(Re)Constructions of Autistics in Human-Computer Interaction

by

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Abstract

This three-paper dissertation argues that human-computer interaction (HCI) research constructs autism and autistic people in ways that enable and normalize harmful research practices. As an autistic researcher studying autism research, I employ critical discourse analysis, semi-autoethnography, and inductive citation analysis to expose discursive, rhetorical, and citational mechanisms through which autistic people are framed as passive recipients of technologically-mediated interventions rather than knowers, makers, or stakeholders in research that affects us.

The first paper examines the field's ideological stances through the rhetorical construction of autistic people as robot-like – mechanistic, computeristic, and possessing "natural affinities" for technology. Building on existing literature, I trace how these narratives position autistic people not merely as less-than-human but as less-than-living: things to be acted upon rather than self-determined agents. I argue that these constructions normalize human-computer interaction's complicity in violent behavioral intervention paradigms and explore the political economies that sustain this research. Drawing on crip technoscience and cyborg theory, I propose the figure of the "cripborg" as an alternative framing that recognizes autistic technology use as agentic and political rather than robotic.

The second paper investigates claims that autistic people have "a natural affinity for technology," which appears throughout autism-related human-computer interaction research. Through an inductive analysis of 77 claim-containing papers and 48 cited-for-claim papers, I find that this essentializing claim lacks meaningful evidentiary support. Citations either point to other papers making the same unsupported claim, to sources that do not contain supporting evidence, or to nothing at all. I identify troubling citational mechanics, finding that a significant number of "natural affinity" claims derive from a single paper that (A) does not support the claim and (B) contains the claim and cites an unsupportive paper in support of it. I find that the rhetorical patterns of citations lend the appearance of scientific merit without accountability to evidence and evidence of inadequate peer review. In effect, autism becomes a container for

whatever meaning a given researcher requires to make their work appear properly warranted. These findings raise serious questions about the veridicality and rigor of HCI research, particularly regarding marginalized populations. I discuss the need for accountability and clearer agreements within the field about what constitutes rigorous and meaningful research.

The final paper turns to #ActuallyAutistic Twitter, where I examine how autistic people use the platform to discuss, engage with, resist, and intervene in autism research. I find that autistic counternarratives align with the neurodiversity paradigm, while dominant academic discourses adhere to the medical model of disability. Though both orientations sometimes share stated research priorities, they represent fundamentally irreconcilable approaches – the same words carry radically different meanings and implications. I explore how autistic Twitter users interact with researchers across this paradigmatic divide and conclude by articulating the implications of these findings for HCI researchers interested in conducting ethical, non-violent autism research.

Together, these papers show that autism in HCI is treated less as a population to be served and more as a resource to be extracted. Researchers claim social impact while perpetuating harm. These problems are endemic to the field's commitments to progress, productivity, and utility, and a fundamental reorientation is required. Autistic people are not belligerent robots made to bear imposed meanings. We are belligerent humans with knowledge and experiences critical to reshaping HCI.

Chapter 1 Introduction

In this three-paper dissertation, I present the cumulative outputs of a multi-year research agenda in which, as an autistic doctoral student in the field of human-computer interaction (HCI), I studied the conditions that allow for some within the field to continue treating autistic and otherwise disabled people as sites for intervention first and people second (if at all). The first paper establishes the field's ideological stances through the rhetorical construction of autistic people as robot-like – mechanistic, computeristic, and possessing "natural affinities" for technology. The second paper further investigates the claim that autistic people have "a natural affinity for technology," which appears throughout autism-related HCI research as the primary justification for such research. The third paper turns to #ActuallyAutistic Twitter to examine how autistic people use the platform to discuss, engage with, resist, refuse, and intervene in autism research. Over the remainder of this introductory chapter, I present the personal context that led me to my doctoral work, my use of the personal narrative as a method, the historical context in which my research and I operate, and then, in greater detail, the three papers that comprise the bulk of this three-paper dissertation. I follow the paper descriptions with an overview of my cumulative interventions and contributions to the fields of HCI and science and technology studies (STS) by drawing on and applying insights from critical disability studies, collective resistance, and first-person lived experience.

1.1 Becoming an Autistic Autism Researcher Researching Autism Research(ers)

I came to grad school to study and design assistive technologies to help keep learning-disabled children in mainstream classrooms. I was awarded significant fellowship funding on the premise (but not requirement) that I'd conduct this work. Becoming an autism researcher wasn't part of the plan. Frankly, being autistic wasn't even a particularly salient identity at the time. The conditions of grad school changed much of this.

Displayed on the walls outside my shared office in the North Quadrangle were recent papers by departmental colleagues. These publications characterized individuals like myself as

burdens to our families, society, and the economy, as fundamentally deficient in understanding others' cognition, and as incapable of maintaining supportive communities without the guidance of non-disabled facilitators. The research described my needs as "special," and referenced their methodologies as "participatory," yet consistently prioritized the perspectives of parents, teachers, and other caregivers over those of disabled individuals.

I attended classes in which, invariably, at least one reading or lecture focused on the promise of new surveillance technologies that support "therapies" ensuring that autistics contort themselves to meet abled expectations for neuro-normative behavior and communication. I went to conferences where people presented radical new ways to help us empathize with robots, or even with mushrooms.

It was a strange time, and it engendered a peculiar and persistent sense of out-of-placeness – a more oppressive out-of-placeness than that which I usually felt. Eventually, someone told me that, fellowship funding or not, the work I'd planned to do wasn't worthwhile. People had studied accessibility years ago. Disability wasn't "sexy" anymore – in a publish-or-perish world, I should pursue more contemporary interests, at least until I earned tenure. I didn't particularly like that advice. And yet, I agreed in a way – it didn't seem like the right time to pursue that line of research. Not because it wasn't "sexy," but because changing the structures and climates within which I worked, those that made it difficult to exist in my department and conduct the research I'd ostensibly been admitted to do, seemed more pressing. Assistive technology research could wait while I sought a way to tolerate and hopefully improve the environments in which I'd have been doing that research.

The proximity of problematic autism research within my field of study,[1] HCI, seemed as good a place to start as any. By then, I'd spent some time on #ActuallyAutistic Twitter and was cultivating new, shared ways of identifying with autism and disability. It was upsetting, but not surprising, to hear how common, among academic autistic Twitter users, were experiences like mine. And yet, knowing others encounter similar obstacles within their respective institutions and fields assuaged doubts that these were "me" problems.

Through Twitter, I learned the Autistic Self-Advocacy Network's (ASAN) Autistic Campus Inclusion (ACI) Leadership Academy, which I attended in the summer following my

[1] I still refer to HCI as my field of study, insofar as I study the field, although not necessarily *within* the field.

first year of PhD. I left with tools and strategies for organizing and effectuating change. That August, I returned to campus and joined every disability-related committee I could find. I connected with disabled members of the campus community with anti-ableist agendas aligned with my own. These experiences and relationships, and my comrades in Disability Culture at the University of Michigan (DC@UM),[2] circa 2019-2021, sustained me during a period of precarity, when I was known by my ACI friends as Jeff, the Advisor-less Ghost of North Quad.[3]

Ultimately, it was my co-advisors, Drs. Oliver Haimson and Silvia Lindtner, who, by taking me on as their advisee and supporting my research interests, gave me the security and solid ground from which I could package and launch my invective interventions in the everyday doings of autism-related HCI, balancing bite with publishability. No longer a ghost haunting my department's hallways, I embarked on the research that now comprises my dissertation. I became an autism researcher and a researcher of autism research(ers). An autistic autism researcher researching and dissertating on autism research(ers) in HCI, if you will.

1.2 Autistic Researcher of Autism Research(ers) Narrative as:

1.2.1 Method

Some readers, at this point, may wonder whether the previous section would be more appropriate in my "Acknowledgments" than at the beginning of my introduction. I acknowledge and respect this critique. I include this narrative in my introduction because these experiences are not only a prelude to, but also a constituent feature of, my research.

My approaches to and interpretations of the research presented in this dissertation are irrevocably shaped by the experiences that brought me to this work and that occurred as I conducted it. I am in each of this dissertation's three papers, albeit some more obviously than others, as, to use a term common in ethnographic fieldwork, an observing participant (see, e.g., Kirner & Mills, 2019). For the first paper in this dissertation, as an autistic person who believes I live a more self-determined life than a Furby, the tensions inherent in the reciprocal production of human, robot, and autistic hierarchies in autism technology research were self-evident. My interrogation of this phenomenon is borne of both genuine research interest and a desire to

[2] Including my now-wife, Ashley.

[3] Someone involved in my admission to my PhD program may or may not have called me Jeff for eight or nine months, and it stuck.

ensure that my colleagues do not erase my agency, delegitimate my cogitation, or otherwise undermine my status as a researcher capable of holding and producing knowledge. The second paper arose directly from the experience of working on the second, during which I repeatedly encountered numerous reused and poorly sourced claims about how people with autism relate to technology, and I thought to myself that, were I to repeat a phrase ad infinitum without any apparent referent, many of these repetitious researchers would recognize such behavior as a core indication of autistic pathology.[4] For the third paper I present, I knew to look to Twitter for autistic epistemic activism because I was there, too, tweeting alongside my participants, for months before conceiving of the study.

Traditionally, researchers maintain a cultivated sense of disinterestedness (see Merton, 1979) and perform ritualistic behaviors to obscure how they influence their work (see Shapin, 1984). In contrast, I choose to subscribe to the view that knowledge is inherently situated and never accessible from a non-subjective viewpoint (Haraway, 1988). Explicitly including one's subjectivities in interpretivist work allows for deeper, richer, and more honest analyses (Behar, 1996). Ruth Behar (1997) sees researchers as both instruments and core methodological components of their research. She argues that by omitting ourselves and presenting others' experiences disinterestedly, we miss opportunities for more textured research that acknowledges the entanglements shaping our sites of study. Bringing oneself to work takes on added significance for autistic individuals, who are sometimes thought not to have, or to recognize having, a self (see Yergeau, 2013).

What's more, as an *autistic* dissertation on autism research(ers), it's only natural, perhaps clinically normative, even, to begin from a place of interiority that fails to anticipate external allistic[5] expectations. In so doing, and in grounding both the individual papers within and my dissertation as a whole in autistic self-narration, I engage in a method Grace (2013) refers to as autist-ethnography. This method renames and adapts Rose's (2005, 2008) conception of the *autie*-ethnography. These methods entail narrative, self-reflexive writing common to general

[4] I.e., as echolalia, a diagnostic indicator of autism, referring to a pathologized tendency to repeat the words and sounds of others

[5] See Yergeau's (2018) discussion on the absurdity of the clinical designation of *aut*ism, which simultaneously defines autistic people as lacking selfhood and self-awareness while also literally deriving from the Greek *autos*, implying self-referentiality. See also Andrew Main's (2003) sarcastic pathologization of *all*ism, from the Greek *allos*, which further illustrates the absurdity of both the naming of and many core components of the clinical pathology of autism.

approaches to autoethnography. From the literature review to the conclusion, all parts of this dissertation filter through my experiences and the self-narratives that give them structure.

1.2.2 Resistance

Unlike autoethnographies, autist-ethnographies are, inherently and by default, acts of resistance.[6] Autist-ethnographic accounts enact resistance by narrating autistic selfhood (which some people might presume to be oxymoronic; see Yergeau, 2018), challenging the notion that one must strive for normativity, revealing the work and harm endemic to comporting oneself in ways compatible with the norms of neurotypical society, and building pathos to resist pathologization (Rose, 2008). The power and impact of the inclusion of the self in one's discourse is not limited to academic contexts. The depth and texture that Behar (1996) argues is achieved only by accounting for our individual entanglements extends outward into our everyday interactions. This is particularly evident in the final paper I present, wherein autistic interlocutors are seen claiming autism as an identity and personal experience as an unalienable indicator of expertise. In doing so, they challenge beliefs about the discursive potentials of autism and autistic people (see Yergeau, 2018) while also challenging – or demanding that – the people who hold those beliefs consider whether they might be dangerously misinformed. These are my narratives, too. It's within this context – autistic Twitter – that I found and sharpened my narrativistic knife.

Whereas peer reviewers and funding bodies often expect us to consider the broader merits of our research beyond the confines of the academy, my research exemplifies a more complex directionality. The voices – mine included – at the heart of my interventions come from the "real world," seeking ways to affect academia from the outside. Only after breaking into academic discourse can these long-extant external narratives be rebroadcast by academics to a broader academic, clinical, caretaker, and general publics. From within academia, and as I discuss in chapter 4, these attempts to break through the rhetorical ivory fortress may come across as overly contrarian and combative. I contextualize this within Hamraie & Fritsch's (2019) notion of "access as friction," which I discuss in detail in chapters 2 and 4. This idea holds that points of contention are where access work happens. They argue that access isn't

[6] Non-autistic autoethnography is a powerful mode of resistance, too, when used as such. The distinction I make is specific to the resistance intrinsic to autist-ethnographies, which is not, by default, a quality found in all non-autistic autoethnographies.

comfortable, and perhaps can't be comfortable, because the need to create access necessarily means that something is or was inaccessible and harmful to begin with.

Within chapter 4, I describe aggressive autistic attempts to intervene in autism research as a form of trying to exert influence without a desire or willingness to build bridges. I've come to think of this as belligerence. As a refusal to be quiet or otherwise cowed.

Autistic belligerence relates to Erevelles' (2000) explication of unruly bodies. However, whereas Erevelles (2000) focuses primarily on attempts to discipline bodies that cannot be ruled, belligerence additionally encompasses and primarily foregrounds the choice some autistic people can and do make to eschew normative expectations that they hide their neurodivergence, instead leveraging their personal experiences and self-narrating their refusals as an interventional and political tool. In clinical settings and within biomedical paradigms, such belligerence marks one as a target for vicious behavioral interventions (see Roscigno, 2019).

In my experience and my research, I've found that it's through persisting in resistance that self-narration – and collective self-narration – creates enough friction to demand attention and reconciliation. My research is, in part, my way of leveraging my privileged position as an academic to uplift long histories of autistic belligerence – mine included – to help ensure they reach their targets, and packaged in a form my colleagues may find familiar. Williams and Boyd (2019) describe researcher refusals to be subverted to normative disciplinary expectations for critiquing and calling out harms perpetrated by their colleagues and within their field as "passion witnessing," and call on those less directly affected by said harms to take up the more subtle emotional labor and reconciliatory work of enrolling the critiqued as allies or could-be allies. In the words of Mell Baggs, "non-compliance is a social skill" (qtd in Egermann, 2022, p. 8). I hope the collective work comprising my dissertation communicates why narratives of non-compliance are necessary, particularly in light of the consequences – explored later on – of remaining within others' conceptions of ourselves. I hope that, by reframing our belligerence, we become people to be reckoned with rather than bodies to be disciplined (see Bascom, 2012; Roscigno, 2019).

1.3 Autism, Disability, and HCI

In this section, I provide a selective overview of the intersections between autism, disability, and HCI pertinent to this dissertation. I cover these intersections in significantly greater detail throughout each of the three papers comprising this dissertation.

In brief, HCI is constantly evolving. It endlessly iterates upon itself, creating new (or at least different flavors of existing) methods and theoretical framings, and broadening its scope to subsume emerging sub-fields (see Rogers, 2012). Ideals of progress, productivity, production, use, utility, and social good often drive the field's inexorable forward momentum (see Bowers, 2018; Irani et al., 2010; Lin & Lindtner, 2021; Pal, 2017). Some (e.g., Harrison et al., 2007) argue that, amidst the field's push towards progress, HCI has undergone two distinct paradigmatic shifts (see Kuhn & Hacking, 2012). An alternative Kuhnian reading of the field might suggest that practitioners have never stood still long enough nor been unified enough in our disciplinary approaches to have ever reached a state of "normal science" (see Kuhn & Hacking, 2012). Or, to present another alternative, perhaps our version of "normal science" resembles a self-propagating, transdisciplinary pastiche which endlessly endeavors to reinvent itself without ever successfully breaking away from its fundamentally neoliberal commitments.

Roughly 15 years ago, in a widely influential paper seen as a sea change in overall attitudes toward disability within HCI, Mankoff et al. (2010) implored HCI researchers to work with and listen to disabled people as experts and partners and to incorporate insights from disability studies into their practices. Despite creating new space for critically important conversations and paving the way for disability-led and disability-studies-grounded research to be seen as legitimate and publishable, many autistic and otherwise disabled people within the field find that much work remains to be done (Hofmann, 2019; Hofmann et al., 2020; Ymous et al., 2020). All too often, it's still the case that a pretension of beneficence belies the ways HCI research frequently harms marginalized people in the name of progress and productivity (see Bowers, 2018; Irani et al., 2010; Lin & Lindtner, 2021; Pal, 2017; Williams & Gilbert, 2020; Ymous et al., 2020). These harms are evident in autism-related HCI research, which, to render autistic people more "normal" and productive (Roscigno, 2019; Yergeau, 2018), overwhelmingly supports contentious behavioral interventions (see Kupferstein, 2018; Roscigno, 2019; Sandoval-Norton et al., 2019; Spiel & Gerling, 2021; Yergeau, 2018) linked to disproportionately high rates of autistic suicide (Beck et al., 2020; S. Cassidy et al., 2018; S. A. Cassidy et al., 2020; K. Rose, 2018).[7]

[7] Recent evidence suggests suicide among autistic people is between three and 10 times higher than within the general population (Kõlves et al., 2021; South et al., 2021).

A growing and determined group of HCI scholars continues to push the field towards a more liberatory approach to autism and disability within the field (e.g., Keyes, 2020; Ringland, 2019; Spiel et al., 2018; Williams, 2021; Ymous et al., 2020), but progress is a slippery hill to climb. Just as these researchers work for a future within the field in which autistic and otherwise disabled people are just that, people, a more prevalent approach to autism involves the co-optation by and adaptation of disability to the field's ideology of ability (Siebers, 2018), imperative toward usefulness (Lin & Lindtner, 2021), and orientation toward medicalization under the guise of social justice (Costanza-Chock, 2020; DiSalvo, 2018; Irani et al., 2010; Spiel et al., 2019).

In a paper often cited by "neurodiversity"-oriented HCI research and credited as responsible for bringing neurodiversity[8] into HCI in a meaningful way, Benton et al. (2014) suggest that neurodiversity "seeks to positively reframe certain neurological conditions … by concentrating on their strengths" (p. 3747), and discuss neurodiversity in terms of what it has to offer HCI. This misunderstanding of neurodiversity as a rhetorical shift in focus from lack to surplus maintains a grounding in the medical, enabling further interventions to overcome traits perceived as deficits while simultaneously finding ways to extract profit from those understood as strengths (Begel et al., 2020; Benton et al., 2014; Keyes, 2020; Zolyomi et al., 2019). At the same time, by understanding neurodiversity as a value proposition, we implicitly devalue neurodivergent people who cannot be readily exploited for their labor.[9]

The papers within this dissertation align with the contingent of autistic and otherwise disabled researchers and experts, along with their allies and co-conspirators, pushing for a version of HCI that recognizes the value of treating autistic and otherwise neurodivergent and disabled people well because we're human, irrespective of what we have to offer others. It arises from my earlier described experiences of occupying these spaces and their inevitable tensions.

[8] Neurodiversity is an umbrella term covering developmental, intellectual, learning, and psychiatric disabilities that mediate one's experiences of and interactions with the world. Someone is "neurodivergent" if they have a disability that falls under the umbrella of neurodiversity, which includes autism (see Neurodivergent K, n.d.). The neurodiversity *paradigm* holds that neurodivergent people have intrinsic value irrespective of their capacity to contribute to society (Kapp, 2020). The neurodiversity *movement* advocates for autistic and otherwise neurodivergent people's access to adequate material and social supports, necessities for physical and emotional well-being, and agency over their everyday lives without any prerequisite level of productivity or rehabilitation (Robertson, 2009; Robertson & Ne'eman, 2008).

[9] Most typically, knowledge labor.

1.4 Chapter 2 Overview – Not Robots; Cyborgs – Furthering Anti-Ableist Research in HCI

This theoretical essay, co-authored with Dr. Oliver L. Haimson, builds on existing literature to draw out the consequences of dehumanizing and disseminating autism discourses within the field of HCI. Focusing mainly on narratives in HCI that frame autistic people as or like machines, we explore how dominant constructions of autism in HCI work to normalize the field's complicity in violent autism intervention paradigms, despite HCI researchers' well-meaning intentions. We work towards developing crip-cyborgs as an alternative framework for understanding autistic people (as opposed to computers or robots) and suggest crip technoscience as a research framework grounded in this understanding. In doing so, we hope to enroll misguided but well-intentioned researchers in dismantling anti-autistic ableism, both in and beyond HCI.

1.4.1 Contributors

My doctoral co-advisor, Dr. Oliver Haimson, contributed to and significantly enriched this paper with his experience in and knowledge of trans-studies and trans technologies. He wrote the fifth through eighth paragraphs in the "Cyborg affinities along the cyborg/tryborg continuum" section of this paper and provided editorial support throughout.

1.4.2 Acknowledgements

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1.5 Chapter 3 Overview – Veridicality, Rigor, and Endemic Autistic Affinities in HCI

Building on previous work that identified a tendency in autism-related HCI research to warrant studies by invoking an apparent "natural affinity" that autistic people have for technology, this paper traces this claim to uncover its origins, impacts, and implications in HCI. In deepening my previous investigation of this claim, I find that, even when reviewing a much larger corpus, no evidentiary backing for the claim emerges. I go on to argue that this citational, representational, and rhetorical malfeasance is indicative of a much broader problem throughout

the field. I mark the need to regain a tether to, if not a shared reality, a set of standards to which we might hold ourselves and each other accountable.

1.6 Chapter 4 Overview – #ActuallyAutistic Twitter as a Site for Epistemic Resistance

The Internet has played a critical role in autistic self-advocacy and community building for several decades. In this semi-autoethnographic, interpretivist paper, I turn to #ActuallyAutistic Twitter to examine autistic concerns about autism research. In particular, I focus on how these concerns differ from those of autism researchers and how autistics interact with autism research and researchers. I find that #ActuallyAutistic Twitter discourses align with the neurodiversity paradigm, while dominant autism discourses in the academy align with the medical model of disability. Though both orientations towards autism research sometimes share research priorities, they represent fundamentally irreconcilable approaches to these priorities and autism, more broadly. I explore how autistics on Twitter interact with non-autistic researchers and how the tenor of these interactions varies according to which research paradigm a particular researcher subscribes to. I conclude by discussing the implications of these findings for HCI researchers interested in autism.

1.7 Interventions and Contributions

The papers I present within this dissertation draw on first person narratives, examples of collective resistance, and critical disability studies to make several key interventions in and contributions to HCI and STS. These interventions revolve primarily around methodological and perspectival choices that force us to focus on the political in ways and places where it's often paved over, albeit often unintentionally.[10]

In a seminal contribution to science and technology studies, Winner (1980) asks whether artifacts have politics. His answer is yes: artifacts are non-neutral reflections of complex political and interpersonal histories, often obscured by the final product (see Woolgar, 1990), but always present for those who look. But do people have politics? Actor-network theory (ANT; see Callon, 1984) would seem to say yes. By imposing a flat ontology, ANT displaces the primacy of human agents and eschews established hierarchies of power, treating all elements of a situation as agentic and co-constitutive. The framework proves particularly powerful when

[10] This lack of intent exemplifies the scope of the problem.

actants share a focus but understand it differently, revealing how divergent interests must negotiate with or against each other to achieve mutual intelligibility. Yet the methodology is poorly suited to situations in which its commitment to radical symmetry risks reifying – or worsening – existing hierarchies with significant material and corporeal implications.

Autistic people, for example, have long been understood as lacking a *Theory of Mind* (ToM) a construct that denies them capacities for selfhood, self-knowledge, and self-determination (see Baron-Cohen et al., 1985; Frith, 1989). As Yergeau (2013) elegantly explicates, the theory of mind is first defined as a fundamental component of human cognition and then immediately applied to autistic people as an inherent deficit. Given that my work is centrally concerned with contested constructions of autism and autistic people, it appears to lend itself to ANT. If approached through network or political-economy perspectives, such as Broderick and Roscigno's (2021) "autism industrial complex" framework, and in the same vein as Bowker and Star's (2000) treatment of the ICD, autism appears to be a ready-made boundary object. The experience of the autistic person implicated by such a boundary object lends itself to the notion of "torque" – the experience of being twisted and under tension at the intersections of adjacent, yet divergent constructions of multiple actants (see Bowker & Star, 2000). Further, this notion of torque has resonances with Hamraie & Fritsch's concept of access as friction, discussed above. However, the methodology's forcible flattening risks obscuring the fact that autistic people are, by definition, already positioned as less agentic than Callon's (1984) scallops, or even as lifeless robots (see Rottier et al., 2022). Ascribing agency to the inanimate while overlaying an allegedly symmetrical ontology does nothing to challenge these hierarchies. Rather, it underwrites their neutrality.

Treating autism as a social construct is not new within STS – Hacking (2000, 2009a, 2009b) has written extensively on this topic, including on autistic autobiography (Hacking, 2009a). My intervention lies elsewhere: in explicating method selection as refusal to be subject to normative expectations for and constructions of autism and autistic people. This aligns with my broader focus on belligerence as a disposition for resisting acclimation and effect change. In refusing one or another articulation of actor-network theory (see Law, 2004, 2007) and instead foregrounding autistic agency, epistemology, and self-narration, I avoid a set of often unrecognized pitfalls. That is, the boundaries between autism, autistic people, and technoableist (Shew, 2023), techno-solutionist (DiSalvo, 2018) intervention research are saturated with

unresolved politics and power asymmetries – dynamics prevalent in HCI and not absent from STS. Methodological neutrality cannot engage them; it only obscures them.

Suchman (2008), whose work on subject objects I cover in greater detail in Chapter 2, occupies the intersection of HCI and STS. She dispassionately articulates her observations of the co-constitutive mechanics through which, as robots are defined by their behavioral and cognitive proximity to humans, humans likewise become defined against robots. She then introduces robot-mediated autism interventions into her analysis, but leaves largely unexamined the implications of a politically neutral treatment of autistics as approximations of robots, while robots are approximations of humans, thus creating a troubling and, as I argue in Chapter 2, dangerous, hierarchical power structure that cannot responsibly be overlooked.

This tripartite co-constitutive meaning-making among humans, robots, and autistic people, while presumably understood by Suchman (2008) to at least a moderate degree as a social construction with potential political ramifications, is tacitly accepted as reflective of a neutral reality in HCI. As I've already discussed in a previous section, the field and those working within it go to significant lengths to obfuscate and neutralize the political implications of their work, and the ideological imperatives that drive these decisions (see Lin & Lindtner, 2021; Pal, 2017; Rosner, 2018; Ymous et al., 2020). The field punishes complaints and critique (see Williams & Boyd, 2019; Ymous et al., 2020) in ways that align with and extend Ahmed's (2021) observations of academic institutions' propensities to punish complainants by positioning them as problems to avoid engaging with the substance of the reported problems. In Chapter 2, I draw on the critical works of Williams (2021), Roscigno (2019), and Yergeau (2013; 2018) to explicate how the discourses of technologically-mediated autism intervention research quadruply disenfranchise autistic people.

In the first degree, the field of HCI's normative orientation toward critique and complaint is one of hostility, defensiveness, and denial (Lin & Lindtner, 2021; Ymous et al., 2020). In the second degree, autistic non-compliance is pathologized and interpreted as clearly indicative of a need for normalizing interventions (Roscigno, 2019; Yergeau, 2013, 2018). This requirement that a mythical normal child be recovered from deep within an empty autistic fortress warrants technologically-mediated autism intervention research. In the third degree, clinical definitions of autism preclude the possibility that autistic non-compliance in interpretable as complaint, instead positioning it as a deficit of the critical cognitive component that provides the faculties required

for a sense of self-awareness on which complaints depend – if there is no self to recognize the existence of a problem, there is no possibility of willful dissension (see Yergeau, 2013, 2018). And, in the fourth degree, the long-standing tradition within HCI and computer science of describing autistic people as mindless mechanical automata (see, e.g., Weizenbaum, 1983) seperates autistics not only from humans, but from living creatures, altogether. Here, my explicit decision to employ critical discourse analysis for its theoretical commitments (see van Dijk, 1993) resists and re-politicizes the hierarchical relationalities in autism research in HCI, in a similar, but inverse, fashion to how my decision to avoid ANT is an explicit step away from comparable risks of dissemination within STS framings of my work.

Throughout my dissertation, the papers, when read in order of arrangement herein, I also challenge and reverse the recovery and curative orientations toward autism (see Roscigno, 2019; Sinclair, 2012; Yergeau, 2018), disability, and illness more broadly (see Goffman, 1986; Kim, 2017; Parsons, 1951). Whereas these dominant understandings of autism hold that a normal person must be recovered from within an autistic person – that an autistic person must be rehabilitated to have recognized personhood and rights (Mitchell & Snyder, 2015; Roscigno, 2019), I take the reader on a journey that recovers the personhood and politics of autistic people from the discursive constructions of those who would work against our existence in favor of versions of us we can never be. And, returning to a central theme, it's through belligerence and refusals that this recognition might be achieved.

1.8 Chapter 5 Overview – Conclusion

I conclude with a synthesis of this dissertation's constituent papers and a rearticulation of the notions of narrative-as-method and belligerence-as-intervention. As is particularly clear in the first and third papers I present, HCI's discursive constructions and actual treatments of autistic people are political, as are autistic acts of resistance, and even mere autistic existence. I implore my colleagues, once more, to recognize our belligerence as a necessary and protective tactic for effecting changes that supports the politics and corporeal realities of autistic existence, and invite them to join us in demanding better and more from HCI and society at large.

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Chapter 2 Not Robots; Cyborgs – Furthering Anti-Ableist Research in Human-Computer Interaction

2.1 Contributions

My doctoral co-advisor, Dr. Oliver L. Haimson contributed to and significantly enriched this paper with his experience in and knowledge of trans-studies and trans technologies. He wrote the fifth through eighth paragraphs in the "Cyborg affinities along the cyborg/tryborg continuum" section of this paper and provided editing support throughout.

2.2 Introduction

Many HCI researchers insist upon the likeness of autistic[11] people to computers, robots, and other machines (see, e.g., Rottier et al., In; Weizenbaum, 1983; R. M. Williams, 2021). Research at the intersection of autism and technology often claims that autistics have a "natural affinity for technology" (e.g., Caria et al., 2018; Lavian & Alshech Press, 2015; Navedo et al., 2019; Valencia et al., 2019). In this theoretical essay, building on related work (e.g., Rottier et al., In Press; R. M. Williams, 2021), we explore the history, motivation for, and effects of defining autistic mechanistic, "computeristic" (Yergeau, 2018, p. 19), and robotic descriptions of autism. Mechanistic characterizations of autism are not unique to HCI (see R. M. Williams, 2021; Yergeau, 2018) or new within (e.g., L. A. Suchman, 2007; Weizenbaum, 1983). Similarly, these characterizations are not unique in drawing rhetorical lines between autistic people and other humans. As Yergeau (Yergeau, 2010, 2013, 2018) explains, common public and psychiatric autism narratives categorize autism as apart from humanity.

We argue that narratives about the similarities between autistic people and computers, like those popular within HCI, go a step further: In positioning autistics alongside, like, and less than machines, HCI constructs autism as a category apart from the realm of the living. We hold

11 Throughout this paper, we use identity-first language ("autistic person") over person-first language ("person with autism"). This choice reflects the preference of the first author, who is autistic, respects a general preference among many autistic adults (see Botha et al., 2021; Brown, 2011; Bury et al., 2020; Gernsbacher, 2017; Kenny et al., 2016), and resists the physical, anti-autistic violence person-first constructions may help normalize (McGuire, 2016).

that this classification of autistic people as *things* is critical to understanding some forms of anti-autistic violence. Specifically, we relate these narratives to violence in certain strains of autism research in HCI (see Rottier et al., In Press; R. M. Williams & Gilbert, 2019). These narratives contribute to political economies contingent upon autistics-as-raw-materials (Broderick & Roscigno, 2021; Moore, 2021). These political economies, in turn, explain why these strains of autism research persist, despite calls for autism researchers to reevaluate their commitments (e.g., Kender & Spiel, 2022; Rottier et al., In Press; Spiel et al., 2018; R. M. Williams & Gilbert, 2019; Ymous et al., 2020). We add our essay to this growing corpus calling for change. Drawing on crip-cyborg (cripborg) politics (Earle, 2019; Hamraie & Fritsch, 2019; Kafer, 2013; Weise, 2016; R. M. Williams & Gilbert, 2019), we attempt to resituate autistics within the realm of the living. In arguing that autistics, despite differences from other people, are entitled to research *for* (rather than against or on) them, we highlight crip-technoscience (Hamraie & Fritsch, 2019) as a framework for valuable and liberatory HCI research.

2.3 "Natural Affinities"

Yergeau writes, "In all things discursive, autism represents decided lack" (Yergeau, 2018, p. 7). Popular discourses frame autism as a void once occupied by a "normal" child (see Sinclair, 2012). In clinical discourse, frameworks like ToM (Baron-Cohen et al., 1997) characterize autism as the absence of essential human faculties. As mentioned in Chapter 1, ToM is a theoretical cognitive mechanism said to account for empathy, recognizing the existence of others' minds, knowledge of one's own mind, and having a mind that can be known (Baron-Cohen et al., 1997; Yergeau, 2018). As Yergeau (2013) explains, in defining ToM as essential to humanness and describing the lack of ToM as fundamentally characteristic of autism, ToM draws a line between autism and humanity. Discourses that explicitly position likeness with computers and other technological artifacts (e.g., typewriters) as fundamental to autism go a step further. Such discourses remove autistics not only from humanity but from the category of living things (Rottier et al., In Press).

Discourse about a likeness between autistics and robots is not new and not limited to HCI (L. A. Suchman, 2007; Weizenbaum, 1983; R. M. Williams, 2021; Yergeau, 2018). Robotic characterizations of autistic people long predate the existence of technologically-mediated autism interventions, computers, and HCI as a field of study. Yergeau (2018) traces robotic descriptions of autism to Bettelheim's 1959 article, *Joey: A Mechanical Boy*. An influential historical figure

in the construction of autistic pathology, Bettelheim described his subject Joey as an unskilled infant but a successful machine (Bettelheim, 1959). Bettelheim recorded Joey as articulating a fondness for machines, and even claiming to be a machine himself as a means to cope with and deny the emotions associated with human experience (Bettelheim, 1959). Williams (2019) notes that, as an adult, Joey denied a recollection of these claims. Bettelheim indicates that comparisons between machinery and autistics precede his writing about Joey, noting that "many other autistic children are fascinated by rotation and things mechanical" (Bettelheim, 1967, p. 248 qtd. in Williams, 2021). Williams (2021) articulates that cultural tropes about robot-like autistics lack a single identifiable point of origin but likely emerge from descriptions used in some of the earliest clinical writings about autism.

Autistics-as-machines tropes have existed within modern computing for decades, going as far back as some of Weizenbaum's writing in 1974 (Weizenbaum, 1983). In the early days of interactive computing, computer scientists debated whether computers understood human users, or merely provided an illusion of understanding (L. A. Suchman, 2007; Weizenbaum, 1966). Arguing the computer's capacity for understanding was illusory, Weizenbaum (1983) suggested against reading too deeply into computers' programmed responses to stimuli. He explained that typewriters, too, responded to stimuli, typing letters in response to keypresses, but surely typewriters do not understand the words they imprint. He described interactive computer programs, typewriters, and "infantile" autistics as having equivalent capacities for genuine conversation (i.e., none whatsoever; Weizenbaum, 1983).

Since Weizenbaum's days, like with broader cultural robot/autism tropes, mechanistic characterizations of autism in HCI have become diffuse, lacking an identifiable origin. The prevalence and staying-power of this trope in HCI are evident in numerous repetitions of the claim that autistics "have a natural affinity for technology" (e.g., Boitnott, 2012; Brandão et al., 2015; Caria et al., 2018; Carvalho et al., 2015; Dees, 2021; Elliott, 2017; Frauenberger et al., 2012, 2013, 2015; Guldberg et al., 2017; Lavian & Alshech, 2015; Majeed, 2017; Md Shamsudin et al., 2021; Menzies, 2012; Navedo et al., 2019; Newbutt & Bradley, 2022; Valencia et al., 2019)[12]. Very few of the citations given for this phrase (if any source is referenced at all) provide supporting evidence. More often, the citations provided point to similar works. Said similar

12 Each of these papers we cite as referring to autistic/technology relationships in terms of "natural affinities" was published within the last ten years, indicating the continued and contemporary nature of this claim.

papers either justify technological interventions on assumptions of affinity themselves or find that a small-sample or preliminary study showed promising, if inconclusive, results about a specific technological intervention (e.g., Parsons, 2015; C. Williams et al., 2002; Wojciechowski & Al-Musawi, 2017). Paradoxically, some citations even point to papers suggesting technologically-mediated autism interventions *lack* foundational evidence (e.g., Fletcher-Watson, 2014). These citational practices raise questions about standards within HCI for sourcing claims, particularly those purporting an entire category of people possess some essential characteristic.

Chasing these "natural affinity" claims in HCI through a deep citational rabbit hole, we eventually found *some* theoretical support for technological affinities as an essentialized characteristic of autism (Murray & Lesser, 1998b, 1998a). This theory, *monotropism*, refers to the autistic tendency to focus incredibly intently on a single interest (Murray, 2018). Murray (2011) positions monotropism in contrast to *polytropism*, the non-autistic tendency to divide energy across many interests (Murray, 2011). Murray and Lesser (1998b, 1998a) built their theory of monotropic on evolutionary theory and mathematical modeling of atypical biological survival mechanisms. That is, Murray and Lesser (1998a, 1998b) argued that the theoretical distinction between autistics and non-autistics is natural – something biological and essential to autism. They say that, like autistic people, computers (at least in 1998) are "naturally monotropic," singly-focused machines (Murray & Lesser, 1998a). Over two decades, Murray promoted monotropism as a mathematically and biologically grounded framework for autistic difference (Murray, 2018; Murray & Lesser, 1998b). In their work, Murray and Lesser (1998a, 1998b) clearly explain that, by positioning monotropism as biological, they intend to frame autism as a natural variation of humanity rather than something apart from it. We want to clarify that we support this intention of normalizing autistic existence as part of a broad spectrum of what it means to be human. Murray and Lesser (1998a) present monotropism as a way for non-autistics to understand better and build relationships with autistic people, which is highly laudable. The problem arises when this research is taken up uncritically and used to support claims about technological affinities as an essentialized characteristic inherent to all autistic people. While essentializing claims about autistics and technology remain popular, monotropism theory remains purely theoretical, having some explanatory benefits over alternative frameworks but lacking meaningful supporting evidence or empirical work (Milton, 2017; Wood, 2021).

Through its commitment to this claim about autistic technological affinities, or techno-autism, HCI perpetuates cultural narratives that position autistics as *things*, not people.

2.4 Robo-Autism

Robot interventions for autism represent a flourishing niche within HCI (see Spiel et al., 2019), wherein research is often predicated upon claims that autistic people are more similar to and prefer machines over people. Suchman describes robots in human-robot interaction research as *model (in)organisms* (L. Suchman, 2011). Model (in)organisms play on the concept of *model organisms*, which refers to using a particular creature as a proxy for scientific experiments trying to answer questions about other creatures or broader biological phenomena (see, e.g., Kohler, 1991). For Suchman (2011), robots provide a model that *approximates* humans – one that can pose as a substitute for people in experiments about human phenomena.

Suchman (2011) explores how, through robot model (in)organism research, our understanding of human behavior and cognition is informed by tests on and with robots. And, as we gain a deeper understanding of humans, our understanding of robots (as human proxies) likewise adapts. Roboticists design robots to behave like humans. Humanoid robot design requires complex computer modeling intended to mimic human cognition. When robots respond to stimuli in expected – humanlike – ways, they take it to indicate their models' validity. Our understanding of human cognition, then, is reorganized around robotic algorithms. As robots behave more humanlike, our understanding of humans becomes more robot-like (L. Suchman, 2011). Understandings of humans and robots become recursive and co-constitutive (L. Suchman, 2011).

Robots and computers never quite match their human counterparts. There remain critical gaps between humans and robots (Mori, 1970), despite the ways our understanding of one is co-produced (see Jasanoff, 2004) with and by our understanding of the other (L. Suchman, 2011). Critical gaps between humans and computers reside in robots' peculiar ways of moving (Mori, 1970) and limited capacity for mutual intelligibility with human users (L. A. Suchman, 2007). The disjunctures between humans and robots are the same as those observed or alleged between humans and autistics (Baron-Cohen et al., 1997; Weizenbaum, 1983; Yergeau, 2013, 2018), leading to Weizenbaum's comparison of computers and autistics. More recently, Kaminka (2013) stated that nearly all robots are autistic. In understanding robots as autistic, it seems inevitable that notions of autistics (replete with natural affinities for technology) as robots

follow. As we show next, such characterizations can harm autistic people in technologically-mediated autism research.

2.5 Robot(ic) Autism Therapy

Socially assistive robot therapy represents an extension of the vast, pre-existing surveillance and control apparatuses (Roscigno, 2019; Yergeau, 2018) endemic to these interventional frameworks. Within robot-intervention research for autism, robots are deployed to assist in or augment formalized autism intervention paradigms, such as applied behavioral analysis (ABA) (Spiel et al., 2019). These interventions seek to rehabilitate autistic bodyminds, rendering them indistinguishable from their peers (Lovaas, 1987). More specifically, through continuous observation and highly regimented reward and punishment structures, the interventions enforce cisgender, heterosexual, and ablenormative behavioral and communication norms on non-conforming bodyminds (Yergeau, 2018). In essence, prevailing behavioral autism intervention paradigms are predicated upon curative (Kim, 2017) and normative (Butler, 2004) violence. The desired outcomes of these projects, creating autistic people independently able to monitor and mask their autistic traits, are associated with disproportionately high rates of autistic suicide (Beck et al., 2020; S. Cassidy et al., 2018; S. A. Cassidy et al., 2020; Rose, 2018).

As an overarching field, HCI often proclaims to value progress and social good (Bowers, 2018; Irani et al., 2010; Lin & Lindtner, 2021; Pal, 2017). Yet, a considerable proportion of autism research in HCI is complicit in behaviorist autism intervention paradigms (Spiel et al., 2019) – projects of domination, control, and destruction (Roscigno, 2019). Such research within a progress-driven field may appear paradoxical. However, several factors may help explain this vein of HCI research. First, discourses that objectify autistic people may obscure their needs and agency, allowing for interventional research to be framed in terms of progress for non-autistic research beneficiaries. Second, existing political economies, both within and outside of HCI, may incentivize objectifying autism technology research and its facilitating narratives.

2.5.1 Robo-Therapy, for the State

In a field where essentialist claims about the likeness of autistics to machines are naturalized, autistics are cast as inhuman. They are cast as unliving. They are framed as *things*. Raw materials to be acted upon (Broderick & Roscigno, 2021; Roscigno, 2019). If a typewriter breaks, you might repair it, or you might just throw it away. If a computer freezes or starts

performing erratically, you might restart it, or just ignore it and walk away. If autistics are essentially like computers and typewriters, if they are just things, then are their peculiar and problematized features similarly dismissible? Apparently so, at least some of the time, within HCI (R. M. Williams & Gilbert, 2019; Ymous et al., 2020). More often, though, as is evidenced by the proliferation of interventionist autism HCI research, autistics are subjects for repair.

As Lin and Lindtner explain (2021), many HCI research activities are significantly motivated by ideals of progress, utility, and productivity. The field is driven by a sense of doing good – working towards (typically Western conceptions of) social progress (Irani et al., 2010; Lin & Lindtner, 2021; Pal, 2017). Yet, as Ymous and colleagues indicate, "what is allowed to be understood as 'doing good' is reliant upon entrenched sociocultural traditions of ableism" (2020, p. 3). To render autistics less visibly autistic is an assumed good in HCI research supporting behavioral autism interventions. "Rehabilitation" of robo-autistics is an uninterrogated good, despite growing evidence of harm (Bascom, 2012; Beck et al., 2020; S. Cassidy et al., 2018; S. A. Cassidy et al., 2020; Rose, 2018; Unbound Books, n.d.). The unchallenged assumption about the goodness of ABA is not unique to HCI. Instead, it indicates an overlap between the ideals of HCI and ABA. There is a convenient fit between robo-autism discourses and ABA's positioning of pre-intervention autistics as not-quite-people, not yet deserving of rights (see Roscigno, 2019).

ABA shares HCI's commitments to the logics of progress and utility (Roscigno, 2019). As Roscigno (2019) explains, ABA and similar interventions can be thought of in terms of biophilanthropy. Biophilanthropy is a term coined by Schuller (2017) to explain the use of surveillance and control for the good of the state and economy but under the guise of charity. ABA interventions are nominally about helping autistic people move beyond the idiosyncrasies of autism and join the rest of society as productive and useful citizens (Roscigno, 2019). The notion that autistics must be rehabilitated – repaired – to have value within liberal capitalism perpetuates and justifies the violences of behavioral autism interventions (Roscigno, 2019). Further, various autism discourses (including those about technology) rhetorically distance autism from humanity, obfuscating the personhood of these biophilanthropic recipients while simultaneously normalizing the violences they endure as necessary to the well-being of the neoliberal state (McGuire, 2016; Puar, 2017; Roscigno, 2019; Rottier et al., In Press). Within a neoliberal society, to be legible as human and deserving of citizenship and rights, autistic people

must be made capable of productive economic participation (Mitchell & Snyder, 2015; Roscigno, 2019).

Robot research extends beyond behavioral autism interventions in HCI, purporting to help the individual for the good of economic and state interests in many other contexts, too. DiSalvo (2018) notes that design research often seeks to support individual behavior change in the face of economic and social crises. For example, in response to the horrific realities of global climate change, an interaction designer may be more likely to make an app to help individuals track their carbon production rather than acknowledging or addressing governmental policy and industrial practices. DiSalvo describes this trend toward behaviorism and techno-solutionism as "the abdication of the issue in favor of the (purportedly) tractable problem" (2018, p. 481). We do not intend to suggest that HCI researchers harbor malicious intent towards autistics through their involvement in behaviorist autism interventions. Instead, a flawed sense of *for whom* our research should do good, paired with the naturalization and adaptation of objectifying autism discourses within broader society, create the perfect storm for fallaciously thinking supporting ABA constitutes progress and social good. Structural conditions may preclude researchers and designers from arriving at alternative ideas of "doing good," such as working towards dismantling the very structures that naturalize maiming (see Puar, 2017) of autistic children in the name of progress. However, while HCI researchers within this space are likely making well-meaning errors (see Mankoff et al., 2010)[13] and do not intend to cause harm, they are beneficiaries of the political economies of autism medicalization and intervention, which may disincentivize them from adopting alternative research programs.

2.5.2 Robo-Therapy, for HCI Researchers

Mallett and Runswick-Cole (2016) argue that autism has become a commodity, bought and sold by myriad actors, from governments, to companies, to non-profit organizations, and to academic researchers. Broderick and Roscigno (2021) frame this commodification of autism as the *autism-industrial complex* (AIC). Through its involvement in autism intervention, HCI is entangled in the diverse political economy of those who trade in autism. This marketplace is built upon the construction of autism as a distinct ontological category - a deficient category positioned as demanding remediation (Broderick & Roscigno, 2021; Mallett & Runswick-Cole,

13 Albeit, significantly impactful errors.

2016). A diversity of diagnostic, educational, behavioral, and therapeutic professions exist in response to biomedical and dis-animating constructions of autism and comprise the AIC. Autism is their capital. Yet, paradoxically, their work often tries to convert the *things* they trade into people, able to participate in civic and economic life. Thus, as Broderick & Roscigno explain, the various arms of the AIC have an imperative to both perpetuate the classification of autism and autistic people as either broken people or inhuman things and ensure a continual supply of autistic raw materials. We see this in massive lobbying efforts, which have succeeded in legislation deeming ABA as the only intervention for autism coverable by insurance within the United States (Roscigno, 2019). When a child is diagnosed with autism, their parents are given pamphlets about ABA and told it is the only available option for their child. Thus, parents become enrolled in the AIC, creating additional advocates for the continuance and advancement of autism services. And, to complete the cycle, service providers can claim they are simply fulfilling market demand driven by parents of autistic children. Even when evidence emerges that institutionalized conceptions of autism are incomplete or incorrect, these incidents, too, become opportunities for the AIC.

Classically, autism has been constructed as an essentially male disorder. Baron-Cohen (1997) went so far as to theorize autism as characteristic of having an "extreme male brain" – that is, autism represents extreme versions of male characteristics like rationality, mathematical and technical aptitude, and lower (relative to females) empathy. Such a theory rests on gender essentialism and harmful stereotypes. We suspect the male-coded construction of autism is likely implicated in the attachment of technological affinities as an essentialized characteristic of autism and the readiness with which techno-autism discourses were adopted. In recent years, various facets of the AIC have had to reckon with the emergence of so-called "female-autism." The construction of "female-autism" exemplifies the AIC's co-optation of discourses incompatible with dominant autism narratives (Moore, 2021). As Moore (2021) explains, attempts to codify "female-autism" as a distinct autism phenotype resemble gender-essentialist constructions of girls and women. Moore (2021) further articulates that by widening the clinical criteria for autism to include girls and women, including those who present as cisgender, rather than as particularly (extreme) "male" in their demeanor and interests, new markets are created. By potentially doubling the population from which clinicians can legitimately sample for autistic capital, the AIC grows.

Through its adoption of essentializing claims about autism and technology, many autism technology researchers are swept up by and complicit in the AIC. In adopting mechanical and robotic constructions of autism as a thing, HCI autism researchers provide the appearance of scientific legitimacy to objectifying claims that sustain the helping professions. Too, in developing technological interventions for techno-autistics, they create and expand new markets for autism technologies. And through their participation in the AIC, researchers stand to gain status, publications, grants, patents, and personal income. The field's entanglements with the AIC are not limited to a few autism researchers but to the ideologies of progress and utility underpinning much of the field itself. Because HCI is a field that has recognized curative violence as a social good (sometimes explicitly, through "social impact" awards), individual researchers have an incentive to conduct AIC-complicit research. While the AIC is pervasive, it is sustained by myriad, entangled political economies, such as that of HCI and its drives towards industrial production, innovation, usefulness, and progress (Dourish, 2006, 2018; Lin & Lindtner, 2021). Therefore, changing the nature of autism research in HCI must entail addressing not individual research programs but rather systemic and intersecting structures within and outside of the field, incentivizing certain kinds of research.

2.6 Not Robots; Cyborgs

Creating enduring and systemic change is a monumental challenge and beyond the scope of what any single paper can hope to accomplish. Instead, we aim to challenge the robotic and computeristic autism discourses that underpin so much autism technology research. The neurodiversity paradigm (see Kapp et al., 2013) frames autistic differences as variations in human experience and the presentations thereof. Within this framework, autism, disability, and impairment are normalized. Within this framework, it is not the humanity of autistic people that is suspect. Rather, what is suspect is the humanity of an institutionalized conception of personhood that casts autistic people as less human than non-autistics and machines alike. As a replacement for autistic-as-robot rhetorics, we invoke the figure of the (crip) cyborg. In providing alternative framings for understanding autistic relationships with technology, we hope to enroll additional researchers into the growing ranks of HCI scholars attempting to resituate autism research around the wants and needs of autistic *people* (e.g., Kender & Spiel, 2022; Keyes, 2020; Ringland, 2019; Spiel et al., 2019; Spiel & Gerling, 2021; R. M. Williams & Gilbert, 2019; Ymous et al., 2020).

2.6.1 Cyborg Affinities Along the Cyborg/Tryborg Continuum

In classic (Harawayan) cyborg theory, cyborgs are defined by what they are not[14] - by the multiplicity of categories in which they (refuse to) fit and the boundaries they transgress (Haraway, 1990). Haraway (1990) provides four definitions for a cyborg: (1) a "cybernetic organism"; (2) "a hybrid of machine and organism"; (3) "a creature of social reality"; (4) "a creature of fiction" (p. 149). As with Suchman's (2011) co-constructed human-esque robots, Haraway's (1990) cyborgs comprise an artifact/category that challenges existing dualisms between organism and machine and between subject and object. Cyborgian bodies and existences are often *imagined* as those that, through highly integrative technology use, can transcend non-augmented bodily limitations. Such conceptions of the cyborgian are critiqued by disabled writers, who dispute Haraway's notion of the cyborg as "a creature of fiction" (Haraway, 1990, p. 149).

Weise (2018) notes Haraway's cyborg is a metaphorical creature. Too, in common usage, Weise notes that the cyborg represents technological augmentation used to bring about superhuman capacities. Weise (2018) writes that these popular conceptions discount the embodied experiences of the disabled people who, for years, have assimilated variegated technologies to facilitate their continued existence. These disabled people, cyborgs by Haraway's (1990) second definition, predate Haraway's cyborg fictions, which imagine the cyborg as something not yet here or something one might choose to be (Weise, 2018). For these disabled people, whom Weise (2018) refers to as *common cyborgs*, technology use makes critical bodily functions possible. Disability studies scholars and common cyborgs point out the importance of recognizing that cyborg non-fictions are not always as shiny and exciting as cyborg-as-superhuman narratives would have us believe (Earle, 2019; Kafer, 2013; Shew, 2017, 2020; Weise, 2018). Cyborg existence often entails various costs, limitations, and painful bodily sensations associated with one's cyborg appendages. Weise refers to people who expand their capabilities via technology for reasons other than necessity (e.g., leisure, aesthetics, productivity, or other luxuries) as *tryborgs*. These not-quite-cyborgs, cyborgs of metaphor and aspiration, differ from disabled cyborgs because of the ways privilege and power differentiate between their technology usage (Nelson, 2020). Tryborgs imagine metaphorical cyborg futures without

14 Similarly to how autistics are defined according to their lacks (Yergeau, 2018), albeit, importantly, under considerably different power dynamics.

recognizing the historical and continuing existence of non-metaphorical disabled cyborgs (Weise, 2016, 2018).

Weise has used prosthetic legs for decades (2016), but identifies a specific moment in 2010 as marking when cy[15] became a cyborg – when cy transitioned from a purely mechanical to a prosthetic knee (Wong, 2019). Although Weise's identification as a cyborg relates to integrating computerized parts with cy's body, cy is open to all disabled people claiming cyborg (Wong, 2019). For example, Shew considers herself a cyborg, despite not having any computerized parts (Wong, 2019). Scholars have interpreted Weise and Shew to construct different definitions of what it means to be a cyborg. Earle (2019) delimits cyborgs to those disabled people with necessary (for facilitating activities and functions of daily living) technological artifacts that are "within the body, strapped to it, or carrying the body in some way" (p. 48). Yet, Weise's construction of the cyborg includes those whose continued existences are maintained by less mechanical technologies, like anti-depressants. Williams and Gilbert (2019) define cyborgs as "those of us whose life and cognition are reliant and co-constituted by the existence of an interface and technology" (p. 3). This particular definition is helpful within the context of autism, as it explicitly includes people with learning, intellectual, and cognitive disabilities whose cognitive functioning is technologically aided.

There are myriad instances of autistic technology use in non-interventional contexts to facilitate daily functioning. Harrison and colleagues (2018) explore ways autistic people appropriate off-the-shelf mobile computing devices to mediate undesirable / curate desirable sensory experiences for stress management. Zisk and Dalton (2019) address ways autistics use these same devices to communicate non-verbally (see also Alper, 2017) effectively. In considering William and Gilbert's (2019) cyborg alongside that of Weise (2018), there is an argument that these autistic technology use cases are cyborgian. In the case of mobile computers as alternative and assistive communication (AAC; see Alper, 2017; Zisk & Dalton, 2019) devices, essential communicative capacities are moderated by whether an autistic person has access to appropriate technologies.

Importantly, disabled people are not alone in cyborgian necessary technology use. Transgender people represent another example of cyborg becoming. Some trans people

15 Weise's pronouns are cy (Cy [@JillianWeise], 2020).

incorporate technology into their bodies as part of medical gender transition processes, like surgeries and hormones (Gill-Peterson, 2014). Many trans surgeries involve implants incorporated into a person's body to physically manifest gender change. Hormones used for gender change are a technology that fundamentally changes a person's biology. In other cases, technologies can augment or expand trans people's experiences, bodies, and identities (Haimson et al., 2020). As a few examples, in Cárdenas' projects *Becoming Dragon* (2010) and *Becoming Transreal* (2012), virtual reality systems enable gender exploration, and for Nelson (2020), hand chip implants are queer cyborgian approaches. Stone (1995) described trans people as cyborgs because of the ways they sometimes incorporate technology into communication practices (in what she called "prosthetic communication") and also their status as "boundary creatures," occupying liminal spaces not only related to gender but also at the edges of the human/machine boundary. Of course, many trans people are also disabled, and many disabled people are also trans. These intersecting identities mean that some people are cyborgs across multiple dimensions.

While non-disabled and cisgender people also sometimes use technologies that augment their experiences, these augmentations do not raise to the level of cyborg status (Weise, 2016). As Nelson and colleagues (2019) articulate, two unique elements – which trans and disabled people share – are necessary for claiming cyborg: (1) marginality (i.e., augmentations to one's body are intertwined with one's marginalized identity/ies); and (2) change (augmenting one's body changes its fundamental makeup, whether physically, biologically, or in terms of how one relates to the world).

In some cases, other marginalized groups, such as women and racial minorities, may also be considered cyborgs. For instance, Nakamura (2014) drew attention to the gendered labor of technology work by discussing how a community of Navajo women may be regarded as "natural" cyborgs in relation to their technologically-mediated factory work. And of course, Haraway (1990) famously described how women could be cyborgs, particularly women of color. Yet some critique Haraway's cyborg theory as ignoring power differentials between white women and women of color (DeCook, 2020; Puar, 2020; Sandoval, 2013; Schueller, 2005; Wilkerson, 1997). Thus, applying Haraway's theory in disability and trans contexts, which must meaningfully involve intersectionality, is fraught. Cyborg status, then, may involve a third element: (3) multiple layers of marginality.

Within disability studies, some, like Kafer (2013), express concerns about the degree to which Harawayan cyborg theory risks portraying technological relationships as shared, yet depoliticized, phenomena devoid of references to power differentials. Still, Kafer (2013) finds utility in *cripping* the cyborg. Like queer(ing), crip(ping) is both a noun and a verb (see Sandahl, 2003). As Hamraie & Fritsch write, *to crip* is to assert "the noncompliant, anti-assimilationist position that disability is a desirable part of the world (2019, n. p.). Kafer writes, "Cripping the cyborg, developing a non-ableist cyborg politics, requires understanding disabled people are not cyborgs because of our bodies (e.g., our use of prosthetics, ventilators, or attendants), but because of our political practices … Cripping the cyborg, in other words, means recognizing that our bodies are not separate from our political practices; neither assistive technologies nor our uses of them are ahistorical and apolitical" (2013, p. 120). Kafer's (2013) reconceptualization of the crip cyborg (or "cripborg," to borrow a term coined by Stevens in Nelson et al., 2019) requires that we look beyond the interfaces between disabled bodyminds and machines (e.g., autistic children and humanoid robots) to the effects and assumptions of and within these technologies and their disabled usage.

2.6.2 Autistic Cripborgs (and What Their Existence Means for HCI): Centering Disabled People's Needs and Knowledges

A critical distinction between *things* and *people* is that we attribute agency and self-determination to one but not the other. Within robot-assisted autism interventions, Spiel and colleagues (2019) note that autistic children have little or no agency in determining how they interact with the intervening machines, nor are they permitted to engage in sense-making of or with the robots. Autism–robot research appears unconcerned with achieving mutual intelligibility (see Suchman, 2007) between autistic children, robots, and/or non-autistic clinicians and caretakers. Instead, a primary purpose of robot studies can be understood as an effort to render the autistic child intelligible to the non-autistic other. The socialized robot now plays a role in the ablenormative socialization of the (robot-like) autistic child. The significance of imbalances in the order and direction of these relationships go unquestioned in this literature. A hierarchy seems to exist in which humans and robots can act upon one another, but wherein autistics can only be acted upon. Autistics are configured as so "epistemically absented" (Yergeau, 2018, p. 54), so distant from intelligibility, that they have less agency and capacity for sense-making than the robots to which they are so often compared.

In contrast to (dominant constructions of) autistic robots, or robotic autistics, cripborgs have agency. Cripborgs have politics (Kafer, 2013). Autistic technology use is inherently *political*, if only because systemic power structures and the AIC construct autistic-as-robot discourses as *apolitical*. Claims of "natural affinities" may obfuscate the politics of autistic embodiment and practice through convoluted citational practices and inadvertent influence of broader cultural tropes and market forces. However, making essentialized claims about minoritized people is and always will be political. Importantly, autistics are not cripborgs solely because of the technological practices imposed upon them by behaviorists and technology researchers. Autistics are cripborgs because of the ways they appropriate existing technologies to make space for and community with themselves and to advocate for their recognition as *agentic*.

The Internet has been an integral technological component of autistic communities and the autistic self-advocate movement for decades. Sinclair (2005) writes about how, as the autistic self-advocacy movement was first coalescing, autistic community members shared online spaces with parents of autistic people. Parents led the prominent autism organizations, organized the autism conferences, and set the agendas for policy- and research-oriented advocacy (Sinclair, 2005). Sinclair (2005) recalls themself and fellow autistics posting on a parent-dominated forum in the early 1990s in the days following a large autism conference. The parents rebuked the autistic forum users. The parents said the autistic posts were of no interest to them. They had trouble grasping the notion that autistics might conceivably be interested in ongoing discussions about themselves and that the topics of importance to autistics might be relevant to organizations that ostensibly exist to support them.

Before long, an autistic person configured a forum by and for autistic people. Parents were allowed to join, but this forum was autistic space, and parents were subject to community norms (Sinclair, 2005). To our knowledge, this event – along with the year-long autistic vs. parent flame-war that followed – is the first example in a long history of autistics leveraging digital spaces to reclaim narratives about themselves. We can see current-day examples of this kind of online activity on many forums, personal blogs, and popular social media sites (see, e.g., Osorio, 2020; Seidmann, 2020). Before Murray & Lesser (1998a, 1998b) ever wrote about autistic biology sharing similarities with computer architecture, autistics were using computers not because of an affinity for computers but out of an affinity for one another. They used computers and communication technologies to organize. To plot out a political agenda (Sinclair,

2005). Maybe autistics *do* have a "natural affinity for technology;" perhaps confirmatory evidence for this claim will emerge from a groundbreaking study tomorrow. But this autistic computer use would still be cripborgian, agentic, and political, rather than robotic.

Were autism researchers in HCI to understand autistics as cripborgs rather than computers, it would not spell the end for the AIC. Researchers could continue reaping the benefits of autism research (publications, grants, income, and accolades) but could also, at least potentially, provide direct benefits to the autistics within their research studies. The framework of crip technoscience (Hamraie & Fritsch, 2019) can help explain this shift from research about autistics in service of non-disabled needs to autism research in favor of autistic needs. Hamraie and Fritsch (2019) articulate crip technoscience as a means for designers to align themselves and their work with disabled people's activist-oriented needs and knowledges. They place crip technoscience in opposition to disability technoscience, which refers to more traditional forms of individualizing, isolationistic, biophilanthropic, and otherwise (techno)ableist (see Shew, 2017) approaches to disability and technology. We need a shift within autism technology research in HCI that moves autistic people from passive recipients of violent "charity" to active participants in designing their technological futures. Researchers more familiar with robo-autism than cripborgian autism might look to crip technoscience and its four central commitments for inspiration.

The first commitment of crip technoscience is to center the work of disabled people as knowers and makers (Hamraie & Fritsch, 2019). Williams and Gilbert (2019) review disability technologies in HCI and find that HCI researchers struggle to recognize ways their work might adversely impact their users. They suggest this difficulty stems from researchers' lack of familiarity with the embodied and lived experiences of disabled people. Clinical autism discourses paint autistic people as devoid of self and self-knowledge (Baron-Cohen, 1997; Yergeau, 2013). Cripborg autistic existence challenges this notion by highlighting the politics and intentionality of autistic technology use. This commitment to disabled knowledges and to autistics-as-cripborgs suggests HCI researchers should reevaluate their methodological approaches to autism technology research, favoring participatory methods in which autistic people (as opposed to their non-autistic parents, teachers, and caregivers) are enrolled as crucial stakeholders and subject-matter experts. Given issues around working with people with intellectual disabilities and the need for parental consent when working with minors, building

and navigating these methodologies will require care and nuance. Spiel and colleagues (2018) model the necessary reflexivity and nuance for HCI researchers interested in ensuring the well-being of disabled research participants.

The second commitment of crip technoscience is to "access as friction" (Hamraie & Fritsch, 2019, n.p.). This commitment rejects disability design and intervention forms wherein inclusion and accessibility are synonymous with assimilation. Ymous and colleagues (2020), in a paper some HCI researchers felt was contentious, described ways that expectations of non-disablement within HCI are at odds with the realities existing as a disabled researcher within the field. They call out the violence inherent to sweeping ableism within HCI. It would be entirely understandable for HCI researchers involved in the types of practices Ymous and colleagues (2020) point out to feel uncomfortable. Yet, a commitment to "access as friction" asks these researchers not to look the other way - to stay with the trouble, so to speak (see Haraway, 2016). Places where the demands of disabled people diverge from dominant research priorities and perspectives in HCI can be generative. Williams and Boyd (2019) demonstrate that, by not shying away from these frictions, HCI researchers can build coalitions and work towards defining and practicing alternative types of research mutually beneficial to all parties. Such papers, like the present papers, can be treated as invitations to take part in new research programs rather than merely as condemnations. In staying with the friction and accepting these invitations, researchers may avoid the pitfalls inherent to dominant approaches to disability design research in HCI (see, e.g., Shew, 2017; Shew, 2020).

The third commitment of crip technoscience is to interdependence as a political technology (Hamraie & Fritsch, 2019). Hamraie and Fritsch write,

> "We position the crip politics of interdependence as a technoscientific phenomenon, the weaving of relational circuits between bodies, environments, and tools to create non-innocent, frictional access. Mainstream disability technoscience presumes disability as an individual experience of impairment rather than a collective political experience of world-building and dismantling. This perception has two primary consequences. First, disabled people are perceived as dependent and the goal of technoscience becomes to encourage independence. Second, disability and technology are both perceived as apolitical and stable phenomena, rather than material-discursive entanglements that take shape through struggle, negotiation, and creativity" (Hamraie and Fritsch, 2019).

Traditional approaches to autism technology research support behavioral interventions concerned with rendering autistic people independent. Yet, despite Western society's extreme valuation of the notion of independence, independence is a lie. None of us are independent. We are all *interdependent* on one another (Mingus, 2017). As Mingus writes, very few of us grow our own food, produce our own clothing, or create our own energy sources. Interdependence is a fundamental condition of human existence, yet our self-narratives of and preferences for individuality obscure this truth. In committing to interdependence as a political technology, HCI researchers have an opportunity to (working with autistic people) define alternative outcomes to autism technology research that promote care and support (see Piepzna-Samarasinha, 2018) rather than independence and normalization. Cripborgian framings of autism can help identify forms of interdependence that might warrant exploring. As computers and robots, autistics are fundamentally solitary and asocial, sharing more affinities with machines than with people. As cripborgs, autistics share affinities not only with one another, but with other groups of cyborgs. Cross- and trans-identity cyborg affinities represent coalitional and intersectional technology research opportunities with broad impact beyond any single identity group. Working on technology research to support coalitional forms of interdependence can, perhaps, satisfy HCI researchers' desires to "do good" while also maximizing the number of people who might benefit from their research.

The fourth commitment of crip technoscience is to disability justice (Hamraie and Fritsch, 2019). The term disability justice was coined by disabled queer and trans people of color comprising the Disability Justice Collective (Piepzna-Samarasinha, 2018). Disability justice differs from disability rights. Rather than focusing on state-granted privileges, it seeks to dismantle the root causes of ableism: the intersecting forces of heteropatriarchy, white supremacy, colonialism, and capitalism (Sins Invalid, 2019). For some academics, particularly those within fields like HCI oriented around industrial progress and innovation (Dourish, 2006, 2018), perhaps adopting anti-capitalism as a tenet of good research is a bridge too far. But, researchers might operationalize a commitment to disability justice in autism technology research by ensuring research projects include and are led by those most affected by intersecting forces of oppression. Historical autism research has focused on autism as a male phenomenon (Moore, 2021). Researchers might look for ways to support the techno-political practices of, for example, autistics who are women, queer, trans and/or Black, Indigenous, and people of color.

This commitment calls on researchers to sort out what it means to work in close collaboration with autistics with significant intellectual disabilities while remembering *always* to presume competence (see Bascom, 2014). As Costanza-Chock (2020), design justice is a framework for understanding and designing against hegemonic power structures. The framework is significantly built around the precepts of disability justice (see Constanza-Chock, 2020) but, unlike disability justice, has been adapted to be directly applicable to HCI. Following the tenets of design justice may help HCI researchers operationalize disability justice within their work.

2.7 Conclusions

Popular autism discourses are often widespread and deceptively pernicious. They become so naturalized that they go unquestioned. But, as with any assumptions, particularly those about groups of people to which someone does not themselves belong, critical examinations are warranted from time to time. We should avoid justifying research on or with autistic people in claims that *sound* true. We should avoid justifying research on or with autistic people in claims that *sound* true. While mechanical constructions of autism may align with broader, cultural autism narratives, claims about "natural affinities for technology" lack support and may cause harm. Positioning autistic people as or like robots (i.e., things) may normalize forms of coercive intervention that researchers would question if only they more clearly saw their subjects as people. We suspect that despite any particular benefits they may reap from their research, most autism technology researchers are acting with good intentions. In outlining how those intentions are misguided and complicit in violence, we hope those researchers will reconsider their future research approaches. In providing alternative ways to understand autistic people (as cripborgs, rather than computers) and suggesting crip technoscience as a framework for research grounded within this new understanding, we hope to enroll these well-intentioned researchers in the project of dismantling anti-autistic ableism, both in and beyond HCI.

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Chapter 3 Veridicality, Rigor, and Endemic Autistic Affinities in Human-Computer Interaction

3.1 Introduction

In this study, I expand on previous work conducted with Dr. Oliver L. Haimson to provide a broader and more detailed analysis of the repeated claim that autistic people "have a natural affinity for technology," which appears throughout the field's autism-related technology research over the past several decades, apparently without any significant evidentiary backing. This finding raised numerous concerns, not the least of which being the HCI's propensity for prefiguring autistic people as non-agentic, passive recipients of technologically-mediated behavioral interventions (see Spiel et al., 2019). Direct implications for autistic people aside, these findings additionally indicate the existence of one or more mechanisms through which: (A) HCI publications either skirt expected standards of the sorts typically ensured through a peer review process; (B) strategic language selection may obfuscate deficient alignment with standard definitions for good and publishable literature, and/or; (C) otherwise obscurative language or presentations of data render it difficult to identify and challenge underlying facts and assumptions upon which new research is built.

If left unchecked, the apparent author-friendly publication conditions indicated from past findings suggest these researchers, who often wield considerable power and influence relative to the autistic target-recipients of their studies' beneficence, are largely unaccountable to the professional and scientific norms one might expect of positivist research (e.g., the "Mertonian norms"; Merton, 1979). Working from an expanded corpus of claim-containing and cited-for-claim papers, the present study seeks to understand better the scope and nature of the previously noted problematic citational practices and the overreliance on non-purposive repetition of others' utterances rather than on evidence.[16] Through a critical investigation drawing on both systematic

[16] I.e., I entered this research with the suspicion that researchers' inherited, non-referential echolalia, though not inherently an indicator of maladaptive praxis requiring peer-review- and/or editorial-intervention, may not be a firm foundation from which to motivate research studies.

and interpretivist qualitative methods, I identify several problematic underlying citational mechanics that provide "natural affinity" claims the appearance of authority without accountability to the burden of evidence, rhetorical patterns that may give the appearance – if not the actual quality – of scientific merit, and evidence of a sweeping lack of accountability in the peer-review process

3.2 Background

In previous work, Dr. Oliver L. Haimson and I explored the ramifications of the claim that "autistic people have a natural affinity for technology." We explored, in particular, how this claim, which appears in numerous autism-related technology studies, interacts with the assumed facticity of mathematical models of cognition (see Suchman, 2007), clinical constructs (e.g., Theory of Mind; see Yergeau, 2013, 2018), social narratives (e.g., Gibbons, 2017; McGuire, 2016; Sinclair, 2012), and biopolitical intervention paradigms (Roscigno, 2019) to co-produce and sustain the autistic-as-robot(-like) subject position (see Guberman & Haimson, 2023).

Irrespective of whether autistic people are or are not relatively more interested in technology than are non-autistics, the inclusion of the word "natural" in these claims connotes that this particular affinity is something endemic to "autism *spectrum* disorder" – a diagnostic category now named for and defined by its "universally accepted" (Mottron & Bzdok, 2020, p. 1) and empirically supported quality of heterogeneity. While I would generally advise against making essentializing claims or assumptions about anyone, this specific claim is peculiar. What, actually, does it mean to suggest that one has a "natural" or innate attraction toward something not-natural? Can one have a natural affinity for tinfoil? Or perhaps for scarves?

Claims about autistic natural affinities for technology are additionally problematic, as they align with and perhaps derive from or contribute to gender-essentialist theories about the nature of autism itself. Baron-Cohen (2002) is well known for his theorization of autism as resulting from having an "extreme male brain." Baron-Cohen uses this descriptor in several different ways. First, he suggests that autism represents, in the extreme, male-coded characteristics like rationality, mathematical and technical aptitude, and significant deficits in empathy. In recent decades, with changes in diagnostic categories, it has become increasingly clear that autism is not a male condition, but one that was inappropriately standardized to male-reading presentations.

Beyond having potential direct impacts on autistic people, our past findings raise serious questions about citational practices and evidentiary standards throughout the field. In the study to come, I follow my innate autistic disinclination to trust essentialisms[17] and build on the previously described preliminary examination of natural affinity claims in HCI with a broader and systematic study to gain a deeper understanding of this citational conundrum and its current and forward-looking implications.

3.3 Methods

I found it challenging to navigate some of the methodological requirements for this study. I will provide a level of detail that, with some extrapolation, should allow readers to adapt these methods to their own study contexts, if needed. I used a combination of quantitative, qualitative, and interpretivist methods, meeting the demands of my data and ponderings thereof as they arose, and operating within a critical interpretivist framework.

3.3.1 Primary Corpus Data Collection

I collected a total of 118 core publications, referred to throughout as my *primary corpus*, for inclusion in this study. 77 of the included texts contained "natural affinity" claims. 48 texts were cited for one or more claim-containing papers' natural affinity claim. Seven texts both contain and are cited for a "natural affinity" claim. I used Zotero (*Zotero*, n.d.) to store and manage papers' bibliographic metadata and full-text PDFs, when available, as well as the Better BibTeX plugin for Zotero (Heyns, n.d.).

3.3.1.1 Claim-Containing Paper Search Parameters and Inclusion Criteria

I queried four scholarly publication databases to identify papers containing "natural affinity" and "autis*" (case-insensitive). In an oversight, I omitted "asperger*" as a search parameter. While the claim of interest specifically included the word "autism", it's possible that I unintentionally filtered Asperger-syndrome-specific versions of the claim out of the search results. However, it's likely that most papers referencing Asperger syndrome also include the term "autism" and would have been captured by the search parameters described in Table 1. These searches yielded 72 claim-containing papers for inclusion in the primary corpus..

[17] Such as this one

Table 1
Search dates, parameters, and results counts for each of the four databases used to find "natural affinity" papers.

Database	Search Date	Search Parameters	Results (n)
Google Scholar	8/2/2023	Search string: *autis* (computer OR technology) "natural affinity"*	230
ProQuest	8/8/2023	Search string: *autis* AND "natural affinity" AND (tech OR info or ICT or mech or mach or comp or robo**) Limited to "source types" of books, dissertations & theses, and scholarly journals.	556
ACM Digital Library	8/1/2023	Search string: *[Full Text: autis*] AND [Full Text: "natural affinity"]*	10
IEEE Xplore	8/1/2023	Search string: *autis* (computer OR technology) "natural affinity"*	11

From among the search results, I included in the claim-containing corpus all papers for which:

1. The phrase "natural affinity" was used in the service of describing a feature of autism/autistic people
2. The "natural affinity" in question related to technology[18]
3. The text was in English
4. I had full-text access through institutional or professional association affiliations, or for which the text was published as open-access or shared publicly by an author
5. Select the text you want to label in a language other than English.
6. Navigate to the Review tab:
7. Click the Language button
8. From the dropdown list of languages, choose the correct one for your highlighted text.

I excluded papers from the corpus if:

1. I was listed as an author or co-author
2. The paper included the phrase for the purpose of critiquing it or reviewing assumptions about autistic people

[18] Other "natural affinity" claims about autistic people pertained to animals, horses, dogs, music, visual content, creativity, climbing, nature, and exploration. There were no mentions of pathologically intense affinities with water that might lead an autistic person to seek sources of hydration when stranded in the woods (see Ne'eman, 2014).

3. The phrase was included within the context of a meta-review or meta-synthesis, in which the phrase was shared as data, not a claim made by the authors themselves

3.3.1.2 Cited-for-Claim Papers

I manually reviewed claim-containing papers to determine whether they provided citations with their "natural affinity" claims and, if so, which papers they cited. I used a variety of tools and techniques to identify the complete and accurate bibliographic information for each paper, whenever possible. In most cases, this involved searching for the author name(s) and paper title (as cited) in Google Scholar, and, if full-text PDFs were not available directly from Google Scholar, using the University of Michigan Library search to obtain them.

For each cited-for-claim paper for which I was able to locate source text, I manually reviewed the text for "natural affinity" claims. Five additional claim-containing papers were identified this way, and two claim-containing papers found via database searches were also cited for other papers' "natural affinity" claims. The total primary corpus comprised 118 texts, including 77 claim-containing papers and 48 cited-for-claim papers (available in Appendices B1 and B2, respectively), with five papers belonging to both categories. I located 88 "natural affinity" claims across the 77 claim-containing papers, 69 of which included citations for the claim.

3.3.1.2.1 Citation Verifications

Four cited-for-claim papers required additional work to track down the correct bibliographic information and/or the full text associated with the citation. One cited paper, "Murray et. al., 1999," didn't clearly correspond to any papers available through Google Scholar, Semantic Search, U-M Library search, or the personal Web pages of known "Murray"s in the corpus with matching last names. I was unable to verify this citation.

Another cited text, Moore (1998), was published in a small-circulation UK magazine that existed in the late 1990s to early 2000s. I contacted the authors of the papers in my corpus that cited this text, two university email addresses I found for the author, the non-profit organization behind the magazine, and the publishing house that handled printing and distribution. I was unable to locate the text of this article, but I confirmed that it did, at one time, exist. for which I was unable to locate the article's text.

A third citation was to a non-archival study published on a professor's university user page, and the link in the citation was dead. The Internet Archive did not have a cached version of the Web page. Through iterative Google and Internet Archive searches, I discovered the correct URL for faculty user pages at the time the text was published, located the author's user page, and then the study.

The last of these errant citations, Murray & Lesser (1999), was presented at Autism99, an online-only conference in 1999 organized by the UK National Autistic Society, funded by the Steve Shirley Foundation, and evidently opened with a keynote address by then-UK Prime Minister Tony Blair (see "Internet First for Disabled," 1999). Based on cached snapshots from the Internet Archive, the conference website was online for only a brief period and was built entirely in Macromedia Shockwave.

3.3.2 Extended Corpus Collection

To support broader authorship and citation analyses, I extracted and created Zotero items for each unique entry in the bibliographies of the 77 claim-containing papers. I extracted the reference lists from each of the 77 claim-containing papers and saved them to plaintext files using the Poppler PDF library (*Poppler*, n.d.). I then used the AnyStyle command-line interface. (Keil, 2018/2025) to convert each paper's text-based reference lists to CSL/JSON, a file format used for storing citation information, and which is compatible with Zotero. I imported each paper's CSL/JSON reference list into Zotero and allowed Zotero to create a new "collection" (folder) for each. After deduplication, the extended corpus, containing all 77 claim-containing papers and all unique papers they cite, totaled 4,986 bibliographic records and ~9,000 unique authors.[19]

3.3.3 Data Processing and Management

3.3.3.1 Zotero as a One-Stop Citation Analysis Suite

I don't necessarily advise structuring projects as I did. That said, for someone with basic scripting proficiency but unfamiliar with database design and maintenance, Zotero is a workable

[19] The true number is likely somewhat lower. This estimate is based on having disambiguated a majority, but not all, author names within the dataset.

alternative to a standalone database. As one such person, I stored all citation data in Zotero and, when needed for quantitative analyses, accessed it via Python scripts and the Zotero Web API.

While Zotero has a built-in "related" feature that allows users to manually indicate relationships on a per-item basis, for citation analysis, I recommend relying on Zotero "collections" (folders) instead. Zotero stores only one copy of each unique item, and a single item can exist in multiple folders. Because each paper is assigned a unique identifier within a Zotero library, one can use collection names and item identifiers to quickly identify relationships between papers and authors. As a result, with sufficient will, one can perform a complete closed-network citation analysis project using Zotero and the Zotero Web API alone, without requiring a dedicated external data management system. Importantly, unique item or collection identifiers do not persist across Zotero libraries. If data are migrated from one library to another,[20] items and collections will be assigned new unique identifiers. If one wishes to use Zotero for a project like this, the Better BibTeX plugin for Zotero (see Heyns, n.d.) allows for assigning items a BibTeX/BibLaTeX-style citation key, which can be "pinned" (saved) to a given Zotero item's "extra" metadata field. This value persists across library migrations and is relatively easy to write queries for any given library item.

3.3.3.2 Author Name Disambiguation

I manually reviewed the names of each author in the 118 primary corpus papers to pair each name with a single individual and ensure that no two people had the same name in Zotero. Full disambiguation required a variety of methods beyond simple name matching, as multiple authors with the same last name and first initial were, in fact, different people. Post disambiguation, there were 269 unique authors in the primary corpus. I then identified all other papers in the extended 4,986-item dataset on which any given primary corpus author appears and ensured that the names on those papers matched their canonical names within the primary corpus. I used the Zotero desktop app's built-in advanced search features and the RapidFuzz Python library (*Rapidfuzz/RapidFuzz*, 2020/2026) for finding and manually comparing approximate name matches. As Zotero treats all instances of authors with the same name as a single person, careful author disambiguation allows for querying one's Zotero library by author.

[20] E.g., in the case of moving a project from a personal library

3.3.4 Analyses

3.3.4.1 A Citation-Content-Analysis-Inspired Critical Discourse Analysis

Citation analysis has, evidently, been a point of great methodological controversy since the 1960s, with lines eventually breaking down roughly along the lines of positivists and constructivists, but with more minor contingencies within each main camp. These debates play out, among other places, in a series of letters and responses published in Social Studies of Science and Scientometrics and would likely make for an interesting subject of study in and of themselves. New waves of method papers on forms of content- and/or discourse-analysis for evaluating citational practices appear to crop up every decade or so (e.g., Chubin & Moitra, 1975; MacRoberts & MacRoberts, 2018; Swales, 1986; White, 2004; Zhang et al., 2013), but there appear to be few, if any, broadly accepted prescriptive qualitative and/or interpretivist citation analysis methodologies. MacRoberts and MacRoberts, key players in discussions about citation analysis methods for the better part of four decades and frequent targets of frustrated letters to the editor,[21] wrote the following choice selections in one of their more recent papers:

> "For several decades we, among others, have criticized the use of citations for evaluative purposes. Although these criticisms have been noted, they have been largely brushed aside or ignored, not addressed head on. This may be for several reasons, but we believe the main one is that these criticisms undermine the desire to have an easy "scientific" – that is, quantitative – method of evaluation. Consequently, we continue and update our criticism of the use of citations for evaluation" (MacRoberts & MacRoberts, 2018, p. 474).

> "Theories of citing range from the naive, idealized, Arcadian, Pollyanna image of scientists adhering to the 'CUDOS' norms presented by Merton (Sismondo, 2004) to the all-out Machiavellian wars described by Latour (Luukkonen, 1997). We deal with only the two main 'theories' here, the normative-meritocratic and the constructivist" (MacRoberts & MacRoberts, 2018, p. 447).

[21] E.g., Leydesdorff (1987) took issue with their sociological/constructivist approach to studying citations, essentially arguing that by focusing on practices and not on the hard numbers, one loses the "cognitive" perspective.

Clearly, everyone gets along just fine in the world of citation analysis, bibliometrics, and scientometrics.

My methodological approach in this study is best described as a critical discourse analysis (see van Dijk, 1993) that draws on constructivist citation content/context analysis (e.g., Swales, 1986; White, 2004; Zhang et al., 2013). Per van Dijk (1993) argues that critical discourse analysis is explicitly concerned about the relationship between discourse and power. My analysis starts from the position that, whether intentionally or not (likely not), discursive and citational (i.e., also discursive) practices appear implicated in maintaining a particular social reality within HCI, the shape of which, I suspect, is disproportionately defined by beliefs about what others say or believe. My analysis was, at times, guided by Zhang et. al. (2013), particularly with respect to their intention to evaluate both citing and cited papers. At one point, following Zhang et. al. (2013), I used iterative grounded coding (see Charmaz & Mitchell, 2001) to develop a miniature code book for evaluating the fittingness between what a claim suggests a cited text contains and the actual contents of the cited text (Table 2).

Table 2
Code book for evaluating "natural affinity" claims in claim-containing papers against their corresponding cited-for-claim papers.

Code	Values	Description
Source Type	Primary source - empirical	Paper provides original empirical data addressing the claim
	Primary source - theoretical	Paper provides theoretical argument for the claim
	Primary source - anecdotal	Paper provides anecdotal observations
	Secondary source	Paper cites potentially related sources but provides no primary evidence
	None	Paper provides no evidence for the claim
Population Match	Claim matches citation	Claim population matches studied population
	Claim is subpopulation of citation	Claim is about a subset of studied population
	Claim generalizes from citation	Claim generalizes beyond studied population
	N/A	Population comparison not applicable
Hedging/Qualifiers	Valid - matches scope	Qualifiers used by claim-containing paper match the scope of the evidence

Valid - narrower scope	Qualifiers used by claim containing paper are narrower than the scope of the evidence
Invalid - exceeds scope	Qualifiers used by claim containing paper exceed the scope of the evidence

I should note that I use Merton's (1979) "CUDOS" norms, but not as prescriptive rules against which I evaluate citation practices. Instead, I hold them up to illustrate points and the extent of their departure from emic, temporally stable, socially constructed norms that scientists say they strive to abide by in their work. I feel it is important to evaluate the practices identified within my corpus within the contexts of their own epistemological traditions, and, given the extent to which these norms are incorporated into positivist research pedagogy and disciplinary enculturation, they seem as likely a candidate as any for this purpose. Discontinuities between self-expectations may be more readily addressed than critiques seen as beyond the scope of standard practices and values within particular research types.[22]

3.3.5 Citation Validation

As in the case of the previously reported data (in Guberman & Haimson, 2023), no valid evidence was cited for any of the 88 "natural affinity" claims. A total of seven cited texts were primary sources with empirical studies, none of which provided support for the claim. One paper (Murray et al., 2005), already discussed in Guberman & Haimson (2023), provided theoretical evidence that, if validated through empirical testing, could potentially provide support for "natural affinity" claims. One text, a chapter from a textbook about play therapy, offered a one-line anecdotal account indicating that some children with autism seem to enjoy video games, so incorporating them into play therapy may be helpful on a per-child basis (Hardy et al., 2016). The remaining citations were secondary sources. Unless they were among the seven cited texts that also included "natural affinity" claims, tracking down and evaluating evidence cited in secondary sources was beyond the scope of this study. I labelled all such cases as invalid citation support, as it seems to me that essentializing claims about large human populations should directly cite relevant evidence that can support the claim.

[22] E.g., a rare researcher who has spent a career as a social scientist and, during that time, as rarely departed from using experimental designs with carefully controlled conditions, random sampling, and a priori power analyses may or may not be particularly interested in reflexivity in both study design and interpretation.

3.3.6 Claim and Text Analysis

3.3.6.1 Duplicate Publication

Three papers were clearly the same paper, with only minor alterations, and the authors were listed in different orders. Each proposed a pilot study of a "serious game" that would use augmented reality, 3D graphics, and an interactive character. They proposed that this game would effectively help autistic children learn to identify others' emotions. Each publication venue has a copyright agreement that prohibits duplicate publications. A close examination of the authors' Google Scholar and Semantic Scholar pages, as well as their academic CVs (if available), indicates that no studies using the proposed technology have been published. Details are available in Table 3.

Table 3
Table of duplicate publications found among the "natural affinity" claim-containing paper corpus.

Title	Author(s)	Year	Publication Venue
An augmented reality gamebook for children with autism spectrum disorders	Brandão, Cunha, Vasconcelos, Carvalho, & Soares	2015	The International Conference on E-learning in the Workplace (ICELW)
Tobias in the zoo "a serious game for children with autism spectrum disorders	Carvalho, Brandao, Cunha, & Filomena Soares	2015	International Journal of Advanced Corporate Learning (ijac)
Augmented reality for cognitive and social skills improvement in children with ASD	Cunha, Brandão, Vasconcelos, Soares, & Carvalho	2016	2016 13th International Conference on Remote Engineering and Virtual Instrumentation (REV)

3.4 Discussion

In this section, I cover higher-level trends derived from the analyses described above, as well as extensive iterated coding of both claim-containing and cited-for-claim papers throughout this study. In particular, I discuss key findings from my discourse analysis that provide insight into how citations, rhetoric, and appearance of the scientific work together to obfuscate various deficits within research – some of which may be benign cases of misunderstanding or external, limiting constraints, others of which are more likely to represent intentional efforts to skirt expectations for rigor, veridicality, and merit.

3.5 Rounding the Corner

In this section, we'll look at Moore et al.'s (2005) "Collaborative Virtual Environment Technology for People with Autism" and other top-cited papers (See Table 3) for "natural affinity" claims. With 10 of the 77 claim-containing papers citing Moore et al. (2005) for "natural affinity" claims, this text outperforms the next-most-cited papers by a wide margin. The first author, David Moore, also has the highest number of per-author works cited for the claim (four, with the next highest being two), as well as the highest per-author citations across all cited works (16, with the next highest being 12; See Table 4 for a list of cited-for-claim papers by number of unique claim-containing paper citations).

Table 4
Top five cited-for-claim papers listed by total number of unique papers citing each for a "natural affinity" claim.

Paper	Publication Year	Citing Papers for "Natural Affinity" Claim(s)
Moore et al. (2005)	2005	10
Parsons (2016)	2016	6
Putnam and Chong (2008)	2008	6
Hardy et al. (2016)	2002	5
Moore (1998)	1998	4

David Moore is an interesting case for several reasons. First, Moore (2005) is an unusually honest and well-written paper within the corpus. Second, in addition to clearly providing no evidence for the claim (the authors describe the paper as an "empirical exploration" offering only "prima facie" validity), it contains its own "natural affinity" claim, for which it cites another text. The paper describes a well-reported exploratory study in which 34 children with autism[23] were sent CDs with a simple software program. The program showed children virtual faces and provided several response options for labeling facial expressions. They found that 90% of participants could accurately recognize facial emotions. They're clear that "the study offers evidence that the participants who responded understood the emotions of the avatars appropriately" (p. 238), which is distinct from saying that the software *caused* an observed effect. Instead, they argue that they've demonstrated that (A) autistic children can and will use a technology that may, in the future, be used for a real intervention relating to facial expression

[23] One of the larger sample sizes of any study in the dataset

recognition, (B) that mature toolsets for developing these skills already exist, and (C) that combining these toolsets with the type of software tested in this study may be a fruitful pairing. They voice the need for further study to determine whether positive effects are observed in an actual intervention.

In its own "natural affinity" claim, Moore et al. (2005) write, "Many people with autism appear to have a natural affinity for computers and the controlled environment provided by the computer, and they may benefit from individualized tutoring and repetition of exercises." For this claim, they cite Hardy et al. (2002), Moore et al. (2000), Moore and Taylor (2000), and Neale et al. (2002). Throughout the claim-containing papers, I identified six variations of this claim spanning 29 papers, 14 of which directly cite Moore (2005), and another 9 of which are connected to Moore (2005) through bibliographic coupling (see Table 5 for the full list of variants). Some notable qualities of Moore (2005)'s formulation of this claim include the "many" and "appear to" qualifiers, as well as the connection between an apparent affinity for computers and an affinity for controlled environments, such as those provided by computers. While they don't present these linked affinities as causally connected, one can see how they might relate to one another.

The Hardy et al. (2002) text is an introductory chapter in the book "Autism and ICT." They present two rich case studies of children with autism, both of whom, at least as described, are quite clearly drawn to and fond of computers. These case studies represent the strongest and most direct evidence of a "natural affinity" within the entire corpus. However, on its own, two case studies cherry-picked for the specific book in which they appear do not support a sweeping essentialist conclusion. Given that three additional citations are provided, though, it remains possible that this citation, when viewed alongside others, *may* be interpreted as providing meaningful support. We'll keep going.

Moore et al. (2000) dampens hope, the construction of compelling support through citation bundling. This paper presents various prototypes that, like the Moore et al. (2005) paper, are intended to assist children with autism in understanding various social skills. The paper doesn't provide support for the existence of a "natural affinity." However, it does make a logical argument for the idea that computer environments may be well-suited to autistic preferences for controlled and predictable environments. The argument is not overstated.

Table 5
Moore et al.'s (2005) version of the "natural affinity" claim and the seven variations derived from it with list of papers in which each variation appears.

Variation #	Variation of Moore's (2005) "Natural Affinity" Claim and Papers it Each Appears In
Original	People with autism appear to have a natural affinity for computers and the controlled environment provided by the computer, and they may benefit from individualized tutoring and repetition of exercises.
	Appears in: Boytsova (2015), Cheng and Ling (2008), Lozano-Martínez et al. (2011), Moore et al. (2005), and Stevens and Neppl (2009)
Variation 1	People with autism have a natural affinity for computers and the controlled environment provided by computers.
	Appears in: Aguinaga (2006), Frimtzis (2009), Halabi (2015), Pham et al. (2023), Sagia (2015), Schwarze et al. (2019), Spence-Cochran and Pearl (2011), Vasilevska Petrovska and Trajkovski (2019), Zhang (2018), Zhang et al. (2021)
Variation 2	People with have a natural affinity with computers due to the predictable and repeatable nature of technology that can create controlled environments.
	Appears in: Caria et al. (2018), Menzies (2011), Menzies (2012)
Variation 3	Interactive technologies can be valuable tools in supporting computer-based learning of core problematic areas of autism, since people with autism show a natural affinity with computers due to the predictable and repeatable nature of technology
	Appears in: Caria et al. (2019), De Carolis and Argentieri (2020)
Variation 4	People with have a natural affinity with computers due to the predictable and repeatable nature of technology that can create controlled environments, and which thus appeals to those who feel relieved by stability and routine.
	Appears in: Caria et al. (2018), Najeeb et al. (2020)
Variation 5	People with autism have a natural affinity for technology, which can offer safe and predictable environments.
	Appears in: Guldberg et al. (2017), Lorenzo et al. (2022), Newbutt and Bradley (2022), Schmidt et al. (2021)
Variation 6	People with autism have a natural affinity with technology as they perceive it as a predictable and controllable medium.
	Appears in: Frauenberger et al. (2012), Frauenberger et al. (2013)

The remaining two papers provide similarly supportive theoretical foundations, more or less aligned with the idea that "many" people with autism appear to have a techno-affinity. However, Moore et al.'s (2005) hedging may still be, arguably, overstated. Looking at the

derivations of this claim (Table 5), however, one notices that these qualifiers often disappear. There's nothing there, and there never was. However, over time, the citation has morphed into something new, gained a life of its own, and taken autism with it. It helps, of course, that the claim already resonates with cultural assumptions about autism. Merton offers two theories that somewhat relate to this situation. The "Matthew effect" suggests that visible researchers are disproportionately more likely to gain additional citations over time (Merton, 1968). Merton's (1979) idea of "obliteration through incorporation" describes how, over time, findings become so foundational that they're no longer explicitly connected with their progenitors. Some examples include the relatively few papers that cite Einstein for his theory of relativity or Watson and Crick's first paper on DNA. The "natural affinity" cases are an odd, partial inverse of obliteration through incorporation, in that the foundational finding never existed in the first place.

"Natural affinity" claims appear to represent a site for the (re)production of sciences that meet the hopes and dreams of researchers and their research projects. Moore (2005) is only a single case in which a relatively reasonably-qualified "natural affinity" is misappropriated for less-than-valid adaptations and the ends thereof. With each successive near-facsimile, the meaning and content of the claim drifts further from the original, which, while well-qualified, can still be considered as potentially more concrete than as literally worded, given the mere appearance of citations and the claim's occurrence in an academic article. As more "evidence" accumulates, it takes more time, energy, and awareness even to consider peeking around the citational corner to see what's actually there. We end up with an autism that resembles the hyperreal (Baudrillard, 1994) – it exists in reference to itself and to its citational context. The possibility of an on-the-ground truth becomes irrelevant.[24] This reproductive phenomenon is not restricted to the "natural affinity" claims within the claim-containing papers. It's a broader issue in autism-related citational practices, and likely within HCI at large.

3.5.1 Playing Fast and Loose with Facts

Determining what information is worth disseminating, whether it's truthful, and whether it requires citations appears to be a significant problem, with examples in the corpus ranging far beyond the boundaries of "natural affinity" claims. The introduction of dubious details typically

[24] Assuming it was ever relevant to begin with.

follows one or more of the following formulae: (A) Facts from on high that frame atypical assertions as above the need for veridicality; (B) Citation cherry picking; (C) Excesses in citation-buoyed optimism.

3.5.1.1 Facts from On High

Authors shared a number of citation-free statements that, as someone well familiar with autism literature, I found quite novel for information ostensibly presented as commonly accepted beyond the need for citation. Some such claims included:

- "The majority of assistive research focuses on students with ASD" (Kanaga Suba Raja et al., 2021, p. 1).
- "AR is an optimal interface technology and a helpful tool to support autistic children['s] capabilities" (Cunha et al., 2016, p. 1).
- "The Open CV platform can open a wide range of possibilities for the Autistic kids. It can also increase Employment too as they can easily sustain in a work environment …" (Kanaga Suba Raja et al., 2021, p. 4).[25]
- "Learning with autism is characterized by spontaneous – sometimes-extraordinary – mastery of complex content" (Schwarze et al., 2019, p. 3).

While the first three examples are among the most interesting, most examples of this category more closely resemble the fourth I have listed. Without speaking to the authors of these statements, it's difficult to infer their intentions. However, the effect is to expand the already excessive array of a la carte options from which other researchers without can play build-your-own autism. DIY autism-ing doesn't seem nefarious, for the most part, but instead appears to indicate a general lack of subject-area knowledge among HCI researchers practicing within this space and, by extension, an absence of collaborators able to fill these knowledge gaps. It likely also indicates, in at least some cases, difficult time and resource constraints that make decision-

[25] Open CV is an open-source "computer vision" library that can be used for a wide variety of functions, including but certainly not limited to object detection and text processing – it provides a software layer between optical sensors and the program that will process the incoming optical data (if not Open CV, itself). One thing Open CV *cannot* easily do is increase the employment prospects of autistic children. This statement appeared in the last line of this paper, which had no previous references to Open CV or computer vision.

making difficult.[26] As a rule, researchers may wish to consider asking of their statements, "according to whom?" If no ready answer comes to mind, a citation is likely requisite.

3.5.1.2 Citation Cherry Picking

In several studies, the authors appear to have either (A) backfilled citations to support their design studies after the fact or (B) based entire methodologies on a single, fringe paper that provides support for a given notion. One of my favorite cases of this occurs in De Carolis and Argentieri (2020). In their study, they present what they purport to be an "Internet-of-Things" (IoT)[27] based serious game for helping autistic children develop water safety skills, improve gross motor skills, and develop muscle tone. Their playful intervention is a waterproof ball with colored LEDs that turn on and off based on motion sensor input, waterproof Bluetooth earphones playing music selected by the child's therapist, and several other novel components explicitly tailored to the needs of autistic children. The topmost component listed is described as, "A spherical element … will be used to catch the attention of the child, because a simple geometrical shape, preferably spherical, is more suitable to a child with ASD and more functional to the task [16]" (De Carolis & Argentieri, 2020, p. 2). There doesn't appear to be much corroborating research, but that single citation was quite convenient. While citation validation is not generally part of the job of a peer reviewer, an inquisitive reviewer might ask themselves, "Is that citation weirdly specific?" If so, checking a claim or two can be an illuminating exercise.

In these cherry-picking cases, it often appears that the authors may have gone searching for a solution in need of a problem, in one or more aspects of their designs. These designs may have a distinct "ask not what your design can do for autism, but what autism can do for your design" quality. This represents a more purpose-specific build-your-own autism approach than the use of facts from on high, which often appear benign, the result of limited knowledge and resources rather than one of having to fill a pre-existing need. These cherry-picked appear cases are less likely to be imported into or adapted for other projects.

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[26] E.g., as described in the Elaboration Likelihood Model of persuasion which, upon reading while operating within time and capacity constraints, seems fairly convincing (see Petty & Cacioppo, 1986).

[27] While we may wish that it were otherwise calling something an IoT solution four times does not make it so. IoT can be convenient, but it's not Beetlejuice.

3.5.1.3 Excess Citation-Buoyed Optimism

A prime exemplar of this category comes from Bernardini and Porayska-Pomsta (2013). They write, "Among all available technologies, virtual agents are believed to offer particular benefits to children with ASCs for several reasons (Parsons and Cobb 2011)" (p. 362). This claim is distinct from cherry-picked claims in that "virtual agents" are a central, intentional component of their study, which has a generally coherent methodology that does not appear to require excessively circumscribed citations. Additionally, cherry-picked citations tend to support the claim for which they're cited, even if the evidence they provide is low-quality. In contrast, Excessive optimism in the presence of a topically related citation usually responds to a high-quality citation, but one that does not offer support as represented. The paper by Bernardini and Porayska-Pomsta (2013) cite is a critical and skeptical overview of the past decade's work on VR in classroom settings. Generally, the authors find signs of promise, but a dearth of compelling empirical evidence. Specific to virtual agents, they write, "Although the evidence for the use of virtual characters for storytelling is currently limited, the approach offers potential through seeking to address the autistic triad of impairments in social communication, social interaction and imagination" (Parsons & Cobb, 2011, p. 360).

3.6 Design Speculation

As a receptacle for the needs and knowledge gaps of researchers in autism and autism-related HCI research, it enables the development of new and creative methodological approaches to design. Dunne Raby (2013) are known for proposing and formalizing speculative design, a critical and forward-looking practice that designs for, and perhaps tries to prefigure, possible futures. In contrast, what I will call design speculation represents an orientation toward design in which researchers imagine designs as already existing. Design speculation studies appear frequently within the "natural affinity" claim-containing corpus, and share some general features:

1. Designs are described in great detail and with highly technical language that gives credence to the idea that the imagined design is so well thought out that it *could* exist.
2. Designs are described using language that flips back and forth between "the design does" and "the design will do," blurring the boundaries between back-of-the-napkin artistry and tangible reality.

3. Descriptions of the efficacy of the design transition from "we will test" the design in a pilot study to "the design demonstrated high levels of success," without indications of an intervening study, or even having built the design.

Design speculation is clearly a powerful method that appears to function by allowing one to capitalize on public interest in autism and autism intervention to publish work before it even exists.

To give one prototypical example of a design speculation study, we can turn to Raja et al. (2021). One of the key benefits of this approach is that "Instead of eliminating face-to-face intervention, our proposed framework provides learning activities for ASD students in the form of differentiated directions" (p. 1). Over the course of four delightfully detailed pages describing their design down to the discrete components of the Raspberry Pi microcomputer on which it may one day run, they describe an educational IoT system that relies on neural networks and provides relief from COVID-19 isolation by allowing autistic students to select between multiple pre-specified videos using keyboard macros.

3.7 So, What Now?

One of the difficulties of writing an "implications for design"/future directions for a study like this is that a solution that might seem obvious – imploring researchers to make sure they're accurately describing autism – is that all accounts of autism are social constructs that attempt to encapsulate a vast array of similar experiences across etiologies untold. I'm left with several less direct takeaways:

1. There's a clear need for researcher self-reflexivity and reviewer caution around autism-related HCI studies
2. HCI needs *some* standards and community accountability mechanisms that describe appropriate and expected approaches to conducting, describing, and reviewing research

3.7.1 Self-Reflexivity and Caution

Navigating research topics in HCI can be complicated, as many in the field come from technical disciplines, bringing technical knowledge they can deftly apply to topics and populations with which they're relatively unfamiliar. This creates the possibility for fruitful collaborations between computer scientists and engineers, social scientists, science and

technology studies scholars, and researchers from a host of additional disciplinary backgrounds that may not otherwise find opportunities to and reap the benefits of collaborations that bring together such diverse skill sets and knowledge bases. Alternatively, the heterogeneous, pastiche makeup of the field also creates opportunities for those with designs to shop for problems for them. I doubt that a majority of autism-related HCI researchers fall into this category. Design speculation studies represent a minority of the "natural affinity" papers in my corpus. However, because the field provides opportunities for even well-meaning researchers to pursue "real-world impacts" with their research, it's still entirely possible to produce high-quality technological artifacts that are unmoored from the actual needs and/or realities of anticipated target users. This can be particularly complicated in the case of autism technology research, where much of the field's work may revolve around harmful assumptions and interventionist ideals (see, e.g., Spiel et al., 2019).

It's easy to ask researchers just to do a better job. To verify their citations, make sure they know what they're talking about, and perhaps stick to research areas with which they're familiar. My sense is that if that were a workable way of maintaining required levels of productivity in academia, many people would prefer to and be doing that already. My sense is also that we should avoid shutting down "helpers" just because they might be a bit misguided or misinformed. There are only so many autistic and disabled people in HCI, and it's not an easy field for many of us to occupy (Hofmann, 2019; Hofmann et al., 2020; Ymous et al., 2020). Williams and Boyd (2019) suggest that allies are needed to help in the process of enrolling others in more liberatory disability orientations to HCI research, and to smooth frictions between justifiably angry and hurt disabled researchers and the people who most need to hear those impassioned messages. Realistically, I think we likely need those allies to seek out those within the field who are flailing around trying to make a difference and show them, by example and through collaboration, what alternative orientations look like. It would be a pretty big lift.

In the meantime, though, I think the best we can realistically hope for is that researchers will exercise self-reflexivity in their work to the greatest extent possible. Reviewers will similarly comport themselves in their roles. Publication venues might consider facilitating this extra bit of self-oversight by listing it as an expectation in CFPs and submission forms for authors, and in the instructions provided to peer reviewers.

3.7.2 Standards, Expectations, and Some Sort of Accountability

Many citation analysis studies hold up the Mertonian norms (Merton, 1979) as a yardstick against which to measure ostensibly objective bibliometric data (Luukkonen, 1997; MacRoberts & MacRoberts, 2018; White, 2004). Even if you take Merton's norms as an ideal type rather than as a prescriptive and functionalist understanding of scientists' behaviors, they clearly offer little by way of explanatory power when assessing the citation practices I've observed within HCI, nor for how to get the field from where it is now to where Merton's norms suggest it should be. We need *something* to act as a guiding principle in our work, though. I suggest that a broader interpretation of Merton's "organized skepticism" norm might be productive. As described by Merton (1979), "organized skepticism" requires information not be accepted without careful, systematic investigation and subjection to peer review and other systems of accountability. The idea aligns with the fundamental premise of Popperian hypothesis testing, which holds that rejecting the null hypothesis is the best approximation to facticity one can ever hope to achieve. I suggest we think of "organized skepticism" as an expectation we ask of ourselves and others: "why?" Why this study? Why this decision? Why does this fact make sense? This isn't easy to implement in practice. However, it seems that the best places to start are the classroom mentorship relationships, and submission and evaluation forms for would-be publications.

3.8 Conclusion

Citational, factual, and build-your-own autism issues within HCI are at once issues related to the treatment and understanding of autistic people *and* reflective of much broader issues within the field that exist irrespective of the persistence of problematic autism research. This research suggests (A) that autism research and perhaps research involving other disabled and marginalized populations may be ideal places to look for highly concentrated trends one may wish not to exist within HCI and (B) that the field's attachment to "truth" is tenuous at best, a problem for which there are no simple remedies.

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Chapter 4 #ActuallyAutistic Twitter as a Site for Epistemic Resistance

4.1 Introduction

I first discovered autistic[28] social media through Twitter during my first year of graduate studies. During this period, I was openly disabled. I wasn't shy about having multiple learning disabilities and how being disabled affected my experiences with and approaches to research. I wasn't openly autistic, though. Most of the autism related HCI papers I read were deeply upsetting. Some of those papers[29] boasted funding from eugenic lobbying groups. Numerous studies justified themselves by citing rising rates of autism diagnosis and the myriad ways autistic people are ostensibly serious burdens to our families, the economy, and society. One study was built around the a priori assumption that autistic people are incapable of maintaining community with each other without support from non-autistic facilitators. Several others hoped that autistic kids could develop a kinship with potted plants and that this might somehow help them empathize with other humans. Countless more studies marked autistic abnormality as something needing to be surveilled and controlled through technologically-mediated "therapies."[30] It didn't (and often still doesn't) feel particularly safe to disclose being autistic in a field that treats people like me as non-agentic, epistemically disadvantaged problems in need of solving. How could these people ever see me as a colleague if they knew I was autistic?

I spent months feeling alone in the field, wondering whether it made sense for me to stay in a place that didn't appear to value my existence. I wanted to talk through this experience with other people in the academy but was afraid of how my peers and mentors would react to my

28 Throughout this paper, I use identity-first language ("autistic person") over identity-first language ("person with autism"). This choice reflects my personal preference as an autistic person and respects the general preferences of autistic adults (see Botha et al., 2021; Brown, 2011; Bury et al., 2020; Gernsbacher, 2017; Kenny et al., 2016).

29 Following Ymous and colleagues (Ymous et al., 2020), I do not provide direct references to these papers. The papers and their authors are products of their ableist environments. Calling them out, instead of calling out the systemic ableism of which they are indicative, is likely counterproductive.

30 Of these so-called therapies, Julia Bascom writes, "When I was a little girl, I was autistic. And when you're autistic, it's not abuse. It's therapy" (Bascom, 2012, p. 178).

disclosing being autistic. It wouldn't have been the first time if, after such a disclosure, someone's attitude toward me shifted swiftly from collegiality to paternalism. Around that time, quite serendipitously, I stumbled across an unexpected niche of twitter. The #ActuallyAutistic Twitter community became a much-needed lifeline as I struggled to find my footing in academia. On #ActuallyAutistic Twitter, I found community among other autistics, both within and outside the academy.

Using #ActuallyAutistic and several other community hashtags to organize their content and make it more findable, autistic people conversed about their lives and experiences. I learned that my experiences within the academy were far from unusual – indeed, once surrounded by other autistic people who have experienced academic ableism (Dolmage, 2017), my situation seemed rather banal. I found comfort in that banality. Whereas openly discussing these experiences with non-autistic academics was a risky-feeling proposition, on #ActuallyAutistic Twitter, it sometimes felt similar to how I imagine allistics (i.e., non-autistic people (Main, 2003)) feel when they talk about the weather. While this recurrent discourse can eventually seem commonplace, the underlying issues, of course, have much greater import than the neurotypical[31] fascination with ambient temperature.

The sheer number of autistics on Twitter reporting similar experiences to mine hinted at the enormity of the problem of anti-autistic ableism within the academy. I saw and engaged in numerous conversations delineating the specific issues autistics face in research and in higher education, suggestions for how these issues might be redressed, and efforts to build alliances with those positioned to enact the desired changes. I found myself quite interested in the particulars of these efforts. What follows is an investigation of the ways autistic Twitter users engage in discourse about autism research and with autism researchers. My personal experiences as an autistic autism researcher and as a frequent participant in discussions on #ActuallyAutistic Twitter frame this study.

It bears mentioning that, although I only recently found my way to Autistic Twitter, there's a rich history of online autistic communities. Indeed, for decades, the Internet has been an integral component of many autistic communities and the self-advocacy movement. Jim Sinclair

31 Neurotypicality refers to the absence of developmental disabilities, psychiatric disabilities, or any other conditions that render the functioning of one's brain and perception as non-normative, whereas neurodivergence indicates the presence of one or more such conditions (Merriam-Webster.com Dictionary, n.d.; Neurodivergent K, n.d.)

writes about how, as the movement was first coalescing, geographically distant autistic community members shared online spaces with parents of autistic people. As is still often the case today, it was parents who led the prominent autism organizations, organized the autism conferences, and set the agendas for policy- and research-oriented advocacy (Lorcan Kenny [@LorcanKenny], 2019a). Sinclair recalls how, in the days and weeks following a large autism conference in the 1990s, they and other autistics flocked to a parent-dominated online autism forum. At the time, neurotypical users comprised the majority population of such forums. Some of the neurotypicals rebuked the autistic forum users, saying the autistic posts were of no interest to them, asking them to stop "wasting bandwidth" (Sinclair, 2012, p. 47). Many parents didn't feel that autistics should be involved in ongoing discussions about us or that the topics of interest to us might be relevant to organizations purporting to exist to support us. This dynamic led to a year-long autistic vs. neurotypical flame war (see Moor et al., 2010), dubbed by Sinclair and co-conspirators as the Snore Wars (Sinclair, 2012).[32]

The Snore Wars are significant, in part, because they led to the creation of a dedicated online forum made by and for autistic people. Whereas the nascent US autistic community had previously consisted of a few people who communicated via email and newsletters, saw each other occasionally at conferences, and sometimes congregated on forums geared towards the needs and interests of neurotypicals, this forum represented the creation of dedicated, public *autistic space*[33] (or, as Sinclair the forum, an "autistic cyberspace" (Sinclair, 2012, p. 48)). Parents and other neurotypicals were allowed to join the forum, but were subject to community norms (Sinclair, 2012). To my knowledge, the Snore Wars was the first example in a long history of autistics leveraging digital spaces to reclaim narratives about themselves. Current-day

32 The Snore Wars were so named because, as Sinclair writes, "some of the autistic messages the parents first began complaining about were playful perseverative discussions about someone's snoring at the conference" (Sinclair, 2012, p. 48).

33 Autistic space refers to physical or virtual spaces created by and for autistic people and strives to account for differences between neurotypicals and autistics and the vast heterogeneity among autistics. While these spaces may not be the conflict-free, sensory utopia one might wish for, these spaces seek to foster an environment wherein the myriad needs of autistic people are valued, normalized, and accommodated as well as possible, despite the possibility of conflicting access needs (Ne'eman, 2015; Sinclair, 2010, 2012; Winters, 2018). Writes Seidmann, "… what defines an autistic space is not the absence of [neurotypical] people, but rather, it is the fact that the place is run by and for autistic people who are identifying and deciding how to meet the needs of its members" (Seidmann, 2020, p. 7).

examples of this kind of online activity play out on many forums, personal blogs, and popular social media sites.

Twitter is one of many locations where autistics congregate to discuss their lived experiences, but it represents a particularly interesting field site for studying interactions between autistics and academia. Whereas systemic structures of ableism often bar autistic and disabled participation in the academy (see Dolmage, 2017), Twitter is a platform occupied by many autistics and academics alike. On Twitter, members of the two groups can easily enter conversation with one another. These interactions served as my primary site of inquiry as I tried to answer questions about what topics are focused on, how autistic concerns differed from those of other parties involved in autism research, how autistics interact with both research and researchers, and whether there are indications that #ActuallyAutistic Twitter affects the foci and directions of autism research.

Through this investigation, I find Twitter a rich source of autistic counternarratives to dominant academic autism discourses. These different approaches to autism, in Kuhnian terms, represent two distinct research paradigms (Kuhn & Hacking, 2012). The same words have radically different meanings and implications. The questions you can ask in one paradigm don't make sense to or count as valid science in the other. They are incommensurable. As I will explain in the following section, these two paradigms map onto distinct orientations towards disability. Drawing on phenomenology and queer theory, Sarah Ahmed writes about how compulsory heterosexuality (see Rich, 1980) works to create heterosexual orientations while simultaneously making invisible alternative, queer orientations (Ahmed, 2010). Also drawing on queer theory, Robert McRuer writes about how compulsory able-bodiedness makes invisible the possibility of orienting oneself toward disability as a desirable location (McRuer, 2006). Orientations towards or away from normative positions are inherently political and entail making visible and turning towards which hegemonic powers seek to keep hidden. Regarding autism, autistic counternarratives subscribe to the neurodiversity paradigm, while dominant academic discourses adhere to a medical model understanding of autism and disability. I will explain how, as my data show, adherents to either paradigm are fundamentally at odds with one another, even if addressing the same stated research priorities. Further, I will draw on Twitter discourse to highlight and contextualize how autistics use Twitter to interact with sympathetic and hostile academic discourses. I conclude with a discussion about the non-neutrality of these

irreconcilable paradigmatic approaches to autism research, highlighting the need to recognize and respond to each approach's material, political, and ethical consequences.

4.2 Background

For those unindoctrinated in the world of autistic self-advocacy and neurodiversity studies, some background information will help contextualize subsequent sections of this paper. In this section, I provide additional details about competing perspectives on autism, explain how medical-model orientations towards autism manifest in HCI research, and give a brief overview of autistic social media usage.

4.2.1 The Neurodiversity Paradigm

The neurodiversity paradigm frames autistic differences as natural variations in human experience and the presentations thereof (Kapp et al., 2013). Neurodiversity encompasses not only autism but all forms of difference that affect cognition and perception. One is neurodivergent (see Neurodivergent K, n.d.) if they have one or more disabilities that affect how they experience the world, including autism, other developmental disabilities, intellectual disabilities, learning disabilities, and psychiatric disabilities. In common parlance, we refer to those who are not neurodivergent as being neurotypical. Those who are not autistic are referred to as allistic. An allistic person can still be neurodivergent. The neurodiversity paradigm is aligned, although not interchangeable with, the social model of disability. The social model constructs disability as something existing outside of the person. A person can have impairments rooted in physical, cognitive, and/or psychological differences. Under the social model, it is the interaction between impairment and external, disabling factors that lead to disability (Barnes, 2012). These factors can be material, such as a lack of curb cuts or elevators, or systemic, such as discriminatory welfare and hiring policies or a capitalist obsession with productivity. Under the social model, the hardship associated with disability exists not within an individual and arises not because of one’s impairments but is, rather, associated with externalities. Critics suggest the social model goes too far in suggesting that, absent disabling externalities, autistics would not be negatively affected by the impairments associated with autism (Chapman, 2020). Indeed, Mike Oliver argues that the social model has never fully reflected the reality of disability but has served as an important political tool in rights-based disability activism (Oliver, 2013). Thus, under the neurodiversity paradigm, autism is recognized as a disability but is treated as

something natural, worthy, and of value rather than as something in need of prevention or correction.

From the political and ideological groundings of the neurodiversity paradigm, the activism-oriented neurodiversity *movement* arose as a way to challenge harmful, dominant autism discourses (Robertson & Ne'eman, 2008). The autistic self-advocacy of the neurodiversity movement differs fundamentally from traditional autism advocacy. Without trying to change or correct autistic people or behavior, the neurodiversity movement addresses difficulties inherent to autistic life, including the disallowance of self-determination, frequent social exclusion, worsened material conditions, and sub-par levels of physical and emotional well-being (Robertson, 2009).

In contrast to the goals of the neurodiversity movement, traditional, mainstream autism advocacy concerns itself with understanding the causes of, preventing, and curing autism (Ne'eman, 2010). This approach to autism as something that needs to be better understood so it can be eradicated corresponds to the medical model of disability. Under the medical model of disability, disability exists within the individual. It is fundamentally an individual, biomedical problem. This model expects disabled people to strive for normative bodies and minds (Barnes, 2012; Parsons, 1951). Scientific and medical interventions revolve around making the abnormal appear normative or preventing the deviant from ever occurring in the first place.

The differences between these models and approaches entail high-stakes, political and ethical issues with real and sometimes life-or-death consequences. These impacts may be exemplified by the average life expectancy of autistics, which is 36 years (Guan & Li, 2017). Autism is not a terminal condition. Ableism can be, though. Each March, we hold an international vigil for the autistic murdered by their families and caregivers (see *Disability Day of Mourning – Remembering the Disabled Murdered by Caregivers*, n.d.). We read about these victims in the news and see them blamed for their murders – after all, how could anyone have expected someone to live with that sort of burden (Harp, 2012)? We know autistic rates of suicide are, depending on which study you look at, 3 to 10 times higher than in the general population (Kõlves et al., 2021; South et al., 2021). We don't know whether there's a link between these rates of abuse and traumatizing "therapies." We do have evidence, though, that

there's a relationship between "camouflaging"[34] – that is, the laborious process of hiding one's autism and behaving and communicating in ablenormative (see McRuer, 2006) ways – and suicide (Beck et al., 2020; S. Cassidy et al., 2018; S. A. Cassidy et al., 2020). Autistic survivors of behaviorist intervention therapies note that these therapies don't cure them. The therapies just scare them into masking subconsciously to avoid punishment they've been conditioned to expect if they just behave and communicate like themselves.[35] For neurodiversity advocates, challenging medical-model constructions of autism is about much more than ideological differences – it's about creating a world in which autistics are subject to less harm and violence and in which we endure less trauma as a result of existing within a society that only values us if and when we meet certain neurotypical, capitalist requirements for citizenship (see Roscigno, 2019).

Through this study, quite expectedly, I find that autistic epistemic activism on Twitter corresponds to the neurodiversity paradigm. This activism responds to medical-model research(ers) more interested in researching genetics to prevent autistics from being born or treatments to help autistics hide their autism more effectively than in improving the quality of life of the autistics already here.

4.2.2 Autism in (Human-Computer Interaction) Research

The Twitter conversations I analyzed for this study focus on autism research broadly. Many of the discussions revolve around biomedical and behavioral research. While technological research represents a small subset of the research discussed in my corpus, the discussions are still relevant to HCI researchers, as HCI autism researchers often seek to support behaviorist autism interventions. As alluded to earlier, as an autistic person, many of the papers in HCI relating to autism are quite troubling. Outside my office, there used to hang a paper that describes people like me as burdens that warrant parents of autistic children taking to social media and seeking out and giving support in places that promote anti-vaxxer ideologies and violent "treatments" for autism. It's not uncommon for sympathetic studies of social media use of parents of autistic

34 While academic literature frequently uses the word "camouflaging" to refer to social coping strategies whereby autistics try to blend in as non-autistic, this behavior is more commonly referred to as "masking" within the autistic community – a terminology preference that new academic literature is just beginning to reflect (see, e.g., Pearson & Rose, 2021).

35 See (Unbound Books, n.d.) for a curated list of first-person accounts about autistic experiences of ABA.

people to casually mention “chlorine dioxide” as a common topic of discussion, and then to move on without acknowledging the fact that they observed these parents discussing tips for how to orally or anally administer industrial bleach to their children (see Sirucek, 2015; Zadrozny, n.d.). Other studies examining autism in online spaces have presumed that autistics are incapable of forming and maintaining communities with one another without the assistance of non-autistic facilitators (Hong et al., 2015). This a priori assumption is demonstrably untrue, as evidenced by the existence of #ActuallyAutistic Twitter (Osorio, 2020), the autistic blogosphere (Seidmann, 2020), and a myriad of autistic forums dating back several decades (Sinclair, 2012). Yet, the study was published, contributing to the foreclosure of studies of autistic communities, which are constructed in our field as non-existent.

In a review of wearable technology for autism, Rua Williams and Juan Gilbert explore how design research often yields unanticipated and unintended results when it doesn’t consider the perspectives of autistic users. For example, they argue behavior management technologies reinforce ablenormativity by depriving autistics of their natural modes of communication and self-regulation. In a meta-analytic study of a large corpus of technological intervention studies targeting autistic children, Katta Spiel and colleagues note a general non-recognition of autistic agency (Spiel et al., 2019). They find that researchers typically foist autism technologies upon autistic children rather than developing the tools with them, expect autistic people to use the technologies in the ways imagined by the researchers rather than giving them opportunities for self-determined usage, and often deploy these technologies in the context of behavior intervention paradigms like applied behavior analysis (ABA).

Indeed, it’s quite common for autism studies in HCI to support ABA through novel surveillance and control technologies. As Yergeau explains, a key historical figure in ABA and autism, Ole Ivar Lovaas, is notorious for his involvement in the Feminine Boys Project. Through his work with the Feminine Boys Project, using ABA, Lovaas created and refined gay conversion therapy. ABA for autism utilizes the same behaviorist interventions as conversion therapy. Like conversion therapy, ABA for autism is fundamentally related to the enforcement of cisgender, heterosexual, and neurotypical norms on nonconforming people (Yergeau, 2018). Robin Roscigno, drawing on the work of M. Remi Yergeau argues that, at a fundamental level, ABA is a technology of control. It seeks to manage atypical bodies and to undermine (neuro)queer futurity (Roscigno, 2019). Studies in HCI supporting ABA interventions most

likely mean well. They want to reduce discomfort – the burden autistic children place on their caregivers and the presumed burden of autism upon the individual. Good intentions only go so far, especially when, as Ymous and colleagues write, "what is allowed to be understood as 'doing good' is reliant upon entrenched sociocultural traditions of ableism" (Ymous et al., 2020, p. 3). Roscigno (Roscigno, 2019) argues that behaviorist interventions like ABA constitute a form of biophilanthropy. Biophilanthropy uses the guise of philanthropy to obfuscate the biopolitical deployment of control technologies to produce more bodies capable of capitalist production, and therefore worthy of citizenship (Schuller, 2017). Roscigno writes, "ABA 'treatment' requires sorting disabled bodies into those who are includable in the project of liberal capitalism and those who are not" (Roscigno, 2019, p. 406). Positioned as a tool for rendering unruly bodies (Erevelles, 2005) capable of participating in the capitalist project of producing and accumulating wealth, the curative violence (see Kim, 2017) endemic to ABA is excused as a necessary means to an end (Roscigno, 2019). Within HCI, ABA is far from the only project that seeks to produce useful bodies.

Cindy Lin and Silvia Lindtner explain that, on a much broader level, the values subscribed to and methods employed within HCI "help cultivate 'potential,' 'ready,' 'productive,' and 'agile' bodies, spaces, and organizations useful for investors, the state, the corporate university, and the fields of computing and design" (Lin & Lindtner, 2021, p. 3). The field's interest in medical-model approaches that seek to prevent or fix autism does not indicate a few misinformed researchers. Instead, this work reflects troubling systemic issues within the field. HCI presumes that progress and utility are the ultimate goals of research, not just for technologies but for bodies. These assumptions are deeply rooted within Western value systems (Irani et al., 2010; Ymous et al., 2020). In discussing a model for postcolonial computing, Lilly Irani and colleagues argue for recognizing the cultural locations where design and practice occur and sensitivity to non-Western value systems (Irani et al., 2010). These considerations pave the way for recognizing and designing with sensitivity to neurodiverse values and needs, which are, as my data will show, often at odds with Wester, capitalist goals of progress, accumulation, and independence. This paper will demonstrate that attending to autism research through a neurodiversity perspective does not necessarily mean that researchers must focus on completely different research topics. Rather, it means recognizing that there are alternative ways to define

and view the "problems" to be solved in this area (see Williams & Gilbert, 2019) and that choosing one framework over another is a political act.

4.2.3 Autistic Social Media Use

A growing body of literature focuses on autistic social media use. As mentioned previously, the Internet played an integral role in forming autistic early communities and the self-advocacy movement (Sinclair, 2012). A more recent study finds that autistic blogs serve a role building of autistic identity and spaces for autistic discourse (Seidmann, 2020). Further work suggests that social media use has positive mental health benefits for autistic users, including an increased sense of happiness (Ward et al., 2018) and decreased loneliness (Mazurek, 2013).

While autistic Internet communities first formed on forums and blogs, Twitter has become a hub for autistic community conversations, connections, and organizing. Gillespie-Lynch and colleagues note that autistic adults appear to prefer blogs and interest-based communities to social networking platforms (Gillespie-Lynch et al., 2014). It seems possible that the popularity of platforms like Twitter and Tumblr among autistics, relative to that of social networking platforms like Facebook, relates to these sites functioning as both social networks and (micro)blogs, though evidence for this claim is currently lacking. Twitter may lend itself to autistic communication because it's text-based, asynchronous, and highly structured (see Burke et al., 2010; Gillespie-Lynch et al., 2014).

In early autistic use of (micro)blogging sites like Twitter and Tumblr, autistics often posted under the #Autism hashtag. Parent, sibling, and professional perspectives often in conflict with those of autistic people came to dominate #Autism. The alternative hashtag, #ActuallyAutistic, was first used on Tumblr before spreading to Twitter and Instagram (Autistic Self Advocacy Network, 2014; The Lame Dame, 2012; Zisk, 2014). The #ActuallyAutistic hashtag is intended for use only by autistic people, including those with formal diagnoses, those exploring diagnosis, and those who self-diagnose (Luterman, 2015), though this typically "unspoken netiquette" is often violated (Eartharcher, 2017). Other community hashtags include #AskingAutistics (for autistic and allistic people with questions for autistic people), #AutisticsInAcademia (used by and for autistic students, educators, and researchers), and numerous hashtags regarding aspects of autistic culture and intersectionality.

Recently, Ruth Osorio conducted an interpretivist study of the rhetorics of #ActuallyAutistic Twitter (Osorio, 2020). Osorio notes that the topoi of #ActuallyAutistic

Twitter respond to and challenge dominant discourses around autism, which frame autism as "bad," undesirable, and something to be fixed. The three overarching topoi Osorio identifies and details in her paper are prioritizing experiential expertise, embracing neurodivergence, and documenting anti-autistic ableism. My current study builds directly on Osorio's work to articulate the activist-oriented discourses on #ActuallyAutistic Twitter specifically related to autism research.

4.3 Methods

As I will explain throughout this section and the next, the methods and methodology used in this study evolved throughout the project to match the kinds of data collected and the preferences of the people from whom I collected data. I draw on sampling and inductive coding practices common to grounded theory (GT) (Charmaz & Mitchell, 2001), the political commitments, attention to context, and concern with power and dominance inherent to CDA (Wodak & Meyer, 2001; van Dijk, 1993), and the self-referential narrative of autie-/autist-ethnography (Grace, 2013; Rose, 2005, 2008; Yergeau, 2013).

Scientific inquiry has, for centuries, been painstakingly constructed such that the scientist and their subjectivities are almost fully obfuscated (see, e.g., Shapin, 1988). Knowledge exists within knowers, though. Knowers are fundamentally situated in and affected by their sociopolitical contexts. The knowable from any given standpoint is inherently partial (Haraway, 1988). Further, knowledges are affected by the particularities of our bodies (Garland-Thomson, 2005). Ruth Behar articulates how an ethnographer's personal history inevitably shapes their interactions with interlocutors and argues that forgoing the pretense of objectivity and being vulnerable and transparent in the field and writing adds context and richness to ethnographic accounts (Behar, 1997). In HCI research, Williams and Boyd argue against pretending our work is "apolitical, neutral, or dispassionate" (Williams & Boyd, 2019, p. 266). Williams muses,

> "Maybe I don't have to shape my voice into the dispassionate "appropriate" tone for the benefit of others. Maybe I just have to reach the people who are ready to hear it. Maybe they can do the dispassionate work of subtle advocacy for covert change. I don't have it in me. I will be passionate as long as I witness harm" (Williams & Boyd, 2019, p. 266).

In articulating the principles of critical discourse analysis, Tuan A. van Dijk notes that "critical discourse analysts (should) take an explicit sociopolitical stance: they spell out their

point of view, perspective, principles, and aim, both within their discipline and within society at large" (van Dijk, 1993, p. 252). For van Dijk, CDA is fundamentally concerned with how discourses relate to power, particularly focusing on how those in dominant positions leverage discourse to maintain power over marginalized groups. A key part of the critical discourse analyst's role is to take on the perspectives of and be in solidarity with those suffering as a result of domination (van Dijk, 1993).

In that I explicitly include personal narratives in this paper, this work is semi-autoethnographic. Perhaps more precisely, this work is semi-autistethnographic, to borrow a term from Elizabeth Grace (Grace, 2013). As Irene Rose writes, in addition to following similar self-reflexive narrative structures to standard autoethnographic writing, autistethnographies serve several unique purposes (Rose, 2005, 2008). These accounts enact resistance by narrating autistic selfhood (which some people might presume to be oxymoronic), challenging the notion that one must strive for normativity, revealing the work and harm endemic to comporting oneself in ways compatible with the norms of neurotypical society, and building pathos to resist pathologization (Rose, 2008).

In this study, I make no claims to objectivity in its traditional sense of meaning. I cannot possibly separate myself and my experiences with #ActuallyAutistic Twitter and autism research from my analyses. Indeed, these experiences motivated this study, helped steer my data collection, and provided crucial context for my analyses. Aligning myself with my situated perspective as an autistic autism researcher in HCI and a member of Autistic Twitter, through this study, I draw on CDA and autistethnography to advocate for myself and the knowledges of other autistics.

4.3.1 Research Site

Compared to Tumblr and other platforms on which autistic discourse on autism research occurs, Twitter has the advantage (for this study) of having a large and active academic userbase. As such, Twitter is conducive to conversations between autistics and autism researchers. In addition to the demographic aspects of Twitter that facilitate dialogue between autistics and autism researchers, I focus specifically on #ActuallyAutistic Twitter because it is a platform, and a community within a platform, with which I am very familiar. As a participating observer (see Bernard, 2012) of Autistic Twitter, I hold insights and contextual knowledge about this site that allow targeted data collection, nuanced analysis, and a deeper understanding of the discourses

and the people generating the discourses. Within academia and autism discourses writ large, my status as an autistic is likely to be taken as a mark against my credibility as a knower (Yergeau, 2010, 2018). On #ActuallyAutistic Twitter, however, expertise about autism is not located within the so-called autism experts, nor in autism parents, charities, or professionals. As Osorio observes in her investigation of the *topoi* of #ActuallyAutistic Twitter, the experiential expertise borne of autistic embodi/enmindenment is a critical marker of credibility (Osorio, 2020). Similar to how one might go about gaining access to a physical field site, before planning this research project, I spent over a year and a half developing relationships with a breadth of community members, leaders, and organizations both on and offline.[36] I hoped my insider status as an autistic community member and the credibility afforded to me by my relationships within the community would allow me to obtain more in-depth and forthcoming narratives from participants, to navigate the subtleties of community politics, and to mitigate some of the potentials for re-marginalizing the people with and from whom I collect data.

4.3.2 Data Collection and Analysis

Concerning Twitter data, this study's unit of analysis consists of entire Twitter conversations or sections thereof instead of individual Tweets. In some cases, conversations are limited to a single thread and replies to that thread. In other cases, conversations comprise multiple threads, multi-threaded conversations, and/or a collection of individual tweets about a singular research publication or topic. As a frequent participant in these Twitter conversations about autism research, I wanted to try to have my data reflect not just my interests but those of a wider swath of autistic Twitter users. After receiving IRB exemption, I tweeted a thread explaining my research and asked for autistics to send me tweets or threads they felt might warrant inclusion in my study. My tweets about this study included several popular community

36 My community-building efforts primarily revolved around my active participation on Autistic Twitter. I engaged in Twitter chats and hashtag campaigns, replied to and retweeted others' tweets, and posted personal content on a near-daily basis. I built up a network of mutual followers, many of whom I went on to build one-on-one relationships from DM conversations about research, shared experiences, or common interests. Through Twitter, I learned about, applied for, and was accepted into the Autistic Self Advocacy Network's Autistic Campus Inclusion program, a summer fellowship for autistic university students interested in strengthening their local and national advocacy skills. Through this seven-day, in-person training, I met many other aspiring autistic academics, became acquainted with well-known and respected leaders in the autistic self-advocacy movement, and received guidance on how to engage with the public about advocacy goals. Additionally, I attended the Autspace 2019, a conference and retreat hosted by the Association for Autistic Community, through which I developed personal relationships with additional autistics and self-advocates from diverse backgrounds.

hashtags to boost the study's reach. I didn't compensate people for assisting with data collection. However, I later gave everyone involved in this process a chance to provide input during my analyses and to receive a $20 Amazon gift card as compensation. As data came in from the community, I employed theoretical sampling, a method associated with GT (Charmaz & Mitchell, 2001), to seek additional Twitter data related to emerging and interesting trends in the data I already had. I also used theoretical sampling to choose potential interlocutors, whom I asked to participate in semi-structured interviews, to add more depth and texture to my data. Interviews lasted about an hour, and I offered participants a $25 Amazon gift card for their time. I transcribed each interview and inductively coded them using the same techniques I used for Twitter data.

Initially, I employed inductive coding practices associated with GT (Charmaz & Mitchell, 2001) to label and make sense of my data. I ceased data collection when, having open-coded the data I already had, I felt I had reached saturation. Before continuing with axial coding, I reached out to every individual from whom I collected tweets to inform them of the inclusion of their tweets within my dataset and give them agency over whether and how I used their data. Recent research shows that, while some data are considered "public" and therefore exempt from IRB oversight and informed consent of the creators of that data, many people creating this data are unaware of and uncomfortable with the ways researchers may use said data (Fiesler, 2019; Proferes, 2017). Particularly because I anticipated I might receive tweets authored by people other than those who submitted said data, following the methods of Oliver Haimson (Haimson, 2018), I took an opt-out approach to data collection and usage. I attempted to contact the owners of each Twitter account in my dataset, except those of accounts belonging to public figures or organizations. Whenever possible, I reached out via Twitter Direct Message. If I could not send a Direct Message because the account owner and I didn't follow each other and the account owner had disabled direct messages for non-mutual followers, I attempted to reach out via publicly available email addresses. In one case, I reached out to someone through their "public figure" Facebook page. If I could not find a way to contact with an account owner, I removed their data from my dataset. I gave each account owner I was able to contact an opportunity to opt-out of my research entirely, resulting in removing their data from the study. I told them that if I didn't hear from them in 5 business days, I might use their data in my study but wouldn't quote or reference it directly. Those amenable to my using their data were given control over whether and

how I directly referenced their data. Most people who consented to my using their data were comfortable with me directly referencing their tweets and asked to be cited by name and/or Twitter handle. A few people asked that I make references to their tweets anonymously or using heavy obfuscation (see Markham, 2012), or that I forgo direct references and only use their tweets behind the scenes to support my overall analyses. All account owners with data directly referenced or referenced through obfuscation within this paper have been contacted with an excerpt of the paper, including said references. I asked them to confirm that the reference reflects their comfort levels regarding my use of their data and correctly characterizes their words. I contacted a total of 43 Twitter users asking permission to use their data. One person completely opted out from their data being used in this study. Thirty Twitter users responded, permitting me to use their tweets in per one or several of the options I offered. Two users responded requesting additional information but did not respond when I followed up with them. Ten users did not respond to my request. Most of the people who responded, including the person who opted out, expressed appreciation for the care taken to protect their control over how their content is used and their privacy maintained.

My analyses and findings center primarily around a single Twitter chat from which I collected 266 tweets by 64 unique Twitter users. I was referred to this chat, which focused on priorities for and perspectives on autism research, by a member of the #ActuallyAutistic community. Twitter chats are scheduled discussions on Twitter wherein a "moderator" tweets one or more questions relating to a particular topic. Typically, these questions begin with "Q" (for question), followed by a numeral indicating the question number (i.e., the first tweeted question in a given chat might begin, "Q1"). The questions contain a predetermined hashtag so participants and readers can search for tweets belonging to the chat. Anyone on Twitter can respond to the questions. Responses typically mirror the structure of the questions. They begin with "A" (for answer), followed by a numeral indicating the question being answered, and contain the predetermined hashtag for the chat. The Q/A and shared hashtag structures of these conversations allow the chats to be aggregated, sometimes having been formatted so that tweets are ordered based on the questions they respond to on third-party websites or blogs. The chat I primarily focus on in this paper, which I will describe in greater detail in the following section, was moderated by Thinking Person's Guide to Autism (TGPA), a well-established blog that posts about and invites guest-writers to post about autism from a neurodiversity perspective, and

as it relates to the needs and interests of autistic people. Because the tweets in this chat were organized by hashtag rather than (as in the case of other multi-tweet conversations I collected) as threaded replies, different methods were required for collecting these tweets. Whereas the other tweets in my dataset were collected manually, I utilized the recently expanded academic access to the Twitter API (see Tornes & Trujillo, 2021) to collect all tweets the week of the chat that (A) contained the predetermined hashtag for the chat and (B) had either a "Q" or an "A" followed by a numeral. I sorted the raw JSON data such that answers were nested under the questions to which they corresponded and exported the organized data to a series of text files (a separate file for each question and all the tweets in response to it) for inductive coding.

I open-coded data throughout the collection process. My PhD advisors, Oliver Haimson and Silvia Lindtner, both independently coded a subset of the data, and we discussed our respective codes together. After concluding data collection, having appeared to have reached saturation as indicated by my open-coding, and after contacting the owners of the accounts for which I had data, I continued with axial coding. Owing primarily to the kinds of data community members sent me, the themes into which I coded the data took the form of priorities for autism research. After sorting the data, I went back through them, paying attention to their discursive construction and, in particular, the politics and ideologies embedded within individual tweets and larger clusters of data.

4.4 Discussing Research on Autistic Twitter

The Twitter chat central to my analyses was hosted during the 2019 International Society of Autism Research's (INSAR) annual conference. Some important background knowledge is required to understand the context in which this chat occurred. In 2019, Simon Baron-Cohen served as INSAR's president. In what is arguably a generous characterization of Baron-Cohen, Os Keyes writes, "Simon Baron-Cohen is, interestingly, the cousin of Sacha Baron Cohen. The two could not be more different; one creates deeply bigoted and distressingly popular media content that describes and normalises the worst excesses of society's violence towards marginalized persons. The other wrote Borat" (Keyes, 2020, p. 13). Baron-Cohen is well known for his work on "mindblindness," in which he proposes that autistics lack an essential cognitive capacity called Theory of Mind (ToM) (Baron-Cohen et al., 1997). As Yergeau explains (Yergeau, 2013), ToM is constructed as something fundamental to human existence. It refers to one's ability to infer the existence of others' minds the states thereof and is conceived as a

precondition for empathy. Yergeau notes that while ToM is essential to humanity, autistics are described as lacking this vital capacity. In autism research, by delineating that which is required to be human and then claiming autistics fail to meet these key criteria, ToM functions as a tool for writing off our existences and experiences as invalid (Yergeau, 2013). ToM is a violent instrument of epistemic injustice. The man behind ToM's modern usage in autism research was the president of INSAR, an organization behind one of the largest annual international autism conferences and a leading journal on autism-related science. As Shannon Des Roches Rosa, the managing editor of TPGA, notes, in the two years leading up to INSAR 2018, there were important strides toward addressing the needs and concerns of autistic people. Yet, there remained important gaps. The conference remained inaccessible of the conference to some autistic attendees. There also remained a lack of autistic leadership within INSAR and a persistent lack of autistic representation within research projects (Des Roches Rosa, 2018).

The TPGA INSAR Twitter chat consisted of 8 questions relating to thoughts around research priorities, concerns about current directions of autism research, and barriers faced by autistic people trying to access research. Some of the questions were targeted specifically towards autistic respondents, one towards autism researchers (some of whom are autistic), and several towards a more general audience. The full list of questions is available in the Appendix A to this paper. From the hashtags respondents used and my prior knowledge of many of the people participating in the chat, for most participants, I was able to ascertain whether or they were (or at least, whether they openly identified as) autistic.

This chat was analytically useful for several key reasons. Firstly, although the questions around which the chat was organized prescribed certain kinds of responses, it provided a focused discussion around one of the main topics of interest of this study – namely, autistic perspectives on autism research. It also provided examples of how autistics challenge traditional approaches to autism research and of interactions between autistics and non-autistic autism researchers. Additionally, whereas nearly all the responses within the chat aligned themselves with a particular orientation towards autism and disability, I was able to make direct comparisons against the priorities and concerns around research held by the 29 members of the editorial board of Autism Research, the journal of INSAR. Conveniently, ahead of INSAR 2019, they published an article with their respective commentaries on current gaps in autism research. These commentaries serve as a sample of the types of autism researchers who present at INSAR.

4.4.1 A Brief Interlude

Autism is not a monolith. Nor, for that matter, are non-autistic autism researchers. There were two neurodiversity-oriented research commentaries in Autism Research publication (Amaral et al., 2019) and several more neurodiversity-aligned non-autistic researchers who participated in the INSAR Twitter chat. While the autistic people from whom I have data are highly unified in their positions, they are by no means representative of all autistic people. As one of my interview participants – who has asked to be identified under the pseudonym Tzvi Dav – points out, there's a faction of anti-neurodiversity autistics on Twitter. Dav studies fascism and white supremacy within the broader autistic community. During our interview, Dav explained that there's little ideological cohesion among these anti-neurodiversity autistics who, for a time, assembled under the #AutisticDarkWeb and #ADW hashtags, which are now mostly defunct. Some of these autistics feel neurodiversity is a Jewish conspiracy. Others, Dav told me, may be reacting to the shifting demographics within the autistic population as more people of color and people from marginalized genders are diagnosed. Dav noted that many of these anti-neurodiversity autistics are white men who grew up understanding autism as a disease of the white, upper-middle-class. According to Dav, they came to identify with these parts of their conception of autism and see growing multiculturalism within the neurodiversity community as a threat to this identity.

Additionally, many of these autistics identify with labels such as "Asperger's syndrome" and "high functioning," which the neurodiversity movement repudiates. Neurodiversity advocates feel that these labels both fail to accurately encapsulate the nature of autism while simultaneously creating a hierarchy wherein certain "high functioning" autistics are more worthy of rights and citizenship than others by their proximity to neurotypicality. The neurodiversity paradigm is premised on the inherent worth of all neurodivergent people, regardless of their support needs. Dav suggested many anti-neurodiversity autistics are attached to "Asperger's syndrome" and "high-functioning autism" as marginalized identities and don't want to be lumped together with those *other* autistics, as occurs through the neurodiversity movement collapsing all forms of autism into a single, overarching category.

Again, these anti-neurodiversity autistics are not the autistics for whom I have data, and I do not purport to represent their views. In my personal experiences, these are the autistics many medical model researchers point to, though, when confronted with a critique about not

supporting the interests of autistic people. They also point to the parents of autistic people, stating that their research comports with these parents' pressing interests and needs. As a counterargument to this claim, I contend that parents' understandings of autism are fundamentally predicated upon autism research – that the relationship between parents and researchers is, at the very least, bi-directional. After all, autism, as a diagnostic category or social construct, didn't exist until medical-model autism researchers gave it a name and ascribed to it a set of characteristics. Parental understandings of autism have always been influenced by this research and the medical-model research that followed. In essence, for autism researchers to claim to be supporting the needs of parents is a tautological means of saying they support their positions, which are supported by the parents they influence. Here, I speak only for the neurodiversity-aligned autistics for and from whom I have data, not to anti-neurodiversity autistics or self-described autism parents.

4.4.2 Convergent Research Priorities, Divergent Systems of Meaning

As an autistic researcher who encounters both approaches to autism research on a near-daily basis, I would have thought that, at every level, medical-model-oriented and neurodiversity-oriented research would be radically different. When I encounter these papers and conversations out in the wild, they *feel* radically different. I relate to the sentiments of my interlocutor (P1), who described the latter as "high-quality, relevant, effective autism research" and the former as "really ableist, eugenicist, horrible research." When I read a well-researched paper written from a social model perspective, I feel support from and gratitude for the research and researchers. I feel seen by the research – my personhood recognized, my needs valid, and my existence intrinsically worthy. When I encounter medical-model autism research, though, I return to that place of despair I felt early in my doctoral studies – a place of fear, non-belonging and loneliness, and quiet anger towards ableist systems within the academy that would rather I cease to exist than try to accommodate my presence. In categorizing the stated research priorities across the chat and the published commentaries, though, I was surprised to see that, at a high level, many of the stated priorities and concerns *sounded* quite similar. For example, a priority for both participants of the Twitter chat and some researchers who published commentaries were the disparate rates of autism diagnosis across various demographic lines. Likewise, both conversations were frequently concerned with autism interventions, co-occurring conditions, and

practical concerns about research. Yet, upon closer inspection, the *meaning* of these stated priorities, and the approaches suggested for addressing them, varied widely.

Here, I'll highlight several examples of shared priorities that are interpreted and pursued in different ways that are particularly relatable to the kinds of work HCI researchers focus on or can focus on – research around interventions and treatments, and meta-concerns about how autism research is conducted and disseminated. There were, of course, myriad examples of priorities held by one group, but not the other. The examples below, though, highlight the differences in these two types of discourses – differences that also extend to the other shared priorities (e.g., addressing disparate rates in autism diagnoses across various demographic lines, the mental health needs of autistics, and myriad co-occurring conditions) not discussed in this paper.

4.4.2.1 Intervening in Interventions

Greater research into autism interventions was a common focus for both social and medical model adherents. It is commonly known that early detection of and intervention for autism are crucial to more positive long-term outcomes. Medical-model scientists and clinicians were interested in developing faster and less expensive diagnostic tools (Amaral et al., 2019). For medical-model researchers, the earlier an autistic can be diagnosed, the sooner they can enter treatment. The specific concerns relating to treatment and intervention expressed within the published commentaries relate to (1) acquiring monetary support for interventions found to be efficacious, but which have been shelved because of a lack of research funding; (2) the development of new, targeted treatments for individuals who don't respond to current interventions; (3) more efficient ways to predict a given individual's response to a given intervention and to monitor their treatment outcomes; (4) high quality, rigorous clinical trials of new and existing interventions so families and providers can make informed decisions about treatment options; and (5) an investigation of how early behavioral intervention affects brain chemistry and topology (Amaral et al., 2019). Implicit in each of these concerns is that it is desirable to achieve an outcome wherein the autistic subject is rendered less autistic. The efficacy, validity, and numeracy of options available to achieve this particular outcome are the foci of medical-model approaches to treatment and interventions.

While autistic and neurodiversity-aligned Twitter users are also interested in treatments and preventions, their interest primarily revolves around concerns they hold with the practical

implications and methodological and ethical groundings of medical-model approaches. When autistics tweet about the outcomes of behaviorist therapies, they do so in terms of the "[l]ong term *consequences* of early intervention" (emphasis added Dr Jac, 2019) or the "*[a]ctual* outcomes of ABA" (Julia Bascom [@JustStimming], 2019). The framing of behaviorist interventions in terms of their *consequences* and *actual* outcomes dismisses the normative value of neurotypical behavior and communication as unquestionable goods. As Twitter user @endeverstar tweets, "if we're measuring the wrong things, we get lauded 'evidenced based practices' that are actually intensely harmful" (✨ the neuropunk who lived ✨ (increasingly cyborg), 2019). Rather than gauging these interventions in terms of their success in making autistics appear more neurotypical, neurodiversity advocates on Twitter are more interested in unanticipated outcomes, including, as @ekverstania tweets, "#CRPD violations and trauma in ABA" (Tania ZA AutisticStrategies.net, 2019).[37] Trauma, both as an effect of "treatment" and as a consequence of simply existing in a neurotypical world that expects neurotypicality, was a common theme in the INSAR chat.

Several participants in the INSAR chat expressed concerns specific to technologically-mediated autism interventions. Elizabeth Bartmess tweets, "I'm very concerned about research being translated uncritically into tech for fine-grained behavioral control and surveillance. We urgently need research on harms done, including when implemented as intended" (theories of minds, 2019). Discussing the same kinds of technological interventions, Sue Fletcher-Watson tweets her concerns over the high risk of "intrusion and privacy issues" (Sue Fletcher-Watson, 2019). Even beyond the confines of the INSAR chat, concerns about technologically-mediated interventions are prevalent on #ActuallyAutistic Twitter.

In response to a recent research study on wearable technologies that prompt autistic children to perform various normative behaviors, @AutSciPerson tweets, "I cannot emphasize how much I hate research that uses technology to force autistic people to mask" (AutisticSciencePerson, 2021a). As @endeverstar noted, choosing the wrong outcome measures for a study creates a risk of inflicting unanticipated harms (✨ the neuropunk who lived ✨ (increasingly cyborg), 2019). To reiterate a point made earlier in this paper, research suggests

37 CRPD, here, refers to the United Nations Convention on the Rights of Persons with Disabilities (see OHCHR | Convention on the Rights of Persons with Disabilities, n.d.).

that masking – affecting neurotypical communication and behavior styles – is related to increased risk for suicide (Beck et al., 2020; S. Cassidy et al., 2018; S. A. Cassidy et al., 2020). Discussing wearable technologies for disabled people, Williams and Gilbert write in a recent paper, "This framing of assisted normalization as access legitimizes historical abuses of institutionalization and reminds us of 'The Ugly Laws' which denied disabled citizens access to public space based on their 'unsightly' difference" (Williams & Gilbert, 2019, p. 4). Wearables are new and exciting, and making an autistic person appear less autistic, and therefore appear to better fit in within a neurotypical society, might sound like a positive outcome. However, autistic people – the victims of these kinds of novelties – implore researchers to consider the consequences of this kind of research.

In response to an INSAR chat question about concerns with current directions in autism research, several members of the list the recent trend in autism technology research involving "social robots" as a source of consternation.[38] Spiel and colleagues observe that, over the past decade, technological intervention research for autism has increasingly focused on the use of robots (Spiel et al., 2019). They also note that these robot interventions are often used to reinforce "treatment" paradigms like ABA. As I have written elsewhere, this autism–robot research is premised on complicated rhetorical acrobats through which autistic people are positioned as simultaneously less human than their neurotypical counterparts and even than the robots meant to teach them how to become more human (Rottier et al., 2022). This robot research reasserts negative and dehumanizing stereotypes about "robotic" autistics while, at the same time, attempting to "coerce autistic children, through normative violence, into a less autistic … state" (Rottier et al., 2022, n.p.).

The departure between medical-model and neurodiversity-paradigm approaches to interventions is fundamentally about whether we value and accept autistic people as who they are, or about whether their potential worth is tied to whether they can be shaped in ways that obfuscate their non-neurotypicality. These medical-model perspectives are ultimately related to the values of use, utility, production, and consumption inherent to the field of HCI and inscribed

38 These users did not respond to my request to include their data in my study. In accordance with the data-use practices I communicated with them via Twitter direct-messages, I have referenced their tweets only in aggregate without any direct citations.

within ABA (Lin & Lindtner, 2021; Roscigno, 2019). Autistics implore researchers to listen to their experiences with these kinds of "treatments" and consider how the assumptions and values inherent to these approaches inflict harm, even if, as I tend to assume to be true in most cases, the researchers have good intentions.

4.4.2.2 Autistic Research, not Autism Research

Medical-model researchers and neurodiversity proponents frequently discussed issues I categorized under the code “practical considerations for research.” These concerns focus less on individual research topics than on meta-level considerations about how research is conducted and disseminated. Here, divisions between medical-model and neurodiversity-paradigm views relate to the kinds of methods and research designs autism researchers should focus on, the roles autistic people should play in research, and differences in the intended audience for research findings.

Related to methods and research design, many researchers in the published commentaries (Amaral et al., 2019) are interested in improving the quality of research, irrespective of the type of research. One of the key considerations here was about choosing the right methods to produce valid results based on one’s research questions. The particularities of these concerns tended to focus on which kinds of imaging technologies to deploy for studies of autistic brain functioning, which kinds of genetic investigations make sense given what we know about the heterogeneity of autism and how very few cases of autism appear related to single-gene variance. Also relating to brain imaging studies and again noting the vast heterogeneity among the autistic population, one researcher urged their colleagues to employ within-group study designs. There was also a focus on ensuring research is translational and that, where possible, it’s interdisciplinary.

In contrast, neurodiversity-oriented people – both in the published commentaries and in the INSAR chat – were interested in, irrespective of research topic, participatory methodologies. There was a significant focus on the desire for research to be autistic-led or, at the very least, co-produced with autistic people. Cheryl Dissanayake, in the published commentaries, writes, “Of particular need is research that is co-produced with autistic researchers” and suggests that to make this feasible, there needs to be a “focus on training autistic scholars to contribute to these research efforts” (Amaral et al., 2019, p. 9). Further, as Sarah O’Brien specifies on Twitter, co-production must be “done meaningfully and not to fulfill diversity criteria in all areas” (sarah o’brien, 2019). Likewise, in the Twitter chat, the Centre for Autism Research and Education calls

for "more participatory research throughout the entire research process. From writing the grants, to designing the study, to analysing and collecting data, to taking the findings back to the community" (CRAE [@CRAE_IOE], 2019). One of Laura Crane's tweets stresses the need to have serious conversations about "*how* we include and involve autistic people as research partners" (emphasis added, Laura Crane, 2019), and a tweet from Lorcan Kenny calls for research "assessing how autistic involvement actually changes how research gets done" (Lorcan Kenny [@LorcanKenny], 2019a). In addition to exemplifying neurodiversity perspectives on critical research design and methodological issues, these conversations about autistic-led and fully participatory research exemplify how neurodiversity proponents view the role of autistic people in relationship to autism research.

As alluded to earlier, autistic people are wary of the possibility of research claiming to be participatory or autistics or inclusive of our knowledges, but which doesn't fully include or respect autistic participation. This is exemplified by concerns that researchers might turn to publicly available social media data in order to exploit autistic knowledges without crediting or meaningfully involving autistic people in the research. In a separate Twitter chat about autistic preferences for autism research, and particularly pertinent to this study, autistics expressed their preferences for and concerns about how autism researchers engage with autistic social media. Many people were very interested in having autistic knowledges such as those present on social media included in research papers, but they were also concerned about exploitative use of their data in autism research. Speaking to the importance of autism researchers engaging with the autistic community, Elizabeth Bartmess tweets, "I think it's important for researchers who study autism and similar neurodivergences to learn from autistic and nd communities, and doubly important for autistic/nd researchers to also have access to social support from those communities" (theories of minds [@theoriesofminds], 2019). Alyssa Hillary Zisk feels autistic social media is an important source of autistic knowledge but wants this knowledge to be used respectfully. They tweet, "I do want autism researchers to read autistic writing, and not just writing by autistic people who get published in peer-reviewed journals. That doesn't mean I want researchers treating our writing like a zoo exhibit" (Alyssa, 2019a).[39]

39 Zisk's mention of zoo exhibits is an "in" reference to a term coined by Jim Sinclair, self-narrating zoo exhibits, which refers to the ways autistic people are frequently treated in neurotypical spaces (see Sinclair, 2012).

Several people also noted the importance of consent and credit when using autistic social media data for research. @Endo_Gremlin tweeted, "I think following our blogs and social media ect [*sic*] is fine but any use of it should be with informed consent from all involved" (sam♿, 2019). A conversation between Rua Williams and Alyssa Hillary Zisk directly informed the data-use practices of this present study. In a series of threaded tweets, Williams tweeted,

> I find the emerging practice of "scraping" publicly posted data for research purposes troublesome. It Can be extractive and exploitative. People consent to public posting but they don't consent to research interpretation. … interpretation of findings should be validated with original posters. This means requesting retroactive consent. Not everyone will respond, but those that do are entitled to editorial control, anonymity (or note), and veto power. … sound like work? So was the original labor in the tweets and blogs you're scraping. Also, I've seen projects like this were blogs are "anonymized" but literally anyone who's been in the community long enough can identify the original content. It's theft. Cite us. (Rua M. Williams, 2019c, 2019a, 2019b)

Similarly, Zisk tweeted, "I very much appreciated the researchers who asked whether I wanted to be anonymous, pseudonymous, or named, rather than assuming anonymity was what I'd want or what 'had' to happen" (Alyssa, 2019b). When I reached out to get consent to use data for this study, the response I received from the community was overwhelmingly positive. It certainly took a significant amount of work, but it was worthwhile to know, with certainty, that I was properly representing the needs and interests of the people about whom I was writing.

For neurodiversity advocates, autistic people and knowledges are fundamental to every aspect of autism research. Under the medical-model, biomedical and psychological research is intended for clinicians, who are then positioned to disseminate knowledge to (non-autistic) laypeople (Amaral et al., 2019). One researcher also expressed concern over how we communicate genetic research to the general (non-autistic) public – to be clear about what can and cannot be inferred from or about genetic findings (Amaral et al., 2019). Neurodiversity proponents, on the other hand, feel that research about us should be *for* us. One anonymous Twitter user wrote about how significant amounts of autism research they encounter doesn't appear to have asked the fundamental question, "how will autistic people benefit from this

work?"[40] This sentiment that autism research should be for us goes beyond wanting research to be about autistic interests and needs. To people on #ActuallyAutistic Twitter, it means making sure papers are written using accessible language, non-pathologizing, non-eugenicist language (see tweets Dr Jac [@JacdenHouting], 2019; Lorcan Kenny [@LorcanKenny], 2019b; Melissa Chapple [@melissachapple], 2019), publishing papers outside of paywalls (see tweets Dr Jac [@JacdenHouting], 2019; Helen Rottier [@helenrottier], 2019; Lorcan Kenny [@LorcanKenny], 2019b; Melissa Chapple [@melissachapple], 2019), and providing funding and accommodations for autistic people to attend and participate in research conferences.[41]

4.4.3 Crossing chasms without building bridges

One of the things that stood out to me from the INSAR chat was how autistic and non-autistic people, all of whom approached research from a neurodiversity perspective, were essentially saying and advocating for the same things. These interactions were amicable. There was no fighting or arguing. The tenor of these interactions corresponds to other such interactions happening on Twitter outside the confines of the INSAR chat. In one such instance, @AutSciPerson responds to a thread by Noah Sasson, an allistic autism researcher who takes a neurodiversity approach to autism, about some of his research. @AutSciPerson points out gender disparities related to various aspects of the study's design, including the study's participant sample, and asked for Sasson's thoughts on the matter. Sasson responded to the concerns, simultaneously validating them while also defending aspects of the study's design. He went on to say that his research team is very interested in further work that follows the directions suggested by @AutSciPerson (AutisticSciencePerson, 2019; AutisticSciencePerson [@AutSciPerson], 2019; Noah Sasson [@Noahsasson], 2019a, 2019b, 2019c). This professional and cordial tone is typical of these conversations between autistic Twitter users and researchers doing work that autistics support – the kinds of work P1 described as "high-quality, relevant, effective autism research." This is research that, as P1 says, "has [positive] impacts on the community" and provides "answers to these questions we want to know [the answers to]." P1, who has several

40 This user did not respond to my request to include their data in my study. In accordance with the data-use practices I communicated with them via Twitter direct-messages, I have referenced their tweet anonymously and have obfuscated (see Markham, 2012) the tweet's text.

41 I collected several tweets relating to academic conferences' financial, physical, and sensory accessibility but did not obtain permission to cite these tweets directly.

thousand followers on Twitter, makes a point of sharing, retweeting, or quote-tweeting this good research done by non-autistic people. P1 further says of the researchers doing "good" research and who engage with autistics on Twitter, "part of what makes their research valuable is that they are interacting with the community throughout the research process." This kind of transparency and interaction with the community goes a long way towards building positive relationships with neurodiversity advocates. #ActuallyAutistic Twitter users take a much different approach when interacting with medical-model research(ers), though.

Throughout most of the INSAR chat, autistics were calling out medical-model research as insensitive to the needs and priorities of autistic people, violating research ethics, and perpetrating violence leading to long-term harm. While these critiques were not personal attacks against individual researchers, they did not mince words when describing this research in terms of its negative impacts (e.g., as mentioned earlier, talking about this research in terms of abuse, trauma, violence, and CRPD violations). While P1 shares "good" autism research to draw attention to and reward it, autistic Twitter users tweet about the "really ableist, eugenicist, horrible research" (P1) to share critiques and to forewarn other researchers. These critiques typically take the form of multi-tweet threads. Some are directed towards the autistic community, while others are directed towards the researchers. It is rare for researchers to interact with these critiques and, when they do, they typically only engage long enough to dismiss the critiques without actually acknowledging or responding to them. As one example of the ways autistics engage with this kind of research, I turn again to @AutSciPerson's thread critiquing a study about a new wearable device for autistic children. Below, I share some excerpts from that thread:

> The only consideration for the autistic person's well-being is the Tactile sensitivity survey to see if she could wear the smartwatch. Who takes the survey, you might ask? The autistic child's father. Not the autistic person herself! We have no idea if that's accurate. … The main goal is seeing how well the autistic 9-year old girl follows directions using the watch. It's not about increased quality of life outcomes. It's about [how] often she looks at the watch and what it says. … Here's the scary part. They used a "Treatment acceptability survey" to assess how useful teaching assistants, special education teachers, and SLPs found the smartwatch. That's right. They asked everyone how well the "treatment" worked except for the autistic person. … This is where it gets really quite devastating. Here are the results of the acceptability survey. …. In this

> survey, 67% of professionals disagreed with the statement "I believe this treatment is likely to result in permanent improvement. … [Professionals also responded to the statement,] "I believe that it would be acceptable to use this treatment without children's consent." 67% agreed, 33% strongly agreed! Why is this question even being asked? It's not ethical to perform a study on someone without their consent. So how is it ethical to force an autistic student to wear a smartwatch? Esp. with all of its sensory stimuli. How can you make an autistic person use this when the majority [of professionals surveyed] disagreed that it helped?! (AutisticSciencePerson, 2021b, 2021c, 2021d, 2021e, 2021f, 2021g)

This thread is particularly interesting because, in response to the concerns about the ethics of compromising a child's right to bodily autonomy to deploy a treatment of dubious efficacy, the journal in which the study was published responded. The official Twitter account of the Journal of Augmentative and Alternative Communication responded to say:

> "Per policy, the AAC Journal does not publish studies without IRB approval. Here, informed consent was obtained from the legal guardian. Not sure how you arrived at the conclusion that the child was forced to wear the watch." (AAC Journal [@AACjourn], 2021)

This response is typical of the occasions in which medical-model researchers engage with autistics over critiques of their research. @AutSciPerson wasn't suggesting the study lacked IRB approval. They were questioning the study's choice to ask a question about deploying a technology out "in the wild" without consent, noting that, in a research setting, this would likely violate ethical research guidelines. The journal's glib response treats @AutSciPerson as someone unfamiliar with or unable to read academic research. Clicking over to @AutSciPerson's profile, though, it's readily apparent that they're a PhD student studying neuroscience and one with 20,000 followers, no less. Yet, the response from the AAC Journal could be interpreted as reacting to an autistic person as if they are simply too impaired to understand the nuances of academic studies. @AutSciPerson provided clarifying responses to the AAC Journal's tweet, but the journal did not deign to reply again.

There's a distinct lack of autistics trying to engage collaboratively with medical-model researchers, as they often do with researchers doing "high-quality, relevant, effective" research.

Combing through the data I was sent for this study, as well as my archives of relevant tweets I've collected myself, I saw no instances in which autistics tweeted about these studies in ways that extended a metaphorical olive branch to the researchers. Likewise, I saw only one instance (which I cannot quote for lack of response from the researcher) wherein a medical-model researcher meaningfully engaged with autistic criticisms. They did so reluctantly, taking a defensive posture, and stopped engaging when their responses, too, were critiqued, but they tried, nonetheless. Discussing the present study with a colleague, I was asked whether *I* would engage with such harsh, public critiques of my work and whether this is a truly effective way to stop or lessen future medical-model research. My response was and is that it's not my job to do emotional labor on behalf of researchers who make it more difficult for me to exist within or outside of the academy through their violent research. Once again, I'd like to draw your attention to a quote from Rua Williams:

> "Maybe I don't have to shape my voice into the dispassionate "appropriate" tone for the benefit of others. Maybe I just have to reach the people who are ready to hear it. Maybe they can do the dispassionate work of subtle advocacy for covert change. I don't have it in me. I will be passionate as long as I witness harm" (Williams & Boyd, 2019, p. 266).

By calling out the violence in medical-model research, autistics are not trying to make nice with these researchers. They are taking on the role of the passionate witness (Williams & Boyd, 2019), calling attention to injustice as best as possible, given the means by which they can partake in academic discourses. Autistics aren't trying to build bridges here. Allies can do the more dispassionate work of building bridges. Here, autistics make it clear to whoever will listen that there is a wide ideological chasm between their neurodiversity view of research and those of medical-model researchers.

As for whether this mode of interaction with medical-model researchers is effective, I defer to the opinion of P1, who has spent far more time on autistic Twitter than I have. When I asked them this question, they replied:

> Yes, because I think some people see this discourse[.] … [I]t's why we have these good researchers[.] … [T]hey've seen the mistakes that bad researchers have made, especially in engaging with and incorporating perspectives from the community. So yeah, I think I think it does have an impact, and it has an impact on … autistic people and

> neurodivergent people and all people who are the subjects of research to see … we have agency to say, "this isn't … our reality. … These are the flaws in this research, certainly …. [I]t doesn't reflect what we are experiencing. (P1)

Calling out medical-model researchers might not have a direct impact on the researchers who are called out. But it might serve as a warning to other researchers, who will not make the same mistakes in their work in the future to avoid the same public critiques. One of the non-autistic researchers in the INSAR chat reflects on their past work and how exposure to the neurodiversity paradigm has changed how they approach and talk about autism research. Talking about how the researchers often use ableist terminology, which renders their research inaccessible to autistics who don't want to read about themselves characterized these ways, Laura Crane (Laura Crane [@LauraMayCrane], 2019) tweets, "I cringe at my old research articles where I used words like this…I'm trying to be a better ally now!" Having been influenced by the autistic community, Crane, through her research and public engagement on Twitter, now contributes to the more nuanced work of building bridges with the people autistics don't feel safe interacting with themselves.

4.5 Towards anti-ableist HCI research

This study contributes to a growing body of HCI literature that approaches autism research from a perspective sensitive to the needs, interests, and personhood of autistic and neurodivergent people (e.g., Frauenberger et al., 2019; Keyes, 2020; Spiel et al., 2018, 2019; Williams & Gilbert, 2019; Ymous et al., 2020). It also builds on recent work highlighting autistic social media as a site for community building, creating autistic space, nurturing autistic culture and identity, and epistemic activism (Osorio, 2020; Seidmann, 2020). This study is unique in that it focuses specifically on autistic online discourses about autism research. My investigation demonstrates that, in a Kuhnian sense, the medical-model and neurodiversity paradigm represent incommensurable research paradigms. The questions you can ask in one paradigm don't make sense to or count as valid science in the other. On #ActuallyAutistic Twitter, neurodiversity proponents show us that there is another way to approach autism research and autistic people – a way that supports us as we are, rather than eradicating us or predicating our recognition as humans, deserving of rights and self-determination (see Rottier et al., 2022) on pretending to be something we're not. Within the neurodiversity framework, it is not the humanity of autistics that

is suspect, but rather the humanity of an institutionalized conception of personhood that casts autistic people as lesser beings than their allistic counterparts.

Whereas Ahmed describes queer orientations as directing oneself away from the straight lines of heteronormativity (Ahmed, 2010) and McRuer positions crip orientations as those which resist the forces of compulsory ablenormativity (McRuer, 2006), we might understand autistic orientations towards the neurodiversity paradigm as pushing against and turning away from the compulsory sociality (see Rodas, 2008) of the medical model of disability. Autistics live in a world that frames our existence and our apparent strangeness in terms of sinister forces that steal allistic children in the middle of the night, leaving autistic changelings in their places (Autistic Self Advocacy Network, 2016), environmental toxicity and devastation (Gibbons, 2017), an epidemic disease outbreak in need of eradication (Gernsbacher et al., 2005), and a formidable enemy against which our society wages war (McGuire, 2016). It is through these framings of autism that violent interventions are justified. "Treatments" like ABA weaponize compulsory, normative expectations for sociality and behavior. They attempt to keep autistics oriented towards pathological conceptions of autism, under which our unaltered existences render us non-includible, until and unless we comport ourselves in normative manners demonstrably harmful to our well-being (see Beck et al., 2020; S. Cassidy et al., 2018; S. A. Cassidy et al., 2020; Roscigno, 2019). Medical model approaches to autism, including those widely adopted within autism-related HCI research, are complicit in this violence through their support and normalization of these "treatments" and of these negative framing of autism.

Julie Miele Rodas writes, "Without the strength and will to resist the world and build a functional private space, the autistic individual is prone to imprisonment and extermination. Resistance to the encroaching world, and to tyrannical expectations of compulsory sociality, is necessary to autistic survival and self-determination" (Rodas, 2008, p. 127). Autistic life depends on resistance to the medical model, and a turn towards the neurodiversity paradigm. #ActuallyAutistic Twitter is a site of resistance within which autistics create a space for themselves and their forms of sociality. It is a site with which autistics make visible the otherwise hidden, hegemonic discourses and forces that construe allism as the inevitable and only desirable goal for autistic existences. Autistics use Twitter to imagine and discuss anti-ableist alternatives to the entrenched values of normativity and production inherent to the medical model of disability and the academy writ large.

These autistic and neurodiversity-oriented discourses on Twitter reveal a viable alternative to pathologizing conceptions of autism. In exploring the uncovered ways in which similar research priorities can be approached from different orientations towards autism, and how autistic interactions with researchers work to change researchers' orientations, we see that medical-model approaches to autism aren't a foregone conclusion. As did Laura Crane (Laura Crane [@LauraMayCrane], 2019), researchers have the agency to *choose* to adhere to one paradigm or another Further, autistics and their supporters on Twitter tell researchers that their choices here may have grave consequences on our lives and the quality and longevity thereof.

Aimi Hamraie and Kelly Fritsch, in their manifesto on crip technoscience, delineate a framework for HCI researchers interested in choosing to align themselves and their work with the needs, knowledges, and activism of disabled people (Hamraie & Fritsch, 2019). They place crip technoscience in opposition to disability technoscience. Like the medical model of disability under which it operates, disability technoscience positions enhancement and capacitation as progressive moves to overcome disability. Disability technoscience ostensibly focuses on design *for* disabled people rather than with or by disabled people. My exploration of #ActuallyAutistic Twitter provides insights specific to how autism research can fit within Hamraie and Fritsch's framework for crip technoscience and the four key commitments thereof (Hamraie & Fritsch, 2019).

The first commitment of crip technoscience is to center the work of disabled people as knowers and makers. This commitment involves recognizing disabled people as subject-matter experts by virtue of their lived experiences. In reviewing extant literature on wearable technologies for disabled people, Williams and Gilbert (Williams & Gilbert, 2019) suggest lack of familiarity with the local, situated knowledges of disabled people explains HCI researchers' apparent difficulties with recognizing the ways their work adversely impacts their intended users. Of course, the solution to this predicament is for researchers to seek out and recognize the importance of disabled knowledges and experiences. While medical-model autism research frames autistic people as "mindblind" automata devoid of self-knowledge (Yergeau, 2018), #ActuallyAutistic Twitter shows otherwise. Clearly, autistic people are acutely aware of their experiences and needs and how those conflict with dominant approaches to autism research. The idea that autistic people have and produce knowledge isn't a novel concept. Any autistic person knows they know things. For those who doubt the word of just one an autistic on this matter,

Gillespie-Lynch and colleagues find, through an empirical investigation, that autistic people are more knowledgeable about autism than their non-autistic counterparts (Gillespie-Lynch et al., 2017). While systemic ableism – including the access issues addressed by autistic people on Twitter and discussed earlier in this paper – prevents autistic experts from entering into the academy and their knowledges from entering into academic discourse, this expertise is publicly available on Twitter. Not only is it publicly available, but autistics are also eager to have their knowledges, as discussed on social media, included in academic research (with ethical citational practices, of course). Further, I've found Twitter to be an excellent tool not only for finding extant autistic data but for enlisting autistic participation in research. Autistic people want to be involved in your autism research, and they know things that should be important to you, as someone interested in non-violent, ethical, beneficent research. Twitter may be a useful tool to assist you in conducting anti-ableist autism research, led and informed by autistic people and knowledges.

The second commitment of crip technoscience is to "access as friction" (Hamraie & Fritsch, 2019, p. n.p.). This commitment rejects biophilanthropic (see Roscigno, 2019; Schuller, 2017) interpretations of accessibility as synonymous with assimilation and inclusion (Hamraie & Fritsch, 2019). Instead, crip technoscience focuses on the ways disabled people use technology to subvert and render accessible inhospitable infrastructure. Autistic people use Twitter to subvert the inaccessibility and hostility of academia, using informal channels to interact with and address academic autism research. These interactions, themselves, may read as hostile to researchers under scrutiny and to observers unfamiliar with what's at stake for autistics in their self-advocacy for neurodiversity, rather than medical-model orientations towards autism research. Within the framework of crip technoscience, the friction between autistic Twitter users and academic autism researchers – autistics' non-compliance with the medical model's expectation that they strive towards allism – represents a crucial form of autistic access-making (see Hamraie & Fritsch, 2019). When autistics directly interface with traditional autism researchers, they're not trying to mend fences or build bridges. It's a battle for the very definition of autism. It's a battle for the recognition of one's personhood and the human and civil rights that personhood entails. As Williams notes, sometimes we need to leave the more nuanced work involved in reaching out to and calling in the people doing harmful research to allies who aren't actively being harmed by that work (Williams & Boyd, 2019). Rather than turning away from

the friction autistics create through their pro-neurodiversity discourses, HCI researchers are well-positioned to do kinder, more subtle access-making work through taking on neurodiversity orientations to autism in their research. They can accomplish this by having conversations with their peers and colleagues who still subscribe to the medical-model of disability, participating in conference Q&A sessions, peer-reviewing papers, and steering students interested in autism research in the right direction.

The third commitment of crip technoscience is to interdependence as a political technology (Hamraie & Fritsch, 2019). Drawing on Alison Kafer's crip reinterpretations (Kafer, 2013) of Haraway's cyborg theory (Haraway, 1991) and the notions of access intimacy (Mingus, 2017) and collective access (Sins Invalid, 2019), this commitment entails participatory work emerging from within disability community and culture that centers collective, liberatory efforts. This commitment opposes traditional models of disability technoscience, wherein non-disabled benefactors from outside the community descend upon disabled people offering technological fixes to our perceived individual deficits. Hamraie and Fritsch write,

> We position the crip politics of interdependence as a technoscientific phenomenon, the weaving of relational circuits between bodies, environments, and tools to create non-innocent, frictional access. Mainstream disability technoscience presumes disability as an individual experience of impairment rather than a collective political experience of world-building and dismantling. This perception has two primary consequences. First, disabled people are perceived as dependent and the goal of technoscience becomes to encourage independence. Second, disability and technology are both perceived as apolitical and stable phenomena, rather than material-discursive entanglements that take shape through struggle, negotiation, and creativity. (Hamraie & Fritsch, 2019)

Autism, in particular, is framed around individual experiences of disability. Even the etymology of the word "autism" implies an inward-turning self-focus (Main, 2003). Yet, #ActuallyAutistic Twitter represents a site for collective world- and community-building. It's a site for collective efforts to expose and deconstruct anti-autistic ableism within the academy. Autistics on Twitter resist normalizing therapies and highlight the politics inherent to the control and surveillance technologies HCI researchers develop for and deploy against autistic subjects. They demand to be recognized not as passive recipients of beneficent researchers' technological

artifacts (see Spiel et al., 2019) but as key stakeholders in the frictional processes of working as or with researchers to develop artifacts that serve autistic needs, as recognized by autistic users. That these normalizing technologies are often developed by using "participatory" methods raises questions about how HCI researchers currently operationalize participation.

Ironically, the participatory design methodology arose from the Scandinavian labor movement as a liberatory and intensely democratic means to ensure the users of technologies are critically involved in their design (Simonsen & Robertson, 2012). Autistics desperately want to be involved in these projects, yet they are not recognized as the actual users in these studies. As autistics on Twitter make clear, interventions and the technologies that support them which seek to render autistic people less autistic are not for autistic people. Autistic people do not want these tools and experience them as harmful. These technologies are for our allistic society, reflecting shares the assumptions inherent to ABA and the values of HCI demanding that unconventional bodies and minds be reshaped until they're recognized as users with utility under Western, capitalistic conceptions of citizenship (Lin & Lindtner, 2021; Roscigno, 2019). A commitment to interdependence has several implications for HCI research. First, related to participation, it means changing the nature of the relationship between researcher and autistic from one of benefactor and recipient to one of wherein the autistic *is* the researcher or at least one of the researchers. Christina Harrington and colleagues have explored how researchers working with Black communities must understand and account for the privilege they bring to their participatory research and the nuances of their participants' situatedness, or else risk perpetrating unintentional harm (C. Harrington et al., 2019; C. N. Harrington et al., 2019). We must apply these same considerations to our work with autistic people and communities.

A second implication of a commitment to interdependence relates to the kinds of technologies we build. When independence and normativity are removed as required goals for autism technologies, possibilities for new types of designs emerge. It becomes possible, for example, to recognize #ActuallyAutistic Twitter, in and of itself, as a political, sociotechnical technology for interdependence and epistemic activism. It doesn't remove autism from the purview of HCI, but redefines the scope of what designs one can and should consider. Instead of supporting ABA with social robots, researchers might work with autistics to develop sociotechnical tools to explore existing and finding new special interests and connect with and share knowledge with others who share our interests. Instead of using eye-tracking technologies

to diagnose autism earlier so that we can send younger and younger children off to be made includable, we might study the information-gathering practices of parents of autistic children and build interventions designed to provide them with helpful, neurodiversity-aligned information and services as early as possible. These are plausible futures and technologies HCI researchers are well-positioned to help build.

The fourth and final commitment of crip technoscience is to disability justice (Hamraie & Fritsch, 2019). Disability justice is a radical framework for identifying and addressing the ways interplaying forces of heteropatriarchy, white supremacy, colonialism, and capitalism[42] contribute to ableism and the oppression of all disabled people (Sins Invalid, 2019). This commitment involves a view of autism and autistic people divorced from the demands of capitalism. It involves a recognition of autistics as whole and worthy, irrespective of their economic production. And, it involves deep commitments to intersectionality, reflexivity, situatedness, and solidarity (Hamraie & Fritsch, 2019; Sins Invalid, 2019). In this study, I draw on critical discourse analysis because of CDA's commitment to taking a stance – to being in solidarity with and working towards justice for disempowered peoples living under hegemonic powers (van Dijk, 1993). The methods we choose and research questions we ask are inherently political. To choose an apolitical approach to research – if such an approach can be said to exist, which I strongly doubt – is a political choice, in itself. The choices we make as researchers affect the material, social, and psychological conditions of the people with whom we work. Given the strong sentiments among autistics and their supporters against medical-model approaches to autism, choosing to continue adhering to the medical model can only be understood as a willful injustice against autistic people and epistemologies.

This study demonstrates that autistic people have, by virtue of their lived experiences, valid concerns about and priorities for research that, arguably, should view them as primary stakeholders. Yet, because of systemic barriers, autistics have trouble entering the academy to change the face of autism research from within. You, dear colleague, can choose whether to align yourself with autistic people or against us. You can choose whether you want to have a productive, collaborative relationship with the people you study, or one marked by silent disdain at best, or public, excoriating criticism at worst. Instead of continuing to research control and

42 As Imani Barbarin states, "There is no form of capitalism that values disabled people" (Crutches&Spice ♿ [@Imani_Barbarin], 2019).

surveillance tools, you could research technologies with us that support us, as we are. The commitments of crip technoscience provide insights about how you might make these choices and the rationale for doing so.

4.6 Limitations and Future Work

This study focuses primarily on conversations around research priorities that appear in both neurodiversity and medical-model discourses. There are research interests and concerns held by autistic people that are less common among medical-model autism researchers. In this study, to highlight the differences between two research paradigms, I chose to focus on shared priorities. Future research must catalogue these other interests and concerns if our autism research is to be accountable to autistic people.

The findings of this study are limited to the types of people from which I was able to collect data and my own experiences as a white autistic person with high levels of educational privilege. The overrepresentations of white people on #ActuallyAutistic Twitter is a common topic of discussion. Primarily because of time-zone and other scheduling constraints, I was only able to interview two people for this study, both of whom are white. As Jasbir Puar notes, it is less safe for Black, Indigenous, and people of color (BIPOC) to identify with or build cultures around disability (Puar, 2017). Critically, autistic-of-color knowledges are underrepresented on #ActuallyAutistic Twitter and in this study. It is imperative to conduct future research in which these knowledges are intentionally sought out, elevated into, and taken seriously within academic discourse and used to help address the barriers that prevent or make undesirable BIPOC participation in already-existing autistic spaces.

4.7 Conclusion

Our research has real impacts, and those impacts might not be those we intended or even imagined possible. Within the medical model of disability, autistic people are constructed as non-agentic non-knowers. The neurodiversity paradigm challenges this construction of autism, arguing that all conscious beings know things, even if these knowledges don't resemble your own. Twitter is one place in which autistic expertise and preferences about research reside. These knowledges are critical to conducting ethical and just autism research and design in HCI. Because autistic knowledges are more readily available on Twitter than in the academy, I suggest we take these informal data sources seriously as credible epistemic artifacts. Perhaps taking

seriously these knowledges will help the people who hold these epistemes gain footholds within the academy, themselves. Currently, as this research demonstrates, there is a clear ideological divide in autism research, each side of which has significant political, ethical, and practical implications. You can choose a side. You should choose a side.

4.8 Acknowledgements

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4.9 Bibliography

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Lorcan Kenny [@LorcanKenny]. (2019b, May 2). @thinkingautism A7: The results of research is often only described in scientific papers which might be behind a paywall and written in scientific language. To change this we must get universities to incentivise researchers to do public engagement (i.e., make it a promotion criteria) #AutINSAR [Tweet]. Twitter. https://twitter.com/LorcanKenny/status/1124002101766578176

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Noah Sasson [@Noahsasson]. (2019b, March 12). @AspieHuman @kmdebrabander @DanielFaso most of the autistic adults they were rating were male. The tiny sample of autistic adults who were female prevented us making conclusions about whether autistic females are evaluated differently than autistic males, but that is a direction we are interested in going. [Tweet]. Twitter. https://twitter.com/Noahsasson/status/1105547597870182402

Noah Sasson [@Noahsasson]. (2019c, March 12). @AspieHuman @kmdebrabander @DanielFaso The rater sample was 76% female, but we still had well over 100 male raters so we still could examine gender effects. There were just a few. Male NTs rated autistic adults as more attractive and were more willing to hang out with them compared to NT females. Maybe because... [Tweet]. Twitter. https://twitter.com/Noahsasson/status/1105547112157192192

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Rua M. Williams. (2019a, November 3). Q2 con't: Interpretation of findings should be validated with the original posters. This means requesting retroactive consent. Not everyone will respond. But those that do are entitled to editorial control, anonymity (or not), and veto power. #AutChat [Tweet]. *@StarFeuri*. https://twitter.com/StarFeuri/status/1191104246638403589

Rua M. Williams. (2019b, November 3). Q2 con't: Sound like work? So was the original labor in the tweets and blogs you're scraping. Also, I've seen projects like this where blogs are "anonymized" but literally anyone who's been in the community long enough can identify the original content. It's theft. Cite us. [Tweet]. *@StarFeuri*. https://twitter.com/StarFeuri/status/1191105055665139712

Rua M. Williams. (2019c, November 3). Q2: I find the emerging practice of "scraping" publicly posted data for research purposes troublesome. It Can be extractive and exploitative. People consent to public posting but they don't consent to research interpretation. #AutChat (continued in replies.) [Tweet]. *@StarFeuri*. https://twitter.com/StarFeuri/status/1191103123684806661

sam♿. (2019, November 3). #AutChat a2 I think following our blogs and social media ect is fine but any use of it should be with informed consent from all involved. And neurotypicals should always accept that they may be asked to leave a discussion or accept a group may be ranting in general not personal [Tweet]. *@Endo_Gremlin*. https://twitter.com/Endo_Gremlin/status/1191103196283985920

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Sue Fletcher-Watson. (2019, May 2). A3 I'm concerned about technology based monitoring systems that aren't co-created around an autistic-identified need. Massive risk of normalisation here as well as intrusion and privacy issues. #AutINSAR [Tweet]. *@SueReviews*. https://twitter.com/SueReviews/status/1123995726915276803

Tania ZA AutisticStrategies.net. (2019, May 3). Q1 #AutINSAR 1. Treatment of hypo- and hyperkalaemic sensory overstimulation and cofactors such as iNOS overproduction 2. Autistic apraxia (body-mind disconnect) 3. #CRPD violations and trauma in ABA. 4. RCCX Theory. (Ja, I know you said three...) [Tweet]. *@ekverstania*. https://twitter.com/ekverstania/status/1124200068205166592

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theories of minds. (2019, May 2). A3 I'm very concerned about research being translated uncritically into tech for fine-grained behavioral control and surveillance. We urgently need research on harms done including when implemented as intended. #AutINSAR https://t.co/52vayHFOJt [Tweet]. *@theoriesofminds*. https://twitter.com/theoriesofminds/status/1123993046813749249

theories of minds [@theoriesofminds]. (2019, November 3). @autchatmod A2 I think it's important for researchers who study autism and similar neurodivergences to learn from autistic and nd communities, and doubly important for autistic/nd researchers to also have access to social support from those communities. #AutChat [Tweet]. Twitter. https://twitter.com/theoriesofminds/status/1191102193048276992

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Chapter 5 Conclusion

In this three-paper dissertation, I present the cumulative results of my efforts to disentangle how the field of HCI understands and constructs not only autism but also autistic people, and how autistic people and their allies can resist and reshape these narratives. Merely claiming epistemic capacity puts autistic people at odds with the HCI's – and by extension, Western societies, more broadly – underlying commitments to illusory promises of progress, productivity, objectivity, and solutionism (See Lin & Lindtner 2021; Rosner, 2018). I've not yet found a long-lasting way to reconcile the autistic-as-epistemic-agent and decades of disciplinary tradition that require us to be otherwise.

However, Crip technoscience and design justice, as frameworks and tools, offer viable blueprints. Ultimately, what's likely needed is a fundamental reconstruction of the field and its commitments – a reconstructive effort that includes autistic and otherwise belligerent, unruly, and overlooked bodyminds (see Erevelles, 2000; Lin & Lindtner, 2021; Rosner, 2018). Understanding the structures that we may need to break down is a starting point. The autistic belligerence I've described as inherent to the three papers presented in this dissertation is a tool for both learning the shape of these structures and working to erode them.

Autistic belligerence equates to a refusal to be quiet, cowed, or apolitically constructed by people, academic disciplines, and a broader society, any or all of which might at times prefer we simply acquiesce to external expectations. In so refusing, we embody and exemplify Hamraie and Fritsch's (2019) notion of access as friction. This might make one a target for retaliation. Or, alternatively, it might act as a meeting place, an impactful invitation (see, e.g., Williams & Boyd, 2019; Williams et al., 2023), and a site for staging future interventions, as I've already staged some of mine herein.

In the first paper I presented, drawing on critical discourse analysis (see van Dijk, 1993), I disassemble HCI's longstanding treatment of autistic people as or like robots. Further, I disentangle the apparent connections between the field's construction of autism and its underlying ideologies of progress and productivity to the detriment of those not easily subjugated

to prescriptive expectations of positive affect and normative modes of being in and moving through space. I explore how the unwillingness to recognize the intrinsic value and situated epistemologies of autistic people deprives them of their association with humanity – and with the living altogether – and, by extension, of their rights to self-determination and safety. As belligerent robots, our autistic idiosyncrasies are non-purposive, non-agentic, non-frictional operational failures that can and should be quashed. As things, we can allegedly be fixed and put to work.

In further examining the claim that autistic people have a "natural affinity with technology" and finding a trail to nowhere, I identify a pervasive disconnect between what many researchers present as reflective of reality and what is observable, evidentially supported, and veridical. A systematic embargo on appropriate attributions for empirical claims creates a situation in which autism functions as an imaginary. Anyone who pleases may construct a personal Mr. Potato Head autistic pathologies. Just add citations; batteries not required.

In contrast, and as is evident in my exploration of #ActuallyAutistic Twitter, in our belligerence, we can bounce back from our status as recycling bins. We can leverage our lived experiences and refusals to be constrained to collectively create narrativistic waves that wash over and demand acknowledgement from those researchers who benefit from our status as blank slates waiting for them to write our realities. I demonstrate (by way of other autistics having demonstrated) that many autistic people have, know, and can articulate their own needs and priorities for autism research. We can refuse, resist, and aggressively offend the opposition unless or until they acknowledge the existence and validity of our subjective positions. Sometimes we shout into the void, waiting to see whether journals or researchers reach back at us. Sometimes our belligerence works, bringing researchers around to new, less violent perspectives. And sometimes we succeed in finding one another, having subverted tools and political technologies to our own autistic ends, refusing to be objects bounded and circumscribed by others' epistemologies.

And finally, this dissertation is my own act of autistic belligerence – a political artifact I leave behind as proof I, Jeff, the one-time Advisor-less Ghost of North Quad, occupied and affected a space seemingly built to ensure my absence, and as a reminder that perseverance through refusal is possible.

5.1 Bibliography

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Appendices

Appendix A: INSAR Twitter Chat Questions

1. What are your top three priorities for autism research?
2. Which topics do #ActuallyAutistic people discuss that are missing from research conversations?
3. What concerns do you have about the directions in which autism research is headed, based on work presented at #INSAR2019, or in general?
4. Researchers: How do you think your research (or another researcher's work) will improve the lives of #ActuallyAutistic people who are already here – as opposed to autistic people in future generations?
5. Which co-occurring conditions need more research attention, and why?
6. What are some concerns of minority autistic community members that don't get enough research attention?
7. What are some barriers that make autism research results less accessible to #ActuallyAutistic people (cognitive, financial, etc.), and how can we reduce them?

Any topics we've missed that you'd like to discuss?

Appendix B: "Natural Affinity" Corpus

B.1 Claim-Containing Papers

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