LANGUAGE MATTERS: TRANSFORMING HEALTHCARE FOR NEURODIVERGENT PEOPLE

A TOOLKIT FOR STARTING CONVERSATIONS IN YOUR WORKPLACE

LANGUAGE MATTERS: TRANSFORMING HEALTHCARE FOR NEURODIVERGENT PEOPLE

A TOOLKIT FOR STARTING CONVERSATIONS IN YOUR WORKPLACE

This document was originally created by Angie Ip, Mac Landerholm, and Sarah McGowan for The 4th Annual Canadian Children, Youth and Communities. This version was created for Autism Community Training.

The information included is intended as guidance for making your practice more affirming and accessible for neurodivergent people.

This toolkit is a work in progress and will continue to evolve as our understanding of neurodiversity affirming practices and the disability experience changes.

If you have any comments or suggestions for improving this toolkit, please email us at NeurodiversityAffirmingCare@gmail.com.

Our hope is to improve care for neurodiverse families and amplify the voices of neurodivergent people. Thank you to the many neurodivergent people and families who contributed to and inspired this work. Quotes from families are shared with their permission.

NOVEMBER 2024

DEFINITIONS

Neurodiversity is the natural variation in neurocognitive functioning, including 'neurotypical' and 'neurodivergent' populations.

Neurodivergent describes people whose neurotype and brain function differs from the neuromajority.

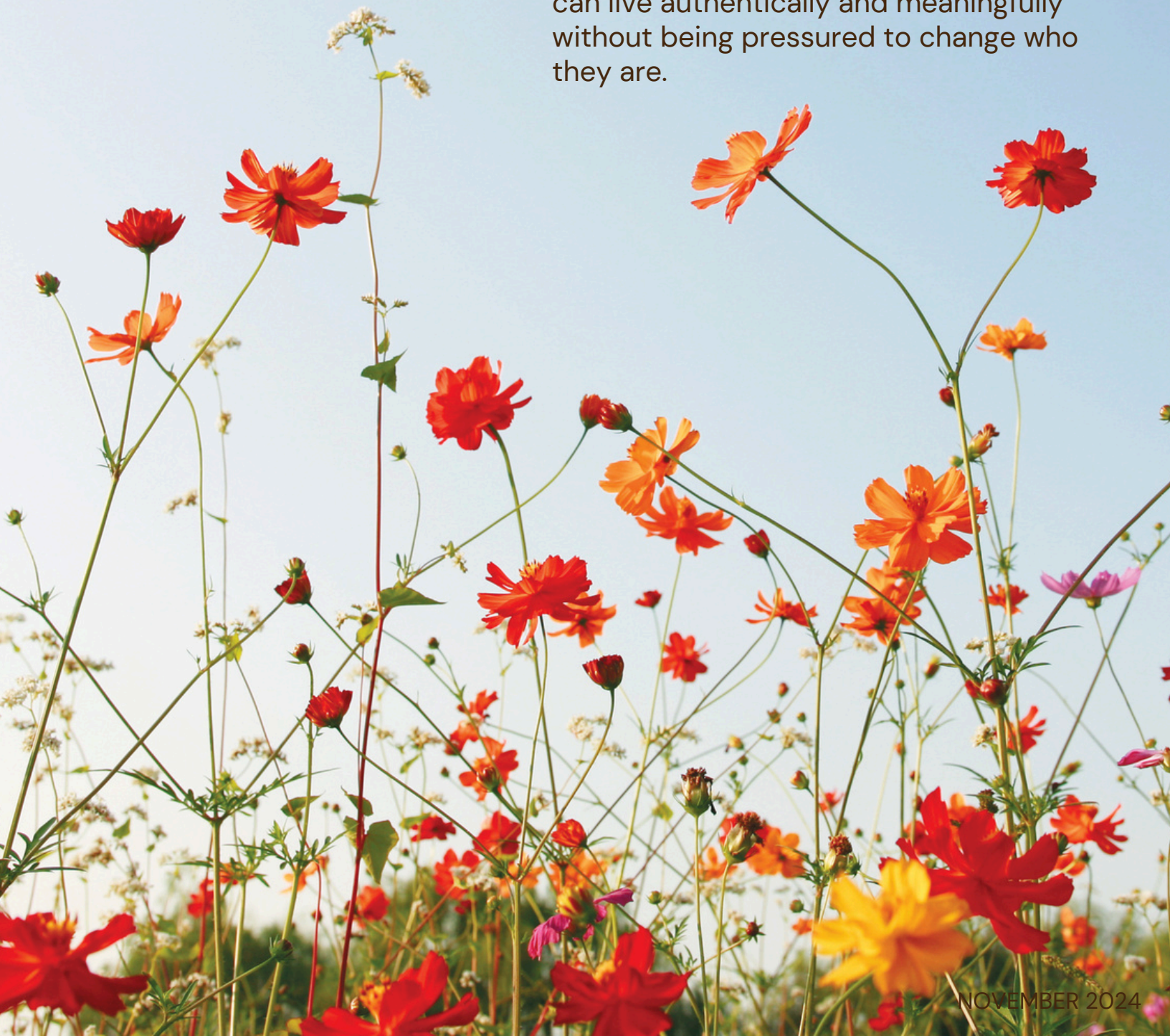
The **neurodiversity movement** is a social justice movement advocating for the inclusion of all neurodivergent people within the disability rights movement. It challenges the notion that neurological differences are pathological and it affirms that it is societal ableism, rather than neurotype, that disables neurodivergent people. The movement campaigns for supports and modifications rather than interventions intended to fix deficits and make people more neurotypical.

Intersectionality is a framework that recognizes how different aspects of a person's identity - such as race, gender, class, sexuality, disability, and more - intersect and combine to create unique experiences of privilege or discrimination. It highlights that people's experiences are shaped by the multiple, overlapping social categories they belong to, rather than by any single factor alone.

WHAT ARE THE CENTRAL GOALS OF NEURODIVERSITY AFFIRMING CARE?

The goals of neurodiversity affirming care include respecting neurodiversity, working collaboratively, encouraging self-determination and agency, promoting well being, and fostering more inclusive and accessible environments (Dwyer, 2019).

Neurodiversity affirming care focuses on celebrating neurodivergence, honoring individual differences, and creating spaces where neurodivergent individuals can live authentically and meaningfully without being pressured to change who they are.



REFRAMING & REWORDING DISABILITY

Using language that respects and empowers individuals is essential for promoting their wellbeing (Dwyer, 2019b). When we consider every person's intersecting identities, neurodiversity affirming care looks different for every person and is also shaped by the intersections of the person providing that care.

The importance of reflecting and changing our language, is therefore not just about words, it is a fundamental shift in how we think about disability and neurodivergence.

In this toolkit, we offer guidance based on current best practices. Keep in mind that neurodiversity affirming health care practices will and should continue to evolve.

GUIDING PRINCIPLES FOR LANGUAGE AND COMMUNICATION

Here are some general guiding principles around language and communicating with clients and families. These guidelines apply both to your spoken and non-verbal communication.

1. Speak to clients and family members about their preferred language.

2. Describe the specific behaviors that you are observing. Focus on what you see rather than what you think is missing. Use relevant and specific descriptions of a person's strengths, support needs,, and behaviors in a context dependent manner (Dwyer et al., 2022).

3. Avoid judgment of the behavior and your own interpretation of the meaning behind the behavior. This includes avoiding replicating the normal and abnormal binary in your language (Bottema-Beutel et al., 2021).

4. Avoid language that medicalizes neurodivergence or suggests that something needs to be fixed or cured.

5. Rather than referring to "treatment for a diagnosis," describe the area of need or challenge we are supporting with adaptations, therapy, and other supports.

Be mindful of your non-verbal communication. How we communicate nonverbally is just as important as the words we use. Our tone of voice, facial expressions, and body language add meaning to our spoken messages and affect how they are interpreted and received.

ACTIVITY

RESHAPING LANGUAGE

This activity focuses on reshaping language that may emphasize deficits or carry value judgments, transforming it into neutral and strengths-based terminology.

Use the following list to explore neutral or positive alternatives for these commonly used terms and phrases to foster a more supportive and affirming environment.

High functioning Low functioning	
Differently-abled Special needs	
Struggles with	
Deficit Impairment	
Abnormal Abnormalities in	

ACTIVITY

RESHAPING LANGUAGE

Obsessed Fixated Unusual interest	
Inflexible Rigid	
Problem Disruptive Non-compliant Defiant	
Childish Immature	
Sensitive	
Mute Dumb Noverbal	
At risk of Red flag	
Curing Eradicating	

RESHAPING LANGUAGE

SUGGESTED ALTERNATIVES

High functioning Low functioning	This umbrella term does not capture the complexity of an individual's diverse profile of supports and modification needs (Prizant & Finch, 2020). It is best to describe specific presentations. For example, you can describe someone as non-speaking and an augmented and alternative communication user. Or you can described someone's support and modification needs. For example, "this person benefits from the presence of a safe-person during social interactions with unfamiliar people".
Differently-abled Special needs	"Disabled" or "has a disability" depending on the person's preference. Disability is not a bad word. Intellectually or developmentally disabled are less infantilizing options. You can also list the person's support needs.
Struggles with	"Needs support with" is a solutions based description recognizing a person's capacity to succeed with support.
Deficit Impairment	Difficulty Differences

> It's not less than, it's difference. Deficit suggests we can get the kid up to some sort of baseline and there is no baseline.
> - Parent

RESHAPING LANGUAGE

SUGGESTED ALTERNATIVES

Abnormal Abnormalities in	Describe the behavior. Using the word abnormal to describe neurodivergent traits, centers neurotypicals as normal.
Obsessed Fixated Unusual interest	Describe the interests and enthusiasms and how they impact that person's life. For example: "engages in X, Y, Z, interests for five to seven hours a day and is distressed when redirection is attempted". Engagement in interests is associated with higher subjective wellbeing and they are reported to have a positive impact across life domains (Grove et al. 2018).
Inflexible Rigid	"Distressed by change" recognizes the root of the behavior. Using terms like selective or discriminating are less admonishing.
Problem Disruptive Non-compliant Defiant	Provide a specific description of the behavior. For example: self-injurious behavior, aggressive behavior, distressed behavior. To consider: Could these behaviors be emerging self-advocacy skills? (Binns 2023)

RESHAPING LANGUAGE

SUGGESTED ALTERNATIVES

Childish Immature	Open-minded, joyful, curious, playful. Or describe the specific behavior.
Sensitive	Perceptive to environment or emotionally attuned are more accurate descriptions.
Mute Dumb Nonverbal	Nonspeaking, minimally speaking, or difficulty accessing speech in specific contexts are more descriptive. Selective mutism may also be the more appropriate term for some people. A person who is non-speaking may communicate with vocalizations, and there are people who communicate verbally using communication devices. Some people may also have difficulty saying what they are thinking, and the words they speak are not what they intend to communicate.

RESHAPING LANGUAGE

SUGGESTED ALTERNATIVES

At risk of Red flag	Increased likelihood, characteristics, indicators, or traits of, are more accurate and less stigmatizing alternatives. Note that when people use “autistic traits,” they rarely use it for neutral or strengths-based characteristics, therefore perpetuating negative perceptions of autism (Bottema-Beutel et al., 2021). This can be applied to other neurotypes and disabilities.
Curing Eradicating	Curing or eradicating come from a medicalized and pathologizing approach to neurodivergence. This approach is dehumanizing to individuals who see their neurotype as integral to their personhood. Rather than referring to treatment for a diagnosis, describe the area of need or challenge we are supporting with adaptations, therapy and other supports.

FAMILY VOICES

I think people might think that something is wrong with him, I don't see that there's anything wrong with him. I don't want people to assume something is wrong with him due to their lack of education on autism. I want them to learn more about it, challenge the picture they have in their head.

His special education teacher was not reviewing sight words with him because they didn't think he was ready, even though he was already doing them at home. At times teachers expectations limit him and do not recognize his potential.

The psychologist highlighting my daughter's strengths during diagnosis helped make it a positive experience.

Apples and oranges are both fruit. One is not more fruit than another. Autism is autism, you're not more or less autistic.

OTHER CONSIDERATIONS FOR CREATING A WELCOMING AND NEURODIVERSITY AFFIRMING ENVIRONMENT

Ask about a person's access needs. In other words, what is needed for a person's optimal participation. For example, will the person need more frequent breaks, adjustments in seating, dimming the lights, an interpreter, closed captioning, visual representations, just to name a few examples. This can include an intake survey that asks for a person's access and sensory needs.

Remember that access needs can change depending on how a person is doing that day, the environment a person is in, and the context of the interaction.

Clinicians have differences in communication and access needs too. **Consider sharing** your needs with your clients to model acceptance and respect.

OTHER CONSIDERATIONS FOR CREATING A WELCOMING AND NEURODIVERSITY AFFIRMING ENVIRONMENT

Many neurodivergent people benefit from **detailed descriptions of the space** so they are cognitively and physically prepared for their appointment. This includes the sensory environment such as lights, sounds, temperature, ventilation, for example. Written and visual directions to your space and bathroom access can also be helpful.

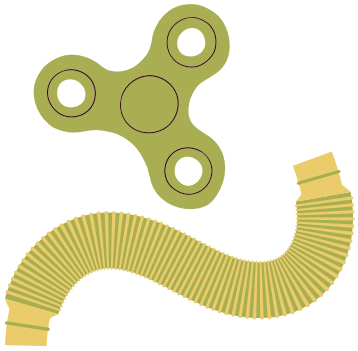
Examples of how to prepare and help orient someone to a new space

The ASAP Lab "Our Space" section of their website:
https://asap.psych.ubc.ca/our-lab-space/

Welcome to Sunny Hill, BC Children's Hospital
https://www.youtube.com/watch?v=qH2W4ntH65M

If you have control of the **space and environment**, features like dimmable lights, noise insulation, air conditioning, and comfortable chairs will improve your clients' experience in your space.

Providing **sensory tools** like headphones, earplugs, stim toys of multiple textures and movements, and multiple seating options curates a safer space to meet different needs and allow people to advocate for their own needs.



OTHER CONSIDERATIONS FOR CREATING A WELCOMING AND NEURODIVERSITY AFFIRMING ENVIRONMENT

This is an example of how we can create a welcoming environment during virtual meetings. Adapted with permission from the UBC Anxiety, Stress and Autism Lab.

We welcome written, spoken, and other forms of communication

you can use the hand raise function or indicate on video that you'd like to speak

feel free to use the chat

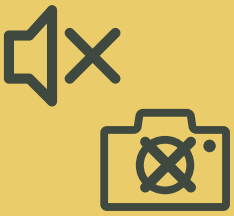
You can use ... to indicate that you are typing or preparing to share so we know to wait.

We welcome stimming

Take breaks as needed

We respect your language preferences

Turn off your camera and mute yourself as needed



Be patient with others' learning

ACTIONS FOR PROVINDING NEURODIVERSITY AFFIRMING CARE

Below are more actions you can incorporate into your day to day practice when interacting with and working with neurodivergent people, their families, and with the community.

- Validate, respect, and learn from the lived experiences of neurodivergent people and their families.
- Advocate for & train neurodivergent acceptance of differences in play, perspectives, behavior & social communication, and sensory needs (Therapist Neurodiversity Perspective, 2022).
- Support robust and self-determined communication.
- Support personal agency, self-advocacy, problem-solving, boundaries, and consent.
- Provide psychoeducation to neurodivergent people, their families and friends, and their community to increase acceptance and understanding of neurodivergence and each person's unique strengths and support needs.

ACTIVITY

CALL TO ACTION

What is at least one thing that you can improve in your clinic or organization to better support neurodivergent people and their families?

Areas to consider

- Intake process
- Physical environment
- Sharing of information with clients and families
- Report writing
- Language use

What is your action plan for enacting these changes?

What is your timeline for these changes?

How will you know you have succeeded?

Reflection

How will these changes improve care for all clients and families?
How will these changes affect and benefit your team?

FURTHER LEARNING

There are lots of great resources created by and created collaboratively with the neurodivergent community. Here are recommendations to help you get started.

AM I ABLEIST?
Disability Awareness in Healthcare

By
Marihan Farid
Abigale MacLellan
R Zachary Ford
2023

https://bit.ly/amiableist

UNIQUELY HUMAN PODCAST

Episode 5
The Harmful Myth of High-Functioning and Low-Functioning Autism, An Autism Fathers' Group, and Guest Dr. Robert Naseef

Barry Prizant and Dave Finch
2020, November 22

https://open.spotify.com/episode/7BtggkaoxEh1yk9AdHCONI?si=Opwp-1d4QWKrt67VbHOYFQ

CHANGE STARTS WITH YOU

This toolkit provides just a starting point for improving care for neurodivergent persons and families and we welcome your comments and feedback to help us continue improving this toolkit.

Implementing and improving neurodiversity affirming practices improves care for everyone.

Changing your own practices and being an agent for change takes unquenchable curiosity, compassion for yourself and others, and a healthy dose of humility. We hope you will continue to listen to and learn from the neurodivergent community.

You can reach us at
NeurodiversityAffirmingCare@gmail.com

ANGIE IP

Angie (she/her) is a family member of neurodivergent persons, a developmental pediatrician at BC Children's Hospital, researcher, and the medical director of the BC Autism Assessment Network. Angie is passionate about empowering neurodivergent voices to guide research and clinical care.

SARAH MCGOWAN

Sarah (she/her) is a Speech Language Pathologist at BC Children's Hospital. She has a background in Linguistics and over 10 years of experience as an SLP providing assessment and therapy for neurodivergent children and their families.

RACHEL FORD

Rachel (she/her) is the mom of three children, one with Down syndrome and two who are typically developing. She's also a Licensed Independent Clinical Social Worker, currently working as a Counselor at a high school. She also facilitates groups for parents of neurodivergent students at the school her children attend.

MAC LANDERHOLM

Mac (she/they) is a neurodivergent research assistant at UBC's Anxiety Stress and Autism Program Lab, facilitating their Community Advisory Board. She also has experience working as a community support worker for adolescents and young adults and inclusion supervisor.

NOVEMBER 2024

REFERENCES

Binns, A., Tran, D., Choi, L. & Oram Cardy, J. (2023, March). Meeting the needs of autistic clients: A pocket guide for SLPs (Affirming language resource). https://www.slpmaps.ca/tools

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. Autism in Adulthood, 3(1), 18–29. https://doi.org/10.1089/aut.2020.0014

Dwyer, P. (2019, June 16). On Neurodiversity: Or, How to Help People without Calling Them Broken (Part II) - Autistic Scholar. Autistic Scholar. http://www.autisticscholar.com/on-neurodiversity-ii/

Dwyer, P. (2019b, September 8). Pathology and Motivation to Access Supports - Autistic Scholar. Autistic Scholar. http://www.autisticscholar.com/pathology-and-motivation-to-access-supports/

Dwyer, P., Ryan, J. G., Williams, Z. J., & Gassner, D. L. (2022). First do no harm: suggestions regarding respectful autism language. PEDIATRICS, 149(Supplement 4). https://doi.org/10.1542/peds.2020-049437n

Farid M, MacLellan A, Ford RZ. Am I ableist? Disability awareness in healthcare. 2024. https://bit.ly/amiableist.

Grove, R., Hoekstra, R. A., Wierda, M., & Begeer, S. (2018). Special interests and subjective wellbeing in autistic adults. Autism Research, 11(5), 766–775. https://doi.org/10.1002/aur.1931

Price, D. (2022). Unmasking Autism: Discovering the New Faces of Neurodiversity. Harmony Books. New York.

Prizant, B., & Finch, D. (2020, November 22). The Harmful Myth of High-Functioning and Low-Functioning Autism; An Autism Fathers' Group; Guest Dr. Robert Naseef (episode 5). https://open.spotify.com/episode/7BtggkaoxEh1yk9AdHCONI?si=Opwp-1d4QWKrt67VbHOYFQ

Roberts, J. (2022) The Neurodiversity-Affirming Conceptual Practice Framework for Social Communication. https://therapistndc.org/wp-content/uploads/2022/10/10-Neurodiversity-Affirming-Principles-for-Therapists.pdf