# Neuro-Inclusion in P2

A Research Paper by the International Association for Public Participation Canada



A group of people sitting around a meeting room.

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#### Introduction

In an era committed to equity, diversity and inclusion (EDI) ensuring public engagement is neuro-inclusive is crucial for truly representative and participatory societies.

In this paper, we explore neuro-inclusion within the broader context of initiatives dedicated to honouring the strengths and contributions of every individual. This research provides a starting point for engagement practitioners, including key definitions, practical tips, and adjustments the public participation sector can take to enhance inclusivity and embrace diversity of the mind.

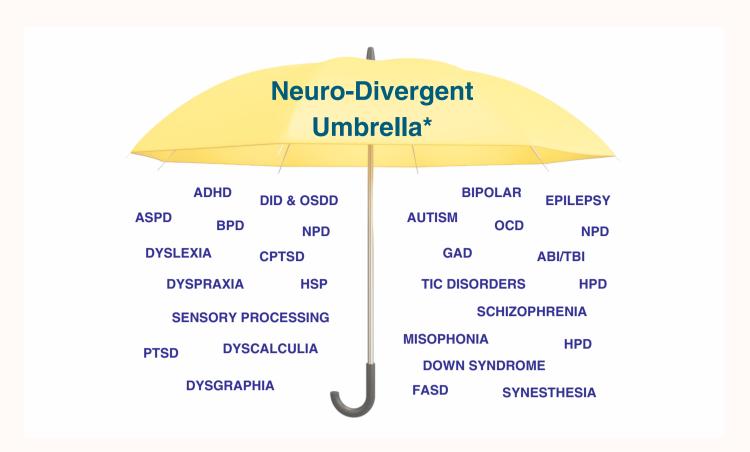
#### **Defining and Framing Neurodivergence**

Let's start with definitions and concepts derived from Wise's "We're All Neurodiverse" (2023). Neurodiversity encompasses the diversity and variability of human minds, describing unique ways individuals exist, think, act, process, feel, and function. The term neurodiverse represents the entire spectrum, including both neurodivergent and neurotypical individuals.

Neurotypical refers to aligning with societal standards, while neurodivergent is an umbrella term for diverging from these norms in cognitive functioning.

Under the neurodivergent umbrella, diverse neurotypes exist. While there is overlap, each neurotype has its own characteristics, which contributes to the richness of neurodiversity. Neurodivergence can occur from birth or be acquired later in life. An estimated 15-20 percent of the world's population exhibits some form of neurodivergence (Doyle, 2020).

In an era committed to equity, diversity and inclusion ensuring public engagement is neuro-inclusive is crucial for truly representative and participatory societies.



The neurodivergent umbrella (\*non-exhaustive list) includes individuals with diverse cognitive functioning, such as Autism, ADHD, Tourette's (a tic disorder) and Dyslexia. Image adapted from: LivedExperienceEducator.com

Wise explains that neurodivergence has historically been framed by the "medical model", labelling behaviours and traits as abnormal or indicative of disorders. This predominantly shapes how neurodivergent individuals are perceived and framed.

In contrast, the "social model of disability" views disability as a consequence of societal barriers, not inherent differences (Wise, 2024). A neuro-affirming approach views neurodivergent individuals as whole rather than in need of fixing. The neurodiversity movement seeks to reshape mainstream perceptions by challenging deficit-based stereotypes, fostering a balanced understanding of strengths and needs and promoting accessibility.

#### **Identity-First Language vs. Person-First Language**

Throughout this paper we use identity-first language. For example, "neurodivergent people" is used, instead of "people who are neurodivergent". There is a preference by the neurodivergent community to use identity-first language (Crisp, 2023). The reasoning is that a neurodivergent person is neurodivergent, they don't have neurodivergence. Increasingly, it is an important part of identity that they are embracing. Some people still prefer person-first language, so it is best to ask someone if you are speaking about or to them which to use. The neurodivergent authors of this paper prefer identity-first language.

#### **Methodology and Literature Review**

This paper was developed combining descriptive and exploratory research methods, with primary and secondary sources. The research was guided by a principle of centering on neurodivergent lived experience and intersectionality. Primary research involved one qualitative and quantitative survey, one focus group, and eight interviews covering topics related to engagement satisfaction, psychological safety, neurodivergent experiences, and professional insights.

The survey garnered 40 responses. Individuals who reported identifying as neurodivergent (27) accounted for 68% of all respondents.

Neurotypes represented included: ADHD, Autism, Dyscalculia, Dyslexia, Dysgraphia, Dyspraxia, Hyperlexia, Sensory Processing Disorders, Tourette's / Tic Disorders. Over half of respondents reported two or more neurotypes.

Research participants also included people who have participated in public participation (P2) before, have a loved one who is neurodivergent, or who identified themselves as advocates.

The focus group brought three P2 professionals together to discuss solutions for other P2 practitioners. While neurodivergence was not a criterion to participate, the participants identified having a neurodivergent diagnosis or suspected they may be neurodivergent (ADHD, Autism, Dyslexia).

Eight interviews focused on the neurodivergent experience and engagement barriers. Neurotypes included ADHD, Autism, Epilepsy (absence seizures), and Tourette's. Our findings and the tips outlined in this report are drawn primarily from advice from these interviews.

The secondary research and literature review is based on books, articles, and online content including blogs and social media. In recent years, there has been a positive shift towards more contributions from content creators and researchers with (neurodivergent) lived experience and intersectional perspectives.



Wooden figures of different sizes and shapes being looked at under a magnifying glass.

"I have found a lot of information about how to support my child at school but nothing for the work we do (P2). I think we have catching up to do."

Current literature focusing on understanding and addressing challenges faced by neurodivergent individuals is growing, however it is most prevalent in areas of education and workplace inclusion.

One interview participant told us, "I have found a lot of information about how to support my child at school but nothing for the work we do (P2). I think we have catching up to do".

Our research uncovered one plain language guide focused on engagement tips to better support neurodivergent participants (BECG, 2021).

#### **How Neurodivergent Participants Arrive to Participate**

Neurodivergent people may present differently and have diverse needs when it comes to memory, self-awareness, self-regulation, focus, sensory processing, communication styles, and more (Aherne & Stringer, 2023; Maskell, 2023, Wise, 2024). For example, neurodivergent people may diverge from "normal" or "acceptable" communication styles. This can include being non-speaking, verbal tics, auditory stimming, communicating at various speeds, more or less than others, being very literal or being more prone to interrupting.

#### **Strengths of Neurodivergent People**

The strengths of neurodivergent people can depend on the neurotype though individuals with the same diagnosis can also have unique strengths. All of our strengths and weaknesses are a web of our intersectional genetics, cultures, and life experiences. Through the survey and interviews (2023), neurodivergent participants identified several strengths in themselves. The top identified strengths were:

- · Concentration, including hyperfocus
- The ability to make connections / find patterns and trends
- The ability to visualize thoughts / information
- · Critical / analytical thinking
- Authenticity
- · Honest and straightforward
- · Passion for justice and fairness
- · Creative problem solving
- · Empathy and understanding
- "Big picture" processing
- Compassion
- Strategic thinking



Brain and lightbulb concept to represent creativity, thinking and ideas.



An upset male sitting alone with a group of people sitting at a table behind him.

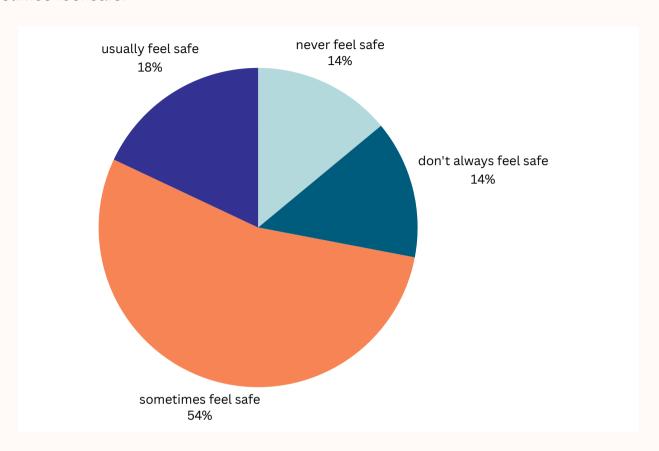
## "I don't think I would go to a public meeting. I don't want to bother people."

Notably having divergent thinking is why a person who is neurodivergent is stronger in areas such as creativity and problem solving than neurotypical individuals (White and Shaw, 2011).

It is a common presentation for a neurodivergent individual to exhibit compassion, creativity and justice or offer their strong analytical and research skills. In activities designed to improve decisions using public feedback it would seem these strengths would be welcome. However, 69% of survey responses identified the understanding of neurodivergence presents a barrier to participation.

Neurodivergent people also share the common experiences of not feeling a sense of belonging, being misinterpreted, misunderstood, stigmatized, shamed, and marginalized. As one young interview participant told us: "I don't think I would go to a public meeting. I don't want to bother people." Ultimately people who feel this way may never share their strengths.

When asked in our survey how often they "feel psychologically safe to express themselves and be who they are", only 18% of neurodivergent participants reported usually feeling safe, 14% reported never feeling safe, 14% reported not always feeling safe, 54% reported sometimes feel safe.



#### Camouflaging

Camouflaging, a survival tactic, involves adjusting to fit societal norms. Belcher (2022) defines camouflaging as a dynamic spectrum, including masking (hiding neurodivergent traits to appear neurotypical) and compensation (making up for traits through learned behaviours). Both are energy-intensive and can contribute to a shame-fueled cycle, prioritizing the comfort of socially advantaged people over the psychological safety of neurodivergent individuals. Chronic camouflaging, especially in combination with other tactics used to fit in such as code-switching (adjusting language, style of speech, appearance, behaviour, and expression to increase the comfort of others for fair treatment, service, and opportunities) (Harvard Business Review, 2019; HowToADHD, 2020), increases the risk of burnout. Understanding and addressing these camouflaging traits can better support neurodivergent individuals in our P2 practices.

#### **Unmasking**

For some, especially those realizing their neurodivergence later in life, unmasking can be challenging due to years of concealing their authentic selves to fit in. Unmasking requires feeling psychologically safe.

Regardless of their experiences and feelings of psychological safety, 96% of neurodivergent participants in our survey reported difficulties when participating in P2 activities and identified adjustments that would better enable them to engage.



A businessman holding a mask in front of his face with his colleagues standing beside him.

#### **How P2 Can Improve**

We must trust that people know themselves and what they need. Across our primary research, we heard that providing options and empowering choice is fundamental in advancing an inclusive environment. By empowering choice, we create a supportive atmosphere where autonomy is honoured, contributing to a more equitable experience for all participants. The facilitator's role is to ensure everyone is included, regardless of how they present themselves.

True inclusivity requires adopting a neuro-affirming, trauma-informed approach. In a trauma-informed approach, the role of building and maintaining trust cannot be overstated (SAMHSA, 2014). Trust fosters a sense of security, predictability, and safety. It allows for open communication, empowering individuals to share their experiences without fear of judgement. Maintaining trust is an ongoing commitment. It is a complex task to plan for the wide spectrum of neurodiversity. Addressing diversity in neuro-inclusion paired with other equity and inclusion needs is challenging. It can be difficult to figure out where to begin and how to improve our P2 work to be more neuro-inclusive.

From the perspective of the neurodivergent participants we spoke to, diversity of the mind is not a visible priority in P2 and EDI strategies. However, strategies for improving accessibility and focusing on inclusion for others experiencing barriers in P2 are likely to be useful adjustments for neurodivergent participants as well. For example, following accessibility guidelines so that screen readers work for people with low vision may also help someone with Dyslexia or ADHD focus on written materials.



A woman sitting at a desk and looking at a computer screen.

#### **Tips and Adjustments**

The following tips have been informed and validated by primary research participants who identified as being neurodivergent.

#### **Material Design Considerations**

Digital and printed materials should follow accessibility guidelines to help neurodivergent participants get through written content. It is useful to incorporate colour coding using accessible, colour-blind friendly palettes. See appendix for more design considerations (The Advonet Group, 2021).

For those with memory or executive functioning differences, providing succinct written materials to support verbal presentations can be helpful (e.g. background materials, supporting documents, instructions, transcripts, etc.).

#### **Planning**

Add adjustments into your engagement plan from the onset. Plan for flexibility and be prepared for someone needing adjustments during the activity. Set aside more time to allow for different processing speeds, communication styles and breaks, especially for activities that are over an hour. The number one barrier to participation reported by 78% of survey participants was presentations that are too long. Keep presentations short or break them up into smaller parts and encourage clients and consultants to do the same.

One barrier noted by neurodivergent survey participants (56%) is a lack of flexibility in how feedback is collected. Offering a range of activities, such as both small and large groups or online activities for different learning styles or for someone who finds traditional open houses over stimulating.

#### In Advance

An important thing you can do for neurodivergent people, or for anyone new to participating in public engagement activities, is to provide detailed information about what to expect as a participant. According to our primary research, mental health conditions, including anxiety are a common co-occurrence for neurodivergent people; feelings of stress and anxiety can be heightened by the unknown.

One study participant explained how much more at ease they would be if maps were provided, both literally and figuratively, to prepare for the session in ways that work for them. Maps can help someone identify adjustments to request beforehand.

In these maps provide key information, including format, topics, and the environment. This can be a building or room floor plan identifying physical items such as tables, chairs, and information boards as well as the topic and type of conversations planned in the space. If a participant knows how the room will be set up, they can identify where to sit in case they need to make a quiet exit. If there is a large group discussion component, the participant can ask in advance not to be called upon to speak if they do not volunteer to. Maps are useful for other equity and accessibility needs, indicating accessible entrances, washrooms, seating/ rest areas, security locations, etc.

In some instances, sending materials in advance can be problematic depending on the topic and its context. Advanced materials without the correct narrative can be misunderstood, taken out of context or even weaponized by some community members or interest holders. When we can't send out advance materials to accommodate neurodivergent participants, let participants know in general what they can expect to be discussed and what they will be providing feedback on.

A friend, colleague or support animal can make a big difference for some neurodivergent participants. They can bring a calming presence, help work through specific struggles (e.g., staying on task or interrupting), encourage strengths or provide an outside voice. When online, turn on assistive technologies such as closed captioning, text to speech, speech to text and other customizable settings on digital platforms. One participant reported, "I've attended a number of virtual meetings where closed captioning was not enabled and I just leave or zone out because I can't follow along." Always enable these and communicate that they will be enabled for every meeting.

Offer pre-engagement questionnaires asking for adjustments, needs, concerns or questions before an activity. In your questionnaire ask questions about needs for communicating or processing, preferred materials etc. rather than asking participants to disclose a neurotype.

"I've attended a number of virtual meetings where closed captioning was not enabled and I just leave or zone out because I can't follow along."

#### The Day of the Activity

The first thing to do as you begin, is to create a safe and welcoming space. In virtual and in-person activities, welcome and orient people as they arrive. Let participants know that you are there to make their experience an excellent one and that you are a safe place to come no matter the request.

Normalize adjustments and offer them without the need to disclose. Disclosing is an individual decision and may feel unsafe. Further, given the prevalence of being undiagnosed or misdiagnosed (Smith, & Kirby, 2022), not all neurodivergent individuals know that they are neurodivergent which can make it more difficult to advocate for oneself. In the survey, 48% of responses from neurodivergent individuals identified a lack of clarity or instruction as a primary obstacle.

As you begin, spark interest by sharing the objectives and purpose of the activity, provide context and allow for questions before starting. Communicate in advance when breaks will happen and commit to the schedule. Be clear with your expectations, instructions, and questions. It is preferred that we are direct and not imply or assume something is known. Repeat key information both in written materials and verbally.

Offer and encourage the use of support tools (e.g., doodling, note taking, focus toys, closed captioning, etc.). There are online fidgets available too. We heard in focus groups and interviews that a benefit of meeting online from home is that they are already in an environment perfectly suited to them with their favourite tools available.



A person sitting at a desk having a virtual meeting with a diverse group of people.

#### **Continuous Improvement**

Let participants know they can come to you or pass you a note before the session or during a break to request what they need. Monitor the room. If people seem to be struggling, adjust. If they express that they are encountering barriers, listen, and adapt. Immediately following the activity, share a short post engagement survey to collect feedback before it is forgotten. Having no opportunity to follow up was a barrier for meaningful participation for 48% of neurodivergent survey participants.

#### **Our Commitment**

This work involves navigating and embracing discomfort. It requires a departure from the familiar and a willingness to embrace other perspectives and ways of being. In the pursuit of equity, we must prioritize each individual's safety and well-being over the comfort of another. A crucial part of the transformative process toward a more inclusive and equitable future asks that we become comfortable with discomfort.

While inclusion is a necessary step, it is not the ultimate goal. Diversity encompasses the variety of voices and perspectives, inclusion involves inviting diverse voices in, and equity moves beyond that. Equity seeks to rectify historic and ongoing imbalances and empower those who have been marginalized (Beyond Inclusion: Equity in Public Engagement, 2020). Equity recognizes that simply inviting someone to participate is insufficient. True equity involves dismantling systemic barriers, and actively involving marginalized, equity-deserving (denied) voices in shaping policies, practices, and society as a whole. It goes beyond representation to address the root causes of inequality.

#### Conclusion

The objective of this paper was to explore the strengths that neurodivergent participants can contribute to decision-making processes, identify the barriers they might encounter, and propose adjustments to alleviate some of these barriers within the broader framework of equity, diversity, and inclusion.

Our suggestions are a starting point. We invite you to join us in making neuro-affirming and neuro-inclusive P2 activities. This involves continuing the conversation and supporting each other as we collectively work through our biases, challenging discussions, and discomfort. Continue to (un)learn and check assumptions. Invest in training on neurodiversity. Moving forward, to effectively remove barriers, prioritize and centre those with lived experience, especially those who offer an intersectional perspective. We are in this together and everyone can make a difference.

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#### **Appendix**

#### **Key Definitions**

#### **Neurodiversity**

Neurodiversity, coined by Judy Singer, encompasses the diversity and variability of human minds, describing unique ways individuals exist, think, act, process, feel, and function. The term neurodiverse represents the entire spectrum (everyone), including both neurodivergent and neurotypical individuals (Wise, 2024).

#### Neurodivergent

Neurodivergent, coined by Kassiane Asasumasu (formerly Kassiane Sibley), is an umbrella term that refers to anyone whose mind or functioning differs from what is considered typical or normal with regards to mental or neurological functioning. Functioning differently can refer to thinking, processing, interpreting, feeling, communicating, socializing, behaving, and more (Wise, 2024).

#### **Neurotypical**

Neurotypical, refers to those whose mind or functioning falls within dominant standards and norms (Wise, 2024).

#### Intersectionality

Intersectionality, coined by Kimberlé Crenshaw, is an analytical lens that recognizes the complex relationship between power structures and individual lived experiences where one's lived experience is influenced by multiple aspects of their identity and social location (e.g., their age, disability, gender, race, sexuality, socioeconomic background, and more). These intersecting factors can "magnify experiences of discrimination and disadvantage, and create unique circumstances that impact accessibility, safety, inclusion and equity in public engagement processes (Beyond Inclusion: Equity in Public Engagement, 2020)".

#### **Neurodiversity Affirming Practice**



Adapted from: LivedExperienceEducator.com

#### A Sample of Helpful Adjustments for Neurodivergent Participants

 Allow participants to keep camera off More frequent breaks (online engagement) • Having the ability to fidget (e.g. Use of visual materials providing fidget toys, doodle pads) and move around (while seated or around room) Having the option to not verbally • Paper provided to write down thoughts participate or to pass and questions • Including a balanced mix of solo, • Minimize additional noise (e.g., ticking partner and group activities clocks, HVAC systems, music) Getting a clear schedule of the day / • Quiet, less stimulating spaces to retreat engagement session to if needed • Written questions, instructions, and More individual activities summaries Getting specific, detailed information Not to be called upon and instructions · Clear questions, instructions and • More partner / group activities summaries Materials shared in advance Larger screens Closed captioning (virtual meetings) Repeat key information in multiple

formats

#### Offering an Inclusive Space

#### Sample script:

Welcome everyone and thank you for joining us today. Before we dive in, I want to take a moment to emphasise that this space is meant to be inclusive and safe for everyone. We value the diversity of experiences and perspectives that each of you brings. Our goal is to ensure that everyone feels welcome and valued. Thank you for being here.

Please feel free to offer feedback in a way that feels safe and comfortable to you. If at any point you need to step back, take a break, get up and move around, or simply pass on sharing, please do so. We encourage you to be mindful of your own needs and take care of yourself throughout our time together.

Let's support one another and create an environment where everyone feels heard and respected. If you have any concerns or suggestions on how we can make this space more inclusive or work better for you, please don't hesitate to let us know.

#### Content considerations including digital content design tips:

- Incorporate graphics and maps where applicable.
- Include alt text for all images (to support the use of screen readers).
- Use short sentences and paragraphs.
- Format text styles. Such as using headings and subheadings.
- Underline links.
- Do not use all caps or all lower-case.
- Use a larger sans font (avoid serif fonts, cursive or complicated letter shapes), at least 16pt where possible.
- Line spacing of at least 1.15 (ideally 1.5).
- Minimize "visual noise". Keep things simple in design and minimize elements that distract the viewer from the most important information.
- · Use colour minimally and strategically.
- Use high contrast, accessible (colour blind friendly) palettes.
- Use dark coloured text on pastel-coloured backgrounds.
- Save PDFs as accessible documents.

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The meetings consisted of personal interviews with neurodivergent participants conducted on November 27 (two occurrences), November 28, December 5, and December 14, 2023. Additionally, there were ongoing personal interview series with neurodivergent participants spanning from December 2022 to January 2024 (two instances). Furthermore, a focus group meeting involving a participant, P2, and EDI professionals took place on December 6, 2023.

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