Observing Neurodiversity: Ethnographic Investigation in Virtual Times

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An ethnographic investigation into discourse, practice, and identity
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How do people understand and use the language and idea of neurodiversity?

1. Discourse analysis
   Systematic search and analysis of academic publications

2. Ethnography
   Interviews with 60 people (Jan 2019 – Jan 2021)
   Observations of public events (July 2020 – March 2022)
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 experience of disability
What neurodiversity does

- Calls for greater decision-making from ND-identified people and communities
- Advocates for people to have their support needs met and set their own goals
- Promotes social change and disability justice – often rooted in autistic activism but expanding more broadly
- Challenges dominant intervention models that can be seen as “normalizing” (e.g. ABA)
Event observation: Plan

Observe local events in Southern Ontario where “neurodiversity” might be discussed
• E.g. conferences, rallies, protests, celebrations, talks, screenings
• Attend in person, note what people are saying and doing in public spaces and interactions
• Avoid identifying individuals and organizations apart from public presenters/sponsors (no expectation of privacy, set the context for the event)
• Answer any questions about observations and presence, be transparent, don’t question others (without research consent)
Event observation: Reality

• With lockdowns starting March 2020, needed to re-think!
• Attended virtual events that took place with participants and organizations in different places.
• Hosted in Canada, UK, USA – but participants were located in other countries as well.
• Mostly conference sessions/ formal talks – but with a range of purposes and intended audiences
• Still governed by ethics protocol of observing “public” interactions and spaces
Event observation totals

TOTAL NUMBER OF ONLINE EVENTS: 7
TOTAL NUMBER OF SESSIONS: 52
TOTAL NUMBER OF OBSERVERS: 5
Methodological adjustments: Pluses

Can take notes “in real time” and review (some things) on recordings

Can attend a wider variety of events without geographical boundaries

Can include a variety of observer-researchers who also live in different places

Events are accessible to people who might not be able to attend in-person or participate through spoken language, who live in a wider range of places

Can observe the chat! More to come on this...
Methodological adjustments: Minuses

Difficult to know who is present, what they are doing, and how they are receiving the presentations, especially when cameras are off.

Difficult to know if/how geographic differences matter.

Non-verbal responses are difficult to track (e.g. people leaving a session, gasps/murmurs, people engaging in other activities).

The “space” requires a different kind of analysis than we are experienced in doing.

Events are inaccessible to people who are not able to access the tech.

Can observe the chat. What do we do with it?
Overall findings

Neurodiversity (ND) is appearing in a variety of online events, but people primarily use other words and concepts – especially Autism/ Autistic people.

The events and sessions were different depending on their presumed audience/ organizers.

Spaces by and for providers seldom explicitly discussed ND principles, and usually focused on an “us” that was presumed to be neurotypical and non-autistic.
When I searched for neurodiversity and related terms, I noticed they didn’t come up as much as I thought they would. It could be because people are in a space where they have shared language, so they might not use these specific terms as much.

-- Reflective observation memo at a community-led event
Online events that were “Provider-led” had a less participatory format and included sponsors and educational credits.

Online events that were “Community-led” had participation built in through break-out rooms, online social events (e.g. games, sharing talents, awards ceremonies).

The chat was lively in “community-led” spaces, sometime unavailable in “provider-led” spaces – and was seldom recorded. The chat made a big difference in the feel of the events and the amount of dis/agreement.
Some conferences brought together diverse groups in ways that varied the presenters and anticipated audiences. **This is where neurodiversity appears the most!**

- Spaces anticipated differences and conflicts
- Focus on improving the services and opportunities that ND people can access: employment, education, human services
- Explicit discussion of ND and how it connects to politics and “the neurodiversity movement”

Neurodiversity is deployed when people gather across groups – and it can be seen in who is “supposed to be” there. **Neurodiversity is being used to offer guidelines and declare common commitments.**
Epistemology of the Chat

The chat was at the centre of methodological discussions. Ethical discussions – could the chat be considered “public space”? Would people have an expectation of privacy?

When observing, should the focus be on the chat or on the presentation? Often difficult to do both.

Sometimes also a Discord discussion associated with the event.

The chat could be experienced as a source of discomfort for the researchers, especially when the chat showed criticism of the presenter or seemed to be a “side conversation”.

“What happened” ended up relying heavily on the chat. The chat – and the multitude of perspectives – added to what the session “was about”.
LOTS happening in the chat – people identifying with what P’s said, happy to have access to this type of information, outsiders learning for the first time, people who wished they had this information decades ago, sharing experiences working in education.

- Summary of chat at a community-led conference session

It’s a bit overwhelming to participate because I’m participating as both myself and a researcher and switching hats a lot for both of those roles. Also there are often verbal and text based conversations going on at the same time.

-- Reflective observation memo at a community-led event
Chat in “provider-led” spaces

Often focused on appealing to institutional or individual authority
E.g. “How do I get my professional credit for this session?”
E.g. “With my child/ client, I experience this problem. What do you suggest?”
The expectation is that knowledge flows from institutional bodies and credentialed presenters
Even when the language of “neurodiversity” might be used in these spaces, the format and focus are centralized and restricted
Thank you for this uplifting presentation. It was truly inspirational.

Amazing presentation! It is very informative. Big inspiration.

Thank you for sharing so many examples of successful pathways.

The students who spoke in videos seemed to be very verbal, and very self-aware. Our situation is that both those areas are challenging, at least in terms of being able to get things across in the actual moment something is happening. This is a big factor in trying to figure out if college is realistic. Any thoughts?

– Quotes from chat in a provider-led conference session
The chat as democratized knowledge?

Events with busy and engaged chats allowed for disagreement, multiple perspectives, confluences, and a wider range of topics.

The building of inclusive spaces relies on opportunities to contribute. The “audience” is also community, and does not need to agree.

There were direct challenges to “neurotypical etiquette” as a guide to what is appropriate in the chat. This can be uncomfortable.
Part of me finds these comments a bit rude (and they start coming very quickly and frequently), in part because P is still speaking and can’t address the comments or respond to questions. This reaction is something I think about in more detail at a later point in the conference and come to feel a little bit ashamed of. In their lecture, a different presenter talks about the bewilderment they experience when neurotypical people are offended or hurt when simply presented with facts, or characterize an autistic person offering those facts as rude. I realize that this is something I do in certain situations and begin to pay more attention to how I am interpreting people’s comments or questions as related to the presentations.

-- Reflective observation memo at a community-led event
Concluding thoughts

Qualitative research has to make adjustments all the time. The pandemic has forced us to grapple more actively with what “observation” and “community” look like. We need to reassess our methods in a virtual space.

Thoughts? Questions?
See also https://uwaterloo.ca/scholar/m23gibso/neurodiversity-matters

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