Observing Neurodiversity, Observing Methodology: Ethnography in Pandemic Times

Margaret F. Gibson¹, bridget livingstone¹, Hannah Monroe¹, Sarah Leo², Julia Gruson-Wood³, and Paula Crockford¹

Abstract
Ethnographic researchers have long relied upon observation as a powerful means to learn about social relations. This paper discusses research observation that was conducted as a part of an institutional ethnography (IE) investigating how people use the language and ideas of neurodiversity across different settings. While our research protocol initially called for ethnographic observation to take place at in-person events in Southern Ontario, our approach needed to be re-formulated with the switch to online events during the COVID-19 pandemic. After the shift to online-only spaces, a total of 52 sessions at 7 online events related to neurodiversity or autism were observed by a team of 5 researchers: these events were no longer geographically restricted but were officially “hosted” by institutions in Canada, the US, and the UK. This paper reflects upon the challenges and opportunities we encountered as we conducted observations in digital spaces, including our experiences of navigating the “chat” feature. We discuss the need to analyze the format as well as the content of online events, and present findings on how neurodiversity appeared in these social spaces. Finally, we consider the implications of this research for people who are conducting ethnographic observation in an increasingly online world.

Keywords
institutional ethnography, observation, digital methods, COVID-19 pandemic, neurodiversity, autism, online events, disability

Introduction
Observation is a fundamental element of research practice for scholars within a number of fields, including but not limited to sociology, anthropology, social work, psychology, and public health. Ethnographic researchers in particular have long relied upon observation as a powerful means to learn about social relations (Fetterman, 2008; Harrison, 2014) and investigate people’s activities and understandings as they extend beyond the abstract and the textual. The specific features of ethnographic observation can vary: researchers may enter into long-term relationships with community members and spend many years in the field, or they may examine discrete and singular events. They can examine social processes that they are engaged in already and can be seen as insiders to, come to spaces as relative or complete outsiders, or examine public spaces or events where they are one of many who are equally unknown to each other within a shared space and structure. Researchers may hide their identity from others, or it may be known to varying degrees.

This paper discusses ethnographic observation conducted in the context of institutional ethnography (IE), an approach developed by feminist sociologist Dorothy Smith (2005). In IE, observation has been a central way in which researchers have worked to start from “the everyday”, focusing on the activities of

¹Renison University College, University of Waterloo, Waterloo, ON, Canada
²Holland Bloorview Kids Hospital, Toronto, ON, Canada
³University of Toronto, Toronto, ON, Canada

Corresponding Author:
Margaret F. Gibson, Social Development Studies and Social Work, Renison University College, University of Waterloo, 240 Westmount Rd. N, Waterloo, ON N2L 3G4, Canada.
Email: Margaret.gibson@uwaterloo.ca

Data Availability Statement included at the end of the article
people as a means to investigate how social structures and practices are coordinated and reproduced – and how they may usefully be challenged (Smith, 2008). By interacting with people and spaces, institutional ethnographers immerse themselves in the social world in order to understand elements of social practice that people might not readily write or talk about in more abstract settings such as interviews or surveys (Smith, 2005).

However, in the context of global transformations resulting from the viral illness known as COVID-19 many everyday and research practices needed to be halted, radically transformed, and re-theorized. As the novel virus was identified and its effects seen in the first outbreaks, many jurisdictions around the world instituted sudden regulations that prohibited or severely curtailed gatherings and movement both within and across borders. The resulting changes to social life were immediate and significant. Events that would traditionally have been held with many people in one place at one time were abruptly halted, and public health orders fundamentally shifted the landscape of everyday social practices. After the initial shock of the restrictions wore off and people realized that the COVID-19 pandemic was ongoing, many event organizers and attendees turned to technological solutions. Specifically, as gathering in-person became ill-advised or impossible, there was a rapid shift towards online events. The format and facilitation of these online gatherings were new for many organizers and participants. Online gatherings and events also posed a new challenge for many qualitative researchers, including ethnographic observers, whose primary research methods have historically relied upon being physically present in social settings (Silverman, 2020a, 2020b) in order to share space with research participants and witness social practices and interactions in “the field” (Harrison, 2014). However, this shift to the online also opened up new opportunities, both in terms of research findings and methods.

In this paper we describe the process of conducting online ethnographic observation at selected events related to neurodiversity. While our research protocol initially called for ethnographic observation to take place at in-person public events in Southern Ontario, our approach needed to be re-formulated in order to share space with research participants and witness social practices and interactions in “the field” (Harrison, 2014). However, this shift to the online also opened up new opportunities, both in terms of research findings and methods.

Background

What is Neurodiversity?

Though the term, and increasingly the concept, of neurodiversity is usually credited to Australian sociologist Judy Singer (1998) and journalist Harvey Blume (1998), recent archival research demonstrates that the concept was collectively developed by members of online autistic communities in the mid 1990s (Botha et al., 2024). Since the term’s inception, discussions and activities based upon neurodiversity have been part of lively online (and, more recently, scholarly) discussions by many others (see e.g. Nick Walker, 2014; Steve Silberman, 2016; Steven Kapp, 2020; Bertilddotter Rosqvist, Chown, & Stenning, 2020). While there is considerable discussion and debate about what neurodiversity means and what a neurodiversity paradigm calls for, neurodiversity advocates and detractors alike usually see the neurodiversity paradigm as a direct challenge to biomedical pathologization. Neurodiversity posits that humans have fundamentally diverse ways of thinking, sensing, acting, and communicating. This understanding often builds upon other forms of “diversity”, including biodiversity, to propose that these differences are expected and may be a beneficial resource for us as a species.

Which differences “count” as forms of neurodiversity remains a topic of debate. Some people focus primarily on autism, while others have a more expansive understanding of neurodiversity that includes diagnoses such as ADHD, dyslexia, learning disabilities, and psychiatrist identities. Regardless, advocates critique the ways in which many professionals and other social actors have often labeled differences as “problems” to be corrected, if possible, or hidden and downplayed if not. Following other disability rights and disability justice models, neurodiversity advocates instead see dominant discourses and practices as “the problem” to address, rather than seeking to eliminate or “cure” neuroinvolved differences such as autism (Kapp, 2020; Gillespie-Lynch et al., 2020). They see neurodiversity as a needed response to ableism and interconnected forms of oppression and one way in which to promote social change, often starting with challenging controversial intervention models such as applied behavioral analysis (ABA, see e.g. Gibson & Douglas, 2018; Yergeau, 2017).

While neurodiversity has existed for over thirty years as a concept and a part of both scholarly and community practice, recent years have seen a rapid proliferation in discussions of neurodiversity across many different social spaces (livingstone et al., 2023). The publication of Steve Silberman’s bestselling book NeuroTribes: The history of autism and the future of neurodiversity (2016) introduced many people to the language and idea of neurodiversity, and social media became an active means to communicate and debate the value and meaning of neurodiversity (livingstone et al., 2023). Autistic and other neurodivergent scholars have also been publishing and disseminating their work on neurodiversity and related concepts such as neurodivergence (Asasumatsu, 2000, as cited in Walker, 2014) and neuroqueer (e.g. Athena Lynn Michaels-Dillon, as cited in Walker, 2015; Walker, 2015; Yergeau, 2017). As a result of this expanded discussion of neurodiversity across multiple platforms, increasing numbers of people working in education, psychology, social work,
counselling, and employment were exposed to the term “neurodiversity” and encouraged to embed it into their own practices.

In some cases, this expansion of the concept of neurodiversity into new social spaces has brought with it a shift away from the movement’s original social justice aims. There have been concerns that some of this recent expansion of neurodiversity discussion has become a “neurodiversity lite” (Neumeier, 2018), which often goes against the central beliefs of most neurodiversity advocates. This watering down is not a phenomenon exclusive to neurodiversity; similar trends can be observed across other social justice movements, such as the shift towards corporate “rainbow washing” in lieu of substantive activism to further 2SLGBTQ + rights. Many people who identify as autistic or neurodivergent have challenged researchers, service providers, and parent advocacy organizations for the ways in which their work marginalizes the very people that they purport to be working “with” or “for”. At the same time, the rapid uptake of neurodiversity in new spaces means that many people who had previously wanted an alternative to the dominant biomedical framing of individual neurological and psychological functioning have been able to learn about and engage with the central critiques that neurodiversity can offer (Chapman, 2019). Our research investigated how people across diverse social spaces are using the language and ideas of neurodiversity in this moment of its explosive but uneven uptake by people from a range of identities. During the COVID-19 pandemic, this examination necessitated a move into digital spaces.

**Virtual Ethnography and Digitalizing Methods**

It is important to acknowledge that online qualitative research did not begin with the COVID-19 pandemic. Digital and virtual methods have a long history in the social sciences, including in the context of ethnography. Specifically, digital ethnography, virtual ethnography, cyber-ethnography, and netnography are well-established research methodologies dating back several decades (Christin, 2020) (see e.g. Hine, 2000; Markham, 1998; for early discussions of online ethnographic methods). Researchers have highlighted the importance of studying online spaces, especially in the context of increased blurring or blending of online and offline worlds (e.g. Addeo et al., 2021; Bluteau, 2021; Mare, 2017), and argued that physical framings of “the field” overlook the fact that our everyday lives are increasingly technologically mediated (Murthy, 2008). Our social world is “going digital”, and this has important implications for our research methods (Lester, 2020). Questions about protecting participant anonymity online (Lester, 2020), disclosing and representing researcher identity in online spaces, and marking the boundaries of virtual settings (Williams, 2007) remain topics of discussion in contemporary virtual ethnography, alongside broader considerations of the differences between online and offline spaces and the possibilities, limitations, challenges, and ethical dilemmas associated with online ethnographic methods (Addeo et al., 2021; Kulavuz-Onal & Vásquez, 2013; Mare, 2017; Morais et al., 2020). There are also multiple viewpoints on the necessity of adapting methodology when doing virtual ethnography. Broadly speaking, some scholars argue that traditional research methods are sufficiently adaptable to be applied in online settings, while others believe that the online world calls for somewhat reworked or radically new research methods (see Mare, 2017, for a helpful summary of this debate).

Though virtual forms of ethnography are well-established, our research was not initially designed to be a digital ethnography or netnography. Instead, we joined many other researchers without prior experience in online methods who changed their original plans and adopted these as a means of continuing their research in the context of the COVID-19 pandemic (Howlett, 2022). Rahman et al. (2021) use the phrase “digitalizing qualitative research methods” to describe their process of adapting their research methods in this context. They reflect on the process of conducting qualitative research during crises, and present the idea of “research resilience,” which is “the ability to adapt and continue the research throughout a crisis while maintaining consistency with the overall research design to successfully complete a research project” (Rahman et al., 2021, p. 3). Similarly, Rogers (2013) has argued in favour of “digitizing methods” instead of “transposing the traditional methods on the Web” (as described by Addeo et al., 2021, p. 273). We consider our research to be an example of digitalizing or digitizing methods (Rahman et al., 2021; Rogers, 2013), where we, as “offline-trained researchers” (Góralska, 2020), designed an in-person institutional ethnography and then adapted our methods to a new online context.

**Virtual Qualitative Research in the COVID-19 Pandemic**

A large body of literature related to qualitative research in the COVID-19 pandemic context has emerged, beginning soon after the advent of lockdowns in 2020 (e.g. Góralska, 2020; Kelemen Saxena & Johnson, 2020; Lupton, 2020 (revised in 2021); Silverman, 2020a). Scholars have discussed their experiences of using a wide range of online or remote qualitative methods in the context of the COVID-19 pandemic: online digital storytelling workshops (e.g. Durant & Kortes-Miller, 2023), video-reflexive ethnography (e.g. Gionfriddo & Dadich, 2023), synchronous and asynchronous online focus groups (e.g. Schweinhart et al., 2023; Frey & Strickland Bloch, 2023, respectively), digitally mediated photovoice (e.g. Ottoni et al., 2023), and online face-to-face (FTF) interviews (e.g. Wakelin et al., 2024), among others. Bibliographic explorations have also been published that outline this new body of work (e.g. Cornejo et al., 2023), as well as commentaries on the efficacy of specific methods in the context of the pandemic (eg. Sakellariou et al., 2021).
crowd-sourced documents (Lupton, 2021), journal special issues (e.g. the Journal of Mixed Methods Special Issue on COVID-19, 2021), reading lists (e.g. Glatt, 2023), and publications that explore the impact of the COVID-19 pandemic on researchers at specific stages in their careers (e.g. Githaiga et al., 2023) or gendered differences in the ways the COVID-19 pandemic has impacted academics (e.g. Watchorn & Heckendorf, 2020).

Other researchers have conducted studies using online or digital ethnographic methods specifically, both before and during the course of the COVID-19 pandemic (e.g. Addeo et al., 2021; Dai & Hu, 2022; Grijalva, 2021; Sakellariou, 2021; Vinte et al., 2023; Zhao, 2024). Addeo et al. (2021) employed covert observation as part of a digital ethnography exploring virtual dark tourism during the COVID-19 pandemic, looking at non-local users’ engagement in three Facebook groups specific to Italian red zone regions (those under quarantine or lockdown). Dai and Hu (2022) used virtual ethnography to study a disability support network in China that emerged in response to inadequate government communication with disabled people during the pandemic. These authors examined the Network’s organization, achievements and use of accessible communication via participant observation and semi-structured interviews in chatrooms on a social media platform called WeChat (Dai & Hu, 2022). Daniela Paredes Grijalva (2021) used social media, digital communication, and Zoom event observation as part of her doctoral ethnographic work exploring mobilities in Indonesia after the 2018 tsunami. Vinte et al. (2023) used a joint authoethnography approach to discuss their experience of remotely observing in-person classes as part of their multimethod study of English Language Teaching across multiple countries. Zhao (2024) used video creation on TikTok as part of their ethnographic exploration of young Uzbek men’s masculinity.

Using methods particularly similar to ours, Rahman et al. (2021) conducted participant observation of virtual events that had been moved online due to the COVID-19 pandemic, noting benefits and challenges, and concluding that virtual participant observation produced data of a similar quality to traditional methods, even though the online format meant that the types of data collected differed. For example, there was significantly lower or no cost to attending, as there was no need for travel. They describe challenges in observing individuals’ interactions with each other due to people only being able to interact in the webcast chat box, but also remark that in later events there was rich discussion in the chat box and it was easier to record data because they could copy and paste or take a screenshot (Rahman et al., 2021).

Research Context and Methods: The Neurodiversity Matters Project

Given the rapid and uneven expansion of neurodiversity across new social realms, ethnographic research examining how people use the language and idea of neurodiversity is an important means of understanding the ways in which differently-positioned individuals are coming to and building upon this concept in their everyday practices. How do people use the language and concept of “neurodiversity”? Do the ways people discuss and act upon neurodiversity change depending on the spaces that they are in and the ways in which they are positioned as neurodivergent individuals, service providers, or family members of neurodivergent individuals? The study discussed here, Neurodiversity Matters: An Ethnographic Investigation into Discourse, Practice, and Identity, used ethnographic observation methods following the tradition and approach of institutional ethnography (IE) (Smith, 2005) as a central element of its design as we investigated these questions. The project also involved 60 qualitative interviews with adults living in South-Central Ontario, a discourse analysis of the ways academic writers are engaging with neurodiversity, and an analysis of the ways that texts function in people’s understandings and practices related to neurodiversity. This paper focuses on our observational findings and associated methodological insights.

The original research protocol for the project included a plan to engage in “naturalistic” or “non-participant observation” at 8 in-person events in Southern Ontario where neurodiversity might be discussed in a public forum. The sample events that were listed in the grant and the ethics application included (but were not limited to) “autism symposia, program information sessions, research talks, political meetings, and/or professional trainings”. The ethics protocol was approved by the University of Waterloo (#41334). This protocol specified that the researchers would attend the events and take notes only on the conversations or spaces that were open to all attendees. That is to say, no conversations or events would be included in the research if there was a reasonable expectation of privacy, and no individuals and specific organizations would be named in the resulting research reports. Observers would not engage in any deception, and would not ask questions of other participants for research purposes – they would not start anything resembling an interview since there was no formal informed consent process in place. Observers would answer any questions about their presence and note-taking honestly and transparently. The ethnographic observation was set to start in Spring of 2020 and continue for 12–18 months, depending on the number of events that were identified in the region during that time.

When COVID-19 appeared and public health measures were put in place in Ontario and elsewhere starting March 2020, the research team needed to adjust how ethnographic observation would take place. The available events were all online and our research institutions dictated that no in-person research would be allowed during this time. Furthermore, the geographic restrictions that had previously been a part of the research protocol due to transportation constraints no longer made sense. We also found that this time period saw some changes in the kinds of events that were available. Some types
of events, such as political rallies, film screenings, and flag-raisings, were canceled during the early COVID-19 pandemic. The events that were available were, instead, panels, talks, book launches, and conferences. Thus, while the online events that we could observe overlapped with our planned list, there were differences between the events that we had anticipated that we would be able to attend and those that were actually available.

Our team ultimately observed a total of 7 English-language events, all online, from July 2020 until March 2022; observations continued longer than anticipated because of the disruption of the COVID-19 pandemic. For events that took place annually, the team only observed a single year’s offerings so there is no observation of how these events might have changed over this time period. The largest event the team selected to observe was a conference hosted by an Ontario organization; this conference had been part of the original in-person observation plan and was the most “mainstream” professional event we attended. The team also selected other events that were explicitly inclusive of neurodiversity language and/or neurodivergent groups and perspectives, and that had aims that were explicitly outside the “mainstream”. We were able to include a number of these less mainstream events in part because autistic-led groups were very quick to organize online events; autistic, crip, and disability justice activism often involves organizing in online spaces (Piepzna-Samarasinha, 2022; Piepzna-Samarasinha et al., 2023), and these groups appeared particularly nimble in shifting formats. Disability justice activists were similarly quick to theorize effective ways of continuing to teach and organize during the pandemic (e.g. see Aimi Hamraie’s, 2020 tips on accessible teaching or Irresistible (2020) for the Healing Justice Project’s podcast, Organizing in a Pandemic: Disability Justice Wisdom) and voice their opposition to the ableism and racism evident in cultural and public health responses to the pandemic (Mingus, 2022; Piepzna-Samarasinha, 2022).

All of the events we observed included participants who had a variety of stated positionalities in terms of neurodiversity, but there were different orientations in the organizational planning of the events: three were organized by groups with a focus on autistic self-advocacy and leadership; three others had an academic (university) affiliation; one was convened through an autism service provider organization. The official organizational hosts were located in the US (4), the UK (2), and Canada (1), although audience/discussion participants and presenters could be located anywhere. The team observed multiple sessions at most of the events, for a total of 52 individual sessions that were observed by at least one team member. Most events had designated speakers/presenters, in a more conventional panel or talk format, usually with a moderated Q & A at the end. One event that was established as a community-driven conference included sessions in the format of an interactive game, a set of performances, and several facilitated discussions on different topics (on Zoom or Discord).

The team of ethnographic observers included 5 team members: 1 member of the core research team who had doctoral training in IE and ethnographic observation, 2 research assistants who each had a master’s degree in sociology, 1 master’s student in social work, and 1 undergraduate student in social development studies. Some sessions were attended by more than one member of the research team. The researcher-observers and authors of this paper also have varied positionalities in terms of the events that they attended: one is autistic, and several are neurodivergent; several identify as disabled; several have neurodivergent and autistic family members. Most of the research team members have also worked as service providers and/or educators as well as researchers. These multiple and overlapping positionalities became part of the ethnographic note taking, discussion and analysis, particularly when some of the events presumed the presence or the absence of certain kinds of participants (autistic, neurodivergent, disabled, family members, service providers).

Following ethnographic traditions, observers took detailed observation memos on each session that described the setting and experience (e.g. what was required to join the event or call, if there were different online settings). Observers maintained a particular focus on how the language and ideas of neurodiversity were present/absent in the discussions and recorded information on the presenters and the format, and also on who/what was visible on camera. As discussed below, they also described the topics in the chat, and wrote brief quotes to help aid recall and provide examples. These notes were reviewed and discussed during the research analysis and writing process. Team members read each other’s memos and engaged in collective discussion and analysis, focusing both on substantive findings related to neurodiversity and methodological insights gleaned from the process of conducting online observations for the first time.

Research activities were still governed by our research ethics protocol, and so we maintained our commitment to observing “public” interactions and spaces online. However, the shift to online events complicated the idea of public space and brought with it unique situations that the research team discussed collectively. The principal investigator drafted an updated set of guidelines specifically tailored to observation in online spaces (see Appendix A), and the team of observers adhered to these guidelines to ensure ethical engagement in this new context. We updated the observation guidelines as new questions and situations came up over the course of observation. For example, the team discussed what a reasonable expectation of privacy might look like in the context of online spaces and collectively decided that observers would avoid recording the names of audience members and chat participants, even though individuals’ names were rendered particularly visible by the online format of events and discussions. In alignment with the original ethics protocol, we have removed any potentially identifying details about individuals and organizations from research reports and papers.
Findings

Benefits and Challenges of Online Ethnographic Event Observation

As many others have noted, there are both benefits and challenges associated with shifting to online research methodologies in the context of the COVID-19 pandemic. Our team noted several advantages to observing online events. Perhaps most significant was the increased accessibility afforded by the online event format. Observers found that being able to work in a familiar setting and on a computer made it easier to take notes while observing sessions, and they often also had the option to review recorded sessions and catch things they might have missed the first time. These events were much easier to access for many participants and observers since they could attend while in a comfortable space, without having to travel, find the event, and cope with sensory stimuli that might be overwhelming. There was also the possibility of viewing captions/transcripts, and commenting in written rather than spoken format, which could be more accessible for many. Additionally, the shift to online events meant that our team was able to observe presenters and audience members who come from many different places in the world. This geographic accessibility opened up a much wider range of possibilities for observation than our original research plan could have afforded, a benefit noted by other researchers (e.g. Sakellariou et al., 2021; Wood, 2020).

Online event observation also came with a number of more challenging adjustments and barriers. Observers often found it difficult to know who was “present” in a space, particularly when people had their own cameras off, or when audience cameras were disabled (e.g. webinar format); people might be elsewhere, distracted, or attending multiple sessions at once, and the observer would not usually be able to tell. Non-verbal responses were particularly difficult to track; for example, we could not see if many people left a session at a certain point in time, or if there were gasps or murmurs in response to comments, or if people present were also engaging in other activities (e.g. eating, checking email, talking, knitting). These other kinds of responses and social cues that characterize “co-present” interactions and are limited in “technology-mediated” interactions (Rusuvauro, 2020, p. 195) can be central in ethnographic observations, and their absence was felt by the research team. Observers also found that it was difficult to know if or how geographic differences might matter in the session, since there was not a common physical space shared by all participants.

As we considered the ways in which online event observation could be more accessible for some researchers and some participants, we also had to consider ways in which these events and analytical approaches were less accessible for some (Lester, 2020; Wood, 2020). People who have limited access to computers and internet, or who lack private spaces and uninterrupted time and quiet while online could struggle to attend (and attend to) online events. Some people might find the technological skills required to be too demanding, particularly when online events were a relative novelty to many in the early part of the COVID-19 pandemic. There were sometimes delays and technological glitches in events. A certain level of technological skill in solving such problems was often required. People who struggle with reading and writing in English would have difficulty with the integration of the meeting chat and frequent written instructions as a part of these events. There is also the challenge of paying attention in an online space where it can be easy to have multiple tabs and tasks open at the same time. Some people do not feel a strong sense of connection in online spaces, and the impact of such events might not be the same as a result.

A key feature of the switch to observing events online rather than in person was the presence of “the chat”. When events used platforms such as Zoom or Teams, they often had a “chat” function that allowed participants to contribute in written text, including emoticons and links to online resources. As researchers, the observers were soon struck by the potential value of the chat as a space where people who might often be considered the passive audience for an event instead became active participants, and shared ideas before, during, or following the formal presentations. The shift to online observation required us to specify the boundaries of this new virtual field and explicitly identify which interactions and aspects of online spaces we would study (Kulavuz-Onal, 2015), and observers quickly identified the chat as a point of analytical interest, both methodologically and in terms of our research questions.

On a practical level, observers found that it could be very difficult to decide where to pay attention. When the chat was busy and lots of people were contributing ideas and comments, observers found that it was easy to lose track of the formal presentation. In addition, if people were typing notes on their computers based on the verbal presentation, it could be difficult to also notice the visual elements of the presentation (e.g. slides or images) and the written material in the chat. This constant challenge of divided attention could be difficult and draining for observers, and they were often aware of how much they were missing. Góralaska (2020) uses the term overabundance (p.49) to describe the vast and overwhelming amount of data generated by digital ethnographic fieldwork, which resonates with our observers and is reflected in their field notes:

The data for this conference is really rich and just watching the chat is really interesting. I’ve decided to join the zoom calls and watch the chat at the time it’s running. Then I will go back and watch the YouTube videos of the panels so I can then focus on what the panelists are saying. There’s also a twitter chat. So much data!

Similarly, the logistics of observing multiple sources of data at once required some finessing on the part of observers:
I have totally neglected to keep an eye on the chat… On other online platforms I’ve been able to open the chat to the right of the screen and keep an eye on it while also looking at the presenter’s slides and taking notes in a small MS word doc window… This time the chat opened up right in the middle of the screen, instead of to the left or right. I left the chat minimized and dragged my note-taking window over the icon so that I didn’t have to see the constant and super distracting notifications popping up as everyone posted.

Perhaps even more importantly, the functional specifics of online platforms directly impacted the process of observation by forcing observers to choose which form of data to focus on:

[The presenter] presented a slide deck with a small video of her on the side. I was annoyed that the screen would not be full screen while the chat feature was available to see, so I opted to view the presentation in full screen and refer to the chat occasionally.

Some observers circumvented these issues by copying and pasting from the chat into their notes in order to save some of it to look at later, a helpful strategy also employed by others who did observational research during the COVID-19 pandemic (e.g. Rahman et al., 2021). The ability to revisit event recordings was another benefit of the online format that allowed our observers to focus more narrowly on certain parts of the synchronous event experience while returning to others in the form of recordings, or archival data (Kulavuz-Onal & Vásquez, 2013).

The last challenge of the chat was that we had no pre-established understanding of how it should be conceptualized as a part of research. Was the chat equivalent to whispered conversations in the audience while someone is doing a presentation in-person, or was it more equivalent to a question at a microphone? Was the fact that this communication was in written form – captured word for word, and generally attributable to a username – a reason to treat it differently than spoken words in a public forum where people’s names might not be readily known? In terms of attribution, ethical concerns about privacy could meet up with ethical concerns about credit (Markham & Buchanan, 2015). As written expressions that could contain analytical elements and warrant direct quotation, would it be ethical to use people’s words and ideas without attribution? Our ethical protocol for events precluded citational practices that we would otherwise give to published materials that were analyzed in a research process (see, e.g. livingstone et al., 2023 for a discourse analysis example from this project).

After discussion and reflection, the team decided that our ethical commitment to preserving the privacy of people attending these events was primary. We would not record or publish the usernames of anyone in the chat, and that we would use short direct quotes from the chat only to illustrate our analysis. We would avoid lengthy quotations that we could not attribute to their author. This stance was partly informed by an understanding of the online “chat” as a space that is not equivalent to formal publication, but closer to informal audience discussion, question and answer segments, and publicly-stated feedback to presenters. Contributors to the chat could not have a reasonable expectation of privacy if they sent their comments to a public space open to all attendees, but they could expect that people would not quote them by name without more extensive confirmation of quotations and permission to release their names.

The Chat: A Key Part of “what Happened” in Online Event Sessions

Many sessions at provider-led events had the chat function disabled or moderated through a “Q & A” feature so that participants were not able to see other attendees’ responses directly. However, when the chat was active during a session, observations of the chat offered a window into attendees’ experiences and responses, suggesting what resonated and what they wanted to add. For example, one observation note in a community-led conference session summarized the chat: “LOTS happening in the chat – people identifying with what P [reseter]’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”. Observers also attended to explicit expressions of emotion in chat given the absence of non-verbal data:

Several commenters express negative emotional reactions to watching the talk and hearing person-first language. People use adjectives like “uncomfortable” and “upsetting” (upsetting comes up particularly often), and one person says they are muting the talk… It’s harder to tap into the affective in online conferences and I appreciate the chat for offering a bit of a window into how the talk is impacting audience members.

In rarer cases, the event participants used the chat in ways that approximated nonverbal forms of data. For example, in autistic-led events, some chat participants responded positively to presentations by commenting things like “flappause” or “stims in happy”, making reference to embodied forms of autistic expression. Observers were acutely aware of how challenging it was to get a sense of the emotions present in the online space, especially when audience members’ cameras were turned off.

The chat also demanded researcher reflexivity, as observers were called upon to think about whether and how they related to the attendees and the sessions that they were observing. When the chat was turned off by the event host, there was no real conflict because the observer could simply watch what unfolded on the screen. However, when questions were given for people to respond to in the chat, researchers on the team needed to think about how their identities as “attendees” were in tension with their identities as “observers”. For example, another researcher-observer who identified as autistic and observed a community-led event for autistic community
wrote, “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.” This observer noted that as they tried to take part in more interactive events, it became more difficult to also take research notes.

The differences of opinion expressed in the chat could be challenging for the observers in other ways and inspire further reflection. For example, one observer unpacked their reactions to chat comments that critiqued the presenter at a community-led event:

Part of me finds these comments a bit rude (and they start coming very quickly and frequently), in part because [presenter] 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.

The analysis of these observations led to an awareness of how “neurotypical” standards of what is polite could also be a part of online conversations. The construction of comments in the chat across different types of events showcased different levels of commitment to including disagreement and, as a result, a true diversity of perspectives. The form that these comments took could also push back against neurotypical social norms. Ethnographic observers can use their own discomfort as a window into social expectations and divergent practices in ways that inform their analyses.

Our analysis led to an appreciation of what we came to call the epistemology of the chat. In these observations, we came to understand the chat as a space where knowledge could be democratized or it could be restricted to a specific hierarchy. Spaces which prepared for and encouraged multiple participants and multiple perspectives also allowed knowledge to become a communal activity, with people sharing and relating their experiences and their responses. These spaces allowed for and even anticipated disagreement. In contrast, online spaces with disabled chat functions, limited options for questioning, and restricted types of contributions to the chat functioned to create knowledge as a professional, elite, and hierarchical resource. People could receive knowledge but not necessarily add to it. The chat was not the only online space where knowledge was being produced or shared, but it certainly showcased online events’ dominant philosophy of what knowledge should be.

In some cases, event organizers were very aware of the potential of the chat to shift power dynamics and trouble the presumed one-way flow of knowledge from “expert” presenters to audience members. For example, one of our observers attended a scientific academic presentation at a conference that also featured a number of autistic scholars and self-advocates. The chat was immediately filled with audience members articulating numerous critiques of the presentation’s framing and deficit-based language, use of invalid models/measures of autism based on neuronormative standards, and objectification of autistic people as part of various practices associated with empirical science. At the Q&A that followed the presentation, the moderator directly addressed these critiques as related to power dynamics, stating:

Thank you for a very interesting talk, that has created quite a lot of controversy, I must say. There are a lot of questions in the chat…This is making me very aware of why these conferences are needed in the first place. We’ve had a lot of talk today about power imbalances. Autistic people in this chat have power that they didn’t have before to challenge these terms that are still being used, about disorder and deficit rather than identity or difference.

The chat offered autistic audience members a platform to respectfully take a psychologist to task and assert clear standards for language use in the online space of the conference, regardless of the disciplinary conventions that likely shaped this presenter’s language choices. This reversal of typical power dynamics was further solidified when the moderator did not shy away from audience members’ frustrations and asked the presenter to respond to critical questions.

Audience members at autistic-led conferences also used the chat to question dominant practices on a wide range of topics that were relevant to their community: COVID-19 pandemic responses that devalue disabled lives, forms of supported decision-making for disabled people, eugenic implications of searching for an “autism gene”, and social norms for Zoom calls, among many other things. People shared resources, asked questions that were unrelated to presentation topics and received answers based on other attendees’ lived experience, and held presenters and event organizers accountable for issues related to accessibility and the use of correct pronouns at event sessions. This was very different from what we observed at provider-led conferences. In provider-led spaces, even when the chat was enabled, it often preserved the hierarchy of expertise that placed the presenter at the centre and reinforced institutional power relations. For example, a common question in the chat at the event run by a large service organization was “How do I get my professional credit for this session?” Such questions show that institutional and professional authority are being placed at the core of the interactions within this online space, such that attending a session can be turned into an institutional “credit”. Other comments in the provider-led conference spaces tended to be complimentary or quick expressions of thanks to the speakers. This is a very different style of interaction than the sharing of experience, the questioning of expertise, or other hallmarks of an engaged community.
**Neurodiversity and Online Events**

In addition to the methodological insights discussed above, what did we learn about how neurodiversity is being discussed and acted upon in these online events? How did the various online spaces communicate and contribute to different conversations and practices, and were the different positionalities of presenters, participants, and organizers important? First, our analysis of our observational data found that the ways in which neurodiversity appeared — or didn’t appear — across these online events depended on who organized the event and who formed the anticipated audience. Neurodiversity appeared most frequently and most explicitly in online spaces that brought together diverse groups and anticipated varied audiences and conflicts between people. When neurodiversity was more directly cited in event settings, it was being used to offer guidelines and declare common commitments that could bridge people’s differences in perspective and experience. There were sessions and whole events that had “neurodiversity” in the title that structured deliberate conversations across neurodivergent and/or autistic community members, service providers and/or researchers, and family members. In contrast, spaces by and for providers seldom explicitly discussed neurodiversity, and usually focused on an audience that was presumed to be neurotypical and non-autistic. Similarly, in the events that were explicitly organized by and for community members, and particularly autistic-led spaces, neurodiversity was more of a background ethic than a term to be discussed.

Secondly, while all the events were “online”, there were important differences in format that connected to differences in the funding, mandate, and presumed audience. We attended a number of sessions from one large event that we described as “provider-led”, which featured the name of professional organizations and had advertisements that highlighted the academic and professional credentials of the speakers. The presenters were introduced in ways that reinforced professional and academic qualifications, and they seldom disclosed their neurodivergent or neurotypical identity. In contrast to many of the community-led sessions, it was usually not possible for attendees to turn on their cameras, and many presentations were pre-recorded instead of live. The expected or presumed attendees of the conference could also be seen in lanyard structures that offered reduced rates for autistic people and family members of autistic people. This was likely intended as an inclusive measure, similar to having a reduced attendance fee for students, but it simultaneously reinforced that the standard attendee would not be autistic or a family member of an autistic person.

In contrast, the online events that were more community-led encouraged participation and discussion from multiple participants, and two of these were specifically advertised as led by and for autistic people. Sessions at these events had cameras enabled for all attendees as well as presenters, and the chat function was active throughout. Some sessions included breakouts rooms or Discord servers for small-group discussion. These events included multi-participant elements such as a talent show that attendees were encouraged to sign up for, awards ceremonies with multiple recipients, or online games. These formats reinforced community connections and promoted multiple perspectives on topics, often taking focus away from the “experts”. Within these spaces, differences of opinion were embraced as a practice that can be part of a neurodiversity “movement” or “paradigm”, and people did not need to use spoken language to contribute. In these ways, common neurodiversity principles of valuing multiple forms of communication and interaction, challenging hierarchies of professional experiences, and promoting community development could be found in these varied and participatory formats.

Finally, our analysis revealed that neurodiversity was associated with a wide range of social aims across these events: from limited adjustments to professional practice, to focused programs or employment initiatives, to social transformation. Neurodiversity is often discussed as a social movement and a part of activism, with a concomitant assumption that those who use the term would support an agenda of social change and social justice. However, these online events showed that the ways in which people use the terminology of neurodiversity do not always reflect an agenda of social transformation, and that the changes people want do not always align. One of the areas in which neurodiversity was explicitly discussed was associated with improving employment opportunities for neurodivergent people. This mandate for social change was more pragmatic and limited than discussions of neurodiversity that were associated with autistic rights activism, or groups that often critiqued capitalist and white supremacist frameworks.

**Discussion and Conclusion**

Our observation of online events where neurodiversity was discussed demonstrated that the long-established value of ethnographic observation can be translated into the online realm. While the specific methods used and the range of people who could be observed were altered by the COVID-19 pandemic switch from in-person to online events, these observations of social spaces and interpersonal interactions were still effective. We were able to learn more about how social relations are being organized through these observations than we would have gleaned by only interviewing individuals or analyzing written texts — both of which we did in other arms of this study. Our observation of these events identified elements of social relations that went well beyond individual intention or expression, and showed that the form of online social spaces can shape who is (and is not) included. The same individuals might have attended and participated in some of these events had they been in person, but the structure of the interactions and the format of the online events fundamentally shifted what could be said, or done, and by whom.
The COVID-19 pandemic experience has shown us all that we can make dramatic changes in how we do our work, and how we communicate with each other. Such a historical moment can offer an important opportunity to extend these restructurings to questions of disability justice and social inclusion. As we move events online, there are new possibilities in who can participate and how. Indeed, disability justice activists have ruefully observed that they had been asking for online or hybrid and livestreaming options for community, professional, and academic events for many years on the grounds of expanding accessibility in terms of disability (mobility, sensory, communicative differences) and financial means (not requiring travel and accommodations expenses) (e.g. Piepzna-Samarasinha, 2022). With the advent of the COVID-19 pandemic, many accessibility measures, such as working from home and shifting social events online, were no longer “impossible”; when it was the majority whose health and safety were at risk, it became clear that it was absolutely possible for many social, work, and research activities to happen remotely. The digitalization of qualitative methods during the COVID-19 pandemic troubles the ongoing assumption that rigorous research needs to happen in person and that online field sites or remote methods are less valuable than physical ones (Góralska, 2020; Howlett, 2022; Prior, 2020; Silverman, 2020a; 2020b). Prior to the COVID-19 pandemic, online interviews in particular were often seen as a second choice methodology (Deakin & Wakefield, 2014), when the shift to online methods has in fact brought numerous benefits. Moreover, as David Silverman notes, (2020b), “mere presence is only as good as the analytical tools that we use to filter what we observe” (p. 206); rigor is neither guaranteed nor precluded by the specific research methods we choose to use. Generally speaking, increased respect for online events, activities, and practices (including research) supports accessibility.

Our ethnographic work also revealed the wide range of perspectives and practices that people bring to the topic of neurodiversity. Neurodiversity across these events did not mean just one thing. Some people wanted neurodiversity to be a more limited adjustment to practice and language, while others called for a complete overhaul of systems and power relations. Observing these events allowed us to see that neurodiversity as a concept is not, by itself, enough to create change, but it can be a backdrop to conversations that bridge divides in our current social landscape. Neurodiversity was operationalized as a way to address differences in power and perspective across groups. Discussions of neurodiversity can build connections between autistic people, between those who identify as neurodivergent, between those who identify as activists, between parents, between researchers, and between providers. However, the most explicit and potentially transformative role of neurodiversity was in how people built upon it to cross group lines, and deliberately enter into the contentious territories between social categories: in particular, in structuring spaces where the voices and perspectives of autistic and other neurodivergerent people can be heard by providers, researchers, family members, and broader disability communities.

In order for online events to become more inclusive of autistic and neurodiverse people’s expertise, changes would need to go beyond more limited models of improvement toward structural change. Fortunately, our research shows that some events have already developed diverse forms and practices that promote broader inclusion, and we are hopeful that others will be able to use their examples as a starting point. For example, the promotion of open chats, and the acceptance of disagreement and challenging perspectives, may be essential elements of a more egalitarian discussion. Games, talent shows, and open discussions with no expected “right answer” all diverge markedly from the more unidirectional, educational, “professional workshop” format and this diversity produces a different culture around what kind of expertise and knowledge is valued. The acceptance of institutional and organizational sponsors also warrants close attention. Once an event designates “credits” for sessions, the structure and meaning of these sessions is shifted toward that institution’s mandate and authority.

Social researchers who are interested in how power circulates across remote events also have an opportunity to consider who and what has been included – and excluded – in our own practices. As social science researchers, we have often insisted that trainees develop the ability to travel, live, and work across a wide range of physical spaces. This requirement has imposed additional burdens on people with care responsibilities, financial barriers, and disability access needs that conflict with the requirements of “field research”. While online ethnographic observation is by no means easier or less rigorous than other ethnographic work, it could be more equitable and accessible for researchers who might otherwise be excluded from social science practices. A proliferation in online ethnographic methods can offer one way to reduce the barriers that we have imposed upon our communities of researchers and trainees, and thus expand the perspectives and talents in our own fields.

Appendix A

Instructions to the research team for online observations.

When observing events:

(i) Always be respectful, discrete, and honest about your role. Do not ask questions in a research capacity – if you initiate contact, this is in your private/non-researcher role and should not be used as data.

(ii) Do not record any identifying information about those observed: names, organizations

(iii) Do not initiate or record any “private” conversations for research purposes – including asking people to participate in the project. If you disclose your involvement in the project and people would like more
information, then you can direct them to email for follow up (or give them the Website info).

(iv) It is fine to record general information about the apparent or known positionabilities of speakers – indeed, this is a good idea. How are people introducing themselves? As researchers, parents, autistic individuals, disability activists…?

(v) Do not record any images of speakers/other participants.

(vi) It is fine to record the texts that people seem to be referring to – unless the reference will make the speaker(s) and/or their organizations identifiable.

(vii) It is fine to copy and paste sections of the chat to review later, but remove all names and identifying information. We will not use long sections of text from the chat in publications.

Recommendations on format:

(i) Write up point-form notes during events as appropriate/possible.

(ii) If possible, write a more narrative/reflective field note/memo on what you have noticed immediately following the session/event (e.g. there is usually a break period following talks). If this is not possible, then write a longer field note at the end of the day. These field notes will become the data we analyze in the project. They are also the first layer of analysis so should be focused on the topics/questions in the project objectives.

(iii) Observe what people say and do, but include the audience’s apparent response(s) as much as possible.

(iv) Include your own feelings, reactions, questions. These are important elements of the research process!

(v) Pay attention to the ways in which ideas and terms circulate in conjunction with – or in distinction from – neurodiversity.

Acknowledgments

Thanks to the larger team of collaborators, co-investigators, and community members who have supported the Neurodiversity Matters project.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by an Insight Development Grant from the Social Sciences and Humanities Research Council of Canada (SSHRC) as well as a University of Waterloo-SSHRC Exchange Grant and two Renison University College Research Grants.

Data Availability Statement

The data used for this study (de-identified event observation notes) can be made available to other researchers upon request. If interested, please contact the corresponding author.

ORCID iD

Margaret F. Gibson https://orcid.org/0000-0002-4568-4798

References


Botha, M., Chapman, R., Onaiwu, M., Kapp, S., Ashley, A., & Walker, N. (2024). The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. Autism, 28(6), 1591–1594. https://doi.org/10.1177/13623613241237871


