointment every three months or so." But having a doctor who's willing to work with the pharmacy directly has been really helpful for accessibility of medication."*
>
> Neurodivergent Focus Group Participant

c) Section Summary

Neurodivergent Canadians face numerous barriers to access, particularly regarding physical and social accommodations, including assistive and accessible technologies. Several pieces of literature provide guidance on how to improve supports. Supporting neurodivergent people by allowing flexible hours or opportunities to work from home reduces sensory distractions by giving people autonomy over their time and work environments (Doyle, 2020). Good examples of approaches and accommodations in higher education settings include:

- Strengths-based approaches and activities that focus on self-determination and regulation skills
- Flexible teaching and learning approaches (including flexible assessment methods such as extended test time, note takers, distraction free test areas, flexible deadlines, and recorded lectures)
- Providing breaks (Clouder et al., 2020; Khan et al., 2022; Patton et al., 2019; Sarrett, 2018)

Changes to improve supports and accommodations for neurodivergent students also include giving them a single contact person to set up their individualized accommodations, making it easier for them to show they are eligible for accommodations, creating transition programs to support these students as they arrive and leave college, and establishing mechanisms to help students who are denied accommodations (Dwyer et al., 2022). Some

specific technological supports that can be provided include word-processing and other assistive technologies, including speech-to-text software and text-to-speech software, which can reduce demands on literacy and handwriting skills and improve concentration. Mind mapping software can support a shift from overview to detailed thinking. There are also specialized spell checkers designed for dyslexia. In addition, planning and memory software helps everyone, not just neurodiverse people (Doyle, 2020).

4.4 Evaluating neurodiversity awareness

a) Literature Review: Awareness and education about the needs of neurodivergent people

Neurodivergent people in Canada may also experience stigmatizing or negative attitudes, and overlapping, intersectional difficulties and misunderstandings based on their neurological differences. In higher education contexts, neurodivergent students experience negative emotions and stigmatization. The stigma experienced by autistic students is often associated with cultural differences or the perceived need to conform to societal norms. Many autistic people reject disclosure of their neurological differences to the wider community because they want to develop new social identities. Students with dyslexia experience a particular fear of stigma because they do not want to be labelled and so only disclose when necessary. Neurodivergent people more generally take judgmental and discriminatory attitudes into account when they disclose their learning difficulties (Clouder et al., 2020). Likewise, Robertson asserts that, in workplaces, social stigma related to neurodivergence leads to a lack of acceptance and many professionals work with the assumption that autistic people cannot reach self-determination (*Roberston, 2010a*).

Intersectional challenges: There exist historical disparities in diagnoses of neurodivergence among people of color; moreover, Black people are excluded from dominant narratives of autism (Rodas & Paulin, 2021). In the same way, there is limited research focused on the challenges at the intersection of race and disability for Black men on the autism spectrum in encounters with law enforcement (Hutson et al., 2022). Also, experiences of trauma and abuse are higher in neurodivergent people (White & Boue, 2015).

b) Focus Group Findings: Neurotypical privilege, expectations, prejudices, and stigma limit inclusion

In our focus groups, participants emphasized that increasing awareness and education about neurodivergence and neuroinclusivity is crucial for ensuring equitable access to resources and services for everyone in Canada. Many participants highlighted that a

generalized lack of understanding of true inclusivity, its meaning, and what it can look like, has created significant barriers for neurodivergent individuals in society. One participant shared their challenging experience at a local store that claimed to be neuroinclusive by considering the sensory needs of shoppers. However, the store failed to meet its objective due to a lack of genuine understanding of the community's needs:

> *"unfortunately, my local store had a sensory-friendly space, but they also decided that was the best time to unload all the products in the aisles. So, it was low light, no sound. Great. But it was impossible for me to walk up in the aisle, there wasn't enough space. So that was the—it's often, unfortunately, so many places are trying to tick the inclusive box without fully understanding what that means in the wholeness of it."*
>
> Neurodivergent Focus Group Participant

Other challenges related to a lack of awareness include:

- Neurotypical physiological and communication expectations of neurodivergent people
- Stigma and prejudice affecting neurodivergent people stemming from:
    - Misconceptions about money and education (e.g., assuming people do not need more support if they are in higher education, stigma attached to part-time work)
    - Racism and sexism in healthcare (medication is not typically tested on women, women are often misdiagnosed or mistreated due to power imbalances)
    - Misconceptions leading to late diagnoses
    - A lack of normalization and incorrect beliefs about who should be qualifying for accommodations

> *"I have a story that actually has to do with a colleague of mine. I'm blessed in that I've had two accommodating jobs through autistic hiring. But unfortunately, I felt that often even when companies, which they rarely do, if they intentionally hire autistic employees, they're seen to be second-class employees. There was this one place where I worked and another man who was hired through the same cohort, for some reason he had to wear noise-cancellation headphones. Lots of people with autism wear them. But the company started sending out these memos reminding people that they're not allowed to listen to music while at work. But nobody was listening to music. Basically, it was a way of harassing this guy because he would wear headphones all the time. And I felt that was very hurtful, not just to me, but for all the employees who had been hired through this. This is a company that actually intentionally hired people on the autism spectrum. So that's as good as you can get. And this is how we're being treated."*
>
> Neurodivergent Focus Group Participant

c) Focus Group Findings: Awareness and education about neurodivergence encourages inclusion

Some solutions to these barriers are to increase awareness and understanding of neurodivergence which participants mentioned would reduce masking or masking fatigue.

> *"Most effective allies/support have been people who come in willing to "unlearn" what they have wrongly learned or are new and open-minded...To answer your question— What works is flexibility of structure and flexibility of mind."*
>
> Neurodivergent Focus Group Participant

While participants noted that younger people tend to be more receptive and knowledgeable about neurodiversity, some approaches that are currently working to improve awareness include:

- Having a core team at work, who are knowledgeable about neurodivergence
- Trained staff at the dentist
- Dedicated ND aware doctors
- Diagnosis is helping to normalize ND conditions
- Freedom and acceptance when using personalized meaningful strategies such as:

- Ear plugs, noise-cancelling headphones, stem tools and fidgets, among other strategies to self-regulate and reduce sensory overload
- Being able to tailor environments to fit personal needs (e.g., own workspace)
- Using assistive technologies to help with organization and communication such as Alexa, AirTags, ridesharing apps, text to speech applications, among others
- Preparing an advanced and staying organized (e.g., taking notes, bringing lists when shopping, etc.)

Participants recommend that standards developers increase their awareness, understanding, education, and training about neurodivergent people and their needs (e.g., awareness about the importance of taking neuroinclusivity into consideration, sensory needs, and providing flexibility and support when needed). Attitudes, beliefs, and stigma need to change and those who need accommodations should be offered them without suspicion. As one participant stated:

> *"people tend to jump to conclusions. And I understand that that's what you're trying to avoid. Even doctors. We were talking about medication. A doctor would jump to a conclusion because there's too many people out there that might be abusing the use of Adderall because they're a first-year student that didn't do their homework. Or you see somebody that's distracted somewhere and - I don't know - just people just tend to jump to conclusions about what's actually happening when they don't really know. I am failing to elaborate on that right now. I don't know. But yeah, anyway, people shouldn't jump to conclusions. And people should give people an opportunity to explain themselves and to actually think that there's more going on than what you see, basically."*
>
> Neurodivergent Focus Group Participant

The responsibility for inclusion should not rest solely on the neurodivergent community. Instead, policies and mechanisms should be put in place to support neuroinclusivity, which will contribute to a more inclusive Canada.

> *"I think that, built in, needs to be compassion, empathy, understanding, and an openness to other ways of being. I think that applies both with neurodivergence and also culturally, religiously, etc., etc."*
>
> Neurodivergent Focus Group Participant

In the same vein, participants emphasized the importance of including neurodivergent people when making decisions that will directly affect them. Participants stressed that many decisions are often made without neurodivergent voices at the table, and when they are included, they are not treated or paid fairly.

Standards developers need to put the people who experienced the challenges themselves on the boards, creating the standards, and doing research. By doing this, two different inequalities currently experienced by this population can be tackled. First, this would give more opportunities for neurodivergent people to work and engage in various sectors, an opportunity that they are often denied. Second, their lived experiences can be shared directly with those who oversee policies and standards creation in Canada, significantly increasing the chance that their needs would be taken into consideration, and at the same time educating other leaders and decision makers.

d) Section Summary

We heard from the participants that changes in attitudes and beliefs about neurodivergence would be the most impactful in increasing accessibility. This sentiment emerged as a common theme throughout our discussions. Some approaches to creating more accepting spaces include a combination of social-emotional learning and Universal Design for Learning theories to help mental-health professionals provide acceptance, adaptable or flexible spaces, and the conditions for self-acceptance to neurodiverse and autistic clients (Mitran, 2022).

Likewise, universal-design approaches to learning can help neurodivergent students to manage anxieties and stresses in higher education, because they cater to students' diverse different sensory preferences and leisure activities, as well as providing sufficient rest and opportunities for social learning (Clouder et al., 2020). In the social sphere, the development of programs to support autistic people in navigating face-to-face interactions (*Robertson, 2010a*) and social accommodations, including sensory-friendly events, trained peer mentors and mediators are encouraged (Sarrett, 2018).

Some strategies for integrating plain and non-oppressive language into workplaces include understanding differences in identity-first and person-first language. Autistic self-advocates and family/friends of autistic individuals showed a stronger preference for using identity-first language. On the other hand, neurotypical professionals showed a more widely distributed preference for person-first language (Lei et al., 2021).

4.5 Neurodivergence and Intersecting Identities

The barriers that neurodivergent people face are pervasive and can hinder their active and autonomous participation in life. The intersections between neurodiversity and other

identities create unique roadblocks for individuals. Intersectionality highlights different combinations of social identities (e.g., sexual orientation, age, gender, race, etc.). Neurodivergent people often also identify with other identities, such as belonging to the LGBTQ2+ community.

In our research, we found that many of the barriers that neurodivergent people are facing were noted by participants to be amplified by one or more of the following: pregnancy, age, experiencing chronic pain disabilities and other physical disabilities, traumatic brain injuries, identifying as female, identifying as queer, and coming from a household where no one has previously attended higher education. Other researchers have found that many women with ADHD have been previously misdiagnosed or have gone undiagnosed due to a lack of research on this neurodivergent type specifically in women (Hinshaw et al., 2021; Walters, 2018). Our research echoes these findings in showing that many of the women we spoke to experience such challenges. More specifically, women with ADHD from our focus groups were sharing that they were only diagnosed in later years:

> *"One of the reasons that I wasn't diagnosed until I was 54 years old is because I'm a woman. And nobody in my decades of trying to get help ever, ever considered that I could have ADHD. So, because there exists within the medical model this idea—I think it's finally starting to change - that only boys who can't sit still in class have ADHD. And I was misdiagnosed and not given the right type of care and had to deal with all of the various things related to that. So, I guess what I'm trying to say is that there—and it goes back to assumptions and ways we think about certain—I hate to call them conditions, but some people have a fixed idea about autism or ADHD or whatever. And it's those baked-in sort of biases that prevent people from accessing the things that they need."*
>
> Neurodivergent Focus Group Participant
>
>
> *"I feel you. I was diagnosed at 36 after working in the field for years and not even knowing because of how autism and ADHD were presented."*
>
> Neurodivergent Focus Group Participant

4.6 Focus Group Findings with Standards Developers

a) Standards developers' backgrounds

Fourteen standards development professionals participated in this research. These verified participants were highly diverse: nine identified as neurodivergent themselves, and all had significant expertise in standards development, having served on technical committees that helped to produce standards or had consulted with standards development organizations. Participants were from across Canada with eight participants from Ontario, two from Nova Scotia, one from Alberta, one from Saskatchewan, one from British Columbia, and one from Quebec. Five held, or had held, governmental roles, especially in the federal government; two worked directly for standards development organizations; one is a policy developer, and one works in the academy (please see Appendix A for more information on participants' demographics).

In the focus groups themselves, all fourteen participants agreed that there were barriers to the inclusion of neurodivergent people in Canadian institutions and public life, as well as in the labour market. The government employees and the non-profit workers all shared that they were working in their departments, and serving on technical committees, in order to promote the needs of neurodivergent people as an equity-seeking group. Each standard developer shared some of their experiences of ableism and bureaucracy interfering with the rights of people who are neurodiverse, on the one hand, and best practices of compassion and solidarity on the other.

b) Neuroinclusivity in current standards development

Individuals who work in the development of standards were asked to share their thoughts on the role of neuroinclusivity in current standards development. Results revealed that neurodivergence was not or was minimally considered and is usually an "afterthought." One participant noted that:

> *"Neurodivergence is considered as an afterthought, people capitalize on 'neurodivergence' for grants, but they are not actually improving quality of life for neurodivergent people"*
>
> Standards Developer Focus Group Participant

This may be due to:

- a lack of awareness and or education around accessibility and neurodivergence,

- visible disabilities are more often captured due to their visible nature (e.g., you can see someone who is in a wheelchair may need support with a staircase) than non-visible disabilities,
- considerations are taken more seriously when there are formal requirements in place, e.g., respecting the Accessible Canada Act is a requirement for developing standards in the built environment (Prince, 2017)
- there are general barriers to inclusion (e.g., conflicting groups of users)
- neurodivergence considerations are perceived as too complicated or costly

When neuroinclusivity is considered, it is usually brought up by a committee member or chair of a given technical committee who is invested in promoting inclusion for this population. Standards developers emphasize the importance of including neurodivergent people in standards development in order to create more balanced, and representative, committees involving those with diverse abilities. Furthermore, standard developers discussed the importance of opening doors and creating environments that are inclusive for everybody. One example of promising inclusion practices is the Hidden Disability Sunflower initiative. The Hidden Disabilities Sunflower is a tool that an individual can use to visually cue others that they have a disability that may not be directly apparent. In wearing the sunflower lanyard, they signal to others that they may need some help, support, or understanding in public spaces.

Other examples of promising neuroinclusive approaches include:

- Providing resources for employees and managers to educate them about neurodivergence
- Modernizing the self-identification process to include neurodivergence

c) The potential impact of neurodivergence being considered in standards development

Our results showed that standards developers believed that if the needs of neurodivergent people were considered in standards development, it would open doors and create environments and inclusive spaces for everyone. This would substantially reduce barriers for neurodivergent people, as one participant wrote:

> *"I think the overall confidence and agency over your life you could feel when you have these struggles when you're considered more in the environment, socially in workplace environments, educational environments, it's just the peace of mind to know that you're considered and that you're going to be able to function just as easily as others. I think as someone who doesn't struggle with these challenges that I think I take for granted, like how easily I move around in the world and the education system and such. So I think it's just the confidence and the agency over your ability to operate the same as others once you're considered just as much as everyone else."*
>
> Standards Developer Focus Group Participant

In addition, once accessibility and neurodiversity are consistently considered, this will reduce the need to advocate for it. Inclusive standards should be created and updated in an iterative fashion as our knowledge grows. The participants reinforced the idea that standards developers need to ensure that all standards and policies are as accessible as possible for as many people as possible in a variety of formats. They emphasized that standards developers need to know how to do this as a first step.

> *"Without the how, nothing gets done. People need a roadmap."*
>
> Standards Developer Focus Group Participant

d) Recommendations for resources and toolkit

Participants were asked several questions about our toolkit and resources. First, they were asked at what stage of standards development they felt that our tool and corresponding resources would fit best in. Standards developers stated that active inclusion of everyone throughout the process (e.g., including public review and testing at every part of the process) is encouraged:

- Throughout standards development
  - The resources should be incorporated at all stages of the standard development process to ensure comprehensive coverage (e.g., starting off with an educational tool and consistently getting insights and perspectives from a diverse group of stakeholders)
- At the start of the standards development process
  - The toolkit would be best implemented at the beginning of the standards development process and can be used as a starting point for conversations on this topic. Also, this can guide developers through the process.

- Drafting/co-creation stage, and public consultation stage
  - The toolkit would be most helpful before the standard is implemented at the co-creation stage with the voice of those who it is intended to serve.

Furthermore, when asked who should be considering our resources (related to promoting neuroinclusivity in Canada), they said:

- Anyone working in a senior leadership position, developing processes or policies, in charge of anything related to safety or serving the public, regulatory bodies, architects, accessibility, experts, researchers, and academia.

When asked what types of tools or resources standards developers prefer themselves or believe that other standards developers would be most receptive to, participants shared the following:

Types of tools/resources:

- All resource materials need to be accessible in multiple formats
  - Materials should be made accessible to users directly given that many links can be blocked by certain organizations
  - Captions and sign language present in all videos
  - Materials should be made accessible for everyone in different formats across different platforms:
    - Written text (such as in a word document),
    - Educational video (participants specifically stated that shorter videos are preferred because they are easier to digest)
    - Audio,
    - Visuals (such as infographics)
    - Templates (workable templates that someone can fill out)
    - Checklists
    - Interactive components
    - Knowledge checks (it is important to note that some participants did not recommend knowledge checks or quizzes due to added pressures when learning)
    - Webinars and workshops
    - E-learning tools and phone applications
  - The toolkit should be written in a clear fashion with short and manageable chunks

Considerations when creating or curating toolkit items:

- Resources need an accompanying guideline

- - o A separate guideline accompanying the tool kit should be included to explain how to use it and why
    - o A glossary should go in a coordinate guide
  - Examples
    - o Example of how-to delivery information accessibly
    - o Leading questions that prompt brainstorming
    - o Samples of standards written with neuroinclusivity in mind
  - The toolkit needs to simplify the information that is out there

4.7 Community Feedback on Resources and Tools

A draft of the recommended practices was brought back to the community to assure that it was reflective and resonated with their lived experiences. They were also asked to provide feedback on if our tools would help standards developers better understand and consider neurodivergence in the standards development process. The participants reiterated and strongly endorsed that standards developers directly consult with the neurodivergent community when engaging in the development of standards.

Additionally, the draft practices and tools were also brought back out to standards developers. They were asked to share their insights on whether they felt that these recommended practices may influence the standards development and review processes, if our tools will help them to better understand and promote neuroinclusivity in the standards development process, and where in the standards development process they foresee our tools fitting best (e.g., review stage, drafting stage, etc.). Standards developers shared that they felt that our list of recommended practices and toolkit items were comprehensive and would open up conversations about neuroinclusivity. Furthermore, they emphasized the importance of showing these recommended practices and corresponding resources at the beginning of standards development, during evaluation stages, and throughout the entire process to revisit (e.g., evergreen document that updates and changes with time).

5. Key Recommended Practices

5.1 Introduction

In this section, we will outline five key higher-order recommendations for promoting neuroinclusivity in the standards development process. These recommended practices were derived from the combined results of our literature reviews, environmental scans, focus groups, interviews, a survey, and webinars with the neurodivergent community and

standards development professionals. These five recommended practices focus on promoting neuroinclusivity for neurodivergent Canadians within:

- The *content* of standards (e.g., ensuring that new and revisited standards do not contain information that creates barriers for neurodivergent people)
- Key stages of the standards development *process* including:
  - Identification of a need for a standard
  - Development of technical committees
  - Deliberation and drafting of a standard
  - Consultations with the public on proposed standards
  - The review, publishing, and maintenance of a standard

Our findings highlight that increasing education to facilitate attitudinal shift and reduce stigma and prejudice against neurodivergent people, involving neurodivergent people in standards work, and creating spaces and procedures that are sensory aware, clear, supportive and flexible are key actions to promote neuroinclusivity for neurodivergent Canadians.

The following five recommended practices that can be used within standards development are:

1. Use education to improve awareness, reduce stigma, address attitudinal barriers and adjust neurotypical expectations related to neurodivergence to increase neuroinclusivity
2. Ensure that diverse and neurodivergent voices are involved in research and standards development
3. Reduce ambiguity in communication, processes, and procedures
4. Recognize and accommodate the sensory needs of neurodivergent people
5. Design proactively and be responsive to the needs of neurodivergent people

Recommended Practice 1: Use education to improve awareness, reduce stigma, address attitudinal barriers and adjust neurotypical expectations related to neurodivergence to increase neuroinclusivity.

When standards developers increase their knowledge about neurodivergent experiences, they will be able to incorporate those considerations into standards of all kinds. This gives standards developers an enormous opportunity to impact the neuroinclusivity of a multitude of systems, policies, products, service offerings, and built environments. By simply taking the time to consider neurodivergence and neurodivergent experiences from the outset, standards can be a facilitator of inclusive design that is neuroaffirming. To do this, standards developers must themselves access education and learning resources,

and first-person accounts that will help to shift attitudes and assumptions. To impact change in people's attitudes and perceptions of neurodivergent people, we recommend that anyone involved in standards development increase their awareness and education about neurodivergence. This includes individuals in standards development organizations (SDO's), creators of standards in Canada, committee chairs, technical committee members, and the general public providing feedback during the public review stage. This education should be obtained at the start of their involvement in standards development to ensure that a neurodivergent lens is considered throughout the entire process.

We recommend:

1.1. Implement Educational and Training Programs on Neurodivergence

Individuals involved in standards development should engage in education and training to become more familiar with and better understand neurodivergence, so they can best apply it to their work in developing standards of all kinds. These programs should cover topics such as but not limited to:

Understanding Neurodiversity and Related Concepts

- Definitions and descriptions of terms such as neurodiversity, neurodivergent, neurodivergence, and neurotypical
- Explanation of neuro-types, including the evolving criteria for what is considered neurodivergent
- Importance of neuroinclusivity and its impact on creating inclusive environments

Models and Theories of Disability

- Overview of the medical model of disability
- Exploration of the social model of disability and how systemic barriers limit the participation of certain groups
- Discussion on ableism and its role in perpetuating stigma against non-visible disabilities

Intersectionality and Neurodiversity

- Examination of how intersecting identities can amplify barriers faced by neurodivergent individuals
- Strategies for addressing and mitigating these compounded challenges

1.2. Engage with Neurodivergent Individuals

- Read first-person accounts by self-advocates to explore the wide diversity of neurodivergent perspectives and experiences

- Establish direct connections with neurodivergent individuals to listen to their stories and perspectives
- Understand the specific challenges and barriers they encounter in society and incorporate their insights into standards development

1.3. Foster Understanding

- Promote interactions with neurodivergent individuals that are grounded in empathy and an appreciation for diversity
- Encourage a culture of respect and inclusivity in all engagements

1.4. Disseminate Key Educational Resources

- Share important resources on neuroinclusivity with all stakeholders involved in the development of standards in Canada
- Ensure that these resources are accessible and widely distributed

1.5. Use Mindful Language

- Be conscious of the language used when referring to or speaking about neurodivergence or neurodivergent individuals
- Acknowledge and respect individual preferences for identification
  - Use person-first (e.g., person with ADHD) or identity-first language (e.g., autistic electrician) as preferred by the individual

This approach aims to build a more inclusive and understanding environment for neurodivergent individuals within standards development processes.

Recommended Practice 2: Ensure that diverse and neurodivergent voices are involved in research and standards development

Our second recommendation follows from our first. We recommend diverse, neurodivergent voices be actively involved in research and standards development, including serving on technical committees and providing feedback during public review stages. Specifically, we suggest the following actions:

2.1. Recruit Neurodivergent Individuals for Technical Committees

- Standards developers should proactively involve a diverse group of neurodivergent individuals by recruiting them to participate on technical committees
  - Their lived experiences will provide valuable insights during the standards development process

2.2. Seek Input During Public Review

- Actively solicit feedback from neurodivergent individuals when distributing standards materials for public review

2.3. Promote Diversity Among Standards Creators

- Ensure that the teams responsible for creating standards are diverse, encompassing various types of neurodivergence and other intersectional identities, including gender, gender identity, sexuality, race, ethnicity and more

By taking these steps, standards developers can ensure a more inclusive and representative process that better addresses the needs and experiences of neurodivergent individuals.

Recommended Practice 3: Reduce ambiguity in communication, processes, and procedures

To reduce barriers related to communication and simplify complex procedures, we recommend that standards developers prioritize clarity throughout the standards development process. This recommendation is applicable to both the content and process of standards development. We specifically recommend that clarity be a guiding principle in all communications with neurodivergent people, all materials presented to technical committees and the public during the deliberations and review phases of standards development, and in any outputs that are generated by this work. Specifically, we suggest the following actions:

3.1. Create Simple and Transparent Standards

- Develop standards that are simple, transparent, flexible, and easy to understand
- Avoid using jargon or overly complicated terms without providing corresponding glossaries

3.2. Adopt Universal and Inclusive Design Principles

- Base standards on Universal Design and Inclusive Design Principles to ensure they are accessible and functional for many Canadians, including those with non-visible disabilities

3.3. Account for Different Communication Styles

- Make space for all communication styles (including verbal communication, sign language, augmentative and alternative communication [AAC] devices, and text-based or written communication)

3.4. Simplify Materials for Public Engagement and Recruitment to Standards Development Committees

- Ensure all materials are clear, straightforward, and specific. Avoid abstract descriptions. Or requests. This helps in recruiting technical committee members and sharing standards information with the public

3.5. Provide Clear Instructions

- Offer clear and detailed directions and instructions, using step-by-step guides, color coding, and supporting visuals in plain language

3.6. Distribute Work Materials in Advance

- Provide all participants in standards development with work materials in advance and share written agendas before and after any meetings

3.7. Designate Support Personnel

- Assign a designated person, such as a peer-support worker or employee, to assist throughout the standards development process.
  - This person should provide detailed notes, summaries, and assistance and clearly outline all rules and regulations involved

By focusing on these principles, standards developers can create more inclusive and accessible processes and outcomes, effectively reducing barriers for neurodivergent individuals and other stakeholders.

Recommended Practice 4: Recognize and accommodate the sensory needs of neurodivergent people

To address sensory differences, we recommend that standards developers familiarize themselves with the sensory needs of neurodivergent people and apply this in the creation of standards, specifically in the built environment. This recommendation is applicable to both the content and process of standards development. We recommend the following actions:

4.1. Redesign Built-Environments with Sensory Needs in Mind

- Provide options for neurodivergent people to tailor their physical environment based on their preferences (e.g., desk space and organizational systems)
- Provide diverse and plentiful seating options, such as bean bags, cushioned chairs, yoga mats, and other soft seating

- Ensure furniture is modular and adaptable, and provide ergonomic, adjustable options and options that can accommodate larger bodies
- Maintain physical space between seating arrangements
- Ensure as many options to adjust lighting as possible
    - This can include lighting that is dimmable or flexibly controlled lighting to accommodate individual needs
- Create clearly defined zones or boundaries (using half-walls, curved walls, drapes, partitions, and more) to help create a sense of privacy and safety
- Ensure good sound insulation, proper ventilation, temperature controls, and no strong smells
- Implement visual supports, such as signs and wayfinding aids with pictures, pictograms, colors, or small sentences, to assist with navigating the space independently and easily

4.2. Design Minimal Stimulation Spaces

- Designate quiet spaces on each floor and in each building with clear, simple layouts
- Create sensory-safe rooms that are separated from other environments with organic, curvilinear forms, natural lighting and/or warmer LED lighting (600-800 lumens), increased sound absorption in walls and comforting sensory items
- Offer ear plugs or headphones, sunglasses, fidget toys to help reduce sensory overload

By considering and accommodating the sensory needs of neurodivergent individuals, standards developers can create more inclusive and supportive environments that enhance the well-being and participation of all users.

Recommended Practice 5: Design proactively and be responsive to the needs of neurodivergent people

To enhance neuroinclusivity in standards development, it is essential to consider the diverse needs of neurodivergent individuals. This recommendation applies to both the content and process of standards development. We specifically recommend that standards developers:

5.1. Empower Neurodivergent Participation

- Allow neurodivergent individuals to choose how they participate, such as joining virtual committee meetings without their camera on and using their preferred communication style (e.g., spoken vs. written – see Recommended Practice 3)
- Provide flexibility in the choice of hardware and software for their computers

- Offer flexible physical environments (see Recommended Practice 4)

5.2. Offer Accommodations Without Barriers

- Provide accommodations to anyone who needs them without suspicion or overly complicated procedures to qualify

5.3. Accept and Support Personalized Resources

- Embrace the concept of presuming competence, which requires believing that neurodivergent individuals are capable of change and growth. Understand that through active engagement with the world, neurodivergent individuals will exhibit complexities in thought and action that may not have been anticipated (Biklen & Burke, 2006)
- Avoid interpreting performance difficulties as indicators of intellectual incapacity. Instead, assume there is a rational or empathetic explanation for their actions and strive to understand this explanation from their own perspective (Biklen & Burke, 2006)
- Be accepting and aware of the various personalized resources individuals use to navigate society meaningfully

5.4. Design with the experiences, needs, and strengths of neurodivergence in mind from the outset

- Consider neuroinclusivity during the planning and design stages to reduce the need for reactive interventions later on in the standards development process
- Content of standards should include universal and inclusive design strategy, particularly when relating to new developments (i.e., new buildings, new educational programs, new services being implemented, etc.)
    - When neurodivergent experiences are considered in the design, the outputs will be more neuroinclusive
- Consult with other standards developers who have been working to infuse neuroinclusivity into their process and/or the content of the standards that they develop
    - Including architectural standards related to sensory-friendly design, building standards related to acoustics, communication professionals who design inclusive signage and wayfinding

6. Implementation Guidelines

This document will help you implement the key recommendations for promoting neuroinclusivity in the standards development process.

Please visit our webpage: https://carleton.ca/accessibility-institute/standards-development/

Below is an overview of how and when to integrate our recommended practices into the standards development process. Please note that education about neurodivergence is emphasized as a key recommendation at the start of the development process, but we encourage you to always take the initiative to learn more about neuroinclusivity at any stage of standards development.

Stage 1: Identification of a need for a new standard

- Take educational and/or training programs about neurodivergence (e.g., understanding who falls under the umbrella of neurodivergence and that the inclusion criteria to be considered neurodivergent is flexible and always evolving), models and theories of disability, and intersectionality.
- Speak with neurodivergent people who are interested in advocating and teaching others about their experience, to learn more about their lived experiences navigating barriers in Canadian society. Approach these conversations with an open mind, readiness to self-reflect and intentionality to apply your learnings
- Share educational resources on neuroinclusivity with colleagues and others involved in this stage of standards development.
- Be accepting and aware of everyone's sensory preferences and the ways in which people use personalized meaningful resources to navigate society.

Stage 2: Forming the technical committee and drafting the proposal

- Actively work to recruit a diverse group of neurodivergent people (e.g., neurodivergent type, and other intersectionality identities they may hold) to sit on technical committees.
- Ensure that all recruitment materials are clear, straightforward, and do not focus on abstract abilities which can deter potential interest in participation when recruiting technical committee members.
- Provide detailed directions and instructions to participate in the technical committees using plain language.

Stage 3: Draft the standards document

- Create standards that are simple, transparent, flexible, and easy to understand (jargon words or overly complicated terms without corresponding glossaries).
- Create standards based on Universal Design and Inclusive Design Principles to ensure that they will work for many Canadians, including those with non-visible disabilities.
- Have a designated person (who is familiar with accessibility) who can support everyone by providing detailed notes (in advance), meeting summaries, and assistance throughout the standards development process.
- Offer accommodation to anyone who needs it without suspicion and overly complicated procedures required to qualify for it.
- Offer tools and resources to reduce the impacts of sensory overload such as ear plugs or headphones, adjustments to lighting, sunglasses, fidget toys, flexible seating, and quiet places with seating.
- Create flexible environments where committee members can tailor their environments based on their preferences.

Stage 4: Engage in public consultation on the proposed standard

- Actively work to get feedback from a diverse group of neurodivergent people.
- Once again, ensure that all materials are clear, straightforward, and do not focus on abstract abilities which can deter potential interest in participation when looking for feedback on the proposed standard.

Stage 5: Review, publish, and maintain standards

- Ensure that published standards are written in plain language, are easy to understand, and provided in accessible formats.
- Provide options for standards to be widely available and accessible in different formats or through various communication methods.
- Review existing standards through a neuroinclusive lens, such as our recommended practices (Section 5 outlined above).

7. Knowledge Mobilization

To bridge the gap between research and practice, we have undertaken several steps to ensure that the results of our research project are effectively disseminated. Our project outputs include:

- Conference presentations at both local and international conferences:

- The Autism Alliance of Canada's 10th Annual Canadian Autism Leadership Summitt (CALS), was in Ottawa, Ontario in April 2024. Our team participated in the Community Showcase (poster session) where we asked visitors to share some suggestions, they may have for neuroinclusivity in standards development. Visitors shared the importance of providing neurodivergent people with the same opportunities that are offered to all and having neurodivergent people as representatives in committee work.
  - The City University of New York's (CUNY) Neurodiversity Conference 2024 (Neurodiversity and Mental Health: Navigating Wellness) was in New York City in April 2024. At this conference we presented (oral presentation with handouts) the preliminary results of our findings and discussed the challenges that the audience were facing in their respective fields (e.g., educators, lawyers, etc.).
- Plain-language, accessible reports in both English and French that will be shared with our networks and participants from our research via email at the end of our project.
- We will be launching an online campaign at the end of our research project where standards developers can opt-in to receive additional emails from our team. These emails will contain links to specific toolkit resources, and educational materials that they can use when creating standards in their sectors. We will also be sharing the toolkit and relevant resources with standards development organizations via email.
- Our project findings with a select focus will be published in a peer-reviewed journal.
- Project outputs will be hosted long-term on the Accessibility Institute website.

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9. Appendix A: Demographic Information

Table 5 Neurodivergent Community and Standards Developers Demographic Information

What is the year of your birth?		
Year	**ND Participants**	**SD Participants**
2000-2005	9	0
1990-1999	19	1
1980-1989	20	4
1970-1979	19	5
1960-1969	7	1
1950-1959	0	2
How many years have you worked in standards development?		
Years	**ND Participants**	**SD Participants**
1-2	N/A	3
3-5	N/A	5
5+	N/A	6
What is your race and/or ethnicity?		
Race/Ethnicity	**ND Participants**	**SD Participants**
White	58	10
South Asian	1	1
Métis	3	0
First Nations	2	0

Middle Eastern	1	0
Latin American	2	0
Chinese	2	0
Black	4	1

Other than your primary language, what language(s) do you read, write and/or speak fluently?		
Language	ND Participants	SD Participants
Tamil	1	0
Spanish	4	0
Russian	1	0
Scottish Gaelic	1	0
Fula	1	0
French	18	3
Arabic	1	0
English	2	1
Italian	1	0
Latvian	1	0
Cantonese	2	0

What is your gender identity?		
Gender Identity	ND Participants	SD Participants
Woman	42	8
Man	15	3

Two Spirit	0	1
Unique Individual Gender Trajectory	1	0
Transmasculine	1	0
Nonbinary	3	0
Genderfluid	2	0
Butch	1	0
Genderqueer	3	0
Gender Nonconforming	1	0
Femme	2	0
Autigender	1	0
Genderfae	1	0

What is your sexual identity?		
Sexual Identity	**ND Participants**	**SD Participants**
Heterosexual/Straight	39	8
Questioning	1	0
Queer	10	0
Lesbian	3	0
Dyke	1	0
Pansexual	3	1
Homosexual	1	0
Gay	1	0

Demisexual	4	0
Bisexual	13	1
Asexual	4	0
Almost asexual	1	
Polyamorous	1	0
Aceflux	1	0
Neuroqueer	1	0

What is your neurodivergent type?		
Neurodivergent Type	**ND Participants**	**SD Participants**
Autism (ASD)	40	N/A
Attention-Deficit/ Hyperactivity Disorder (ADHD) /Attention Deficit Disorder (ADD)	53	N/A
Obsessive Compulsive Disorder (OCD)	4	N/A
Learning Disability	10	N/A
Highly Sensitive Person (HSP)	1	N/A
Depression	1	N/A
Anxiety	3	N/A
Post Traumatic Stress Disorder (PTSD)	1	N/A

Seasonal Affective Disorder (SAD)	1	N/A
Dyslexia	1	N/A
Dyspraxia	1	N/A
Sensory Processing Disorder	1	N/A
Dyscalculia	1	N/A
Alien	1	N/A
Bipolar	1	N/A
Auditory Processing Disorder	1	N/A
Post Concussion Syndrome	1	N/A
Other	1	N/A
Are you a newcomer to Canada?		
No participants identified as newcomers to Canada		