

Student Research Presentation

NEURODIVERSITYMATTERS



Neurodiversity matters: An ethnographic investigation into discourse, practice, and identity

Josh McGonegal BSW, MSW candidate (presenter)

Margaret F. Gibson MSW, PhD

bridget livingstone MA

Implications for Mental Health Professionals



OAMHP

Ontario Association of
Mental Health Professionals

UNIVERSITY of GUELPH



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TORONTO



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WATERLOO



RENISON
UNIVERSITY
COLLEGE



Social Sciences and Humanities
Research Council of Canada

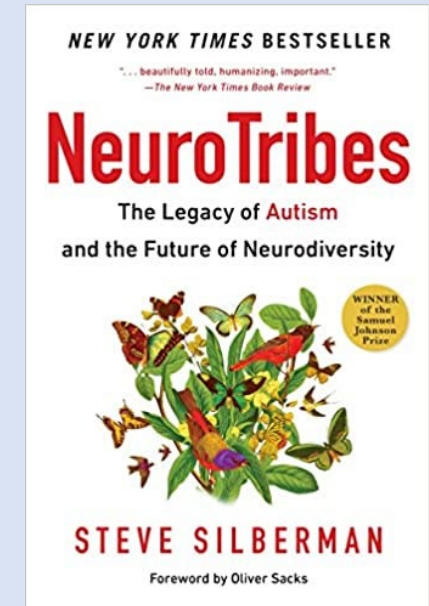
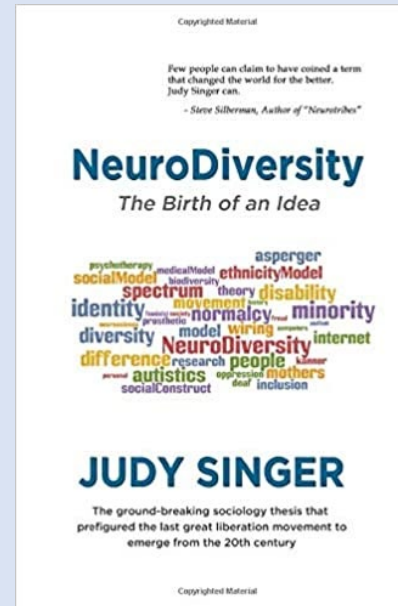
Conseil de recherches en
sciences humaines du Canada

Canada

What is neurodiversity?

- Judy Singer & Harvey Blume in 1998; Steve Silberman, 2016; many activists
- People are different! Move away from devaluing, pathologizing, and the search for “cure” for autistic and other neuro-involved differences

*ND does **not** negate the importance of support or the experience of disability



A ☰ 🔍 Popular Latest *The Atlantic*

TECHNOLOGY

Neurodiversity

On the neurological underpinnings of geekdom.

HARVEY BLUME SEPTEMBER 1998 ISSUE

If you've happened across [Jon Katz's columns](#) on "Geek Force" in recent editions of *HotWired*, you're likely to have read pronouncements like the following: "The idea of geek pride [is] stirring, ascending. The rise of the geeks has an epic feeling." As Katz describes them, geeks are nerds plus modems; they have the nerd's

Neurodiversity
matters: An
ethnographic
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into discourse,
practice, and
identity

Two branches of the research

1. Discourse analysis

Systematic search and analysis of academic, organizational and professional, and popular texts

2. Ethnography

- Interviews with 60 people who had thoughts to share about neurodiversity (2020-2021)
- Observations of public events (2020-2022)

Research was funded by a SSRHC Insight Development Grant and a University of Waterloo SSHRC Exchange Grant.

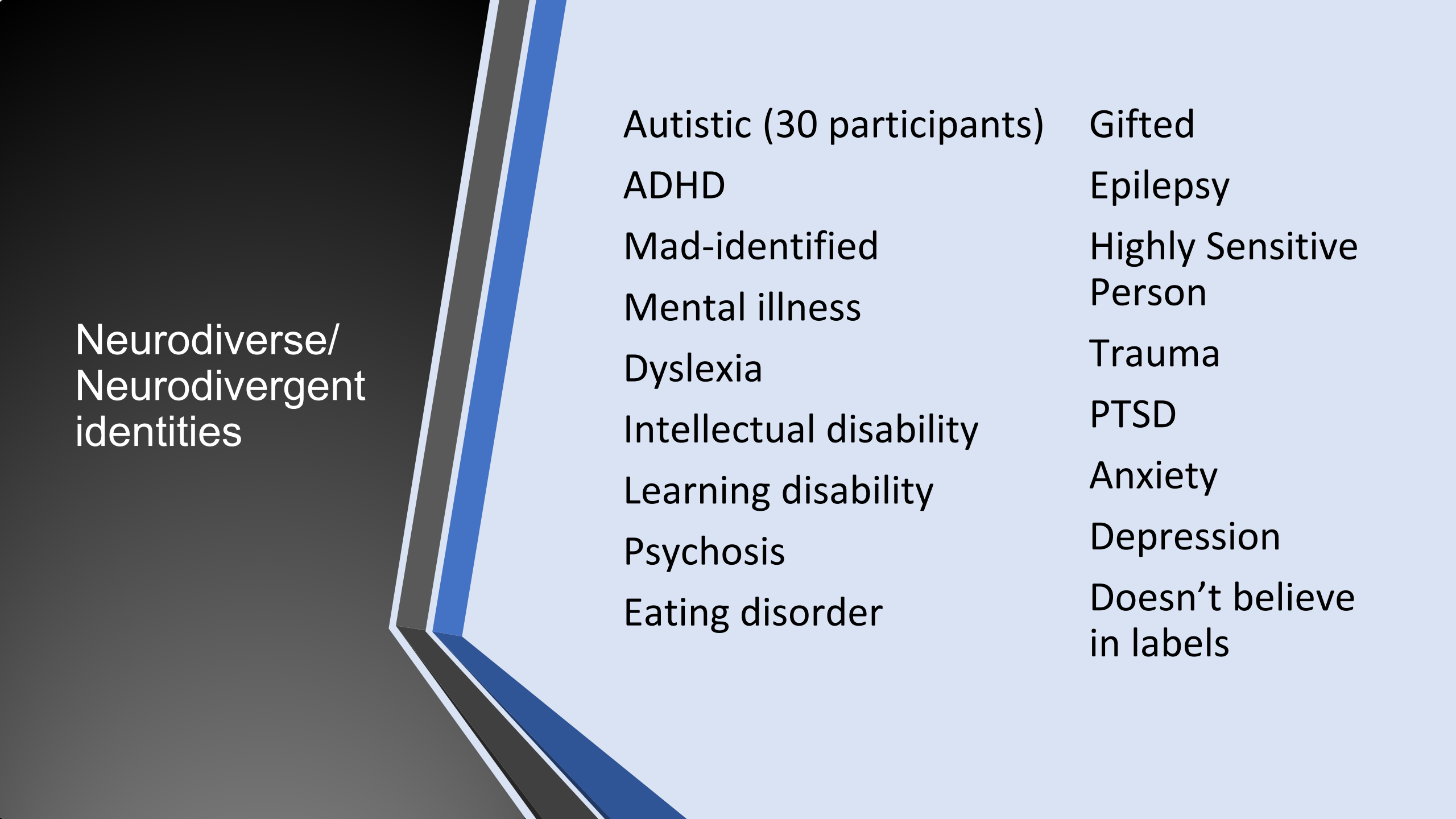
Interviews =
60
Participants

44 identified with Neurodiversity.

34 identified as service providers.

31 identified as a family member of a Neurodiverse person.

Many participants had overlapping identities in multiple categories.



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

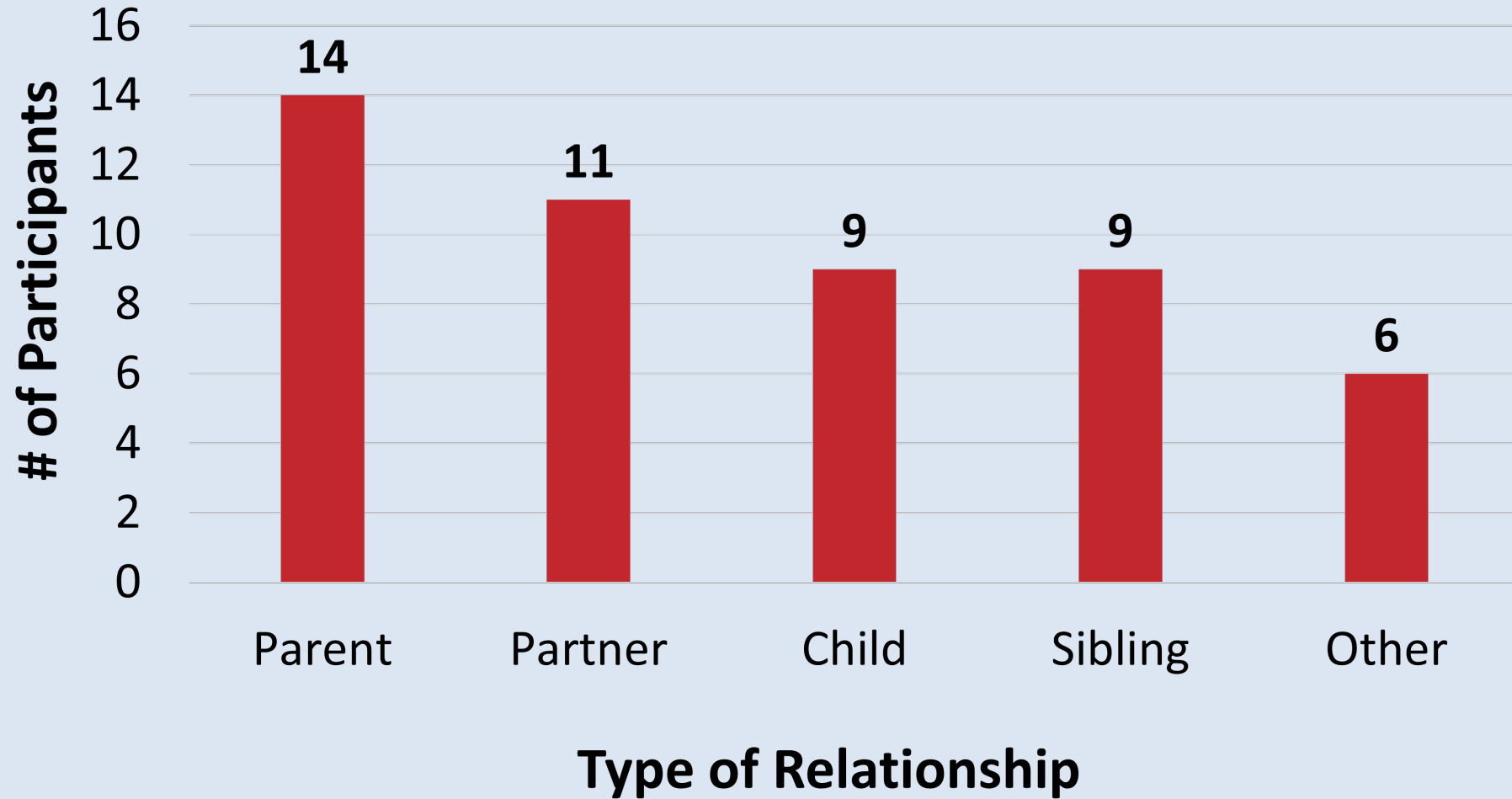
PTSD

Anxiety

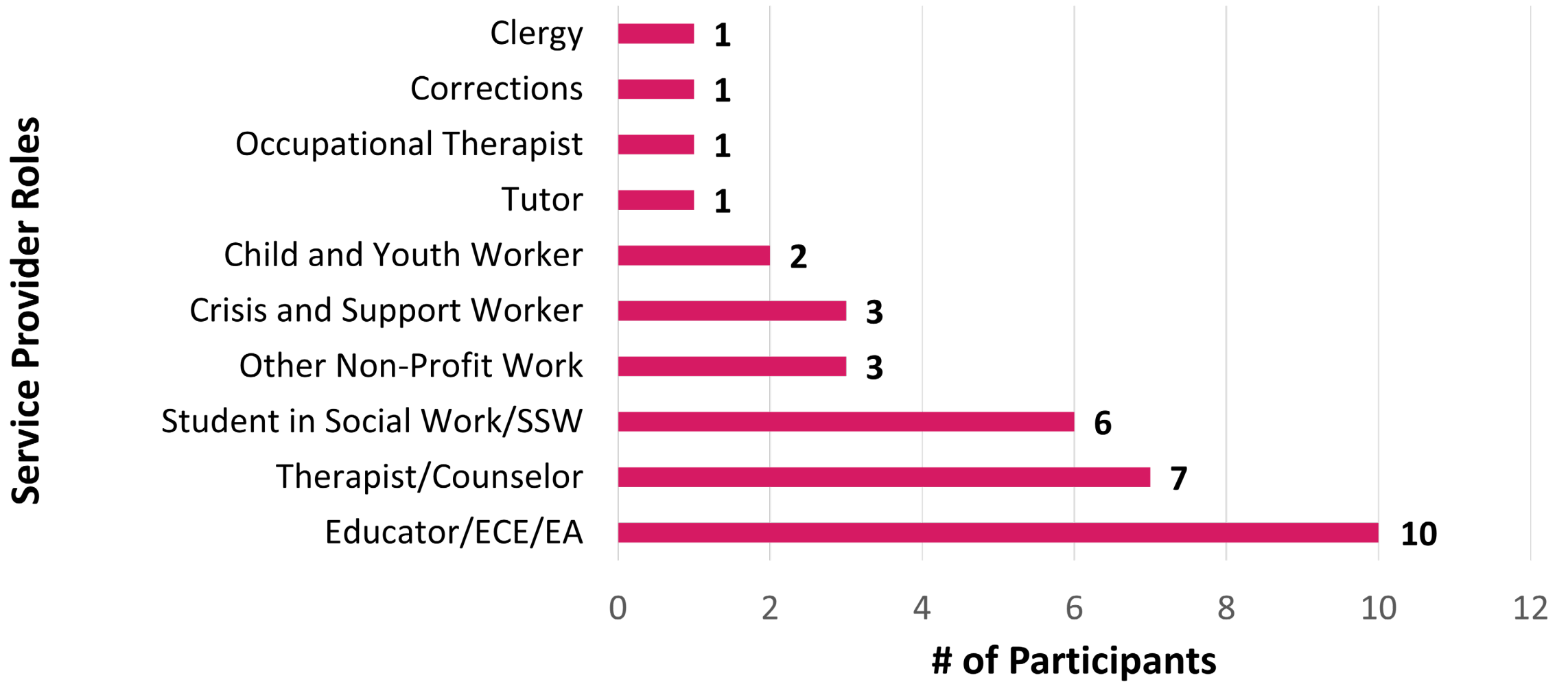
Depression

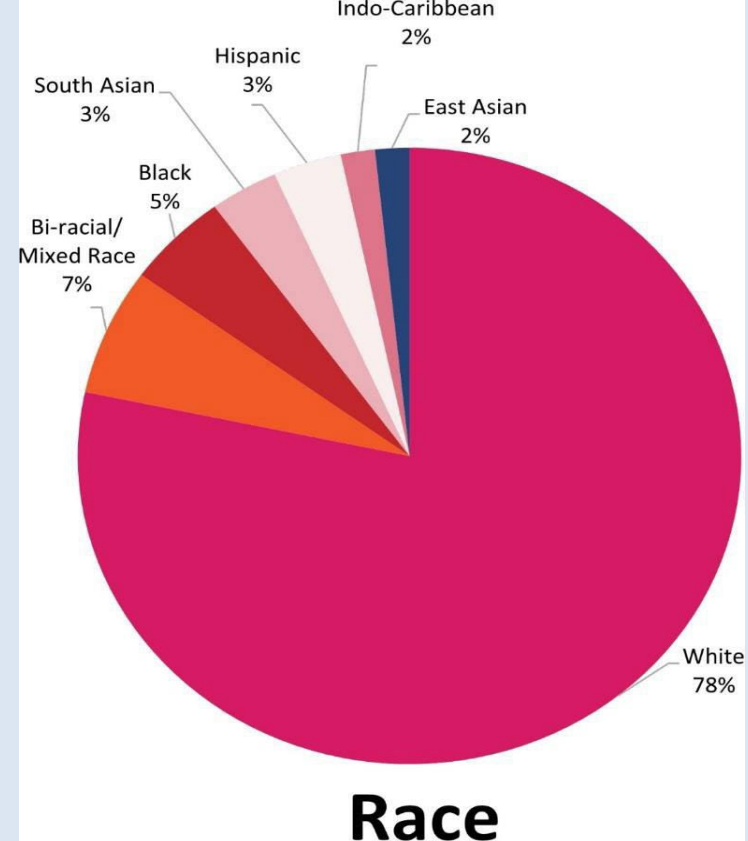
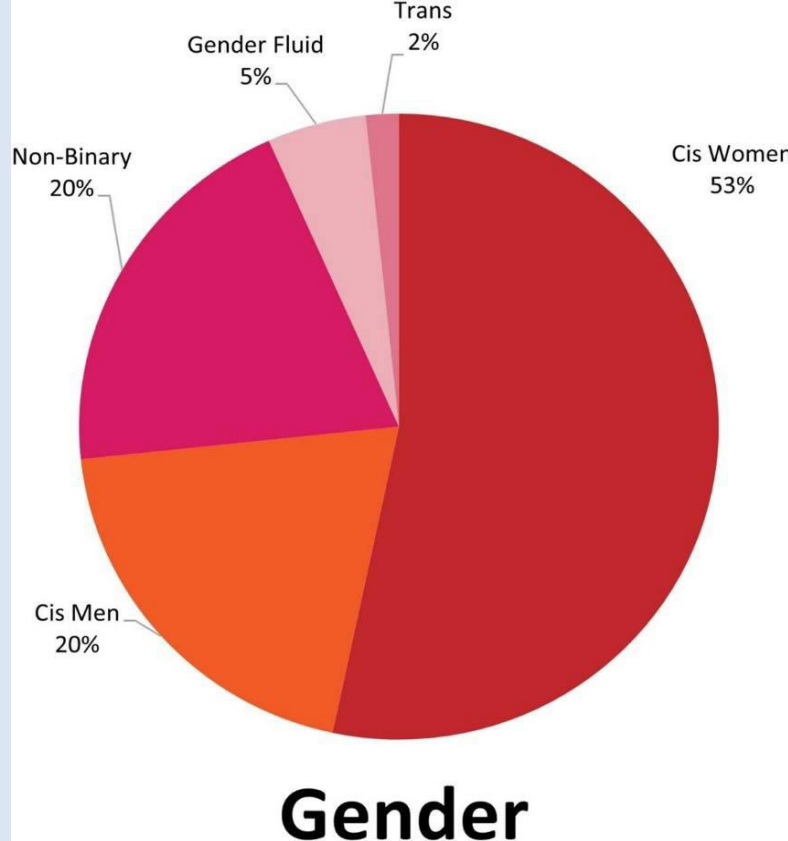
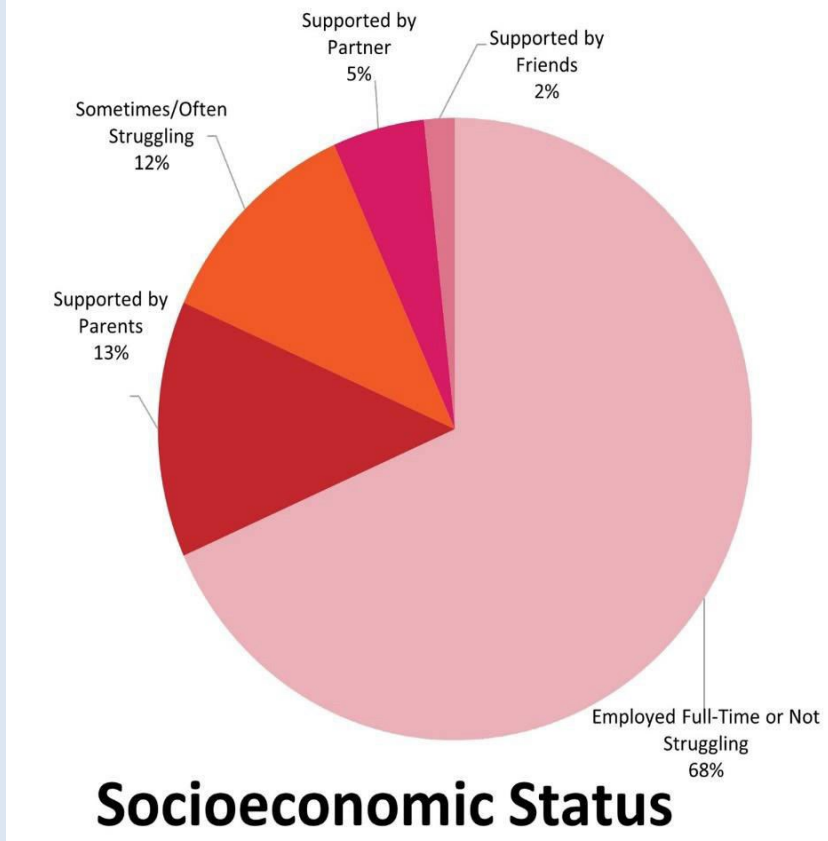
Doesn't believe
in labels

Neurodiverse Familial Relationships



Service Providers





Tips For Service Providers

- Use the language that people prefer
- Start from the assumption that people know their own experiences better than anyone else does

Tips For Service Providers

- Move away from goals that are just about blending in or seeming “normal”
- Be familiar with community resources and encourage people to connect with their community

Tips For Service Providers

- Learn about neurodiversity and question your own practices.
- Support neurodivergent/neurodiverse providers

Thank you!

Questions? Email

jmcgoneg@waterloo.ca

margaret.gibson@uwaterloo.ca

To Learn more about project, and the rest of the Neurodiversity Matters team. Find us at

<https://uwaterloo.ca/scholar/m23gibso/neurodiversity-matters>

Thank you to Patty Douglas, Izumi Sakamoto, Julia Gruson-Wood, Hannah Monroe, Sarah Leo, Steacy Easton, Paula Crockford and to all the participants and community collaborators.

NEURODIVERSITYMATTERS



Neurodiversity matters: An ethnographic investigation into discourse, practice, and identity

Josh McGonegal, Margaret F. Gibson, bridget livingstone



Introduction

In this project we learned from people who have lived and professional experiences with neurodiversity language and ideas. We asked questions about how these ideas influence people's identity or practices, and what opinions and experiences they associated with "neurodiversity"

Methods

Discourse analysis

Systematic search and analysis of academic, organizational and professional, and popular texts

Ethnography

Interviews with 60 people (2020 – 2021)

Observations of public events (2020 – 2022)

Research was funded by a SSRHC Insight Development Grant and a University of Waterloo SSHRC Exchange Grant.

Participants

(overlap among groups occurred)

1. Individuals who identify or have been labeled with "neurodiverse" or related terms such as "neurodivergent" or "neuroqueer".
2. Parents or other family members of individuals with neurodiverse identities/diagnoses.
3. Service providers who use neurodiversity in their work

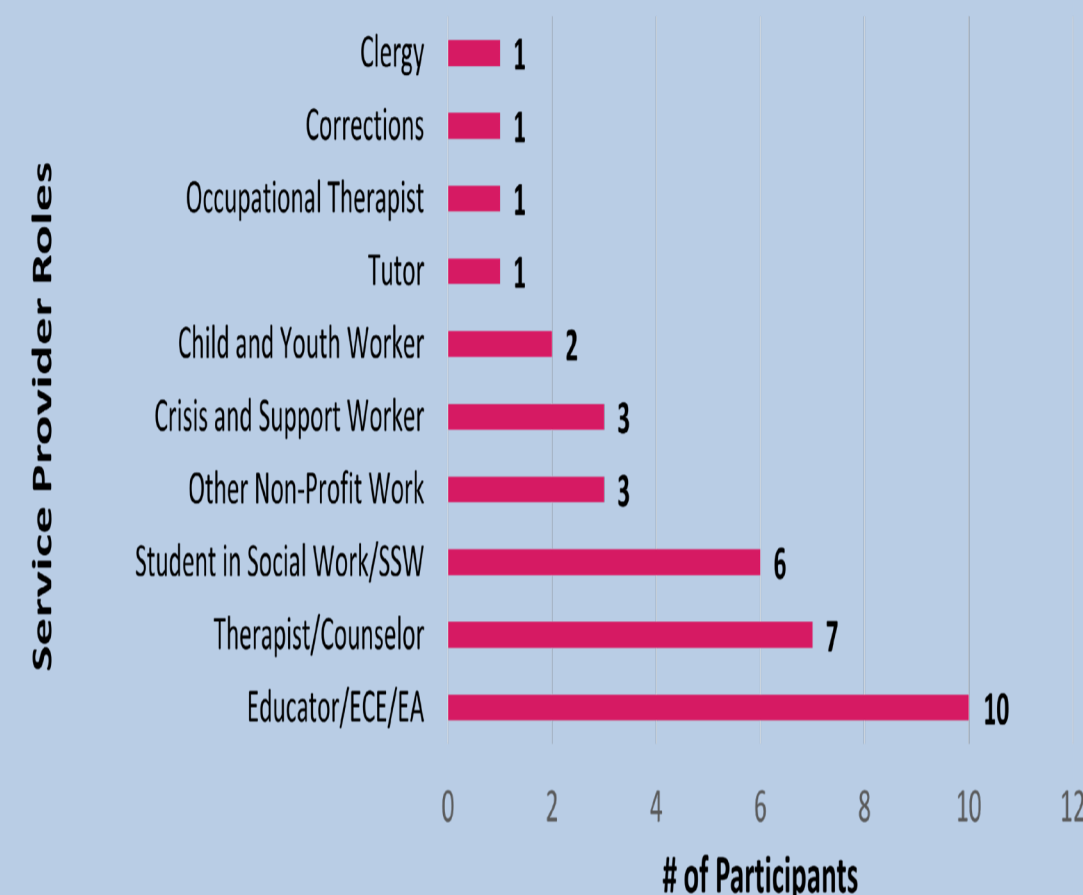
Neurodiverse/ Neurodivergent Identities

- Autistic (30 participants)
- A range of other neurodiverse/ neurodivergent identities were also present that included ADHD, Mad-identified, mental illness, dyslexia, intellectual disability, learning disability, psychosis, eating disorder, gifted, epilepsy, highly sensitive person, trauma, PTSD, anxiety, depression and doesn't believe in labels

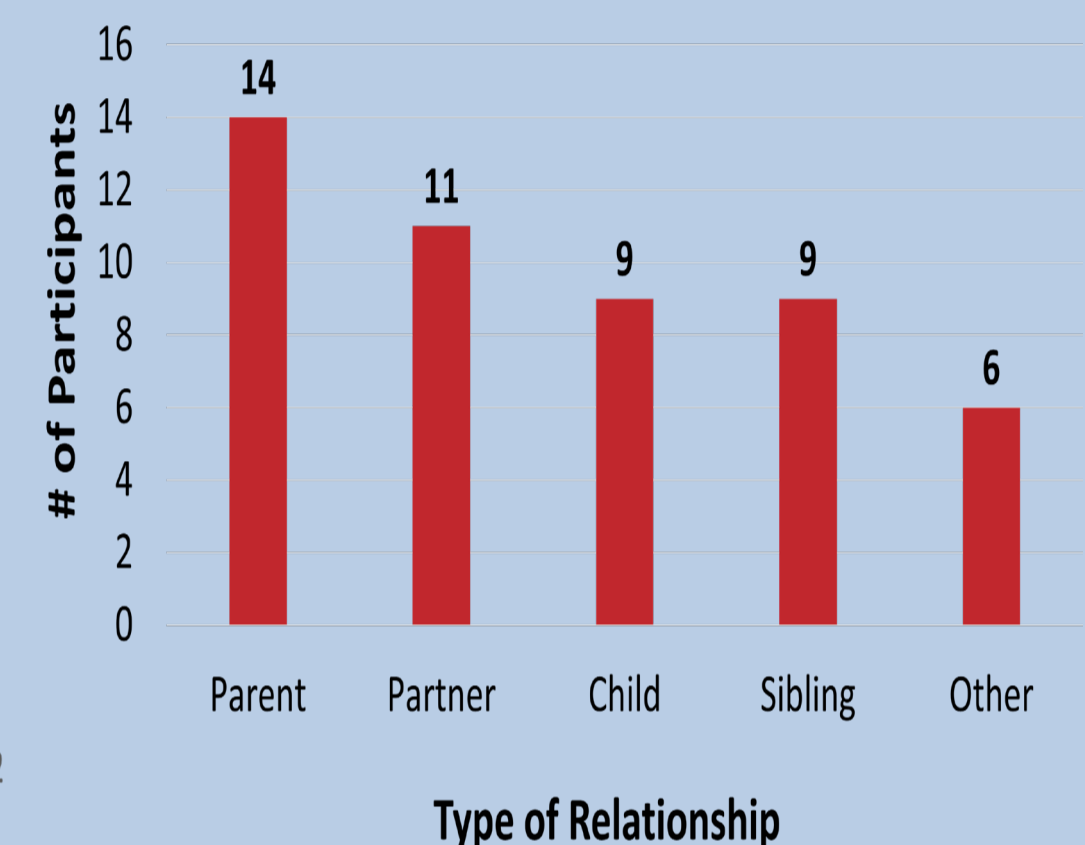
Tips for Providers

1. Use the language that people prefer
2. Get rid of functioning labels
3. Move away from goals that are just about blending in or seeming "normal"
4. Start from the assumption that people know their own experiences better than anyone else does
5. When people share their diagnosis with you, don't assume that you know what it means for them
6. Be familiar with community resources and encourage people to connect with their community
7. Support neurodivergent/neurodiverse providers

Service Providers



Neurodiverse Familial Relationships



We should be accepted the way we are, whether we're neurodivergent, autistic, any of the neurodivergences. The way we are is the way we are and people shouldn't try to change us and make us what they want.

- o Participant who identifies as neurodivergent and as a family member

I think we do a disservice when we have a mental health system that is so focused on these categories of experience and these tests that are not objective in terms of assigning labels to people and then that label follows you around and maybe it opens up doors, but how does that label affect your sense of self? How does not getting access to that label affect your sense of self?

- o Service provider (therapist)

...we're just left to fend for ourselves and figure it out and are viewed as odd for rejecting the system, so more support in that sense would be great and, of course, more support for approaching autism and related therapies, but ways to help cope with autism or other neurodivergent ways of being that is not, for example, ABA-specific. So, provide funding, but don't shuffle us into a particular approach because it might not even be something that people think is therapeutic.

- o Family member

For more on the project, visit <https://uwaterloo.ca/scholar/m23gibso/neurodiversity-matters> Or email margaret.gibso@uwaterloo.ca or jmcgoneg@waterloo.ca

Thanks to Patty Douglas, Izumi Sakamoto, Julia Gruson-Wood, Hannah Monroe, Sarah Leo, Steacy Easton, Paula Crockford and to all the participants and community collaborators.