NEURODIVERSITYMATTERS

An ethnographic investigation into discourse, practice, and identity

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CASWE, YORK UNIVERSITY

Land Acknowledgement

We recognize that many Indigenous Nations have longstanding relationships with the territories upon which York University campuses are located that precede the establishment of York University. York University acknowledges its presence on the traditional territory of many Indigenous Nations. The area known as Tkaronto has been care taken by the Anishinabek Nation, the Haudenosaunee Confederacy, and the Huron-Wendat. It is now home to many First Nation, Inuit and Métis communities. We acknowledge the current treaty holders, the Mississaugas of the Credit First Nation. This territory is subject of the Dish with One Spoon Wampum Belt Covenant, an agreement to peaceably share and care for the Great Lakes region.

◦ see https://www.federationhss.ca/sites/default/files/2023-02/Indigenous-protocols-Congress-2023.pdf

"Neurodiversity Matters" research project

- Funded by a SSHRC Insight Development Grant, 2019-2022; UW SSHRC Exchange Grant 2022; Renison University College Research Grants 2018, 2022, 2023

- Two branches of the research

  1. Discourse analysis

  - Critical examination of academic publications on neurodiversity
    - livingstone, Gibson, Douglas, Leo, & Gruson-Wood (In Press). Weighing in: academic writers on neurodiversity. *International Journal of Disability and Social Justice*.

  2. Institutional Ethnography (Dorothy Smith, 2005)

  - Observations of 7 public, online events

  - Interviews with 60 people who had thoughts to share about neurodiversity – this is our focus for today

What is neurodiversity?

- Attributed to Judy Singer & Harvey Blume in 1998
  Increasing popularity and recognition in recent years
  (e.g. Silberman, 2016)

- ND challenges the dominant beliefs that many human
  differences and experiences are "pathological" or that
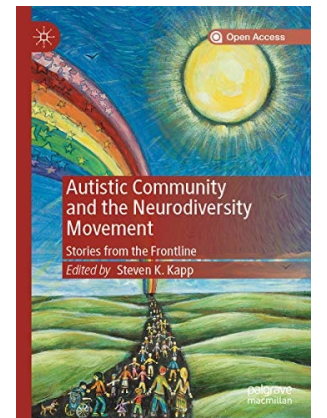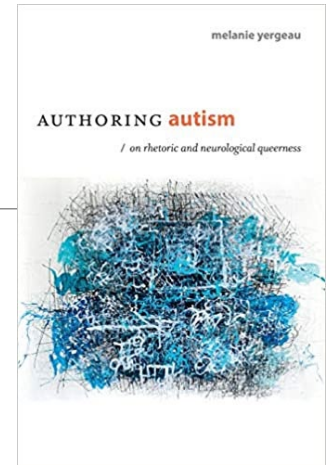 they should be "fixed"
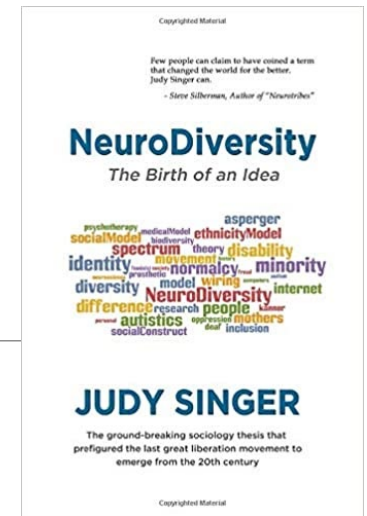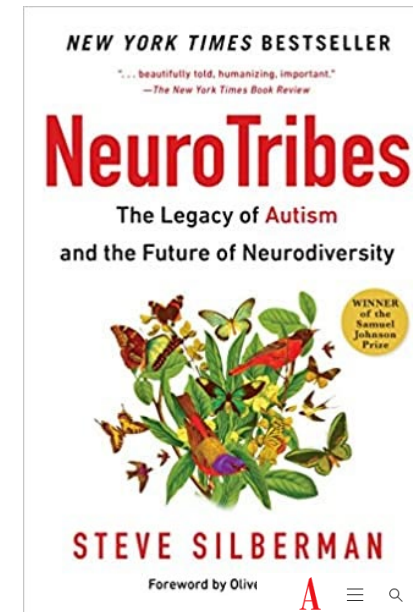
What does neurodiversity challenge?

Calls for greater decision-making from ND-identified people and communities

Critiques functioning labels and interventions that "normalize"

Advocates for people to have their support needs met and set their own goals

Promotes anti-oppressive social change and disability justice

Why ask people about neurodiversity?

Lots more people are talking about it, writing about it, hearing about it.

◦ This includes our students, our colleagues, ourselves

Neurodiversity is a source of controversy. How can we understand the debates and divisions?

◦ Some social work theories and practices are critiqued by neurodiversity advocates. Why?

What do people mean by neurodiversity? What hopes and fears does neurodiversity inspire?

◦ Can we open up more connections and supports within our own communities and classrooms?

Interview methods

Conducted from January 2020-January 2021

◦ 25 in-person, 35 through remote methods due to the COVID-19 pandemic

Semi-structured interview guide, audiorecorded and transcribed

Data analysis using NVivo as a means of indexing/ coding

Following Institutional Ethnography methods, interviews emphasized practices– what people do and why.

What can we learn from these interviews about how our society is organized?

Finding #1: People who care about ND can't be restricted to just one group.

60 Participants

_____

44 identified with neurodiversity

34 identified as service providers

31 identified as a family member of a neurodiversity-identified person

ND-identified, provider, and family member are overlapping categories – even as there are important differences between them.

Neurodiverse/ Neurodivergent identities

Autistic (30 participants)

ADHD

Mad-identified

Mental illness

Dyslexia

Intellectual disability

Learning disability

Psychosis

Eating disorder
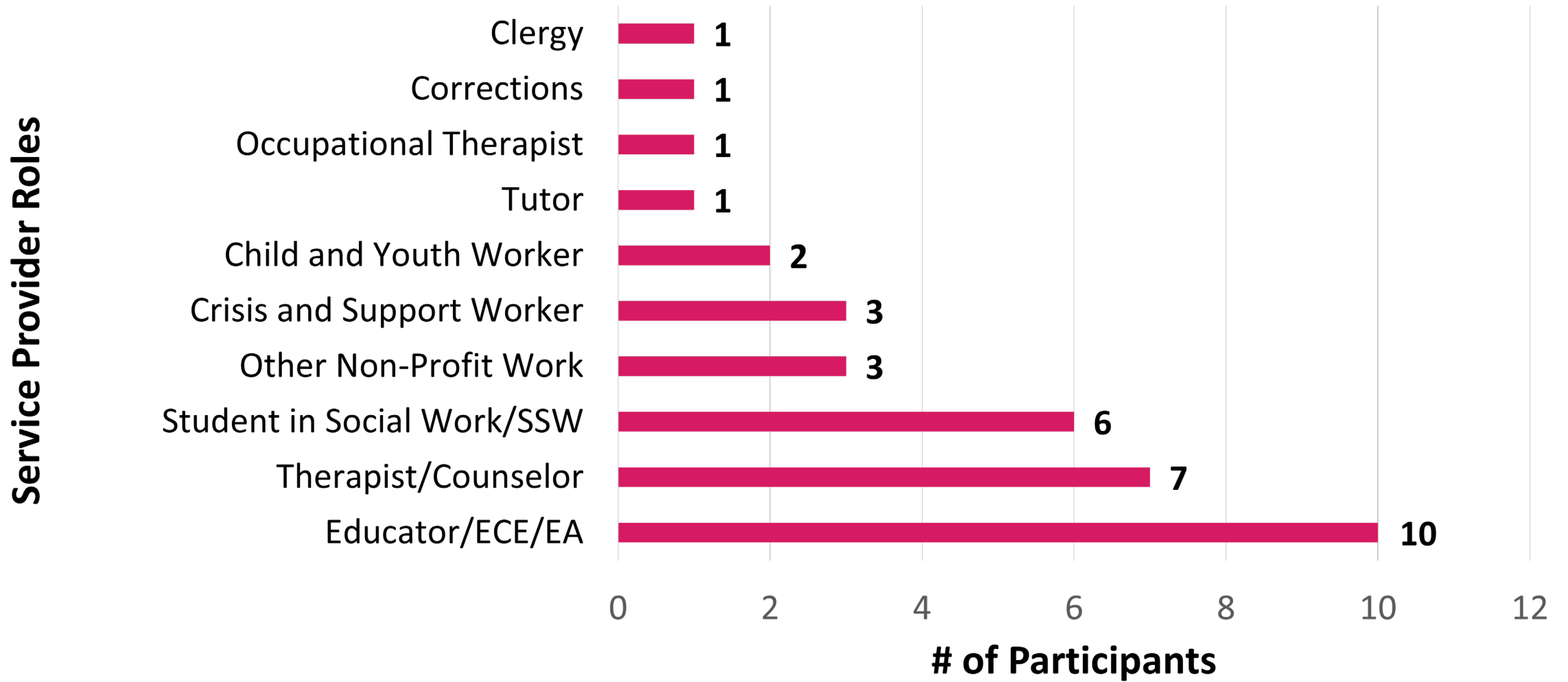
Gifted

Epilepsy

Highly Sensitive Person

Trauma

PTSD

Anxiety

Depression

Doesn't believe in labels

Service Providers
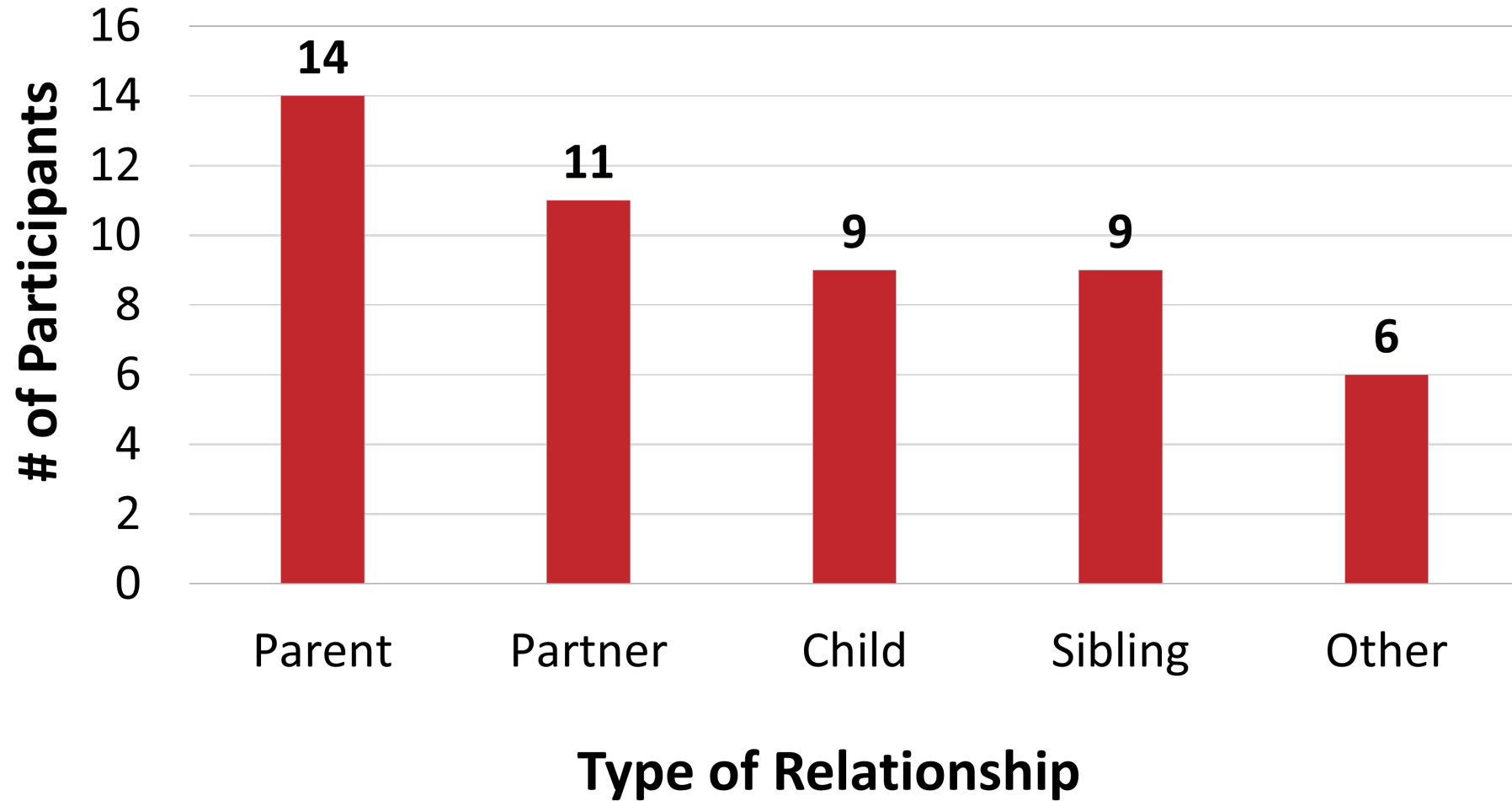
Finding #2: People come to these discussions from different identities and contexts

Race, gender, sexuality, class/ income, other disability identities were all important in these conversations

Socioeconomic Status

Supported by Partner 5%
Supported by Friends 2%
Sometimes/Often Struggling 12%
Supported by Parents 13%
Employed Full-Time or Not Struggling 68%

Gender

Trans 2%
Gender Fluid 5%
Non-Binary 20%
Cis Women 53%
Cis Men 20%

Race

Indo-Caribbean 2%
Hispanic 3%
South Asian 3%
East Asian 2%
Black 5%
Bi-racial/ Mixed Race 7%
White 78%
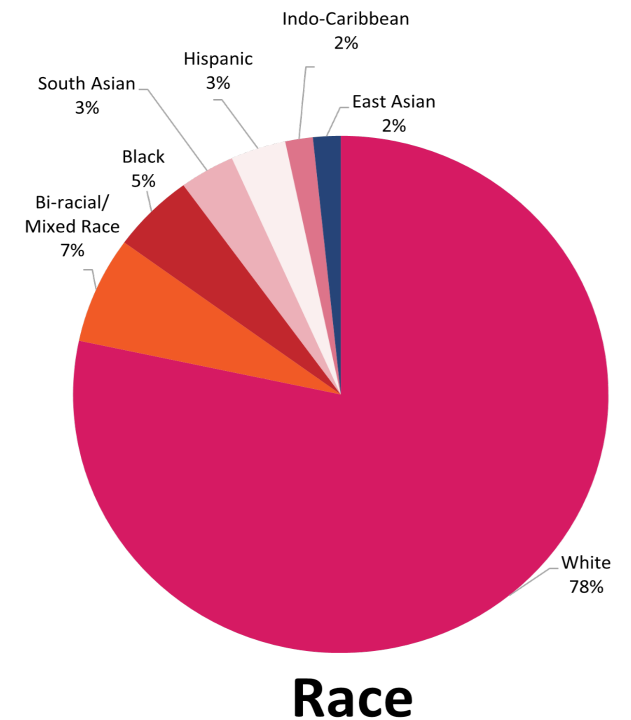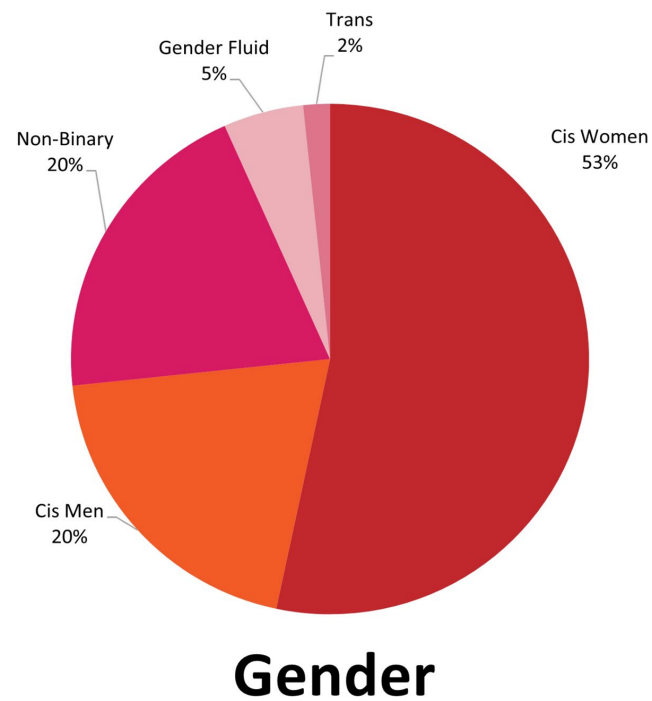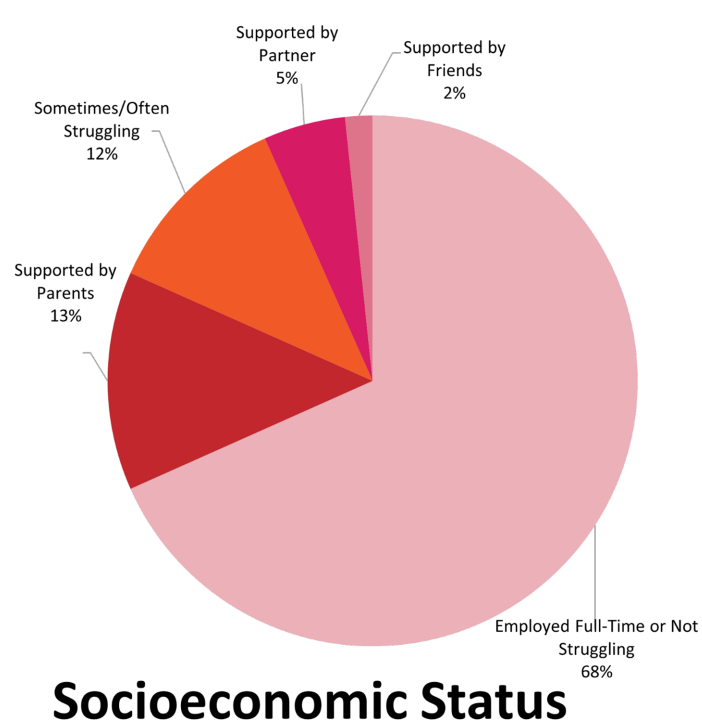
Finding #3: Neurodiversity is understood and practiced in community

People mostly agree on the overall definition

◦ Most want to move away from seeing people as being "wrong" or "broken"

Areas of disagreement: e.g. Who gets included?

◦ Sometimes seeking more or less radical social change: e.g. seeking acceptance/ accommodation vs. challenging colonialism and capitalism

◦ Tension: If ND is a really broad framework, does the social justice cause get diluted?

Defining neurodiversity

Well, I mean, like, literally and technically, it's a term that describes how differently – how wildly people's sensory perceptions vary and how differently people's brains work, like all the different ways that our brains can work when faced with a specific problem and all the different ways that people can perceive things, like the same sensory inputs and stuff.

Less technically, I think neurodiversity is just magical. I think it's so cool how complex the human brain is and how many different ways people are able to perceive and process information.

-- Neurodiversity-identified social worker

Defining neurodiversity in community

I'm definitely part of a group and community that uses the term in a lot of different ways. We're very open with the term. -- Neurodiversity-identified student

Sometimes, within the community, there are debates. They'll say, "No, I'm Mad; I'm not neurodivergent." Or people will say, "No, Mad people aren't neurodivergent," who themselves aren't Mad, and I'll be like, okay, well, I'm neurodivergent and Mad. -- Neurodiversity-identified SSW student

I went online and I started doing some research and I got lucky in that I found some blogs by autistic people pretty quickly, so I was sort of able to get to a point where I thought, oh, okay, neurodiversity, thinking/acting differently, doing things differently, that's okay, that's a normal part of the human experience. -- Neurodiversity-identified student

Hopes and fears

Maybe because neurodiversity and neurodivergence are newer terms… it could almost feel like a new term that doesn't have all that nasty baggage…

I think it's a great direction to go and I'm also a little worried because, as an Autistic myself, I have that urge to categorize things efficiently and, in a way, neurodivergence makes the term even more watered down. It has so many things under it that it becomes like, wait, what are we specifically talking about in terms of the issues that this person might have or how we can prepare for their needs?

--Neurodiversity-identified service provider

Finding #4: Neurodiversity is widely used in some circles, and rarely heard in others

Some people are really well-connected to discussions of neurodiversity and others are not.

◦ Some people participated in the research to learn more about neurodiversity

◦ Activist, online-savvy participants were most familiar with the term

Racism, sexism, and other interlocking oppressions can shape who is able to claim neurodiversity and find community supports. Neurodiversity can also exclude some people.

◦ See our previous CASWE presentation on this!

◦ https://uwaterloo.ca/scholar/sites/ca.scholar/files/m23gibso/files/caswe-acfts-decolonizing_neurodiversity-june_3-pr-v1-0900.pdf

Finding #5: Systems and practices need to change

Participants pointed to struggle and trauma being caused by dominant beliefs and practices

◦ Diagnostic criteria, systems, stereotypical representations…

Education was a central area where people described ableism, violence, confusion, inaccessibility, and hostility

Social services were also seen as pushing out the ideas and contributions of ND people, or forcing them to mask their differences

Employment and other income supports were seen as ableist domains

Objections to ABA

We were on the wait list for [organization] program some years ago. When we finally got near the top, my wife and I went in and they went over the services they offered. This was my first introduction to what ABA [Applied Behavioural Analysis] looks like in practice. On the way out, we both said, yeah, there's no way in hell we're ever doing that. Thanks, but no thanks.

-- Neurodiversity-identified parent and educator

Lack of provider education

Interviewer: Have you heard service providers using this [neurodiversity] language?

Speaker: Not really, no. I do notice a trend of a service provider only using it because they end up having a neurodivergent client for the first time ever. Basically, this client would end up teaching them.

-- Neurodiversity-identified individual

Social change is required

I feel that, generally, the public looks at autism as almost like a pitiable, taboo thing to have... – all of this insecurity about what starts it ... It has to be "why are they like that?", where, honestly, they need to relax and just realize we're everywhere. Whether they like it or not, we are everywhere. I would like to even take a tally. Maybe we even outnumber neurotypicals. Who knows?

...I don't know, but we've always been here. It's always been a thing... It's just been so focused on this negative and this taboo and this pitiable thing. It's just so much more than that. It just needs to be broadened and normalized. Normalize it, I think, would be the key takeaway. That would be my two cents.

-- Neurodiversity-identified service provider

Points for reflection/ discussion

1.   What would it look like to build programs and institutions around neurodiversity?

     ◦ How and when do we require diagnoses? Are accommodations stigmatized?

2.   How could our knowledge and practices reflect neurodiversity?

     ◦ What models and theories do we use? Do we present critiques?

3.   How could our ideas of "good practice" and "expertise" incorporate diverse ways of knowing, relating, and acting – and see these as important resources?

     ◦ How/why do we do job interviews? What do we evaluate in performance reviews?

Thank you to…

The Funders

The Participants

The Neurodiversity Matters Team
◦ Including many current and past students

The co-investigators and collaborators
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https://uwaterloo.ca/scholar/m23gibso/neurodiversity-matters

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