

Grounded Design of Affective Computing Accounting for Social, Emotional, and Sensory  
Experiences of Autistic Adults

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A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2021

Reading Committee:

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Program Authorized to Offer Degree:

Information School

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Abstract

Grounded Design of Affective Computing Accounting for Social, Emotional, and Sensory Experiences of Autistic Adults

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We use digital communication technologies to augment or replace face-to-face interactions in our work and daily lives. People's emotions and affective responses play a significant role in establishing mutual understanding. Technologies such as video calling and chat bots allow people to express themselves in implicit and explicit ways, such as through facial expressions and vocal tone. As digital technologies increasingly mediate emotionally-rich communication, technology is called upon to become emotionally aware and detect, transmit, and respond to emotional cues.

This dissertation examines affective computing through the lens of autism. The phenomenon of autism—with its unique expressions of cognitive, sensory, and social styles—offers the research community valuable perspectives for designing inclusive communication and affective computing technologies. According to the Center for Disease Control, around 1 in 54 children in the United States has been diagnosed with autism. This research confronts a crucial concern in technology design: how can we design affective computing that is inclusive of autistic ways of being and does not exacerbate inequities formed by neurotypical social norms and infrastructural barriers. As technologists encode social norms into affective computing, communication technologies, and artificial intelligence, it is imperative that they design experiences that are comfortable for autistic individuals, rather than perpetuate burdens typically placed upon disabled people.

This dissertation investigates how to improve the design of affective computing to support face-to-face interpersonal communication between neurodiverse dyads—pairs each composed of an autistic young adult and a non-autistic conversation partner. My research engages autistic young adults to identify problems with communication technologies that they encounter during early adulthood—a time period in which they are taking more ownership of their technology decisions and adopting technological practices of adulthood. Autistic young adults must navigate a world in which the vast majority of people they communicate with daily are neurotypical. The burden is often placed on autistic individuals to modify their behavior to adapt to neurotypical socio-technical norms. During interpersonal interactions, neurodiverse dyads co-construct their emotional and social experiences while communicating across boundaries of neurological differences. Current computer-mediated communication (CMC) and affective technologies do not adequately address neurodivergent individuals due to the lack of

scaffolding for non-normative conversations and emotional exchanges. This technology gap is particularly detrimental for autistic individuals, since miscommunication and social tensions contribute to their social isolation, reduced agency, and (more broadly) limited education and employment opportunities.

Through Grounded Design research—composed of a context study, participatory design, and technology appropriation—this dissertation engages autistic research participants as co-designers in envisioning affective computing that works for their communication needs. Empirically-based insights informed conceptual contributions of this work, including a social-emotional-sensory design map that highlights the embodied and co-constructed nature of the emotional experiences of autistic adults within the context of physical environments, social relationships, and technology use. The design map serves as a conceptual tool to help designers and researchers recognize rich design sites to improve affective computing for neurodiverse communities.

This work also contributes a speculative design concept and prototype of an emotion translator that explored alternative ways to augment a conversation with rich visual imagery to convey emotional states. Through design and appropriation studies, participants conveyed their conceptualization of emotions and often unspoken social norms of conversations. By appropriating a low-fidelity prototype of a chat with “Wizard of Oz” emotional translation functionality, neurodiverse dyads preserved, re-configured, and critiqued the emotion translator. This dissertation contributes empirically based insights, a theoretical framework, and design artifacts that expand scholarly knowledge of how neurodivergent young adults experience social interactions and emotional states. By presenting deeper understanding of neurodivergent

experiences and offering design strategies, this works opens up design horizons for more inclusive affective computing and participatory design.

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# Acknowledgements

I extend my sincere gratitude to a whole community of people who has supported me. I thank my advisor, Jaime Snyder, for her mentorship and guidance. She generously shared insights into her research process, which I learned from immensely. I thank my other committee members. David Hendry is a role model of reflective and value-sensitive design. Julie Kientz supported my interest in autism research and design starting as a Master's student in Human-Centered Design through my doctoral studies. Ilene Schwartz helped me orient myself to autism research and educational practices at UW.

I thank my husband, sons, and family who have cheered me on from the beginning and supported me at every step. I thank my father, who passed away during my doctoral studies, for being my role model of a lifelong learner. I thank my Information School Ph.D. cohort for being my early research collaborators and friends, especially Wes Eli King, Marc Schmalz, and Katya Yefimova. My writing process was made so much better with the Mango Island writing group, including Dharma Dailey, Elena Agapie, Annie Spencer Ross, Liz Mills, Mar Drouhard, and Amirah Majid. I thank the various research labs in the Information School for supporting me and inviting me into their spaces, primarily Jaime Snyder's Visualization Studies Research Studio, and also Wanda Pratt's iMed lab, Jacob Wobbrock's Accessible Computing Experiences lab, and David Hendry and Batya Friedman's Value Sensitive Design lab. I learned so much from the professors and students in those labs. I am thankful for the support and guidance of Kate Starbird and Leah Findlater. I thank doctoral students who were my mentors and friends along the way, including Kiley Sobel, Kristen Shinohara, Cynthia Bennett, Katie O'Leary, and Martez Mott.

Specifically for my dissertation research, I thank Jessica Scott, Angela Liu, Andrew Schrock, as well as artists Jacqueline Calladine and Rukmini Poddar, for contributing their talents. I am lucky to have collaborated with wonderful researchers on other projects, including Arpita Bhattacharya, Lauren Milen, Joseph Tennis, Hala Annabi, and Sean Munson.

I thank the broader UW community, including disabilities studies department, especially Joanne Woiak. The Design-Use-Build (DUB) group has been invaluable, including the DUB Consortium. I've been lucky to participate in wonderful research workshops outside of UW, including the 2019 Consortium for the Science of Sociotechnical Systems (CSST) Summer Institute, and the ACM ASSETS Doctoral Consortium. I am grateful to have learned from other researchers conducting autism-related research, especially Kathryn Ringland, and LouAnne Boyd. I am proud to consider the ACM accessibility (ASSETS), Computer-Human Interaction (CHI), and Computer Supported Collaborative Work (CSCW) communities my academic home. I am grateful for my invaluable internship at Microsoft Research, during which I had the pleasure of working with Meredith Ringel Morris, Andrew Begel, John Tang, Jennifer Walden, Michael Barnett and other fabulous researchers in the Ability team. I thank Arnie Lund, Richard Ladner, and Libby Hanna for believing in me as I transitioned from Microsoft to my doctoral studies.

I thank organizations who have funded my doctoral studies. My doctoral research was funded by Jaime Snyder's NSF CAREER award (#1845023). My early doctoral studies were funded in part by the Top Scholar Award from the Graduate Opportunities and Minority Achievement Program and the Harlan Hahn Disability Studies award.

I extend my sincere thanks to the autism community—my research participants and co-designers, self-advocates who shared their experiences and advice with me, and supportive

organizations including the University of Washington Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Fellowship program, University of Washington Autism Center, D Center at the University of Washington Spokane Community College IMAGES program, Autism Self Advocacy Network (ASAN), Northwest Behavioral Associates, Ben Wahl at Ryther, and Seattle Square Pegs.

# Chapter 1 Introduction

In our work and personal lives, we use digital communication technologies to augment or even completely replace face-to-face interactions. Technologies such as video calling and texting provide avenues for people to express themselves in implicit and explicit ways, such as facial expressions and emojis, respectively. As digital technologies increasingly mediate emotional cues, being emotionally aware requires detecting, transmitting, and receiving such cues. People are using these emotional capabilities of technology to facilitate human-to-human communication and human-to-computer interactions, such as with social robots. In 1995, Picard coined the term “affective computing” as computing that “relates to, arises from, or influences emotions” (Picard, 1995, p. 1). In this dissertation, I use “affective computing” to describe digital experiences and underlying algorithms that relate to, arise from, or influence affective phenomena. I consider affective phenomena to include the five major affective phenomena as defined by the Handbook of Affective Sciences: emotion, feelings, mood, attitudes, and affective style (R. J. Davidson et al., 2002).

As we communicate with each other, we attend to both the content of the interaction and the social dynamics surrounding it. To balance content and social dynamics, we establish common ground through a complex negotiation of conversational moves and communicative acts. These communicative acts help us negotiate the intent of the conversation and manage the flow of interaction. According to psycholinguist Clark (1996), “common ground” is an interpersonal theoretical framework that describes and explains interpersonal interactions in terms of establishing and negotiating a shared frame of reference. Interpersonal interactions can

be conceptualized as joint activities centered around goals, which are both public (external) and private (personal). People’s emotions and affective responses contribute to mutual understanding—or misunderstanding—of each other’s point-of-view.

When thinking about how common ground and affective phenomena relate, consider these descriptions from research participants about times they experienced heightened emotions during interactions with others:

*“I’m just really sensitive and the world is very intense, and I just take it all in, and I can’t block it out,”* said our research participant, Sarah, during her interview. Kendall, another participant, described a situation in which she *“ended up yelling and screaming and exploding, and that causes headaches and panic attacks...I’m just really irritated and frustrated because they just don’t get it.”* A third participant, Jack, described that when his feelings escalate to a burst of anger, it is similar to how he *“can numb my whole body to take the impact of a punch [from a bully], but instead it’s letting all the energy from all the punches out all at once with my fists. So basically, completely taking the energy from all the punches I have taken over the years and just let it all out at once.”*

These research participants were describing to me how they experienced emotions within their bodies and through the context of their social relationships. These adults were on the autism spectrum<sup>1</sup>—a life-long neurological condition that impacts people’s expression of emotions, verbal and non-verbal communication, physical behaviors, and desired way of establishing social

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<sup>1</sup> I use identity-first (“autistic people”) and person-first (“people on the autism spectrum”) interchangeably to reflect the diversity of preferences within the autism community (Kenny et al., 2015) and to respect the terminology choices of my research participants.

bonds [2]. In disability studies academic publication and self-publishing venues (e.g., blogs and YouTube), autistic individuals describe experiencing difficulty communicating with others due to their differences in using verbal communication and interpreting non-verbal social cues (J. Davidson, 2010; J. Davidson & Henderson, 2010). Autistic individuals also describe sometimes having difficulty expressing or perceiving emotions. Returning to the above response from my research participants, we gain insights into the complications that arise as autistic individuals interact and establish common ground with others. These complications often must be negotiated through digital communication technologies. However, this diversity is not adequately addressed by current computer-mediated communication and affective technologies. This is particularly detrimental for autistic individuals since miscommunication and social tensions contribute to social isolation, reduced agency, and, more broadly, limited education and employment opportunities (Burgess & Gutstein, 2007).

## 1.1 Problem Statement

This dissertation examines how to improve the use of affective computing to support face-to-face interpersonal communication between neurodiverse dyads—an autistic young adult and a non-autistic conversation partner. By focusing on experiences of neurodivergent communicators—those who are autistic—this dissertation identifies technological design strategies that make affective computing more inclusive of diverse perspectives and not encode neuro-normative biases into systems. Neurodiverse pairs communicate across boundaries formed by neurological differences. Their perspectives, behaviors, and interpretations determine how they interact with each other, and the meaning they attribute to those interactions. As theorized by disability study scholars, the nature of social interactions depends on the “people and places, selves and spaces,

are mutually constitutive, that they come into being relationally, produced and performed in interaction with each other” (J. Davidson, 2008a, p. 792). From the perspective of the autistic individual, the social assumptions embedded in an interaction can make them feel as if they are perpetually experiencing culture shock and experience difficulty trying to find common ground. At the level of speech dynamics, the neurotypical speech, rhythm of exchanges, facial expressions, and lack of precision complicate communication. Neurotypical communication seems “alien to AS [autism spectrum] worlds.” (J. Davidson, 2008a, p. 792). As a result of different communication styles, often mediated through digital communication technologies, autistic individuals tend to experience social unease when trying to adapt to neurotypical patterns of communication and language. Yet, researching neurodiverse interactions shows how a social exchange between a neurotypical and neurodivergent person can be rich and mutually constitutive.

This dissertation examines why affective computing does not account for the nuanced emotional experiences of neurodiverse adults. Technologists in affective computing take particular stances on long-standing questions in the psychology and neuroscience fields, such as: do humans experience discrete emotions? Can emotions be consistently identified from physiological information? The predominant approach that affective computing technologies take is to consider biometrics and body language—especially facial expressions—as the “ground truth” for affective states. Biometrics (e.g., heart rate, breathing rate, and skin conductivity), voice, and body language are components of affective responses—physical and cognitive reactions to affective phenomena. Given the scientific basis of physiology on affect, technologists have developed techniques for modeling affective responses and emotions computationally by training machine learning algorithms on body language and biometric data.

These underlying models support different types of experiences with technologies including wearable devices that sense a person's emotional state, such as Feel (Sentio Solutions Inc., 2020), automobiles designed to support safe driving by tracking and responding to the emotions of drivers (Elgan, 2019; Jeon, 2017), and chatbots that promote self-compassion (Lee et al., 2019).

Affective modeling is a technology that attempts to classify people by constructs of human identity including gender and psychology. While affective modeling is a dominant approach, it has also resulted in racial, gender, transgender, and intersectional biases (Hankerson et al., 2016; Keyes, 2018; Scheuerman et al., 2019). Current emotion recognition systems are likely to produce biases due to inequities encoded into data sets (Howard et al., 2017). To build more ethically-sound and representative technologies, this dissertation identifies alternative design strategies that challenge assumptions and stereotypes embedded in digital systems. As I argue in this dissertation, normative views of emotional experiences are at risk of being encoded into algorithms. In response, this work provides an example of more inclusive methods and data practices (Dourish, 2006) that both more ethically represents neurodivergent users and helps the neurodiverse dyad establish common ground.

## 1.2 Research Focus

To address the problem of a mis-match between the lived experiences of autistic young adults and the trajectory of normative affective computing, this research focuses on (1) surfacing ways in which the emotional, social, and sensory lives of autistic young adults are rich and nuanced, and (2) using this data to identify novel co-designing novel strategies to generate affective computing concepts with autistic young adults. In this context, “social” refers to interpersonal

social interaction in which communication activities are mediated by affective computing. In keeping with the social model of disability (Oliver, 1990), researchers are called to consider the inter-related, connected nature of social interactions within communities. By “emotional,” I refer to emotional states that are connected to stimuli and are time-bound. Finally, “sensory” refers to internal and external sensations centered in an individual’s physical body and processed by an individual’s cognitive system. This dissertation explores how these aspects influence each other in neurodiverse communication mediated through digital technologies. Through co-design—in which autistic young adults can configure and manipulate design elements—I identify ways that affective computing can holistically account for the social, emotional, and sensory experiences of autistic adults. Improving the design process ultimately leads to more effective technology-mediated interpersonal communication.

This dissertation is situated in the field of human-computer interaction (HCI) and one of its sub-fields, accessible technology. Scholars in these fields are concerned with how technology can foster social inclusion. Around 1 in 54 children in the United States have been diagnosed with autism, according to the Center for Disease Control (Maenner, 2020). Local communities, educators, and employers are increasingly concerned with guiding autistic young people from childhood into adulthood. Although this institutional recognition is welcomed, autistic young adults still must navigate a world in which the vast majority of people they communicate with daily are neurotypical. My research engages autistic young adults to identify problems with communication technologies that they encounter during early adulthood—a time period in which they are taking more ownership of their technology decisions and adopting technological practices of adulthood. As young adults, my research participants (ages 18–33) were navigating their education and employment and expressed interest in maintaining and developing

relationships. Some participants lived at home with their parents, while others lived independently or with significant others. Thus, by studying autistic young adults, rather than limiting participants to a proxy community such as caregivers or family members, my work highlights the factors at play as young, autonomous adults negotiate and manage choices about technology use. During the course of my research study phases, autistic participants were asked to invite a trusted conversation partner to a pair interview, to engage with their design artifact, and to the appropriation interview. The purpose of engaging with both autistic participants and their conversation partners was to (1) explore how neurodiverse pairs established common ground, and (2) to identify affective computing design concepts that could make a tangible difference in their lives.

This qualitative design research study first collects insights about the lived experiences of young autistic adults, then engages with the research participants as co-designers of affective computing technologies. This study follows the framework of Grounded Design (Wulf et al., 2018), a research approach that uses an iterative and collaborative design process to engage with a community of practice. As its name implies, this methodology allows researchers to become deeply familiar with a context of use, work closely with stakeholders in the design process, and continually validate conclusions and findings with members of the community. In the first phase of our study, I conducted a context study of the lived experiences of autistic young adults within the context of face-to-face interpersonal interactions. The following research questions guided this phase of the qualitative study:

**RQ1:** During daily interpersonal interactions, how do autistic young adults conceptualize and share emotions and sensory experiences?

**RQ2:** In what ways do autistic young adults use or respond to digital technologies within the context of their social, emotional, and sensory experiences?

The subsequent design study explored three design themes that arose from the context study: (1) making interactions clearer, (2) making emotions more explicit and easier to share, and (3) increasing independence and agency during interactions. I developed a remote participatory design research method exploring the following research questions:

**RQ3:** From the perspective of autistic young adults, what are the crucial elements of a face-to-face conversation that contribute to their social-emotional-sensory experience?

**RQ4:** In what ways can communication interactions and emotions become clearer during face-to-face neurodiverse conversations, in ways that benefit the autistic individual?

Using the insights from answering RQ1-RQ4, I “speculated-through-design” about neurodiverse affective computing (Dunne & Raby, 2013). According to Dunne and Raby, the speculative design approach explores preferable futures by opening up “possibilities that can be discussed, debated, and used collectively define a preferable future for a given group of people” (Dunne & Raby, 2013, p. 6). By using speculative design, I sought to give autistic adults a means to express their desires for expressing and interpreting affect during everyday conversations in a material, observable fashion. The choice of speculative design worked well with the Grounded Design approach to bringing technology concepts into the hands of the participants for critique, manipulation, and “the establishing of new social practices in light of new technologies” (Wulf et al., 2018, p. 139). The speculative design concept appropriated by my participants emerged

from the context study inquiry and was substantiated through participatory design. The concept that emerged was that of an “emotion translator”—a means of expressing one’s emotions through communication in ways that feel most natural to neurodivergent individuals. Then, through technology mediation, they can have their emotions translated in a way that their neurotypical conversation partner can fully understand. This design concept explores alternative ways to augment a conversation with imagery and material sensations to convey emotional states. This concept also addresses the challenge of emotional experiences being co-constructed by enabling neurodiverse partners to develop the emotional tenor of an interaction together.

In the Grounded Design framework, the final phase is termed “appropriation” and is an alternative to a classic HCI technology user evaluation, in which the participants use the technology as-is and the researchers assess the technology according to specific usability metrics. To enable the participants to appropriate this concept, I created a low-fidelity prototype of rich visual emoji’s to augment a conversation. During this phase, the guiding research question was:

**RQ5:** Through engagement with a speculative design concept of an emotion translator, what does a neurodiverse dyad desire to preserve, change, repurpose and convert?

In exploring this question, we learn more about the preferred direction of affective computing for neurodiverse conversation pairs, including the perceived values and harms of affective computing. By addressing these five research questions, this work contributed empirically-based knowledge and formalized empirical insights as theoretical concepts and design artifacts, which I outline next.

## 1.3 Contributions of Dissertation

Throughout my Grounded Design research, the work generated three main types of contributions—empirical, theoretical, and artifact. I contribute the following empirical understandings:

- Emotional experiences of autistic young adults are embodied and co-constructed through engagement with physical environments, social relationships, and technology use.
- Conventional approaches to visually representing emotion in affective education and computing systems fail to accurately represent the experiences and perceptions of autistic young adults.
- Crucial communication interactions, expressions of emotion, and sensory needs during interpersonal communication from the perspective of autistic young adults.
- The ways neurodiverse conversation partners interrogate and reconfigure the speculative design of an emotion translator, including their perceived values and harms.

I make a theoretical contribution by introducing the following:

- The concept of the connected nature of social, emotional, and sensory experiences of autistic young adults that need to be holistically considered in design, rather than considered in isolation.

I contribute the following artifacts:

- A social-emotional-sensory design map, to guide designers in creating more diverse and nuanced affective computing interfaces that are enriched by accounting for neurodivergent users.

- An emotion translator speculative design concept, that envisions ways that affective computing mediates mutual understanding of emotional experiences between neurodiverse conversation dyads.

Together, these contributions expand scholarly knowledge about neurodivergent young adults experiences with social interactions, thus, opening design horizons for more inclusive affective computing and participatory design.

## 1.4 Definition of Terms

This section introduces key concepts in this dissertation. They are defined here as a reference for the reader, plus to provide context for the choices I make about terminology, which is an important issue in disability communities (Zolyomi & Tennis, 2017). My choices about terminology are made to support my cultural competency as I research a community that I am an ally of, but not a direct participant.

**Agency:** Capacity or state of taking actions on one’s own behalf. One’s sense of agency is “the pre-reflective experience or sense that I am the cause or author of the movement (e.g., an experience that I am in control of my action)” (Gallagher, 2007, p. 347)

**Ally:** Supporter of person with disability

**Affective computing:** “Computing that relates to, arises from, or influences emotions” (Picard, 1995, p. 1)

**Autistic individual:** Person on the autism spectrum. To respect both identity-first and people-first preferences of participants (Kenny et al., 2015). I use terms such as “autistic adults” and “adults on the autism spectrum” interchangeably.

**Autism spectrum disorder (ASD):** A life-long health condition that stems from neurological wiring in the brain. Even though the condition is a spectrum- meaning people fall along different levels of severity in autistic characteristics – everyone diagnosed with ASD is impacted in the areas of social interactions, communication, and restricted or repetitive behaviors. Also called autism.

**Common ground:** An interpersonal theoretical framework defined by psycholinguist Clark (Clark, 1996), which describes and explains interpersonal interactions in terms of establishing and negotiating common ground. Interpersonal interactions can be conceptualized as joint activities centered around goals, which are both public (external) and private (personal).

**Computer-mediated communication:** Digital technology that enables two or more people to communicate.

**Neurodiversity:** “The whole of human mental or psychological neurological structures or behaviors, seen as not necessarily problematic, but as alternate, acceptable forms of human biology” (G. Barrett, 2004). The neurodiversity paradigm, which is attributed to (Singer, 1999), espouses a generative, accepting stance on autistic life. People who are neurodivergent are “differently brained” (Armstrong, 2011).

**Participatory Design:** A design method used by researchers and designers to elicit design input from the end-users of a technological system. Participatory design aims to distribute power to the people impacted by technological changes in their organization and environments (Bratteteig & Wagner, 2016).

**Sense-making:** Sense-making is the act of constructing meaning (Dervin, 1983) and is driven by our need to gather, reflect upon, and synthesize information about our experiences and identity (Erikson, 1994).

**Sensory Processing:** The detection, organization, and integration of information one receives via one's senses.

**Social-emotional-sensory experiences:** Term introduced in this dissertation to focus design on the interdependency between social interactions, emotional expression and interpretation, and sensory processing of autistic individuals.

**Social model of disability:** This model considers disability to be a social condition because society presents barriers and fails “to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization” (Oliver, 1990, p. 2). It is in contrast to the medical model of disability, which focuses on the origin and treatment of a disease or disorder.

## 1.5 Dissertation Approach and Outline

This work was initiated through a grant received by Dr. Jaime Snyder to study the visual encoding of personal data for vulnerable populations (NSF #1845023). Dr. Snyder's approach to design research values the situated expertise and vernacular data practices of marginalized communities and uses visual elicitation research activities to empower participants (Snyder, 2020b; Snyder et al., 2019). Extending Dr. Snyder's approach, I crafted highly participatory Grounded Design research that examines personal data and visual representations related to affective responses such as facial expressions and emotional states. Throughout this manuscript, I will most often be using singular first person pronouns when talking about my research activities; however, I fully acknowledge that this work exists in conversation with my collaboration with Dr. Snyder.

Woven into the studies are touchpoints done with the broader autism community, which was a key commitment of my research to conduct research with goals and methods aligned with the autism community. I followed a Community-Based Participatory Design (CBPR) approach, as recommended by a leader in the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) organization. The purpose of the CBPR approach is to respectfully conduct socially relevant research to facilitate alignment and collaboration between researchers and autistic adults (Nicolaidis et al., 2011). The CBPR AASPIRE approach identifies key points of alignment between researchers and autistic adults throughout a research project. For example, during the research development phase, community priorities should influence the research focus of inquiry and study design. In accordance with the CBPR approach, I gathered input on our research plan from, and reported on my progress to, autistic-led groups, autistic self-advocates, and other representatives of autism service organizations.

This manuscript builds upon theoretical understanding of autism, communication, and affect, then details the methodology and findings of my Grounded Design study. First, for background and context, I provide a theoretical framing of autism that draws from disability studies and psychology in Chapter 2. I also provide a summary of affective phenomena as theorized by psychologists. This psychological literature on affect informs how this dissertation considers emotional states, affective responses, and moods of neurodiverse conversation partners.

In Chapter 3, I provide a review of literature in the field of human-computer interaction related to accessible technology, communication technology, and affective technology.

Researchers in the field of accessible technology examine the practices of disabled people with technology, barriers to technology use, and ways to improve the usability of technology for

disabled people. These insights also improve experiences with technology for all users, a phenomenon colloquially known as “the curb cut effect,” referring to sidewalk ramps that were advocated for by wheelchair users but also benefited non-disabled people with strollers and skateboards. Video captions are an example of a digital curb cut that are necessary for Deaf people reading text of spoken dialog and sounds and beneficial for hearing people in loud environments. By improving communication, social interactions, and cognitive processing, such as executive functioning and processing of information—with neurodivergent individuals, we might similarly improve experiences with technology for neurotypical people. Autism is relevant to HCI researchers because it forces us to engage with issues that are core to designing usable technology interactions. I discuss dominant research methods used to study the use of technology by autistic individuals, then articulate the literature gap addressed by this dissertation.

The next set of chapters describe my dissertation’s methodology and findings. In Chapter 4, I describe the study’s methodology, the autistic young adults (who are the primary research participants), and their neurotypical conversation partners (who are the secondary research participants). I then detail the Grounded Design phases, beginning with context study in Chapter 5. During the individual and pair interviews of the context study, I used visual elicitation methods that were inspired by Dr. Snyder’s work with bipolar patients (Snyder, 2020a; Snyder et al., 2019) and designed to probe participants’ perceptions of emotion and conversational dynamics. Visual elicitation research methods supplement the verbal aspect of typical interviews by introducing visual prompts or ways of responding to questions (Benton et al., 2014; Francis et al., 2009). These methods often help participants articulate mental models associated with sensitive issues such as managing serious mental illness (e.g., (Snyder, 2020a; Snyder et al., 2019)). In this case, I was also inspired by the prevalence of visuals used in the educational and

therapeutic experiences of autistic individuals, such as daily schedules, reward charts, and communication aids (Dettmer et al., 2000; Hayes et al., 2010; Rao & Gagie, 2006).

Following the context study, I describe the design study in Chapter 6. My Grounded Design research culminated, as detailed in Chapter 7, in generating a speculative design concept, creating a low-fidelity prototype, and conducting an appropriation study. As I conclude my dissertation in Chapter 8, I synthesize my findings and discuss implications for the design of inclusive affective computing and conducting research with the autism community. I summarize the contributions of the dissertation and present opportunities for future work in the area of affective computing.

As in keeping with Grounded Design, the research questions build upon the cumulative knowledge generated by both the researchers and the participants. As a reflective researcher (Finlay, 2002), I acknowledge my position as a non-autistic adult. Reflective research and design emphasizes that reflective practices are needed for a designer to stay attuned to the design actors and constraints (Schön, 1990). Conducting qualitative research using Human-Computer Interaction (HCI) research methods, gave me the opportunity to think critically about research methods that, while well-established for neurotypical research populations, have not been thoroughly exercised in research with autistic participants. Therefore, as I developed the research methodology, I engaged with the autism community using CBPR and adapted my research interviews and participatory design activities to incorporate alternative ways-of-being and communication styles. Through research insights and research methodologies, this dissertation aims to expand our scholarly understanding of the scope and diversity of communication and affective experiences through digital technology design.

# Chapter 2      Theoretical Framing of Autism

“If you have met one person with autism...you have met one person with autism.”

– Dr. Stephen Shore, autism self-advocate<sup>2</sup>

In the public sphere, autism has been the target of controversy and confusion. It has been subjected to biased, unfounded claims about its cause and a search for a “cure” that strips people of their fundamental value. One such long-standing controversy stems from a medical research paper that falsely claimed that autism was caused by the measles, mumps, and rubella (MMR) vaccine (Flaherty, 2011). The paper was retracted due to misconduct and fraudulent science, and no subsequent research substantiated this claim. Still, there remains confusion in the autism community and an emergent anti-vax community. Confusion also stems from the unstable nature of medical knowledge and classification of autism. For example, the meaning of autism itself came into question by the community when the Diagnostic and Statistical Manual of Medical Disorders (DSM), 5<sup>th</sup> edition (American Psychiatric Association, 2013), removed its “Asperger Syndrome” diagnosis and other pervasive developmental disorders, collapsing them into an “Autism Spectrum Disorder” (ASD) diagnosis (Giles, 2014). Conflicting voices from health, government, education, political, and media communities can misrepresent and even obfuscate,

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<sup>2</sup>[https://www.limeconnect.com/opportunities\\_news/detail/leading-perspectives-on-disability-a-qa-with-dr-stephen-shore](https://www.limeconnect.com/opportunities_news/detail/leading-perspectives-on-disability-a-qa-with-dr-stephen-shore)

the realities of the lived experiences of autistic people (Davidson and Orsini 2013). Further complicating matters, autism is a “spectrum disorder” that encompasses a range of characteristics that manifest differently in each person. As the above quote popularly attributed to Dr. Shore highlights, the autism community is diverse, composed of people with a range of experiences, perspectives, and behaviors.

Amid evolving knowledge and persistent controversies about autism, autistic individuals and their families desire to articulate their own needs, concerns, and perspectives (Kenny et al., 2015). It is imperative that human-computer interaction researchers working with stakeholders in the autism community clearly articulate how they conceptualize autism, and which scholars and communities they draw from to frame their research. In this chapter, I describe the theoretical models and accounts of autistic individual’s lived experiences that inform my dissertation. I describe how my research is aligned with the paradigm of autism as naturally occurring neurodiversity. This neurodiversity paradigm emerged from disability studies and is rooted in the social model of disability. Then, I review relevant theoretical framings from psychology and autism theory concerning embodied sense-making and affective phenomenon. Together, these sets of theories form the theoretical lens for this dissertation’s understanding of the social, emotional, and sensory lived experiences of autistic adults.

## 2.1 Disability Models

The framing of autism for my dissertation is rooted in the embodied, technology-mediated life experiences of autistic individuals and the socio-technical barriers they face when navigating a neurotypical-dominant world. This frame is aligned with the *post-modern perspective on the social model of disability* (Mankoff et al., 2010). To unpack this perspective, we start with the

medical model of disability, which is concerned with the clinical pathology of disease, emphasizing its cause, origin, and nature. Disability studies scholars and self-advocates describe the medical model as locating the “problem” of disability within the individual due to “the functional limitations or psychological losses which are assumed to arise from disability” (Oliver, 1990, p. 4). They oppose disability being medicalized to the extent that the goal becomes medical intervention and control over conditions that deviate from the norm (Linton, 1998). In contrast, the social model considers disability to be a social condition because society presents barriers and fails “to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization” (Oliver, 1990, p. 4). The social model puts a finer point on the problem of viewing the normal as an ideal—that our society places the “normal” on a pedestal and discriminates and devalues those who do not meet the normal. In the context of autism, the social model frames social interactions as dependent on the “people and places, selves and spaces, [they] are mutually constitutive, [and] they come into being relationally, produced and performed in interaction with each other” (J. Davidson, 2008b, p. 792).

The *post-modern* perspective of the social model diverges from the social model’s conceptualizing of the realities of one’s physical body. Although the social model stipulates that illness can require medical treatment, critics view the model as dismissing the possible anomalies of one’s body and the pain and illness that can occur. Partly in response to these critiques, a post-modern model has emerged that “privileges each individual’s unique lived experience, complete with the complexity and nuance of everyday life... a cultural understanding of disability is needed to avoid the mistaken assumption that the ultimate goal is ‘normality’” (Mankoff et al., 2010, p. 4). By aligning with this perspective, my dissertation examines the socio-technical

barriers faced by autistic adults, as well as the realities of their embodied experiences, which may include sensory and social discomfort.

## 2.2 The Neurodiversity Paradigm

Autistic self-advocates and disability scholars have grappled with whether—and what extent—the social and medical models resonate with the lived experiences of autism. Autistic self-advocate and sociologist Judy Singer has argued that “we need to transcend the construction of binary oppositions such as “medical model vs social model” (Singer, 2016). Singer proposed the neurodiversity paradigm as a synthesis that builds upon the medical and social models’ positives attributes and espouses a generative, open stance on autistic life (Singer, 1999). At the beginning of my doctoral studies, I wanted to better understand the term “neurodiversity” and its relationship to other autism terminology. I conducted a domain analysis in the tradition of knowledge organization. A domain analysis is a classification strategy for examining the terms used to construct a concept. In my case, this concept was neurodiversity. Dr. Joe Tennis mentored me through this process, and we published a domain analysis examining neurodiversity, on which this section of my dissertation is based (Zolyomi & Tennis, 2017). Our domain analysis followed research in knowledge organization that is concerned with understanding particular domains (Campbell, 2012; Hjørland, 1998), the power of naming (Olson, 2001), and conflicted conceptual structures (Fox, 2016).

The term “neurodiversity” may have been isolated to an academic thesis if it had not been embraced by the autistic community. In the “Double-Tongued Dictionary Index” curated by the disability community, “neurodiversity” is defined as “the whole of human mental or psychological neurological structures or behaviors, seen as not necessarily problematic, but as

alternate, acceptable forms of human biology” (G. Barrett, 2004). There is not a definitive list of neurodiverse conditions since neurodiversity is claimed by a community or an individual, not determined by a medical classification. Some people with other neurologically-based conditions like attention deficit / hyperactivity disorder (ADHD) and learning disabilities, self-identify as neurodivergent. There remain open questions in disability studies and among self-advocates about which conditions fall under the umbrella of neurodiversity, and, importantly, who has the power to claim it.

For our domain analysis, we collected and analyzed terms related to neurodiversity commonly used in medical model resources, such as the DSM-5, and social model resources, such as disability studies and public writings of autistic self-advocates. Our analysis found points of tension and values embedded in terminology. For instance, there is a set of terms used to describe people in relationship to their neurology. Most of these terms, such as “neurodivergent” and “neurominority,” foreground neurology as a point of distinction, rather than a deficit. However, one exception is the positioning of “neuro-typical” as opposed to “neuro-*atypical*.” This positioning sustains the problematic juxtaposition of “normal” as opposed to “other.” When describing human nature as one entity as opposed to another, we place one group of people as “the other.”

By capturing terms related to diagnosis, we see that there are many paths to an individual’s self-awareness of, and identification with, autism. For example, some people have described not self-identifying as autistic until someone in their circle of friends suggests that they may be on the spectrum. There can be a period where an individual is what I call “neuro-curious”—learning more about autism and considering ways they may identify with descriptions of autism. They may or may not choose to pursue an official diagnosis. A person’s identity may

change over time and across groups. This implies that there are people at different stages of outwardly identifying as autistic within the broad neurodiverse community.

Even though these attempts at classification appear to be contained within a medical or social model, they are often in dialog. That is, each model contains views that are dissenting and cross different models. For instance, autistic people have individual preferences for disability-first or people-first language (Kenny et al., 2015). Although there is a prevailing preference for disability-first language, this preference is not necessarily held by the entire community. Some autistic people embrace the concept of neurodiversity, while others do not. These disagreements are not easily resolved, and perhaps, do not need to be resolved by choosing one dominant term. We can give the individual the power to claim the terms they prefer.

My domain analysis found that autism and neurodiversity are far from static phenomena. As the medical field discovers more about the genetic underpinnings and the biological impacts of autism, medical professionals are working to keep their diagnostic and treatment practices current. The autism community is evolving as well. The sheer size of the community is expanding due to children being diagnosed earlier, more women being recognized as autistic, and adults self-diagnosing or being community diagnosed. The nature of the neurodiversity movement will continue to shift as self-advocates add their voices to the dialog. We posit that articulating and respecting an individual's identity is a mechanism for disentangling the complexities of the autism phenomenon.

## 2.3 Post-Modern Social Model and Neurodiversity Lens for

### Dissertation

Our neurodiversity taxonomy will continue to evolve as the community grows and evolves. Medical advances will also impact the taxonomy by introducing new terminology into the public discourse. There may be future modifications to the DSM as diagnostic needs change. In this dissertation, I navigate a path forward by forefronting the voices of the individuals in the community. To avoid perpetuating this problematic juxtaposition of “normal” as opposed to “other”, I use the term ‘neurodivergent’ rather than ‘neuro-atypical’ in this dissertation. Both the post-modern perspective on the social model of disability and the neurodiversity paradigm reject a strict dichotomy between the social and medical models of disability. In my research, I allowed for participants to foreground the embodied, physical experiences and social interactions that are important to them. I sought to be attuned to participant’s viewpoints as conveyed through their terminology and multi-faced identities. In the next section, I present the theoretical foundations for understanding autism as embodied sense-making of the world and other people.

## 2.4 Embodied Sense-making of Autistic Individuals

Autistic adults describe that they have a different way of being in the world that results from the cumulative effect of neurological-based differences. Autistic individuals “tend to experience unpredictable environmental and embodied affects that are baffling to themselves, as well as others” (J. Davidson & Henderson, 2010, p. 466). Autistic adults report limited social interactions, sometimes debilitating social anxiety, and a need to withdrawal to an inner sanctuary—“an alternative world of one’s own, where perceptual rest and regrouping can take

place” (J. Davidson & Henderson, 2010, p. 465). A core symptom of ASD is exhibiting difficulties with social interactions. Autistic individuals tend to exhibit different ways of interpreting and enacting social norms such as taking turns, sharing, and being flexible. Difficulties with social interactions can affect interpersonal, coping, and adaptive skills for an entire lifetime (Volkmar et al., 1987). Autistic individuals may benefit from adapting ways of communicating, learning, planning, and performing tasks (Orsmond et al., 2004).

Technology-mediated communication could provide autistic individuals with more control over the environment and more predictable interactions. Autism self-advocates and theorists have explained that embodied experiences shape the interactions autistic individuals have with the neurotypical world. As described by the cognitive scientist De Jaegher, autistic individuals engage in embodied sense-making composed of “emotion, knowledge, mood, physiology, background, concepts, language, norms, and crucially, the dynamics of the interaction process” (De Jaegher, 2013, p. 10). This is the crucial link between emotional and sensory (or embodied) experiences.

De Jaegher’s theorization of autism includes sense-making—a framework for understanding how people construct knowledge from shared identities, experiences, and ideas by processing information (Dervin et al., 2003). Theories of embodied sense-making concern how people process information through their physical engagement with the world around them. Sense-making as a concept originated in the 1970s with organizational psychologist Karl Weick (1995). He used this concept to undergird his notion that organizations were an active, continually negotiated entity rather than a static rule-defined structure. Subsequently, Dervin evolved sense-making into a meta-cognitive theory for information science, which she posited was applicable to all levels of communication, ranging from intrapersonal to societal (Dervin et

al., 2003). The core activities of sense-making are seeking, processing, creating, and using information (Savolainen, 1993). Importantly, it is an ongoing process, rather than a single interaction or transaction. De Jaegher emphasized that sense-making for autistic individuals is an embodied and participatory process that enables them to “self-organize and self-maintain through processes of coordination, including its breakdowns and repairs” (De Jaegher, 2013, p. 6). Sense-making is a participatory process because engagements with a social partner involve “emotion, knowledge, mood, physiology, background, concepts, language, norms, and crucially, the dynamics of the interaction process” (De Jaegher, 2013, p. 6).

Autistic individuals describe experiencing the world in part through hyper- and hypo-processing of sensations such as bright lights, loud sounds, and physiological conditions of the body. “Self-advocates have long tried to describe their unique phenomenological experiences—and many talk about not being able to trust, feel, or control their bodies as they would intentionally prefer. Many tell us that parts of their bodies seem to disintegrate experientially, that sensory stimulations are either too intensely invading or go unnoticed, entirely collapsing into each other as echoes” (Brincker & Torres, 2013, p. 1). An individual can exhibit both hyposensitivity and hypersensitivity, depending on the context of the sensory experience (Allely, 2013). Underscoring the newly recognized importance of sensory processing for autistic individuals, updates to the latest Diagnostic Statistical Manual-5 (DSM-5) added hyper- and hypo-processing of sensory inputs as potential indicators of autism (M. S. Goodwin et al., 2008a). Autistic individuals and their families may modify their environment and daily routines to decrease overstimulation and add calming sensory activities (Schaaf et al., 2012). Autistic individuals may also engage in repetitive body movements as pleasurable mechanisms for self-

soothing and engaging kinesthetically with the world (Iarocci & McDonald, 2006). For instance, they may flap their hands, fidget with an object, stroke their hair, and spin around.

Sensory processing difficulties can be experienced by people, independent of autism. For people of all neurotypes (autistic and non-autistic), there are two categories of sensory inputs (Ayres et al., 2005). The first category of sensory inputs are external to oneself, such as dim lights or a tickling feather. The second category of sensory inputs are internal to oneself. This latter category produces sensations that we can feel in our bodies and, sometimes, imagine in our minds. The two primary examples are the vestibular system and proprioception system. For example, autistic adults have described having “highly acute hearing, difficulty smelling extreme odors, having a high pain threshold, and trouble measuring proximity to other people” (Alper, 2018).

To deepen our understanding of the particular sensory experiences of autistic individuals, we turn to weak central coherence theory (Frith, 1989; Rajendran & Mitchell, 2007). Psychologists posit that people of all neurotypes exhibit either a strong or weak central coherence style depending on their focus on a global or local processing, respectively. The cognitive systems involved in this processing include perception, attention, linguistic, and semantic functions. Autistic individuals tend to have a weak central coherence style, which implies that they attend to one system at a time. This can make it appear as if they are hyper-focused on sensory input and repetitive noises. This theoretical perspective helps explain “the tendency of some individuals with ASD to respond only to a very limited amount of the relevant sensory information” (Allely, 2013, p. 1). For example, “incoming information might be distorted; rain might sound like gunfire, clothing might feel like sandpaper, or fingers

shampooing a scalp might feel like sharp metal” (Allely, 2013, p. 1). Next, I present the theoretical perspective of another key component of the embodied experience: affect.

## 2.5 Dominant Theories of Affective Phenomena

Human emotions have long intrigued scientists in psychology and neurology. Our conceptual framing of emotions begins with the overarching concept of affect that covers “all experientially nonneutral, hedonic or value-laden states or stimuli” (Fiedler & Beier, 2013, p. 37). Core affect, as defined by psychologist Russell, is “that neurophysiological state consciously accessible as the simplest raw (nonreflective) feelings evident in moods and emotions” (J. A. Russell, 2003, p. 148). Russell posited that affect combines two fundamental neurophysiological systems related to pleasure and arousal (J. A. Russell, 1980). Depicted as the circumplex model of affect (Figure 1), dimensions of valence and arousal map possible emotional states.

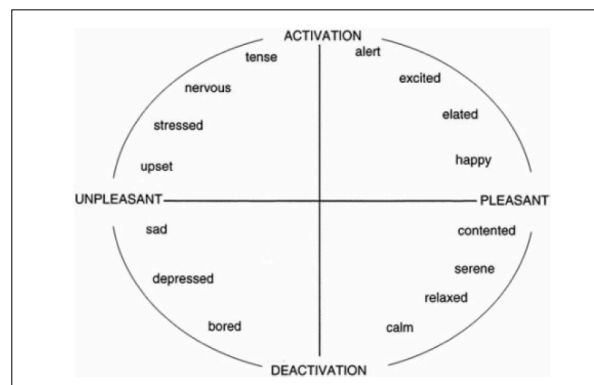


Figure 1. Russell’s circumplex model of affect (Posner et al., 2005) showing valence on the horizontal axis and arousal on the vertical axis. Emotional states are mapped onto the two space.

Five major affective phenomena are prominently studied: emotion, feelings, mood, attitudes, and affective style (R. J. Davidson et al., 2002). Humans experience affective states as “psycho-physiological constructs used for characterizing emotions (short-term) and moods (long-term)” (Wampfler et al., 2020, p. 1). Examples of emotional states are mapped onto the

circumplex model of affect shown in Figure 1. The connection between emotions is a topic of conceptual and empirical inquiry. A dominant theory from Ekman posited that there were six basic, discrete emotions—joy, surprise, sadness, anger, disgust, and fear—experienced universally by all humans (Ekman, 1999). According to this theory of universality, our neurological and physiological systems express these emotions in reliable and predictable ways across cultures. For example, facial expressions of emotions are used to define precise positions and movements of facial markers including eyebrows, facial lines, and lip position. A body of research has substantiated this theory, sometimes expanding to seven basic emotions to include contempt, as shown in the research image in Figure 2 (Matsumoto et al., 2008; Matsumoto & Hwang, 2011). In this image, six actors of different genders and races demonstrate pre-defined facial expressions of basic emotions. Data sets of facial expressions are currently used by technologists to develop computational models of emotional expression and recognition, and images such as these are at risk of embedding cultural, gender, and racial bias—a subject of current critique and research. (Howard et al., 2017).

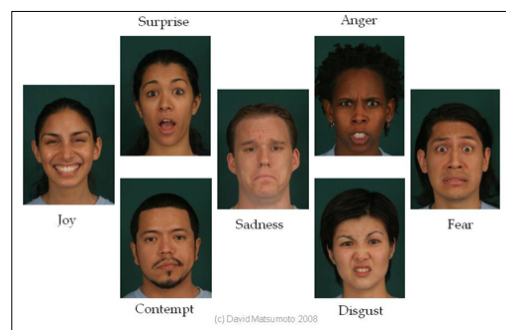


Figure 2. Facial expressions of emotions (joy, surprise, sadness, anger, fear, contempt, and disgust) as depicted in research on basic emotions (Matsumoto et al., 2008; Matsumoto & Hwang, 2011).

One critique of the theory of basic emotions is its hypothesis that predictable “patterns of autonomic activation and facial innervation are specific to each basic emotion” (Posner et al., 2005, p. 717) have not been consistently validated by research. In addition, the presence of a

single facial expression is not sufficient to classify an emotion, thus, disputing the reliance on facial expression to categorize emotions. Nonetheless, the notion of basic emotions as expressed through facial expressions remains a prevalent area of inquiry for neuroscientists and human-computer interaction researchers, as well as the autism therapists discussed later in this section. Russell's circumplex model of affect was proposed as an alternate to the theory of basic emotions as better aligned with neuroscience research and clinician knowledge. The circumplex model was a more accurate depiction of people's experiences discerning emotions and articulating emotions (Saarni, 1999). On the extreme end is alexithymia— affective and cognitive difficulties recognizing and describing one's feelings, including distinguishing between feelings and bodily sensations (Goerlich, 2018).

Some emotion theorists have explored the experience of emotions as sensations within the body, felt through one's interoception. Interoception is defined as an awareness of internal senses, including temperature, heart rate, and our sense of balance (Dieter, 1996). "Models of embodied emotion posit that we understand others' emotions by simulating them in our own bodies, meaning that we should be able to construct bodily representations of others' somatovisceral states when observing them expressing specific emotions" (Nummenmaa et al., 2014, p. 648). Biomedical researchers have explored how people associate bodily sensations with different emotions. For example, Nummenmaa et al. (2014) created maps of bodily sensations as self-reported by participants responding to emotional stimuli associated with the six basic and seven non-basic ("complex") emotions plus a neutral state (Figure 3). Their findings suggested that people perceived both basic and complex emotional states that they embodied in different ways. However, they also found overlap in the bodily maps, with emotional states sometimes affecting the body in similar ways.

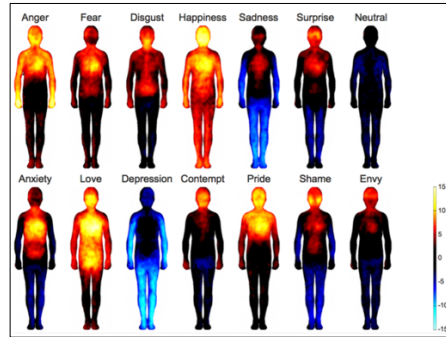


Figure 3. Bodily map of emotions depicting self-described embodied sensations associated with anger, fear, disgust, happiness, sadness, surprise, neutral, anxiety, love, depression, contempt, pride, shame, and envy (Nummenmaa et al., 2014).

Psychologist Lisa Barrett argues that our understanding of emotions needs to change from the “classical” view of emotions—in which our bodies reliably broadcast perceptible biometric signals that correspond to universal emotions—to a constructivist theory that emotions that are created within oneself and socially (L. F. Barrett, 2017). From a constructivist perspective, a person’s emotional experiences are formed based on their neurology, access to related emotional experiences, and context of social actions. Next, I synthesize the theoretical perspective on affect within the context of autism.

## 2.6 Affective Phenomena in Autism

In this dissertation, I have explored the social interaction experiences of autistic adults within the context of their emotional experiences. In this section, I present an overview of how affect and emotions are theorized and manifest in therapy and education for autistic individuals. Evaluation of affective responses and emotions is used to diagnose and assess autism, stemming from when autism was first characterized as a psychological and behavioral condition. “The role of emotion in autism is still debated” in autism research, literature, and community discourse (Uljarevic & Hamilton, 2013, p. 1). At a high level, emotional wellbeing enriches one’s quality of life. In general, the quality of life of autistic children tends to be lower than that of non-autistic children,

“with a majority having little or no social support, meaningful relationships, future employment opportunities or self-determination” (Burgess & Gutstein, 2007, p. 83). Emotional wellbeing is supported by social-emotional learning and enacting skills, thereby building emotional competence (Payton et al., 2000). Emotional competence are predictors of academic and social success, as well as gains in social aptitude (Conallen & Reed, 2017).

A key emotional competence is the ability to identify and recognize emotions in oneself and others. According to a meta-analysis of emotion research in autism by Ujarevic and Hamilton (2013), emotion recognition has been found to be difficult for autistic individuals. Difficulty with emotion recognition may be connected to alexithymia. As described above, alexithymia entails difficulty identifying and recognizing emotions, and autistic individuals have been found to have a higher rate of alexithymia than non-autistic populations (Milosavljevic et al., 2016).

Another important emotional competency is self-regulation of emotions. “Emotion regulation involves modulating the temporal features, intensity, or valence of one’s emotions in the service of adaptive or goal-directed behavior” (Mazefsky & White, 2014, p. 15). Emotional outbursts, aggression, and self-injury can stem from ineffective management of emotional states in response to stress or overstimulation (Konstantareas & Stewart, 2006). Sources of stress for autistic individuals include social pressure, feeling in discord with others, and trauma. Children and youth with autism have been found to have been exposed to trauma including abuse, neglect, and peer victimization (including physical, social, verbal, and cyber-bullying) (Cappadocia et al., 2012). Autistic children are exposed to traumatic events at least as often as their neurotypical peers, with bullying found to occur more often against youth with ASD more often than non-autistic youth (Hoover, 2015). Research on the effects of these events on autistic people suggests

ostracism, loneliness, internalization of emotional symptoms, and suicidality. More research is called for, along with supportive interventions and policies.

Psychologists, social skill therapists, and educators target both of these emotional competencies—recognizing emotions and self-regulation of emotions. These professionals use traditional and modified social-emotional learning strategies when working with autistic children. To support multi-modal learning and to assess emotion competencies, professionals use a variety of visual aids, including those containing facial expressions and taxonomies of emotions (Grynszpan et al., 2014; Hayes et al., 2010; Rao & Gagie, 2006). Cognitive-based therapy (as opposed to behavioral approaches) sometimes use emotion taxonomies to teach autistic individuals emotion recognition and emotion regulation skills (Figure 4).

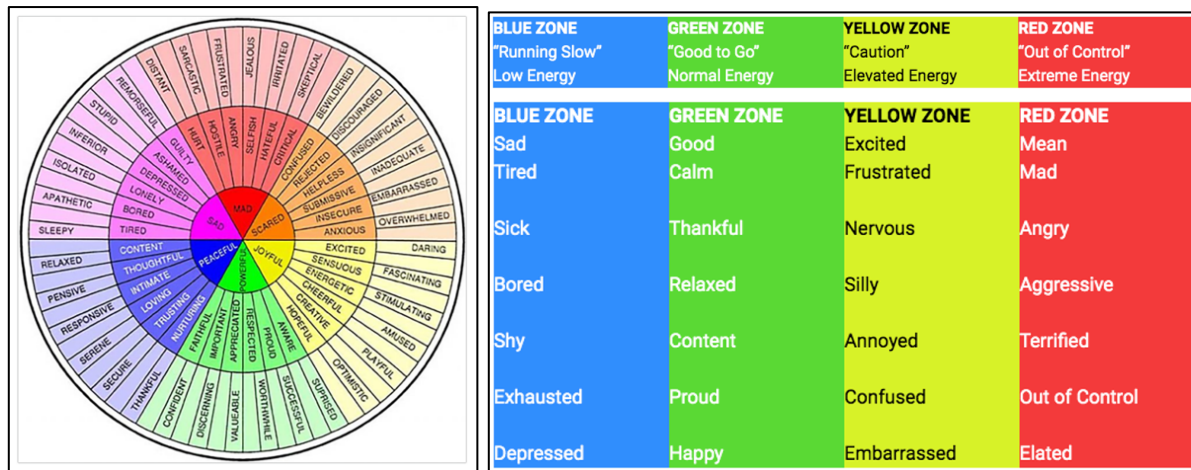


Figure 4. (a) Feeling wheel used in psychological counseling with autistic adults (Smith, 2017). Copyright: Fair use. (b) Feeling Zones curriculum designed for teaching teens to first identify their energy zone (blue, green, yellow, red) and then a corresponding feeling within each zone (Kuypers, 2011; Simple Steps to Teach Teens with Autism Spectrum Disorder (ASD) to Effectively Communicate Emotions – Part One | The Heritage Community, 2017). Copyright: Fair use.

These approaches for building emotional competencies of autistic individuals exhibit a range of visual representations and mental models of emotional states. Based on the use of visual representations of emotions in educational and therapeutical scenarios, this dissertation examines

visual representations such as these, inviting participants to modify them and create novel representations.

## 2.7 Summary of Embodied Sense-making and Affect of Autistic Individuals

In this section, I synthesized theoretical perspectives from medicine, social science, and information systems. The theory of embodied sense-making serves establishes a strong connection between cognition and embodiment. In this dissertation, I explore sensory experiences within the context of social-emotional experiences, as suggested by disability studies. This approach is motivated by the scholarship of critical autism scholars, who “attend closely to the views and voices of autistic people themselves” to counter traditional autism literature in which “it is not unusual... to encounter descriptions, indeed definitions of autism as an ‘empathy disorder’” (J. Davidson & Orsini, 2010, p. 131). Critical autism studies offer alternative, more expansive perspectives. For example, Milton theorizes about a “double empathy problem,” describing how challenges to empathy do not stem from a “singular problem located in any one person. Rather, they are based on the social interaction between two differently disposed social actors” (Milton, 2012, p. 884). These perspectives expand our understanding of autistic adults beyond research that typically focuses on autistic children in psychology, education, and human-computer interaction (HCI) research.<sup>3</sup> My dissertation

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<sup>3</sup> With notable HCI research exceptions (Boyd et al., 2016; Burke et al., 2010; Hong et al., 2012; Mazurek & Engelhardt, 2013; Zolyomi et al., 2019).

explores how technologies can improve neurodiverse dyadic communication by improving social, emotional, and sensory factors in communication technologies.

# Chapter 3 HCI Research for Autism

This dissertation contributes to HCI scholarship, and more specifically, one of its sub-fields concerned with disability: accessible technology. In this chapter, I begin by presenting related work through a brief overview of the field of accessible technology and what accessibility means in the autism domain. Next, I synthesize HCI research on communication technologies, such as online forums and social media. This research demonstrates that although technology provides some autistic adults with a means for pursuing interests and social relationships, autistic adults also experience particular social, emotional, and sensory difficulties using communication technologies, such as video calling. Finally, I summarize research on affective computing designed for mainstream, non-autistic users, and then contextualize affective computing within the autism domain.

## 3.1 Accessible Technology Architecture and Design Approaches

Researchers in the field of accessible technology examine the socio-technical practices of disabled people, barriers to technology use, and ways to improve the usability of technology for disabled people. From a technology architecture perspective, a product needs to enable access to the user interface and modes of interaction. For example, a desktop computer needs to be usable through a keyboard and screen reader application used by blind people. Developers of computer operating systems build programmatic hooks into the operating system so specialized assistive software and hardware can translate interactions into the modalities that work best for the user. Disability advocates have argued for technologists to increase equity of technology access

because, historically, technology has not been immediately accessible upon release and assistive technology is costly in terms of money and effort (Vanderheiden, 1998; Wobbrock et al., 2011). Researchers have investigated ways to reduce the technology access gap between the general population and disabled people. They have predominantly focused on people with physical disabilities related to vision, hearing, mobility, and speech. Factors that have reduced the technology access gap include adding basic assistive technology functionality to operating systems (such as making the operating system screen readers more robust), lowering the cost of hardware and assistive technology software (especially the iPad device and the iPad application ecosystem) (Ok, 2018), and more developer and designer guidance for supporting accessibility from large technology companies, including Apple and Microsoft.

There exists an inherent tension between universal design and customization. With universal design, the goal is for “the design of all products and environments to be usable by people of all ages and abilities to the greatest extent possible” (D’souza, 2004, p. 3). Taking inspiration from the architectural design of the built environment, universal design seeks to provide “equitable use, that is the design should be useful and marketable to any group of users” (Newell & Gregor, 1997, p. 39). According to universal design principles, general-purpose technology should be accessible immediately out of the box, eliminating the need for assistive technology. However, the ideal of universal design is a significant challenge for commercial products (Newell & Gregor, 1997; Vanderheiden, 1998). First, universal design would require a company to make a long-standing commitment of resources and priorities to satisfy the needs of all users throughout the lifespan of the product. Also, some user requirements are at odds with the needs of other groups. For example, the video captions and audio descriptions needed by deaf and blind users, respectively, can be distracting to users with cognitive disabilities and those who

are neurodivergent. This illustrates the importance of providing a customizable user experience, so people can optimize the experience based on their needs and preferences.

Considering these complications of universal design, researchers have proposed alternative approaches. Vanderheiden proposed a three-pronged approach: “(1) change the individual [including training], (2) provide the individuals with tools they can use, or (3) change the environment” (Vanderheiden, 1998, p. 30). The appropriateness of these three proposed approaches depend on the context of use, individual, and environment. A holistic approach such as this is crucial for technology in the public arena, such as transportation kiosks. In contrast to asking the user to change, Wobbrock et al.’s (Wobbrock et al., 2011) ability-based design approach argues for technology to be flexible at the architecture level to adapt to user needs and capabilities. For example, user interfaces can detect a user’s touch input and to adapt to their touch patterns (Mott et al., 2016).

Autistic technology users’ needs are different than people with physical disabilities. They have the ability to see, touch, and hear and so do not need alternative means of accessing technology such as provided by screen readers, alternative input devices, and captions. This raises the question: what does it mean to make technology “accessible” for autistic users? Researchers have explored this question by developing commercial technology products focused on supporting communication and cognitive processing. The dominant autism-related commercial technologies are augmentative communication aids for people who are nonverbal or minimally verbal, as well as educational technologies that deliver educational material to learners with cognitive difficulties. For instance, a learner can benefit from multi-modal content that provides information in both text and visual formats (Kientz et al., 2013). The broad scope of accessible technology for autistic users highlights wide-ranging needs within the autism

community. To design novel technologies for autistic adults, a highly contextualized research approach such as Grounded Design can be attuned to the personal needs of particular target users. Next, I present the key insights from HCI research related to topics relevant to this dissertation: communication, social relationships, and affective phenomena.

## 3.2 Communication Technology for Autism

A core criterion for a person having autism is that they experience challenges perceiving and interpreting social interactions and social cues. These social processes add up to form a culture's social norms, or "standards of behavior that are based on widely shared beliefs about how individual group members ought to behave in a given situation" (Fehr & Fischbacher, 2004, p. 185). Dominant themes in HCI research related to autism are independence, learning, and social life (e.g., (Boser et al., 2014; Burke et al., 2010)). Researchers have explored applications designed to aid in the social skills and cognitive functioning of autistic individuals (e.g., (Carmien, 2016; Tentori & Hayes, 2010)). Autistic adults engage in computer-mediated communication (CMC), gaming, and other screen-based activities (Kientz et al., 2013; Mazurek et al., 2012). Autistic individuals have reported an affinity for technology, especially the internet (Gillespie-Lynch et al., 2014; Pinchevski & Peters, 2016). The autism community views the internet as a valuable meeting space, and it is even touted by some autistic adults as the "ideal country for autistics" where they "can interact without getting on each other's nerves—gently, carefully". Social spaces of the Internet may thus be in some senses Utopian—a literal "no-place' where good things come to light" (J. Davidson, 2008b, pp. 796–797). Online, they engage in social relationships and interests. The perceived benefits of CMC and online social engagement include the (1) consistency of interactions, (2) freedom from having to decode body

language and tone of voice, (3) the tendency of CMC to be clear and straight-forward, (4) the asynchronous rhythm of online communications allows the user to communicate at their desired pace, and (5) the act of typewriting aids some in clarifying their thoughts (Burke et al., 2010; J. Davidson, 2008a; M. R. Morris et al., 2015). In essence, “the internet challenges stereotypes surrounding the competence of people with autism to communicate effectively” (J. Davidson, 2008a).

Social norms differ by the computer-mediated communication (CMC) platform; however, autistic adults tend to have difficulty translating social rules they have learned in one context to another (Burke et al., 2010). Burke et al. found that autistic adults tend to have difficulty discerning social rules across a wide range of CMC sites and platforms, including Facebook, Twitter, MySpace, Second Life, and World of Warcraft. However, in general, autistic people can feel more at home using CMC than interacting face-to-face. According to Davidson and Henderson's summary of autistic autobiographical authors, “individuals with ASD generally find face-to-face communication challenging in the extreme” (J. Davidson & Henderson, 2010, p. 463).

Gillespie-Lynch et al. classified the social benefits of CMC for autistic people along two dimensions: (1) “increased comprehension of and control over communication” and (2) “contact with and social support from similar others who may be geographically distant” (Gillespie-Lynch et al., 2014, p. 457). Along the first dimension of comprehension and control, CMC enables autistic people to engage with other people without the strain of experiencing sensory overload and having to manage the ambiguity of communication (Pinchevski & Peters, 2016). Due to the asynchronous nature of some CMC (e.g., email), autistic users can take time to assess communications that may be ambiguous or contentious. They can formulate their response and

follow up with communication partners to clear up miscommunications. Morris et al. (2015) found that among a sample of technology workers, autistic people had higher self-reported levels of comfort with text messaging relative to neurotypical employees, but lower self-reported comfort levels with phone calls, video calls, and face-to-face conversation in the workplace.

Along the second dimension of social contact and support, autistic individuals report valuing using CMC to meet people with similar interests. Platforms dedicated to autistic users, such as the Autcraft Minecraft gaming server, are especially effective socio-technical environments for developing meaningful friendships and sharing experiences with like-minded people (K. E. Ringland et al., 2016a). However, as reported by Burke et al. autistic adults reported difficulty in maintaining online relationships due to issues regarding “knowing whom to trust, knowing how much to disclose, and understanding CMC-specific social norms” (Burke et al., 2010, p. 428). Compounding these issues is the research insight that people do not always present their full, authentic selves online (Hogan, 2010). Interestingly, autistic adults, more so than neurotypical users, perceive CMC as an opportunity express their true selves.

### 3.3 Affective Computing for Interpersonal Communication

Researchers of affective computing aim to enrich interpersonal and large-scale communication of human-to-human and human-to-machines. Developers’ conceptualizations of emotional states, use of biometrics as signals, and application of computational models to classify affective phenomenon underpin affective computing technology. Affective computing systems have been targeted for mainstream users (not specifically non-autistic users) in settings including the workplace, healthcare, education (e.g., (Fessel et al., 2012; R. R. Morris et al., 2018; Wu et al., 2016)), and everyday use, such as Amazon’s reported emotion-detection wearable (Humphries,

2019). Technologists can use cloud-based emotion recognition services offered by cloud-based platforms. Google's Vision API, released in 2016, processes images to detect faces, landmarks, and objects (*Features List | Cloud Vision API*, n.d.). It calculates likelihood ratings for emotional states (joy, sorrow, anger, and surprise). Microsoft's Cognitive Services includes the Emotion API for perceived facial expressions for six emotional states (anger, contempt, disgust, fear, happiness, neutral, sadness, and surprise) and a corresponding confidence level (Microsoft, n.d.).

Researchers have investigated how to provide emotionally-aware mental health through technology, such as a wellbeing chatbot that infers mood and adjusts its delivery of interventions accordingly (Ghandeharioun et al., 2019). Emotion recognition functionality is sometimes built into a platform without the express knowledge of the user. This has been used to detect distress in a social media user's online behavior (Notredame et al., 2019) and provide critical support. In another case, Facebook conducted an experiment in which content was shown or omitted from users' news feeds based on the emotional expressiveness of posts (Kramer et al., 2014). This Facebook experiment, which was conducted with users without their consent, came under ethical scrutiny as an example of algorithmic emotional manipulation. Andalibi and Buss conducted interviews with social media users about their attitudes regarding emotion recognition on social media platforms (Andalibi & Buss, 2020). They found that people "view emotions as insights to behavior, prone to manipulation, intimate, vulnerable, and complex" (Andalibi & Buss, 2020, p. 1). They describe ways the complexity of emotions is difficult to define for the person experiencing them, let alone a computing algorithm. One challenge they note is how algorithms are often designed to classify an emotion as one of a set of universal feelings or moods; however, emotions are felt differently by each person. They found that participants perceived potential

harms of emotion recognition at individual and societal levels. Concerns included that vulnerable individuals could be manipulated and exploited based on their emotional state, leading to negative impacts on emotional and mental health, and identity and digital image misrepresentation over time.

Affective computing systems for autism are primarily software applications used in educational and therapeutic settings. In these programs, autistic children are instructed to complete computer application tasks that are “designed to elicit the affective states of liking, anxiety, and engagement that are considered important in autism intervention” (Liu et al., 2008, p. 1). Autistic children also use computer applications that teach the meaning of facial expressions. These emotional literacy skills then form the basis for learning a wide range of social skills that are contextualized based on the individual’s age and communication goals. Researchers have found that using video technology and virtual worlds to practice social skills for scenarios such as public speaking and job interviews has benefitted autistic individuals (Hayes et al., 2015).

In autism technology research, the expression of emotions, emotional empathy, and emotional regulation have received significant focus (e.g., Betancourt et al., 2017; Kaliouby et al., 2006; Washington et al., 2017). As an extension, empathetic artificial intelligence (AI), which strives to mirror and model human emotions, has been applied to autism scenarios. Empathetic AI, in the form of social robots and avatars, has been used with autistic children to promote social engagement and emotionally aware interactions. Specifically, it is used while “assisting in the diagnostic process, improving eye contact and self-initiated interactions, turn-taking activities, imitation, emotion, recognition, joint attention and triadic interactions” (Pennisi et al., 2016, p. 165). In other areas concerning physical interactions with digital systems,

researchers have used wearables to detect stereotypical motor repetitive behaviors (e.g., Goodwin et al., 2008) and to attempt to predict emotional “melt-downs.” This line of research focuses on understanding affective responses and repetitive behaviors to develop tools for parents, teachers, and therapists.

In exploring motivations and emotional connections to physical behaviors, we are guided by Picard’s insight that “both brain and body interact in the generation of emotion and its experiences” (Picard, 2000, p. 22). In work exploring the brain-body experiences of autistic individuals, Simms et al. (2014) explored the communicative practices of autistic individuals during stress. The design team created a digital tracking system that mapped squeezes of stress balls (as data input) into a mobile application that would text a trusted friend during a stressful episode. Ringland (2019) also explored embodied digital experiences within the context of Autcraft, a Minecraft server for autistic players. Members of Autcraft created spaces and social interactions tailored to their needs, including sensory-aware spaces ( Ringland et al., 2016b), enacting behaviors to manage emotions (e.g., killing monsters to release anger), and hosting an in-world fireworks show—an alternative to sometimes sensory-overwhelming firework displays in the physical world (Ringland et al., 2017). Embodied experiences are also constructed and felt during digitally mediated social experiences, including the liminal “transitional space between two states of being or the threshold between two spaces” (Ringland, 2019, p. 5).

Recent research in the field of media studies has investigated the intersection of media use with the emotional, learning, and sensory experiences of autistic children. Alper (2018) found that “media play a role in autistic children’s sensory-seeking behaviors at home, the integrated ways in which they experience pleasurable stimuli, and how they learn to interpret their own sensoria” (p. 3565). Children may listen to music while jumping on a trampoline or may hold up

a tablet close to their face while tensing up their whole body. Autistic children may use media to create sensory-friendly experiences, such as creating a virtual fireworks show within Minecraft (Ringland et al., 2017). Alper proposes compelling directions for future research on sensory experiences, notably “the relationship between sensory regulation during media use and one’s ability to process messages in those media” and poses the question: “how might sensory regulation behaviors serve learning and other cognitive processes through media use?” (Alper, 2018, p. 3574).

### 3.4 My Prior Research in Communication and Affective Computing for Autism

Based on related work summarized above, my collaborators and I conducted a series of studies designed to probe more deeply into the ways that communication and affective technologies introduce and reinforce social barriers for autistic individuals. In this section, I summarize that work composed of formative research (Zolyomi et al., 2019), and subsequent design research (Begel et al., 2020). For the design research, my primary contributions were to the usability protocol, helping conduct research sessions, and data analysis. The writing in this section is from, or is inspired by, those publications.

#### ***Formative Research: Motivation and Findings***

Our formative research was motivated by the fact that as autistic individuals reach adulthood and enter the workforce, there are more video calling scenarios involving autistic and non-autistic collaborators. Though video calling affords “some of the intimacies of co-presence,” (Giddens, 1984, p. 68), the desire for that affordance may not be shared by autistic users due to their social

styles and potentially heightened attunement to sensory inputs, such as distracting sounds. The high-bandwidth communication channels offered by video calls may easily trigger an autistic individual's detail-focused cognitive style to devote too much time, attention, and effort trying to read others' emotions and body language, which may cause them to fall behind in conversational flow (Frith, 1989; Rajendran & Mitchell, 2007). In this research, we addressed the following research questions: (1) what factors increase or reduce the comfort of the video calling experiences of autistic adults, and (2) how could video calling tools be changed to better accommodate autistic users? We conducted 22 semi-structured interviews with autistic adults to learn about their perceptions of the benefits and drawbacks of video calling.

We found that autistic adults experienced difficulties with technology-mediated social norms at every stage of video calling, from preparing for calls, initiating calls and conversing with others, to ending calls. These stressors drove them to use video calling technologies in unexpected ways to improve their comfort levels. We found that they employed coping strategies to adapt their video calling environment and their behaviors to support their sensory, cognitive, and social needs during a call. These strategies included (1) managing sensory inputs in their environment and over the video calls, (2) retaining relevant information (such as by writing notes), and (3) developing a clear mental model of their conversation partner's affect and cognitive style. When these appropriate strategies were unavailable, interviewees reported becoming more stressed, less able to interpret social-emotional cues, and less effective in their role for the meeting.

***Formative Research: Discussion of Computer-Mediated Communication (CMC) Affordances***

Based on our research findings, we reflected on how we could suggest ways to design video calling and other computer-mediated communication (CMC) tools to better support the sensory, cognitive, emotional, and social needs of all users—autistic and neurotypical. A primary consideration for the design of CMC tools was to give the user control over which channels, such as text-only or video, they wanted to use. We found that since the use of CMC affords autistic people the opportunity to choose the modality in which to interact, they were better situated to cope with stressors. In fact, they were freer to present their “authentic selves” to conversational partners. This freedom can help someone feel more comfortable presenting their true self online. In addition, by minimizing CMC bandwidth, they can maintain this authenticity over longer conversations because CMC enables them to better conserve their socio-emotional cognitive resources.

A second important factor in the design of CMC tools is that CMC affordances supporting attention are crucial for autistic adults. CMC applications could better help them focus on the important parts of a conversation (i.e. what their conversation partners are saying to them) by providing ways to filter or limit distractions (e.g. limiting other conversations, moving objects, or interesting objects in the background). When autistic people are forced to divide their attention between multiple distractors, it becomes impossible for them to pay enough attention to the conversation at hand. This impedes their abilities to follow conversations and cognitively process their content. Fortunately, the combination of CMC and other technologies can already help autistic adults in the filtering process. For example, the Skype video calling application has a feature that blurs the background, which can relieve the need to pay attention to those details. Using lower-bandwidth CMC channels, which relieve the need to maintain eye contact, could reduce the pressure an autistic individual feels to “perform” paying attention. As our

interviewees told us, by using lower-bandwidth CMC channels, they were able to shift their gaze around the room, and in doing so, increase their ability to focus on the conversation.

### ***Formative Research: Discussion of Making Social-Emotional Cues More Concrete***

Our research highlighted how social-emotional cues generated by neurotypical people are complex and often ambiguous for autistic people, due to possible difficulties with the perspective of another person—a psychological concept referred to as the ability to develop a “theory of mind” (Goldman, 2012). Our interviewees were optimistic about designing technology to help people translate the social and emotional information that is being communicated to a form was easier for them to see and understand. This direction could be supported by machine-learned classification of verbal and nonverbal cues, which could help CMC in a number of ways. First, in the case that someone finds visual information in a video calling overwhelming and minimizes the window, covers it up, or otherwise avoids looking at it, computer algorithms could show only simplified signals or summaries about the activity that is going on. In prior work, facial expressions have been simplified into a bubble visualization to indicate what a person might be feeling (Madsen et al., 2008), a technique that might benefit autistic users. Second, technology could provide a way for people to reflect on rich information after the fact, which could potentially be used as a training or teaching resource. For example, Boyd et al. (2016) created SayWAT, a tool that gave autistic users feedback about their vocal prosody in face-to-face conversations. Washington et al. (2017) provided emotion-recognition training for autistic children using a Google Glass wearable device that could automatically recognize other people’s emotions. Benssassi et al. (2018) presented many ideas on adapting wearable assistive technologies for use by autistic users to help them read others’ emotions. Many of these training-focused technologies could be adapted to operate within the context of a VC. Third, we found

that social-emotional cues were ripe for misinterpretation by our interviewees, especially when a person's words, voice tone, and body language were incongruous. Multi-modal classification could help identify incongruities in subtle cues and flag them. Flagging functionality could also be used to highlight moments that require closer attention.

Making emotional and social cues clearer could increase everyone's confidence and agency. However, our interviewees stressed that it is important that this information is not presented in a prescriptive manner. Rather, it should augment the individual's understanding of the situation and help them make decisions. For example, it can help them decide when to transition from one topic to another, or when to end a meeting. Byun et al. (Byun et al., 2011) created a system that used gestural and nonverbal cues to indicate to VC participants how well their conversations were going. Algorithms may still miss subtle cues and/or misinterpret expressions, so there is still a long way to go before machines approach human abilities. Nevertheless, the output from automated coding can still be useful.

Finally, our design ideas have the potential to increase awareness among video calling participants of the diverse cognitive and communication styles of all of their collaborators, autistic and neurotypical. As teams work together, they would be more likely to explicitly negotiate social norms that would be compatible with all of their members, and more socially inclusive (Zolyomi et al., 2018). As Burke et al. (Burke et al., 2010) suggests, establishing training programs for workers that includes social etiquette, diversity, and best practices for conducting effective video calling could help teams to co-construct mutually beneficial team norms.

Studying video calling through the lens of autistic users enabled us to discover rich user needs that were immediately evident, and also potentially salient for neurotypical users. For example, conversational dynamics, such as turn-taking and knowing when to end a meeting, can often feel ambiguous, even to neurotypical people. Social-emotional cues are easily misinterpreted, especially when a person's words are incongruent with their voice tone and body language.

### ***Design Research: Expressiveness Mirror and Meter Prototype for Video Calling***

After concluding our formative research, we explored design directions to help autistic individuals feel more comfortable and better understood during video calls. In this section, I describe this work and the important lessons we learned about the importance of connecting AI-based prototypes to expectations and data sets representative of autistic individuals. The team decided to pursue making emotional cues more concrete during video calls, which would diminish the cognitive load and anxiety felt by autistic individuals as they scan, interpret, and react to their conversation partner's emotional states. The team developed (1) a Wizard of Oz prototype and (2) a working prototype of an Expressive Mirror mode for video calling (Figure 5). This mirror read the autistic person's facial affect and displayed it (only) to them to give feedback about the way their affect may be perceived by others. to help them feel more comfortable and better understood. The working prototype was based on the group's work developing an AI computer vision system to detect facial expressions and display them live, on-screen during a video call.



Figure 5. The Expressiveness Mirror, which has six emotions depicted by an emoji and a text label (from left to right): fear, surprise, anger, happiness, disgust, and sadness.

By enabling the autistic person to be aware of how others might interpret their facial expressions, we hoped they would be able to clarify the intent of their communication, either by augmenting or modifying their facial expressions or by verbally articulating what they were feeling, especially if it did not match how their facial expressions were being perceived. We hoped that this user experience would help bridge the communication gap between neurotypical and neurodiverse conversation partners. Another consideration for only showing the individual—not their conversation partner—the emoji was the potential for the AI-engine to be inaccurate in its detection of facial expressions and categorizing to emotions. In this design, the individual could interpret the emojis themselves and be able to disregard the emoji with it having been shared with others. As we proceeded with user study, we found that this discrepancy between the felt-emotions of the individual and the AI-inferred emojis would be a bigger block than we had anticipated, which I describe in the following section.

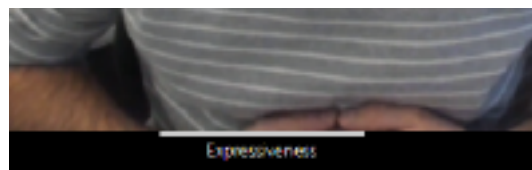


Figure 6: Prototype of Expressiveness Meter that shows a horizontal bar that changes depending on the person's facial expressiveness, as detected by an AI engine.

Another component of the prototype was an Expressiveness Meter (Figure 6) which depicted a conversant's overall expressiveness as a double-sided, horizontal, white meter displayed at the bottom of their video. Beginning at a default of 50%, the conversant's meter

grows longer (from the center) as their expressiveness increases over time. The meter shrinks as expressiveness decreases, dropping to a minimum (but non-zero) length representing a complete lack of detectable non-neutral facial affect. This representation was intended to give the autistic person feedback about their overall amount of expressiveness, relative to their conversation partner. Since autistic people are often perceived as showing flat, unexpressive affect, we hoped this display would help them be aware if they were being perceived as lacking expression, again enabling them to mitigate this perception during the conversation.

### ***Design Research: Unexpected Expressiveness Mirror and Meter Prototype Feedback***

Upon testing the working prototype of the Expressiveness Mirror and Meter with autistic adults<sup>4</sup>, participants gave us predominantly negative feedback about the user experience, which caused us to have strong reservations about its design. We conducted usability test sessions with seven participants (4 men and 3 women between 18–40 years old; one employed full time, and 3 employed part time) and then decided to end the study. Five of the participants were interviewed in the formative study (Zolyomi et al., 2019). All sessions were conducted over video calling using the prototype video calling application. Participants engaged in two 10-minute conversations with the confederate, one with the Expressiveness Mirror and Meter showing and one without (with the order counter-balanced between participants). Using a protocol approved by an internal review board, the confederate engaged the participants in topics designed to elicit happy, sad, surprised, and angry emotional reactions (with care being taken to make the emotional reaction be in regard to topics of discussion, not personally insulting). The researcher

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<sup>4</sup> The group conducted a usability study, which I was not involved with, using the Wizard of Oz prototype. They iterated on the design of the prototype and created the working prototype. I rejoined the research project at this point to provide input on the research design and to participate in conducting and analyzing the usability study.

and participant debriefed about the conversations, reiterating that the goal of the conversations was to elicit emotions, and to establish a baseline, non-negative emotional state. Finally, users were asked about their level of distraction, confidence, emotional awareness, control, and comfort during the conversations. The researchers also asked for feedback about the perceived performance, accuracy, and utility of the prototype.

We observed that participant reactions to the behavior of the prototype were largely negative. Participants were critical about the accuracy and responsiveness of the expression detection AI agent. One participant said that *“It didn’t seem to be accurate and a little distracting.”* Another participant responded that the artificial intelligence (AI) agent was not accurate because, mistakenly, *“happy was lighting up all the time.”* Furthermore, participants were confused when some ostensibly conflicting emojis illuminated at the same time. Another participant explained that he *“paid more attention to it when it was weird: happy and sad at the same time.”* These types of disconcerting discrepancies caused participants to lose trust in the prototype’s ability to accurately infer their emotions.

Beyond the performance of the prototype, participants were critical about the types of emotional states detected and the meaning of the Expressiveness Meter. They observed that the six basic emotions rendered in the emojis were not the expressiveness feedback they wanted. As one participant observed, *“Passion and happiness were confused because it was using basic emotions, but there are the more complicated ones. It doesn’t detect stress.”* They were more interested in seeing anxiety, stress, frustration, confusion, or sarcasm, which are much more complex emotions. Just over half of the participants noticed the Expressiveness Meter, but its design did not communicate how to react to the information. For instance, one participant said of her conversation partner’s meter *“hers was much longer, but I did not know if I was supposed to*

*make mine bigger or not—am I supposed to be more expressive?”* While we had gotten encouraging feedback on the design concept throughout the iterative process with a Wizard of Oz prototype, our user study with the working prototype elicited discouraging reactions.

### ***Design Process Reflections***

We reflected on the problems of AI and Wizard of Oz prototypes to design communication technology for people with diverse abilities, and general issues around designing for accessibility. Wizard of Oz prototypes can too easily gloss over AI implementation details that affect its value as a simulation tool. For example, our working prototype exhibited some noticeable delays in detecting and visualizing an expression, and sometimes triggered more than one emoji at a time (e.g., happy and sad). Our human wizard avoided both issues; thus, negative reactions to these issues were not evoked during the Wizard of Oz testing. Conversely, the wizard could not keep up with the live video as well as the AI could. Nor could a single wizard replicate the fractional likelihood rating given by the AI because the model learns probabilistic estimates for facial images during supervised training on data labeled by multiple raters. Finally, “wizards” found difficult to make the same kinds of mistakes an AI would, especially if trying to generate false positives when no identifiable expression is seen. Though a wizard that is too good may provide an upper bound on the value of a scenario, it cannot help to identify the minimum accuracy required to offer a useful AI-driven scenario. Our experiences with a Wizard of Oz design process added to the challenges being identified as designing Human-AI interaction (Yang et al., 2020).

As we learned throughout our iterative design process, the level of fidelity of a prototype affects the ability of a research participant to imagine what the user experience will actually be

like in practice. This optimism, which is a common reaction in the accessibility design space (Trewin et al., 2015), led us down a design path that ultimately resulted in a prototype that was not useful. More generally, building design probes that leverage AI functionality can be difficult. We encountered ways that Wizard of Oz techniques overestimate the actual AI capabilities in ways that affect the viability of the design concept. In the current stage of development of AI technologies, it is very important to develop a fully working prototype to accurately evaluate users' reactions to the concept.

Our experiences designing this prototype ended up teaching us more about the design process for the autistic population, especially when involving AI technology. Our AI was trained by (presumed) neurotypical raters on (presumed) neurotypical facial expression data. We tried to finesse this by choosing a user scenario in which the autistic person was offered feedback on the way a neurotypical person would interpret their autistic facial expression, but instead our users believed that the system was trying to show them their “true” emotions. They focused on why the system was inaccurate or doubted their ability to understand their own emotional state. Most of the users turned out to be comfortable interpreting most of the six basic emotions on their own but wanted our system to identify much more complex cognitive and emotional states that would help them mediate their conversation. We tried to use an AI agent trained on neurotypical data to a neurodiverse population, in part because of the challenge of training new expression recognition models on much scarcer data from people who are neurodiverse. Developing AI models for populations that have more limited data remains a challenge for the future. Although we involved autistic people in the design process as user study participants, they did not serve on our design and development team. Thus, our well-intentioned design process did not abide by the “nothing about us without us” principle (Charlton, 1998).

### 3.5 Summary

Returning now to the question I previously posed—what does means to provide accessible technology for autistic users?— this body of literature demonstrates that autistic people encounter many accessibility issues through human-computer interaction interfaces, their comprehension of the content delivered through the interface, and their comfort level as they use the product. By “comfort level”, I refer to the social, emotional, and sensory factors that can contribute or detract from the well-being of a person during a technology-mediated interaction. While using the internet, comfort has been shown to include discerning social rules for online spaces, feeling a part of a community, and pursuing interests. While using communication tools, comfort involves being free from sensory overload and having structure and predictability in conversations. Communication and affective technologies do not resolve social barriers for autistic individuals, but rather may provide ways for them to manage and negotiate their interpersonal interactions. However, the design of affective technology is not a straight-forward endeavor. The diversity of individual emotional experiences is at odds with current affective computing AI approaches of concretizing affective phenomenon into normative computational models.

This dissertation builds upon prior work on the social, emotional, and sensory factors for autistic users during technology use. However, this work seeks to examine the *interconnectedness and dependencies* of these factors and then build upon a rich conceptual model to envision novel affective computing. There has been limited prior work on affective computing for autistic users, which tends to focus on specific dimensions of emotional literacy, such as interpreting one’s own emotions as reflected by an emotion AI agent. The research team,

of which I was a part, reflected on lessons learned, including the crucial importance of including autistic individuals throughout the design process.

Therefore, to gain insight into the diversity of emotional experiences and to counter design that potentially introduces harm to people due to hidden and inaccurate representations of emotions, research is needed that holistically examines the rich connections between the social, emotional, and sensory experiences of autistic adults during interpersonal interactions. It is imperative that the research meaningfully includes autistic individuals throughout the design process in ways that shift the power dynamics between the researchers and the participants. Inclusion is important to allow space for the participants to share and reflect upon sensitive topics including social anxiety and isolation that can come with negotiating often uncomfortable and ambiguous social norms and social settings. The research will have to balance foregrounding the voices of autistic adults while accounting for the co-constructed, socially embedded nature of emotional experiences. Finally, to co-create affective computing concepts that are not reliant on current AI approaches, the research should employ design and evaluation approaches that allow for envisioning novel design concepts. This dissertation aims to fulfill these research goals, starting with its methodological choices, which I describe in the next chapter.

# Chapter 4 Methodology

“We invite you to travel in parallel with us for a while, and see how the world looks from our angle.”

– Judy Singer, autistic self-advocate (Singer, 2003)

Singer’s quote invites me to consider how HCI and accessible technology researchers engage with the autism community. What would it look like for a researcher to travel in parallel with autistic adults? What research methods best position the researcher to clearly see what the world looks like from the perspective of autistic adults? This inquiry motivates my methodological choices.

## 4.1 Researcher Stance

Researcher reflexivity is important in qualitative research (Watt, 2007). My research commitment is to forefront the lived experiences, values, and needs of autistic adults while accounting for their interdependence with other people in their communities. I am an ally of the neurodiversity community and have personal connections with several neurodiverse individuals. I acknowledge that my positionality both enhances my knowledge of the autism community and carries some assumptions and areas of sensitivity. To surface and address my potential biases, I have engaged in reflexive research methods and have collaborated with community members.

My choice of methods aligns with the social model of disability, which rather than centering perceived limitations on individual attributes, examines barriers faced by disabled people as a result of society norms and infrastructure (Oliver, 1990). The social model forefronts the voices of disabled individuals. In contrast, the medical model of disability focuses on the

perceived deficits of the individual. Technological supports for autism have traditionally aligned more closely with a medical framing of autism, typically resulting in digital tools designed to be corrective prosthetics. This limiting approach has been critiqued as embodying “normative expectations of a neurotypical society” (Spiel et al., 2019, p. 10). Towards countering that momentum, this work maintains a commitment to forefront the voices of autistic individuals. This is especially important when researching marginalized groups and as part of my reflexivity as a non-autistic researcher (Barron, 1999; Schön, 1990). I recognize that as an ally of autistic individuals with connections to the autism community through personal and academic avenues, my lived experiences are from inherently different perspectives than those I seek to more deeply understand. Towards centering the lived experiences of autistic adults, I purposefully used qualitative methods that value staying close to the data and engaging in joint researcher and community reflection.

## 4.2 Adjusting HCI Qualitative Research Methods

HCI Researchers conducting research with autistic adults reported modifications they made to methods to account for the psycho-social characteristics of autistic adults. Most modifications were in the logistics of running the studies, taking care to clearly communicate with participants. For example, Simm et al. (2016) noted that the participants wanted to know details about the time, location, and expectations for each session, with any changes communicated as soon as possible. Care was taken in choosing the session location. For some studies, the participants were allowed to choose their preferred location for the interview (e.g., Sallafranque-St-Louis & Normand, 2017) or the session took place where the participant would be familiar, such as at home or their autism center. As noted by Burke et al. (2017), a familiar setting “aided contextual

validity, but also meant that the participants had greater control over environmental stimuli” (p. 427). To not overload the participants, some researchers split the session across multiple days for autistic participants, although not for neurotypical participants (Bozgeyikli et al., 2017). A few researchers (e.g., Burke et al., 2010) used a best practice of providing the participants with preparation material a few days prior to their session. (This is an approach used in non-autism research, as well.) Participants may want to read the consent form at their own pace. Participants can be asked to think about scenarios and examples about the research topic, such as online shopping, as preparation for the session.

During the session, researchers considered the cognitive and communication styles of their participants. Some researchers included caregivers and job coaches in the interview or observation to facilitate comprehension and communication, plus giving insight to the interactions of these social groups. Sallafranque-St-Louis & Normand (2017) provided illustrated consent forms supplemented with simplified language. It is important to consider that autistic individuals tend to interpret written communication literally and tend to exhibit black-and-white thinking. Two research projects, Gillespie-Lynch et al. (2014) and Gotham et al. (2015), developed their online surveys with input from the autism community, such as autistic adults, their families, and autism advocacy organizations. Gillespie-Lynch asked pilot survey participants for suggestions on improving the survey questions. Accounting for style also means exploring non-verbal ways to express themselves. Simm et al. (2016) shared that they “asked participants to create their own wearable devices addressing their most pressing health need. Rather than ask directly about experiences with anxiety, the creative process allowed participants to describe their experiences not just verbally, but through the physical objects they imagined and produced” (p. 1278).

Another category of modifications were efforts to include autistic people and professionals in the research process. Gillespie-Lynch et al.'s (2014) research team included a self-advocate. Four studies integrated autism professionals into research functions such as coding qualitative data and participating in design sessions. One study, Burke et al. (2017) explicitly circled back to the autism center to confirm the research claims. Some studies captured multiple perspectives by including different stakeholder groups in the research. Although this is not a strategy unique to autism research, it is particularly important for autism research to gain a holistic understanding, especially when studying neurodiverse social dynamics. Inspired by the examples highlighted in this section, I intentionally adapt my methods as described in this chapter. One critical theme is participation, which I describe next.

### 4.3 Importance of Participatory Design for Disability Research

Driven by disability activists and disability studies scholars, there has been a call for including people with disability in the design and development of technology. There are several approaches that focus on including stakeholders in the design process: (1) user-centered design, (2) participatory design, (3) user sensitive inclusive design, and (4) diversity for design. User-centered design aims to place the human at the heart of the design process and was a move against technology-driven design that centers technological innovation. As disability scholars articulate, when initiatives broadly support accessibility, they tend to dilute and simplify the needs of disabled users. Therefore, universal design “must still center disability access in order to avoid lapsing into the normative template” (Hamraie, 2013, p. 13). Newell & Gregor (1997) attempted to concretize disability into user-centered design by promoting “user-sensitive inclusive design.” Their approach aims to generate method modifications to account for a range

of participant abilities and to generate discourse on ethical considerations for including people with disabilities.

Traditionally, user-centered design does not dictate that designers include actual end-users in the design process. There is not a required level of participation, as called for in disability studies, but rather, it is enough to consider the users' needs. This can lead to some misinformed design decisions and designers acting on behalf of, not with, people with disabilities. In contrast, participatory design is conducted with the actual end-users of a technological system. Participatory design originated in Scandinavian as part of action research that sought to distribute power to the workers impacted by technological changes in their organization (Bratteteig & Wagner, 2016). Building upon the approach of participatory design and being motivated by the social model of disability, HCI researchers called for including neurodiverse users in participatory design (Benton, Vasalou, Khaled, Johnson, & Gooch, 2014). To help designers adopt best practices for engaging neurodiverse people, Benton et al. present a "diversity for design" framework that uses evidence-based practices from education, such as demonstrating tasks to supplement verbal instructions.

Despite including people with disabilities, there are critiques and complications with these design approaches. One critique is that the participants are brought in at the point that the research team is ready to do design. This means they have already established the research agenda, overall approach, most likely basic user requirements, and envisioned the design space enough to prepare a design session (L. E. Boyd et al., 2016). At this point, how flexible is the design team? And what assumptions have been embedded into the preliminary design materials and the structure of the design session? Also, a design session requires skills of the users, such as creativity and working in the abstract. These are not necessarily the strengths of research

participants and may not lend itself to the strengths of autistic individuals, which lie more in the concrete than abstract (Annabi et al., 2017). Thus, it is a challenge to present and engage participants with design explorations, which are by nature, in an ambiguous state that is not in a concrete form factor (Zamfirescu-Pereira et al., 2021)..

HCI researchers studying autism have recently emphasized the need for participatory design (e.g., Frauenberger, 2015). Their research, along with most of the HCI autism literature, focuses on autistic children. A notable exception is Simm et al.'s work (2016). They observed that their co-design workshops surfaced the autistic adults' creativity, something their caregivers had said was an enlightening experience and opened new areas of interest for them to jointly explore. According to Bratteteig & Wagner, participatory design "enlarges the design space and maintains it open to the possibility of change" (Bratteteig & Wagner, 2016, p. 442). Participatory design is an iterative process and should incorporate user input and feedback throughout the process. This dissertation is aligned with several core principles of participatory design (Schuler & Namioka, 1993; Bratteteig & Wagner, 2016). First, although participatory design is collaborative work between researchers, designers, and participants, users are the experts and engage in their particular style of design moves that are situated in their practice (Schon, 1983; Schon & Wiggins, 1992). Participatory design considers technology in context of user's real-life situations. Planning and executing a participatory study needs to take into account power, conflict, politics, and decision making. Finally, participatory design scaffolds 'imaginative freedom' (Schulz, as cited in (Bratteteig & Wagner, 2016)), which helps bridge our participatory and appropriation studies, which in our case, explores a speculative design concept.

## 4.4 Grounded Design

Grounded Design (Wulf et al., 2018) is a research paradigm that uses an iterative, reflective, and collaborative design process to engage with a community of practice. As the name implies, this methodology allows researchers to become deeply familiar with a context of use, to work closely with stakeholders in the design process, and to continually validate conclusions and findings with members of the community of practice. In Grounded Design, knowledge is generated by engaging in research activities comprising context study, design study, and appropriation study. The activities build upon each other and are “treated as overlapping, interleaving, and recursive” (Wulf et al., 2018, p. 31) Insights from one phase serve as inputs into the next phase, and feedback into the analytic understanding of prior phases. Thus, the analysis and the evolution of the technology artifact stays close to the sensibilities of the community of practice. Due to these factors, Grounded Design is well-suited for this dissertation. My Grounded Design research spanned 18 months, beginning with the context study in July 2019 and concluding with the appropriation study in March 2021.

The first phase of Grounded Design is a context study. In this work, the context study comprised community observations, individual interviews, and pair interviews. These research activities provided rich descriptions daily lives of autistic young adults with a focus on interpersonal interactions; technology use; and factors that contribute or detract from their social, emotional, and physical comfort.

Based on the findings of the context study, the second phase of Grounded Design is a design study during which researchers and stakeholders design an artifact. Often, participatory design techniques are used in Grounded Design, which was critical for meeting my community-

based research commitments. In a design study, important elements are the design process, involving stakeholders, and emerging design concepts.

The third phase of Grounded Design is an appropriation study, which according to the Grounded Design framework is to critically engage with an information technology artifact that emerged from the prior context and design studies. Generally speaking, people appropriate an artifact or concept by actions of exploration, manipulation, grasping, reconfiguration, and conversion. The focus of an appropriation study is on “how people might be empowered not just to tailor but to make use of the technology at hand with regard to the local context. This can also include tactical moves to “mis”-use technology, the invention of usages, and the informal processes of learning and sensemaking” (Wulf et al., 2018, p. 157). This is in contrast to a traditional HCI user study, in which participants use the technology artifact as it is presented by the researcher. In these traditional studies, the researcher evaluates the usability of a technology artifact based on pre-established criteria, such as efficiency and performance metrics. The Grounded Design framework enables me to investigate my research questions in a highly participatory manner that invited all voices and perspectives. Together, the research team and stakeholders could frankly critique and imagine ways for technology to better support individual communication styles.

## 4.5 Participants and Recruiting

I conducted a first wave of recruiting in October 2019 to obtain a cohort of 18 participants with whom I could engage for the duration of the Grounded Design research. I distributed emails and a recruiting flyer (Appendix A) through the organizations we connected with during our CBPR outreach. The recruiting message invited autistic young adults to co-design autism technology

relating to communication and collaboration with a University of Washington research team.

Participants were asked to commit to participating in a multi-step research project composed of “Discover”, “Brainstorm,” and “Evaluate” activities.

In this manuscript, I refer to the autistic individuals in the study as the *primary research participants*. Upon request, the primary participants referred me to trusted conversation partners, such as family members or friends, to participate in a pair interview and the appropriation study. I refer to them as *secondary participants*. The primary participants chose family members, romantic partners, and IMAGES instructors, as listed in Table 1: Participant Demographics. The primary participant could chose a different person to join them in the pair interview and the appropriation study. In line with our position that the insights and experiences about the lived experience of autism constitute subject matter expertise, primary participants were paid \$75 for the individual interview, \$50 for the pair interview, \$75 for the design study, and \$50 for the appropriation study (for a total of \$250). The secondary participants were paid \$50 for the pair interview and \$50 for the appropriation study. This research was approved by the University of Washington Institutional Review Board (#STUDY00006397).

Table 1: Participant demographics of primary participants (P01-P24) for each research phase. For phases that involved a conversation partner, the table lists the secondary participant’s relationship to the primary participant.

Participant	Gender	Age	Occupation	Location	Individual interviews (n=18)	Pair interviews (n=30; 15 pairs)	Design Study (n=13)	Appropriation Study (n=14; 7 pairs)
						Conversation partner involved in session		
First Recruiting Wave								
P01	Alana	F	28	Educator	Seattle		Spouse	

P02	Sarah	F	28	Medical; Human Resources	Seattle		Boyfriend	Friend	Boyfriend
P03	Emily	F	28	Software engineer	Seattle		Boyfriend	Boyfriend	Boyfriend
P04	Alec	M	26	Musician	Seattle		Mother	Family	Family
P05	David	M	19	Student	Spokane		Parents	Family	
P06	Jack	M	18	Student	Spokane		Mother		
P07	Matthew	M	19	Student	Spokane				
P08	Joanie	F	19	Student	Spokane				
P09	Sam	M	20	Student	Spokane		Father		
P10	Mitchell	M	19	Student	Spokane		Instructor		Instructor
P11	Daniel	M	18	Student	Spokane		Brother	Brother	
P12	Caylee	F	21	Student	Spokane		Mother	Family	
P13	Chase	M	20	Student	Spokane		Mother		
P14	Jesse	M	18	Student	Spokane		Grand- mother		
P15	Kyle	M	20	Student	Spokane				Instructor
P16	Ethan	M	39	Student	Spokane		Instructor		
P17	Kendall	Non- binary	31	Educator	Seattle		Spouse	Spouse	
P18	Michelle	F	31	Software engineer	Seattle		Parents	Parents	
Second Recruiting Wave									

P19	Paul	M	30	Software engineer	Midwest			Friend	
P20	Steve	M	18	Student	Seattle			Parents	
P21	Rahul	M	20	Un-employed	Seattle			Friends	
P22	Laurel	F	23	Un-employed	Atlanta			(Phone interview only; Blocked by first activity)	Mother
P23	Charlie	Non-binary	33	Writer	California			Friend	Friend
P24	Tanish	M	24	Software engineer	California			Friend	

To augment the original cohort of participants, I conducted a second wave of recruiting in July 2020. This was necessary because, in between the pair interviews and participatory design, ten of the 18 participants became unavailable due to their changed circumstances during the COVID-19 pandemic. I ascertained this by reaching out to them via email and an online survey, which I describe in the Participatory Design Phase section below. The research team desired more participants to increase the robustness of our data and to have parity with the context study. Since all research activities would now be online or remote, I did not need to limit the second wave of recruiting to Washington state. I reached out to two autism organizations I have engaged with in the past: the Atlanta chapter of Autistic Self Advocacy Network (ASAN) and The Asperger / Autism Network (AANE). ASAN distributed my recruiting email and flyer; AANE posted my study on their web page dedicated to open research studies that may be of interest to

their members. I also recruited an autistic individual who lives outside the Seattle area whom I had met at a previous event. From this recruiting wave, I acquired six participants.

By conducting a second wave of recruiting, I was able to exceed our target sample sizes for all phases. A common concern for accessibility research is obtaining an effective sample size, within the constraints of a limited population size and the realities of recruiting people with disabilities. The research team established a goal of 12 participants for the context study and participatory design phase, and six participants for the appropriation phase, in keeping with similar, published research. (Note that a control group was not necessary because this work focuses on neurodivergent experiences, and thus, there is not a methodological requirement to compare a neurodivergent group against a neurotypical group.)

For both recruiting waves, I screened potential research participants via phone interviews and email correspondence. The screening inclusion criteria were that the person (1) self-identified as autistic (using terminology of their choice), (2) was 18-32 years old, (3) could communicate verbally in English *without* the use of a communication device, (3) was conversational, meaning, able to participate in conversations about their experiences and decision-making processes, (4) had experience using consumer technology, such as a computer, tablet, or gaming console, and (5) had fine motor skills at a level able to participate in design activities using design materials (pen and paper). Note that a formal diagnosis of autism from a medical professional was not required due to social and demographic barriers to autism diagnosis (G. Russell et al., 2011), especially as adults (L. F. Lewis, 2017). The first exclusion criteria was having a cognitive impairment that severely limited their ability to carry on a conversation or provide consent. The second exclusion criteria was mental health instability, as indicated by having (1) serious trauma in the past 6 months or post-traumatic stress disorder for which

discussing social interactions or sensory experiences would be harmful, or (2) serious, uncontrolled substance abuse issues. The effects of the inclusion and exclusion screening criteria on the research sample are discussed in the “Representation of Autism Community in Research Sample” section below.

Table 1 contains demographic information of the participants from the first and second recruiting waves. All participants self-identified as “being on the autism spectrum” and/or “autistic.” When talking about themselves, several said they “have a disability” and one described himself as “having a slowness,” perhaps alluding to a cognitive impairment that can be—but is not always—co-morbid with autism. In the original cohort (P01 – P18), six participants live in the Seattle area (3 female, 2 male, 1 non-binary). Twelve participants (2 female, 10 male) live in Spokane and are students in the Spokane Community College transition program called IMAGES. The IMAGES students are 18-21 years old and chose to attend IMAGES to develop their life and job skills. The IMAGES program works with local employers (bakery, feed store, pizza restaurant, computer repair, etc.) to give internship rotations to the students. All of these students live with their parents, and for many of the students, gaining independent living skills was an important issues in their lives. Summarizing the demographics of the second wave cohort (P19 – P24), two live in the Seattle area, 2 in California, 1 in the Midwest, and 1 in Atlanta (1 female, 4 male, 1 non-binary; average age of 25). They all participated in the participatory design phase; two (P22-23) participated in the appropriation phase.

### ***Representation of Autism Community in Research Sample***

Combined, the first and second wave participants represented a diverse slice of the autism community. The first and second wave participants represented a range of racial identities,

including White, Black, Asian, Latinx, and Eastern European. When discussing their daily lives and communication practices, participants brought up their relationship status, which included heterosexual and gay relationships. They live in a variety of settings centered on urban, rural, and suburban lives. They have jobs in technology, medicine, music, and education. Some are currently unemployed or in job training programs. This diversity reflects the diversity in the autism community and counters the (1) the stereotype in popular media of the white, male autistic prototype and (2) the gender bias of males receiving autism diagnoses at higher rates than females (Jones, 2015; G. Russell et al., 2011).

I recruited participants using convenience sampling, which, in this first wave of recruiting, limited geographic diversity and privileged those with access to the autism organizations with whom I collaborate. In the sections below, I provide a summary of the demographics of the first and second wave participants who were active in that phase. Three participants participated in all four phases of the Grounded Design research. Five participants participated in three phases. Regarding gender mix in my research sample, the ratio was approximately 11:7 male: female in the individual interviews (with one non-binary person); 9:5 in the pair interviews; 7:6 in the design study (with two gender-fluid people), and 3:3 (with one non-binary person) in the appropriation study. The male-to-female ratio of autistic people in the U.S. population, as reported by the Center for Disease Control (CDC), is 4.3:1 (Maenner, 2020). However, there are concerns that this ratio is not accurate, and rather, inflates prevalence in males due to gender bias in the clinical diagnostic criteria and barriers to the diagnostic process (Lockwood Estrin et al., 2020). A systematic review and meta-analysis in 2017 suggests the ratio is 3:1 (Loomes et al., 2017). Therefore, our male-to-female ratio is acceptable for representing the autism community, and leans towards including more females, which is likely a more

accurate snapshot of prevalence. Also, we acknowledge gender non-binary individuals, which is a designation typically missing from autism gender reporting.

However, the research sample does not represent the full diversity of the community of autistic young adults. For instance, all participants in our research communicated verbally, and therefore, does not include the perspectives of autistic individuals who are non-verbal. I established this screening criteria to establish consistency in the communication experiences of the participants. For instance, communication styles and interactions would be different for a participant who uses an assistive technology called an augmentative and alternative communication (AAC) device. Using an AAC device, the person typically enters a word, or selects a symbol, and the device speaks aloud using speech synthesis. Another communication requirement was that participants were conversational, which I assessed by asking them to describe their recent technology use and their typical responses to sensory inputs, such as bright lights and loud sounds. During recruiting, a few parents of autistic young adults contacted me expressing that their child was interested in participating in the study. To conduct the screening process, I requested to speak or email directly with the potential participant. In one case, the screening process proceeded in that manner and the young adult met the criteria for the study. In another case, I spoke with the young adult and based on his limited conversational style (short answers and frequently changing topics), I determined he did not meet the recruiting criteria. I explained this situation to his father and we proceeded to have a 30-minute conversation about their family experiences. In another case, a mother conveyed my screening questions to her daughter and emailed me her answers. In response to the screening question asking to share their responses to sensory inputs, her mother shared that her daughter screamed, “I am not happy,” adding that her daughter does not like wearing uncomfortable clothes or riding the public transit.

Therefore, I informed her mother that the research is not a good match because the study explores some potentially uncomfortable topics, like emotions and sensory sensitivities, to which her mother agreed. This screening process demonstrates that it is critical to be flexible in communicating using the modality preferred by the participants, following up on parent inquiries to communicate directly with the potential participant, and to be sensitive to how the study topics may negatively impact participants, even potentially during screening.

The screening process was critical to having a diverse participant sample that felt comfortable engaging with the research activities and topics. As my first cohort of participants was recruited, I embarked on the first phase of the Grounded Design study—the context study, which I describe in the next chapter.

# Chapter 5 Context Study

## 5.1 Introduction

The Grounded Design context study consisted of community observations, outreach, individual interviews with 18 primary participants, and 15 pair interviews with the primary and secondary participants. First, I briefly report on the outcomes of our Community Based Participatory Research (CBPR) outreach. The remainder of the chapter reports findings from individual and pair interviews. The CBPR and individual interview portions of this research was the subject of a recent paper to be published at the 2021 ACM Computer Support Cooperative Work proceedings (Zolyomi & Snyder, 2021) and this chapter includes substantial passages from that manuscript.

The context study asks the following research questions:

- During daily interpersonal interactions, how do autistic adults conceptualize and share emotions and sensory experiences? (RQ1)
- In what ways do autistic adults use or respond to digital technologies within the context of their social, emotional, and sensory experiences? (RQ2)

To answer the first research question inquiring into how autistic adults conceptualize and share emotions and sensory experiences, I first describe the participants' reported daily "rounds" (Taylor et al., 2018), a description of the important factors of one's daily life as grounded by routine activities. I then describe the primary and secondary participants' accounting of how their emotional experiences were impacted by social factors. Next, I surface how emotional

experiences are co-constructed in social relationships and include attending to emotional and sensory needs. Throughout the findings, I address the second research question by reporting on the participants' use or responses to digital technologies within the context of their social, emotional, and sensory experiences. Finally, I present findings that provide evidence of how neurodiverse pairs establish common ground and how technology is implicated even when conversation is not computer mediated. In the summary section, I connect these findings to the design of affective systems by introducing a social-emotional-sensory map to guide the digital representation of emotions. I present further synthesis of the findings in the Discussion chapter.

## 5.2 Method

The context study comprised community observations, individual interviews, and pair interviews. These activities provided rich descriptions of daily experiences of autistic individuals and insights on socio-technical scenarios.

### ***Community Observations***

To engage in current activities and issues important to autistic individuals, the research team began our project by attending autism-related events. Building on previous interactions with the autism community in our region, in July 2019, we attended an advertised “Zoo for All: Celebrating All Abilities” sensory-friendly day at a local zoo. The zoo provided a sensory map of the grounds that marked quiet spaces and a sensory garden. At an indoor space specifically designed for those with sensory sensitivities, we informally spoke with zoo employees, one who self-identified as being autistic. We learned about the measures taken by both designers and program directors to make the zoo more accessible to neurodiverse visitors. Also during the

initial phases of the context study, I attended a conference organized and presented by autistic adults hosted by a local college to better understand the values, priorities, and preferred terminology of at least one group of autism self-advocates. Throughout subsequent phases of the Grounded Design research, the research team participated in additional events including a webinar on autism and trauma, a conference on autism and employment, and conferences on autism-related technology research. I wrote research memos and discussed observations and learnings with the research team, iteratively building a more grounded, informed perspective on the autism community and current issues.

Based on networking during the autism and employment conference, I reached out to the autistic-lead organization Academic Autism Spectrum Partnership in Research and Education (AASPIRE) (Academic Autism Spectrum Partnership in Research and Education (AASPIRE), n.d.). During a discussion about this research project, a representative from AASPIRE recommended their Community-Based Participatory Design (CBPR) approach for conducting respectful and socially relevant research and to facilitate alignment and collaboration between researchers and autistic adults (Nicolaidis et al., 2011). Their CBPR approach identifies key points of alignment between researchers and autistic adults throughout a research project. For example, during the research development phase, community priorities should influence the research focus of inquiry and study design. Following this CBPR approach, the research team gathered input on our research plan from autistic-lead groups, autistic self-advocates, and other representatives of autism service organizations, all of whom I have worked with in some capacity in previous projects. We met in person with the University of Washington (UW) Autism Center, the UW Leadership Education in Neurodevelopmental and Related Disabilities (LEND), and a leader of the Seattle area adult autistic meetup group, Square Pegs. I met over the phone

with the leader of an organization that provides services to neurodiverse (those with autism and other conditions such as attention-deficit disorder) youth and young adults. During these meetings we gathered feedback on our research goals, research questions, study design, and recruiting plan. We also became more sensitized to the needs, perspectives, and challenges faced by autistic adults, adapting our language and approach to reflect this understanding.

### 5.3 Context Study Individual Interviews

After our community outreach and observations, we conducted face-to-face, semi-structured interviews with 18 participants (see summary demographics in Table 2) from October-December 2019 to gain an understanding of their lived experiences, with a focus on their social interactions at work, school, and in their personal lives.

Table 2. Demographics of participants in individual interviews for context study

Attribute	Demographics
Age	18 - 31 (average 22)
Gender	5 female, 12 male, 1 non-binary
Location	United States, living in a rural, mid-size city (12) or living in suburbs of large metropolitan city (6)
Living arrangement	Live with parents (13); live alone or with roommates (3); live with spouse (2)
Level of education	Transition program for life and job skills at a community college (12); Master of Music (1), PhD in statistics (1), medical residency program (1), Bachelor degree (3)
Current employment	Employed in technology, music, and education fields. Internships with local retail shops (bakery, feed store, pizza restaurant, computer repair)

Prior to conducting interviews, I piloted the protocol with an individual who identifies as autistic, and as a result I revised questions to use more direct language and explicitly state that participants could choose to not answer any questions, especially given the sensitive nature of

questions about emotions and sensory sensitivities. While scheduling the interviews, I instructed the participants to bring a ‘personal comfort object,’ which I described as “an object or written process that they turn to for comfort when they are dealing with strong emotions or sensory experiences (such as feeling bothered by bright lights or loud sounds).” During the interviews, I asked participants about their daily activities and their social, emotional, and sensory experiences. (See Appendix B for the interview script.) I inquired about (1) their experiences coming to know they were autistic and the strengths and frustrations that they connect to being autistic, (2) their experiences feeling overwhelmed by sensory inputs or seeking out sensory experiences, (3) ways in which they decode emotions of themselves and others. We discussed the participant’s sensory and emotional well-being practices, including a show-and-tell activity of the personal comfort object they brought to the interview. Throughout the interview, I probed into their technology and media use during the experiences they described. I then led the participants through an activity, described in the next section, designed to elicit responses to visual representations of emotions. To scaffold moving through interview topics, I used a Time Timer visual clock (Figure 7) and a visual schedule (Table 3), which are best practices for supporting neurodivergent individuals in classrooms<sup>5</sup> and technology research (Benton et al., 2014).







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<sup>5</sup> <https://theautismhelper.com/visual-timers-you-can-use-in-your-classroom/>



Figure 7: Time Timer clock used to visually display remaining time left in interview.

Table 3. Visual schedule used during interviews to scaffold switching topics and managing time

Step	Topic	Minutes
1	 Introduction	5
2	 Your background	10
3	 Sensory processing and emotions	10
4	 Well-being	10
5	 Visuals	20
6	 Wrap up	5

***Method for Engaging with Visual Representations of Emotion***

During interviews, we used a visual elicitation method designed to probe participants’ perceptions of emotion recognition and expression. For this portion of the interview, the researcher asked participants to respond to existing visual representations of models of emotions and then to create a visual representation for their conception of a model of emotions. Visual elicitation research methods supplement the verbal aspect of typical interviews by introducing

visual prompts or ways of responding to questions (Benton et al., 2014; Francis et al., 2009). Visual elicitation methods often help participants articulate mental models associated with sensitive issues such as managing serious mental illness (e.g., (Snyder, 2020a; Snyder et al., 2019)). In this case, we were also inspired by the prevalence of visuals used in the educational and therapeutic experiences of autistic individuals, such as the schedule chart shown above, reward charts, and communication aids (Dettmer et al., 2000; Hayes et al., 2010; Rao & Gagie, 2006).

The team prepared visual prompts by selecting four visual representations of emotions (Table 4). The criteria for the visual set was that they were a representative sample from (1) field (autism therapy and affective computing), and (2) image type (ranging from photographic, realistic images to simplified renderings to iconography). The first criterion is important because these are images that autistic individuals are likely to have encountered in therapy or as they are exposed to affective computing as described in the Background section. The second criterion was important because autistic individuals respond differently to images based on how realistic they are (Carter et al., 2016); in addition, current affective computing uses both realistic and iconographic emotion imagery.

Table 4. Visual representations of emotions used in interviews

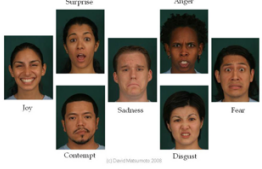
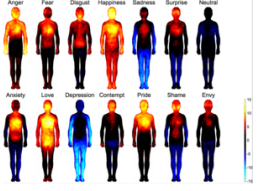


Image	Description	Settings	Realism Dimension
 <p>Facial expressions (Matsumoto &amp; Hwang, 2011)</p>	<p>Facial expressions</p>	<p>Autism therapy, emotion theory, affective computing. We chose an image of adults rather than of children since our research participants are adults and during our community outreach, autistic adults relayed that it was important to tailor the images and future design concepts towards adults.</p>	<p>Realistic</p>

Image	Description	Settings	Realism Dimension
 <p data-bbox="199 512 492 569">Bodily maps of emotions (Nummenmaa et al., 2014)</p>	<p data-bbox="596 310 703 411">Bodily map of emotions</p>	<p data-bbox="735 310 1101 512">Clinical neuropsychological assessments. Used in affective computing models for identifying emotions based on biometrics, especially changes in temperature and heart rate.</p>	<p data-bbox="1174 310 1281 338">Realistic</p>
 <p data-bbox="199 789 508 821">Feeling wheel (Smith, 2017)</p>	<p data-bbox="596 600 683 663">Feeling wheel</p>	<p data-bbox="735 600 1068 663">Autism therapy and education; emotion taxonomy.</p>	<p data-bbox="1174 600 1326 632">Iconographic</p>
 <p data-bbox="199 1056 540 1140">Feel Emotion Sensor and Feel App from Sentio Solutions Inc. (Sentio Solutions Inc., 2020)</p>	<p data-bbox="596 852 709 982">Emotion wearable and application</p>	<p data-bbox="735 852 1125 982">Emerging technology in areas of self-tracking and emotional literacy, emerging affective computing in marketplace</p>	<p data-bbox="1174 852 1326 884">Iconographic</p>

During interviews, the participants were asked to compare each of the four visual representations of emotions to their own experiences and mental models. Digital copies of images were presented on an iPad Pro with Apple Pencil, providing participants with the opportunity to annotate, alter, or otherwise visually register their responses to the images. First, the interviewer introduced the activity and gave a brief tutorial of an iPad Pro drawing application, GoodNotes<sup>6</sup>. The participant was given a few minutes to explore the brush styles and colors in GoodNotes. Next, the interviewer showed the participant the visual representations

<sup>6</sup> <https://www.goodnotes.com/>

of emotion (Table 4) one at a time, asking the participant to reflect upon what the image made them think about in terms of emotions and to mark anything they would change or highlight in the image to better reflect their personal experience. The interviewer probed for elements in the images that fit or did not fit with how participants conceptualize and experience emotions. They were then asked to draw their own visual representation that shows how they think of emotions. They were asked to draw an image and annotate it with text. During the interviews, five participants stated that they did not want to draw, in which case, the interviewer drew images or wrote notes to match what the participant was saying, asking for verification from the participant along the way. Using the iPad for this activity provided participants with the freedom to engage with the digital artifacts at will, including experimenting with different types of annotations. Interactions on the iPad were captured using the QuickTime Player<sup>7</sup>, providing real-time recordings of additions, edits, and notations added to the digital images. By engaging our participants in an alternative, visual mode of communication, we were able to triangulate our findings between the narrative portion of the interview, the visual markings and responses to visual representations, and the vocabulary and attitudes evident in their words.

## 5.4 Individual Interviews Analysis

Data from the context study consisted of research memos written soon after community observations, CBPR outreach meetings, and participant interviews; transcriptions of the interviews; and screencasts and edited images from the visual representation of emotions activity. We analyzed the data following an iterative inductive approach (Saldaña, 2013). Using

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<sup>7</sup> <https://support.apple.com/quicktime>

MaxQDA qualitative coding software, we conducted open coding of the textual data. Note that our analysis included coding both the textual data and the outputs of the visual representation of emotions activity in similar manners. This consistent treatment of the visual activity was informed by related work using interview and visual methods (e.g., (O’Leary et al., 2017)). We identified themes that captured connections between emotions, sensory experiences, and social relationships. We wrote memos on the emerging themes to remain close to the data and refine our analysis. We reported the themes back to the participants and community partners and asked for their feedback. They conveyed that themes relating to making interactions clearer, making it easier to understand emotions, and increasing independence during social interactions were resonant to them.

## 5.5 Context Study Pair Interviews

The goal of the pair interviews was to understand ways that the neurodiverse (meaning, autistic and non-autistic) interaction pair experience and identify, name, represent, and share their social, emotional, and sensory experiences. The design for the pair interviews was inspired by an interpersonal theoretical framework, Common Ground (Clark, 1996), that describes and explains interpersonal interactions in terms of establishing and negotiating common ground. According to Clark, interpersonal interactions can be conceptualized as joint activities centered around goals, which are both public (external) and private (personal). According to Clark, interaction partners engage in joint activities consisting of joint actions (dialog, verbal utterances, and gestures, etc.). Aggregated, these series of moves establish common ground that has layers of meaning beyond the sum of the individual components. Each neurodiverse interaction pair will have their

particular way of entering into an interaction, broaching topics, coordinating their interaction, encountering friction in the interaction, addressing friction, and finally, closing the interaction.

To gain an understanding of how our primary participants described establishing common ground with a conversation partner-and to understand each person’s perspective of their interactions-it was necessary to interview the primary participant with a trusted conversation partner. In February-April 2020, I conducted 15 pair interviews with the primary participants and a trusted conversation partner of their choice (Table 5). Due to participant scheduling conflicts, three primary participants from the individual interviews did not participate in the pair interviews. All interviews were conducted over video calling (Zoom or FaceTime, depending on the participant’s preference).

Table 5. Demographics of research participants in pair interviews for the context study (n=30; 15 pairs)

Attribute	Demographics
Age	18 – 31 (average 23)
Gender	6 female, 9 male
Location	United States, living in a rural, mid-size city (9) or living in suburbs of large metropolitan city (6)
Living arrangement	Live with parents (10); live alone or with roommates (3); live with spouse (2)
Level of education	Transition program for life and job skills at a community college (9); Master of Music (1), PhD in statistics (1), medical residency program (1), Bachelor degree (3)
Current employment	Employed in technology, music, and education fields. Internships with local retail shops (bakery, feed store, pizza restaurant, computer repair)
Conversation Partner (secondary participants)	Mother (4); parents (2); spouse (2); boyfriend (2); instructor (2); father (1); brother (1); grandmother (1)

In the pair interviews, I inquired about their relationship, the nature of their joint activities, and their perceptions of their similarities and differences in terms of how they behave or think. (See Appendix C for the interview script.) I asked them to describe the ways they communicate

with each other-including with the use of technology, if they tend to know how the other is feeling, and the types of communication breakdowns they experience with each other. During the interviews, I asked the pair to engage in a visualization activity, described next.

## 5.6 Pair Interviews: Common Ground Visualization Activity

During pair interviews, I led the pair through an activity, designed to surface and capture their public and private goals and tactics for establishing common ground. This activity also served to inform the participatory design phase by exploring symbols and conceptual structures used by neurodiverse pairs to convey social, emotional, and sensory information (e.g., visual representations, social scripts, formulas in autistic language; flowcharts; timelines). To capture the dyad's interaction episode, I appropriated a business analysis technique of modeling processes in swimlane diagrams. Swimlanes diagrams are multi-column flowcharts commonly used to map business processes across functional units (Jeyaraj & Sauter, 2014). Swimlane diagrams are useful for depicting actions of multiple actors engaged in a joint activity. The swimlane diagram template (Figure 8) had a swimlane (a column) for the primary participant on the left, a swimlane for the secondary participant on the right, and a middle swimlane for their common experience.

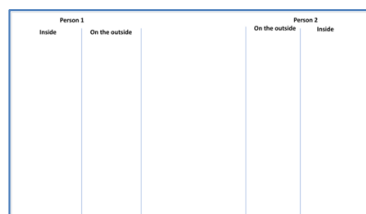


Figure 8: Blank swim lane template slide for diagramming conversations

The primary form of objects in the swim lane diagram were images that serve as metaphors for interaction tactics and internal embodied, emotional states. Although some dialog was captured

to mark important points in the exchange, I did not document the exact utterances because my unit of analysis is at higher levels of abstraction. To seed the visualization activity, I showed the participants a visual communication system comprising *senses*, *emotions*, and *social* images (Figure 9). I selected the *senses* and *emotions* images based on topics and images from the individual interviews, such as the metaphor of a volcano exploding to represent a feeling of rising anger.



Figure 9: Initial Common Ground Visual Vocabulary

The collection of *social* images, represent the interactional moves that occurred during the conversational episode. In Clark’s terminology, these are joint actions and signals that people use to establish common ground. I list below a collection of Clark’s joint actions, along with interactional moves that participants described in the individual interviews. I also list common autistic communication traits that participants may describe as important elements of their interaction episodes. This list serves as the rubric for concepts the visual language should represent. The key joint actions for establishing common ground are as follows:

- Purely from Clark’s conceptual framework:
  - Initiating
  - Closing

- Grounding (establishing background; commonalities)
- Coordinating - negotiating, establishing tasks, becoming aligned in what we will do
- Initial:
  - Proposition - offering / sharing a topic or position
- During:
  - Engaging with proposition - Talking about the proposition
  - Withdrawal - disengage
  - Deflecting, negotiating, accepting, clarifying, etc.
- Outcomes:
  - Accepting (Complying) / Disagreement - could be in agreement or disagreement; exhausting the topic
- Common autism traits that may arise:
- Using scripted conversation
- Verbal or physical stimming
- Deep dive into special interest - fixating
- Distracted (attention elsewhere)
- Perseverating

As the visualizations were co-created by the researcher and both participants, we hoped to obtain a fairly high-level representation of the episode. Participants would likely describe the episode in terms of dialog, actions, and feelings. They would likely describe things at different levels of abstractions, moving from the phrases they said into what they were trying to accomplish. For instance, someone may be angry and want the conversation to end, so they stand up from the table. In another case, someone may not want to state a controversial opinion, so

they do not complete the end of their sentence. Although we did not intend to capture the low-level signals of exact dialog and physical movements, we wanted to capture significant dialog and details along with the higher-level abstraction of the images. By using images, participants would hopefully generate metaphors about their actions, intentions and internal states, although some participants may use the images literally.

I introduced the activity by letting them know that they would, together, recall a recent interaction with each other. I told them that I would be creating a visualization about that interaction, and that the purpose of the visualization was to show the dynamics of their interaction, like the feelings behind the interaction, points of understanding or misunderstanding, and the various ways you try to be on the same page with each other. I explained that we were using a framework called “Common Ground” for this activity - which basically means that our interactions are not only what we say aloud to each other, but also the deeper meaning of our words, actions, emotions, and how we feel in the physical space. I showed and described an example visualization about two people sharing about a hard day at school (Figure 10).

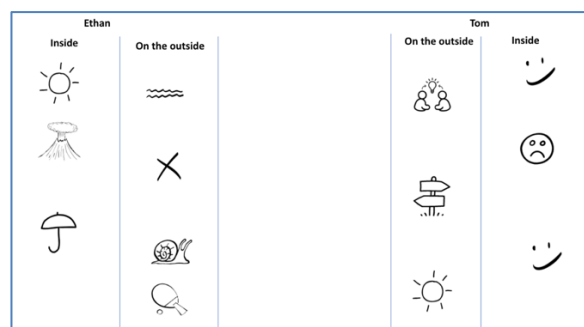


Figure 10: Example visualization depicted a conversation between Ethan and Tom, flowing from top to bottom. Ethan’s internal states (senses, emotions, and social goals or moves) are in the left-hand swim lane; his external states are in the next swim lane to the right.

I asked the pair to come up, together, with an example of a recent conversation that raised some different opinions, goals, or difficult emotions. Examples of these types of conversations

can be sharing difficult news, talking about a controversial topic, or trying to reach a decision. After they jointly chose a conversation to unpack, I asked them to talk through the dynamics and emotions. I asked who started the interaction and where it took place. I asked them to take turns describing what they did, said, and felt, as the conversation flowed. As they walked through the conversation, I prompted them to choose an image that represented how they felt inside and how they thought they presented themselves externally. I populated the swimlanes from top to bottom to represent changes over time as their episode progressed. After we captured the conversation, including how it ended from their perspectives, I asked the primary participant and then the secondary participant to reflect on whether the resulting visual representation of the conversation adequately captured the conversation. I asked them if the conversation they relayed represented a typical conversation. Finally, to explore their imagined ideal conversations and skills, I concluded the interview asking them each to choose a superpower they would most want to have when interacting with the other person.

## 5.7 Pair Interviews Analysis

Data from the pair interviews study consisted of research memos written soon after interviews; transcriptions of the interviews; and Zoom video recordings. As with our analysis of individual interviews, two members of the research team (myself and a Masters student in Human Centered Design and Engineering) analyzed the data following an iterative inductive approach (Saldaña, 2013). Using MaxQDA qualitative coding software, we conducted coding of the textual data. We generated a codebook to capture and align our interpretation of the data. The initial codes were inspired by Clark's Common Ground theoretical framework, and we added codes upon

discussion for emerging themes. Table 6 contains the codebook for the interview questions and Common Ground components of the interviews.

Table 6: Codebook for interview and Common Ground activity

Common Ground concept	Code	Description	Examples
Social interaction partners	People	People in the conversation	
Grounding (establishing background)	Grounding	Background knowledge about each other. Information about activities, relationships, etc. that give each other some context about each other.	Met each other playing bridge (P03). Know someone else who is autistic (P03 - p2; brother knows other autistic kids and the third brother is also autistic)
	Activity	Things they like to do together; things they wish they could do more often.	
	Technology	Technology (devices, applications), media (movies, tv shows, music).	
	Goal	Goal the participant has about their life, activities, relationships, etc. Goal for what happens during a social interaction.	Working on building up her resume. Learning new job skills. Moving into his own apartment. Have more time together.
	Superpower	Desired superpower; if technology could make the superpower happen.	
Social practices	Social	Broad statements about how they interact with people. Can be hypothetical. Broader than 1-1 interpersonal communication. Statement about how they perceive social interactions. Their reflections on their social lives.	I am nervous about large groups. The only activity I do with friends is play D&D. I'm fine with my small group of friends.
Communication moves and acts	Interpersonal Communication	Between the interview participants - how they communicate and interact with each other. How their interpersonal communication has changed over time, things they have in common or different. Discussion about their relationship.	

	Emotion	Explicit statements about how they perceive or process emotions.	I tend to cry a lot. My conversation partner hides her emotions.
	Sensory	Explicit statements about sensory processing or their sensory needs. Experiences connected to how they perceive the world through their senses.	I used to hate loud noises. We didn't go to any Halloween activities because they are scary and I don't want to see skeletons. Touching bed makes me nervous.

Table 7 contains additional codes for the Common Ground activity because they only applied to the activity (e.g., discussing icons). Note that, as with our individual interviews, our analysis included coding both the textual data and the outputs of the visual representation of emotions activity in similar manners. This consistent treatment of the visual activity was informed by related work using interview and visual methods (e.g., (O’Leary et al., 2017)).

Table 7: Codebook with additional codes only used to code Common Ground Activity

Common Ground concept	Code	Description	Examples
Setting of the interaction (the boundaries, both physical and conceptual)	Setting	Setting where the conversation is happening (location, times, occasions, situation)	Living room; one person is at his computer - mom is across the hall; Common Ground example is about an interaction at school; Dinner time; on the way to school.
Roles people take on during the interaction	Roles	Roles people take on during the interaction; position	Passive; assertive; leader; trying to positive and encourage others to be positive; advocate for something that they want.
	Goals	Goals they express having for the social interaction	

Engagement and coordination (the moves one makes to establish tasks, negotiate, accept / reject, clarify, reflect)	Conversational moves	The ways in which people engage and coordinate actions during a conversation. The acts that keep or hinder the flow of conversation. Includes initiating, proposing topics, engaging, and closing. Choices and rules that they tend to follow during the conversation. Social practices that are helpful; confusing; source of conflict. Broader than communicative acts. Practice that is an assemblage of communicative acts.	I try to find free time in her schedule. We made dinner together. I ignored her while I played my game.
Communicative acts	Communicative act	Discrete verbal communication, non-verbal communication actions. Description of what they said or did; specific to one instance.	Close the door; went into my room; yelled; cried; asked them to repeat what they said. Discrete actions.
	Icon	Choosing icons to use, talking about whether an icon makes sense or not.	P03 choosing the puzzle icon to represent her building up her resume.
	Reflection on Common Ground activity	Participants' comments about doing the activity; usefulness.	It was confusing. I learned something new.

## 5.8 Findings: Social, Emotional, and Sensory Factors in Autism

### Community

Community observations surfaced issues relating to autism advocacy and considerations for neurodivergent ways of engaging in social and physical environments. At a conference organized by autistic community leaders, autistic youth and adults presented on topics that they deemed important and that they framed in terms of their perspective and choice of terminology. Topics included the right to be autistic; embodied and emotional considerations related to alexithymia (difficulty perceiving emotions) and interoception (internal sensations, such as sense of balance); neurodiversity (naturally occurring diversity of human neurology) and the social model of disability; thinking with the autistic perspective; and respecting autistic ways of playing and interacting. Within the public spaces that our observations took place, attention was given to sensory experiences. The autism conference was held in person—this was prior to the COVID-19 social distancing restrictions. As alternatives to being in the large auditorium, conference coordinators provided live-streaming for people at home and for conference attendees who preferred to be in at the conference center but in a smaller, sensory-friendly room. This room had dim lights, bean bags, chairs, and sensory aids (e.g., squeeze balls). Similarly, sensory processing was also a consideration at the zoo event with access to a sensory garden and hands-on exhibits with a limited number of attendees. Children could check out “sensory backpacks” containing exploration tools such as binoculars and checklists. By providing sensory objects during community events, organizers enable autistic individuals to engage in their natural sensory-seeking behaviors and incorporate sensorial modalities into learning.

In addition to providing evidence of the importance of designing sensory-sensitive spaces, our direct engagement with autistic self-advocates and representatives from autism organizations raised three primary considerations related to our research: (1) community preferences to identify as “autistic individuals” rather than “individuals with autism,” (2) limitations of clinical instruments designed to assess both emotional literacy and sensory sensitivities, and (3) the importance of minimizing research burden on participants. I incorporated these insights into our research plan and protocols to reflect preferred terminology, to use real-world visual representations of emotions, rather than instruments, and to minimize extra communications and logistics required of participants.

## 5.9 Findings: Communication in Daily Rounds

During the participants’ daily rounds, their communicative practices centered around home, job, and life skills courses; work; and entertainment. These descriptions were based on interviews conducted prior to the COVID-19 pandemic. Participants primarily interacted with family, classmates, work colleagues and mentors, therapists, and online gaming communities.

Participants primarily interacted with people who were non-autistic. However, the interactions with other members of the life and job skills program were neurodiverse, meaning autistic and/or identifying with other neuro-atypical conditions such as attention-deficit disorder or schizophrenia. The majority of participants live with one or more parents and siblings, while three of the participants live with partners or roommates. During the individual and pair interviews, participants shared issues and goals they had related to living with others, such as privacy, autonomy, and demonstrating independent living skills.

The participants described their daily rounds as traveling to their workplace or school, then, for some, going to a second location such as a job, internship, or speech therapy. The majority of participants do not drive, instead relying on public buses or rides from parents and extended family. Some participants needed to walk long distances between transportation nodes. For evening activities, they coordinated with others regarding childcare, meals, sharing computers and video game consoles, and family rules for technology usage. Several participants discussed that they prioritize balancing socializing with regrouping in preparation for the following day, as described by Kyle, *“I do want to socialize with people. But I just want to relax. I don't want to do too much at once...because I get too tired...and if I do too much, I get overwhelmed.”* Participants described spending time on weekends caring for children, doing chores, and pursuing interests such as job skills training or outdoor hobbies. They talked about valuing their imagination and rich inner worlds, cultivating these parts of themselves by reading books, envisioning imaginary characters, and contemplating alternate realities.

All of the participants described their social relationships as grounded in routine, periodic interactions with family, instructors or job mentors, work colleagues, and a small group of friends. The participants shared that they value these relationships because they can talk about and engage in common interests and have the support of someone who encourages and understands them. Some desire more friends and romantic relationships. Some participants are looking for more independence and autonomy, such as being able to take on more job responsibilities or live on their own. They discussed their steps towards independence, such as getting a job by passing an interview and getting their first paycheck, with a sense of pride. They look forward to future accomplishments, such as Kyle sharing steps he is taking towards moving out of his parents' home into an apartment, saying, *“I feel proud when I learn the skills to get*

*ready to move to my own apartment, like cooking, shopping, laundry, pay bills. Okay, peaceful – I'll be peaceful when I'm in my own apartment and say I did it.*” On the other hand, some participants instead felt external pressure from parents and grandparents to be more independent in daily lives, such as managing their medicines or planning their transportation.

When asked to invite a trusted conversation partner to their pair interview, the primary participants primarily selected family members, namely, parents, spouses, a brother, and a grandmother. Other trusted conversation partners were boyfriends and an instructor in their job training program. Chase, who invited both his mother and father, said he chose to invite his parents because he *“trusts my parents more than my friends.”* Family members cited pleasurable activities as going out to dinner, going to movies, taking walks together, and *“beating each other”* (Daniel) at video games. Several families had a playful dynamic with each other, saying they like to *“just having fun with each other doing everyday kind of stuff,”* with a mom saying that she likes to tease her son by *“asking weird questions, like if he wants pink shirts while shopping”* (Chase’s mom). Alec and his mother often discuss scheduling of his upcoming events as a musician. His mother said, *“I guess I’m sort of right now, the executive assistant to him. I help him schedule and understand conflicts and resolve them with all of his different musical commitments and gigs that come up. I drive him to all the places that are farther or more difficult to get to than he’s comfortable doing by himself. He’s making good progress driving, but I drive on freeways if necessary.”* Families used cell phone texting, messenger apps, phone calls, and to a lesser extent, video calls (e.g., Google Duo, Facetime) to keep abreast of daily logistics. When they chose the communication medium, they factor in their personal comfort. For example, Sarah shared that she prefers texting to a video call because she can *“do my own thing at the same time”* and does not have to do as much *“masking”*, referring to the practice of

subduing autistic characteristics and intentionally performing neurotypical social norms, such as making eye contact (Zolyomi et al., 2019). In another case, Alec's mother said, "*When it's giving him instructions, it's over the phone not texting. It takes more detail to make sure he understands things that I tell him.*" This type of family support was evident in many of the families, spanning activity logistics and scaffolding steps to take towards independent living.

Families expressed tensions in wanting to spend more time together and in what constitutes quality time. For instance, Chase said that his divorced parents ask him to do "*anything that can get me to hang out with them, especially my dad since I don't usually see him a lot.*" Chase's mom shared that she would like him to "*get off the computer and do anything physical.*" Daniel noted that he would like to do more with his brother, such as home improvement projects, recalling a time the family "*straight up built a deck from scratch.*" The families cited obligations such as jobs, health challenges, and childcare as sources of time constraints.

Four of the pair interviews were with couples in romantic relationships. They cited pleasurable activities as being going out to movies, going to restaurants, exploring the cities, and sharing hobbies such as playing bridge and hiking. Technology played a part in forming and maintaining their relationships. Sarah met her boyfriend through a Facebook dating app. When they reached the point of wanting to meet in person, her boyfriend wanted to have a phone call first to "*have a voice matched to the person*", which was difficult for the primary participant to agree with due to her feeling "*weird about talking on the phone with someone I have never met.*" Two of the couples in the pair interviews shared that a source of tension in their relationship was negotiating time together and time with a broader social group. As Alana shared, "*I'm very stubborn, and I don't think I need help with social interaction—but I do. I would like to be*

*comfortable in social groups. It's not that I don't want to be social, because I do. It's hard, so I just retreat from it.*" On some occasions when she felt particularly upset, Alana hand-wrote notes to her partner saying it was easier to compose her thoughts and express herself in written form. Other couples expressed bonding over both preferring time together over yearning for time with an extended social group. For instance, the pair interview with Sarah and her boyfriend occurred during the COVID-19 pandemic and they were quarantining together. They sometimes playfully text each other from different rooms. Although they missed going outside as much as usual, Sarah's boyfriend said *"most of the stuff we like to do is already inside. We are both introverts. This hasn't been much of a change for me."* To which Sarah responded, *"I'm kinda like welcome to my life. Social isolation."* This sentiment that the COVID-19 pandemic is causing non-disabled people to face circumstances leading to social isolation resonates with the autism and broader disability community, who call for more empathy for the experiences of disabled people (den Houting, 2020).

To contextualize the participants' social relationships and emotional experiences, it is important to recognize that many of the participants shared past experiences of trauma. These experiences included bullying, feeling separated from peers in school (when in special education classes and mainstream classes), and varying forms of abuse. This finding underscores that *"studies suggest that youth with intellectual and developmental disabilities are 1.5 to over 3 times more likely to be maltreated than their peers"*(Kerns et al., 2015, p. 3476). In our study, many of the participants who experienced trauma described memory loss, emotional numbing, and other feelings and behaviors that are psychologically recognized as traumatic stress. Several participants had a continual fear of getting picked on or being physically assaulted, habitually scanning their environment for unsafe people and situations. These traumatic experiences

continued to impact their stress levels and apprehension about social interactions in their daily rounds. Next, I unpack the emotional experiences of the participants, as situated in interpersonal relationships and sensory experiences.

## 5.10 Findings: Learning about Emotions

All of the participants described their emotional experiences as rooted in their childhood. Some participants discussed “*hurtful*” or “*traumatic*” experiences from social interactions with family, teachers, and peers. As described in the following sections, they all engaged in interpersonal interactions in embodied ways that are informed by their cognitive styles; however, they faced misunderstandings and misperceptions due to disconnects in communicative and emotional styles with their conversation partners.

The participants described learning about emotions in implicit and explicit ways. These early learning experiences stayed with them into adulthood as they reflected upon their emotional experiences. Some participants described learning about emotions from role models, such as parents and teachers. As described by Alana: “*When I was growing up [labeling my emotions] was an issue. Now I’m more in tune with my emotions, and I think as a kid, you just naturally learn from your parents more so than have a sense of your own emotions.*”

Many participants discussed their personal emotional growth from their childhood to the present. When describing how they formed their ideas and mental models about their emotional states, self-reflection in the form of journaling was a method for Sarah to parse and interpret her feelings. She would “*be writing out "I don't know why I feel this way" and I'd be like "I guess*

*this thing bothered me and maybe I'm angry about it. Oh, I guess I'm angry." It would be kind of more intellectualizing, before I realized how I felt."*

By describing the events of a day and emotions they had, participants formulated views on their emotional capacities and perspectives. For example, David had a strong philosophical stance towards how he cultivates a positive attitude for himself:

*"There's drama that I can't control...because been there, done that. I'll stick with just being a peaceful fellow. I remember back then I was usually a big grumpy fellow who was always angry all the time and just roar...But since then, I'm becoming more calm. I pray a lot. I just think peacefully. Because there was this teacher that told me a lot about being positive...and if you're more positive, happiness grows better."*

For many participants, the primary role of technology is having social-emotional resources available through online and other digital media sources. For Alec, some characters in movies were role models for expressing emotions:

*"This is what I like about Disney, especially the older generation, the Walt Disney movies aren't afraid to let out their feelings, even though it kind of scares people...[Some movies] basically sugarcoat it, don't let out the feelings, which bothers me because I like to not bottle it up, and sugarcoating, like being honest, I was raised up on honesty."*

A few participants talked about explicitly seeking out information about emotions from books and YouTube videos. These were sources for definitions of terms related to emotions and information about how people express and interpret social cues. Drawing from knowledge he gained from YouTube videos, David observed body language to pick up on emotions:

“Sometimes when I look in their eyes, I mainly focus on their pupils, actually. Because I watched this video about how to understand a person's view, how they feel, just by looking into their pupils, and I was like ooh, this is interesting. Even looking at their body movements, of how they move, how they act, which legs are they posing, how they use their arms, head, face, eyes, nose.”

David and Emily described their expression of emotions as a form of embodied acting. David said, “I try my best to use my acting skills. I never went into drama... I just watch a lot of movies, videos, try to copy what other people do. Then my expressing emotions from face pictures, like oh, holy cow, eyebrows raising, eyes moving.” Sarah used an app, Brain Works (Brain Works, n.d.), for connecting how she was feeling with recommended sensory, physical activities. The app (Figure 11) calls this balance of sensory inputs and sensory processing as one’s ‘sensory diet.’ Sarah, who was diagnosed as autistic in adulthood, said that the app was “helpful for ideas” as she learned more about autism.

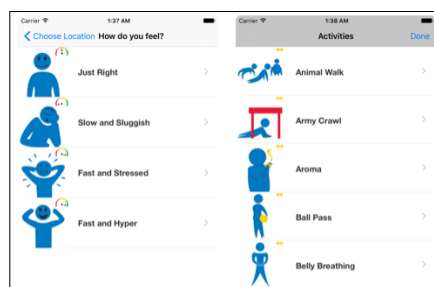


Figure 11. BrainWorks mobile app for the user to track how they feel (e.g., just right, slow and sluggish, fast and stressful, fast and hyper) and follow prompts for recommended activities (e.g., animal walk, army crawl, aroma, ball pass, belly breathing) (Brain Works, n.d.). Copyright: Fair use.

The participants’ descriptions of emotional learning demonstrate that their affective learning is entwined in their technology and media experiences. In contrast to therapeutic perspectives that emphasize that autistic individuals have difficulty learning from social modeling and self-reflection, our findings demonstrate ways that their learning is both implicit and explicitly

detailed, and sometimes self-initiated to seek out knowledge about emotions. This also surfaces the hidden work autistic individuals do to attune to verbal and non-verbal, sensory cues.

### ***Visual Representations of Emotions: Social-Emotional Learning***

I observed that their childhood exposure to imagery of visual representations of emotions during social-emotional learning in therapy, school, or home influenced the participants' attitudes towards visual models of emotions. Their learning experiences with visual representations helped them formulate their conceptual models of emotions, and they had specific reasons why the imagery resonated or did not resonate, with their real-world emotional experiences.

During the visual elicitation activity, participants compared the visual representations of emotions to their educational, therapeutic, and social experiences. For Matthew, the general idea of using imagery to represent emotions reminded him of how emotions were represented as discrete characters with unique personalities in the animated Pixar movie, *Inside Out*. In the film, the internal emotional life of a young girl is depicted as an ensemble cast, including Joy, Fear, Disgust, and Anger, who live in her head and are continually vying for control of her behavior. Like others, Matthew was familiar with the feelings wheel and illustrations of facial expressions shown in the visualizations we shared. Matthew said that he had seen it *“done plenty of times before, using colors to represent certain personalities.”* He quickly noted that he is *“actually more in the yellow section – not energetic but more creative and optimistic.”*

For Alec, when he was shown the facial expression image (Figure 15-A below), he recalled, *“Oh yes, I remember in my high school life skills class, doing face recognitions.”* In his reflection of the facial expressions, he wanted to see the facial expressions on women as well as men, and a wide variety of age groups (*“babies, toddlers, children, teens, adolescents, young*

adults, even senior elderly people.”) He shared that in his place of employment where the general public comes, he “can't always know what they are thinking entirely which is why I am with behind-the-scenes type jobs that don't deal with customers. [I am in] slower-paced jobs which I know what some people are thinking, then this helps and this corresponds to the details (of facial expressions) matter.” These vignettes demonstrate that the participants’ social-emotional-sensory experiences were constructed within the context of technology and media resources, conceptual models of emotions, and social interactions.

## 5.11 Identifying and Expressing One’s Own Emotions

Feeling and expressing one’s emotions is an important aspect of emotional literacy that can be difficult to tap into and describe (Barrett, 2017). Some participants described their baseline feeling being happy or optimistic, although others described generally being, for example, “neutral” or “neutral or sad or anxious.” In this section, I include samples of the personal visual representations of emotions drawn by participants. As depicted in Figure 12, two participants focused on their neutral state when asked to draw a visual representation for how they experience emotions. Their emphasis on their neutral state was evidenced by their focus on a neutral emoji during the participant-generated images.



Figure 12 (a) Ethan’s singular emoji with two eyes and a flat mouth. (b) Matthew’s neutral and angry emojis stylized as bears

Some participants relayed vivid accounts of their sensory, embodied experiences with emotions. For Alana, sadness is felt “like a very physical pain in my chest.” David described his

“anger and upsetness coming from my heart. Because I can literally feel the inside of my ribs being either warm or cold.” He could sense that his blood pressure was really high and his facial expression and voice changing. I observed that many participants described feeling flooded by a sense of “overwhelming” emotions. For some participants, they experienced swings in both “positive” and “negative” emotions. Another participant, Sarah, described her tendency for being flooded with emotions as being “just really sensitive and the world is very intense, and I just take it all in, and I can't block it out.” (Figure 13 (a)). Caylee had developed an imaginary creature, The Flabbergast, who “was known as the guardian of feelings” (Figure 13 (b)). Caylee described that The Flabbergast could, by opening her eyes, take “control of an emotion,” which are represented by different colors within and around her. The Flabbergast “cares for emotions and loves them like her own children. She protects them, with all her might because she’s afraid that they might take control of her.” In Caylee’s case, she imagined the embodied experience of emotion as displaced into the character of The Flabbergast.



Figure 13. (a) Sarah’s visual representations of four key emotions: calm, anger, content, and confusion. (b) Caylee’s imaginary character, The Flabbergast, who controls and protects emotions.

In contrast to swings in the full range of emotions, other participants said their emotional shifts were from neutral to angry feelings (Figure 14). They tended to suppress their anger towards others, and sometimes, on the other hand, could not control their emotional expressiveness. For Mitchell, he depicted his anger (Figure 14 (a)) as a stick of dynamite, saying

that he is usually a peaceful, happy guy, but *“once someone gets on my bad side, then all hell breaks loose.”* When their feelings escalated to *“exploding,”* intense sensory experiences could result in headaches and panic attacks. Kendall described a situation in which she *“ended up yelling and screaming and exploding, and that causes headaches and panic attacks...I’m just really irritated and frustrated because they just don’t get it”* (Figure 14 (b)). Jack described that when his feelings escalate to a burst of anger, it is similar to how he *“can numb my whole body to take the impact of a punch, but instead it’s letting all the energy from all the punches out all at once with my fists. So basically, completely taking the energy from all the punches I have taken over the years and just let it all out at once.”* I report on these emotional shifts to highlight how aspects of time, sensations, and origins in traumatic experiences all contribute to these intense, emotional experiences.

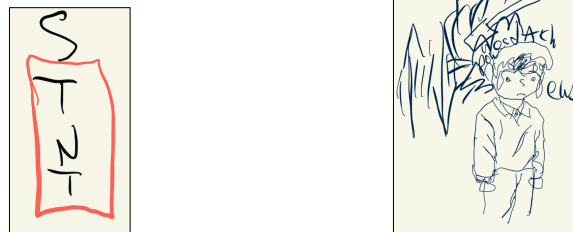


Figure 14 (a) Mitchell’s anger depicted a stick of dynamite. (b) Kendall’s buildup of distress in body.

Participants considered how their social relationships have been impacted by misperceptions of their emotional needs and styles. For Ethan, he expressed that he *“does not get sad like other people do”* and that this was evidence for him that he *“has a different mindset”* than other people. In the case of Emily, she did not want to express her true emotions to her mother when her mother was asking about her decisions and actions. Rather than expressing her true motivations, she tried showing one type of emotion, hiding the different emotions she felt inside. Another participant, David, said that he *“usually does not express through my face when I’m trying to explain something,”* and that he sometimes did not want to show his emotions so he

could keep them to himself. This notion of viewing not expressing emotions as a “*skill*” was echoed by Chase. Chase shared that, when upset, he tends to keep his emotions bottled up—a skill he expressed pride in—until he can let his emotions go. Chase’s parents recognized that “*he likes holding things close to his chest. The funniest thing about it is that we both as parents, we both know when he’s stressing about something or grumpy about something. His whole entire behavior changes, but we don’t really push him on things when he is feeling off like that.*” To share emotions, participants needed to feel safe and comfortable. Then within that context, many participants expressed a desire to be able to more openly share their emotions, as described by Mitchell who wanted to improve “*how to express my feelings more and explaining how I feel about friends and family. (Emotions) in general – positive and negative.*” This sentiment highlights that participants felt there were barriers in conceptualizing, verbalizing, and sharing their inner emotional lives.

During the “show-and-tell” portion of their interview, participants described activities or showed the objects they brought with them that brought them a sense of comfort and pleasure. A sample of participant objects are shown in Figure 15.



Figure 15. Sample of objects that participants turn to for comfort and relaxation. Top row: (a) Notebook for drawing characters from the animated show Steven Universe. (b) A flip phone. (c) A smart phone with applications for

transportation and entertainment. (d) A DVD of a participant's favorite musician and musical educator. Bottom row: (e) Support dog. (f) Two Nintendo DS consoles and (g) finger armor.

Many of the participants displayed technology devices and media (e.g., books, DVDs) as sources of personal satisfaction, happiness, and pride. For Jack, video games and playing card games were a reliable source of happiness, whereas other activities *“to try and make me happy isn't really making me happy for too long. Usually, it makes me happy for a few minutes, five at the most sometimes, and then it just – why am I doing this?”* The pure entertainment value of technology and media use should not be undervalued as a source of positive and contented experiences. Daniel viewed his video watching as purely entertainment, with no connections to education or his future goals, but a way to cultivate the *“entertainment period of my life”* in the midst of feeling *“passive”* about other aspects of his life. However, participants also associated boredom, stress, and family conflict with technology and media. Chase was an avid video gamer who was, as he described, *“what they call a toxic player”* because he talks bad about other players *“for doing the wrong thing”* in gameplay. In response, *“people are just like hey, calm down, it's just a game. For me, gaming has always been my life pretty much.”* His self-described *“addiction”* to video games caused him to *“shrug off doing chores”* and fueled arguments between him and his parents and when he was made to stop playing, he felt *“a lot of emotions happening at once that I do not like.”* These scenarios surface the participants' complicated socio-technical emotional experiences that elicited a range of emotions that could be difficult to discern into discrete emotional states.

## 5.12 Recognizing Emotions of Others

Recognizing the emotions of other people involves perceiving emotional signals and then interpreting those signals. A prominent sentiment among the participants was that they wished

they could better understand other people's emotions. Kendall wished for a superpower to be a "*mind reader to know people's emotions. [I could] hold up a phone to their face and it would tell me what their facial expression is and what their emotion is.*" Recognizing emotions in others was not an all-or-nothing activity for many of our participants; rather, they were more attuned to certain signals over other signals. Several participants noted that they were more likely to notice and understand facial expressions over other emotional cues. Participants shared that they tend to miss emotional signals that were "*more subtle,*" such as tone of voice and the particularities of word choices, such as sarcasm. If they were unsure of how to interpret a non-verbal communication signal, some participants would be, like Alana, "*very direct in that way where I will ask, what's happening here.*" Alana and her spouse shared that they get into arguments stemming from Alana detecting a change in vocal pattern or inflection, even "*energy*". Alana will want to unpack the communication, but if her spouse did not have an explanation or adequate words that "*are literal enough for her to understand what I mean, without being vague*", there is shared frustration at the impasse of not being able to make sense of the communication and not letting it go.

Kyle described a recent conversation with his mother in which he could "*tell she is sad when she's crying. I get it...I was born very slow. When she is crying, I feel like I hurt her feelings by accident...I do get why she's crying, like she can't let go of her son.*" Jack also shared that he has experiences with his mother in which she is crying. For Jack, these were times he did know what she was feeling because he saw "*tears coming out of her eyes.*" Otherwise, he said he does not know her feelings because "*she has a blank face,*" to which his mother alluded to feeling unseen by responding, "*I'm a very blank person...apparently.*" These examples highlight communications in which the primary and secondary participants shared intense, emotional

experiences. I explore the phenomenon of the co-construction of emotional experiences further in section 5.13.

### **Visual Representations of Emotions: Calibrating Interpretations of Emotions**

The visual representation that prompted the most conversation about reading the emotions of others was the facial expression image. Several participants noted that they have seen similar images used in life skills classes and at doctor appointments for “*reassessment of disability.*”

Daniel articulated the key attributes he noticed in the faces, saying, “*I do associate joy with a smile, surprise with wide eyes, slack jaw...Sadness, frowny face, I guess. Anger, baring teeth, low brow, yes. Disgust, scrunched back, yeah. And fear, wide-eyed.*”

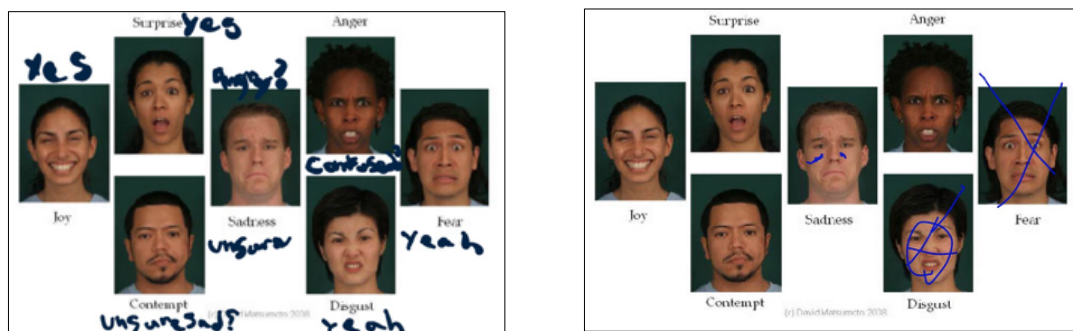


Figure 16. (a) A participant edited the facial expression image to indicate they agreed with the depictions of joy, surprise, disgust, and fear, but not the other emotions. (b) A participant added tears to sadness and did not agree with the expressions for disgust and fear.

Most participants had a strong reaction to the facial expression image, proclaiming that the expression looked “*comical*” and “*over-exaggerated.*” They were also not in consensus with the labels given to the emotions. Some felt that sadness looked more angry than sad or needed tears to truly be sad (Figure 16). Many of the participants did not think the emotions of contempt and disgust were clear or necessary. Some participants asked the interviewer for clarification of what contempt meant and even after hearing the definition, did not resonate with that emotion. A few participants remarked on the unbalance of gender and racial representations of the actors. They

noted the need for full representation of gender, ages, and races for all of the emotional states. Their responses demonstrated attention to patterns and tendencies to systemize, which is a common trait of autistic individuals (Baron-Cohen et al., 2009; Ropar & Peebles, 2007) as well as attention to social factors in reading emotions. This perspective aligns with prior work, described in the Introduction and Background, calling for fuller representation for gender and racial representation in emotion AI and other algorithmic modeling.

### 5.13 Social Construction of Emotional Experiences

Last, I surface how emotional experiences are co-constructed in social relationships and include a component of attending to emotional and sensory needs. These findings contribute empirical evidence of the constructivist framing of emotions, which, as discussed in Chapter 2, Theoretical Framing of Autism, posits that emotional experiences are constructed within a given context, which includes the social context. Most participants shared they were motivated to engage in social activities for their benefit (e.g., attending a dance) and to support close family and friends (e.g., going to an art show). However, participants described that participating in social interactions was often heightened by an underlying emotional state of anxiety and stress. Sarah's attributed part of her stress about social interactions as having to engage in what she termed, "*social dancing*," which consisted of doing "*extra stuff like small talk*." Sarah's boyfriend expanded that Sarah is "*not good at social dancing...trying to go through several steps to get to the point you're trying to make; trying to make sure people feel good; distraction outside of what you are actually saying*." For Alec, feelings of social discomfort were exacerbated—and sometimes accompanied with feeling nauseous—when people cut him off and do not give him enough time to complete his sentences during group conversations, especially given that "*it takes*

*him a while to get out what he's wanting to say."* Alec and his mother were working on strategies to handle these situations, such as taking a break so his frustration does not build up, thinking about what he wants to say, and then following up with an individual, rather than addressing the whole group. Participants were particularly aware of when their sensory and emotional needs were different than their close family, as conveyed by Alana:

*"I just felt extremely alone even inside my family, and so that's another tough spot, because—sorry. [tearful] They would say things like oh, she's antisocial and I didn't know what it was. But I would literally go to a family function and just go to a room by myself with a book, and I would be fine. I didn't think anything of it, because I was happy. But to them I guess it was offensive or oftentimes I wouldn't speak, I wouldn't say hello or things like that. They would get upset."*

Social interactions could be exasperated by sensory experiences, such as a ticking sound in the background or a nearby hyperactive child that *"overwhelms all of your senses."* Social interactions could also be made uncomfortable due to a combination of sensory inputs and social pressures, such as being surrounded by people who want to talk with you or physical closeness between romantic partners. Emily and her boyfriend discussed her fear of being close to particular parts of the body, such as mouths, and depictions of human bodies, such as skeletons at Halloween. She expressed that she *"sometimes feel bad that he has to be careful because I get triggered for a lot of different things, sometimes I didn't even know about."* Her boyfriend, in turn, expressed that his concerns about her being triggered and that he, too, was emotionally impacted by these situations. This example highlights the interdependency between the couple's social, emotional, and sensory experiences.

Participants expressed discomfort due to being questioned by strangers. For example, Kendall described rocking and enjoying the music at a rave when organizers approached them, shined a flashlight in their eyes, and asked her if they were ok. Kendall perceived that they thought they may have been on drugs so they *“came out. I told them I am autistic. I’m fine.”* Kendall felt embarrassed and anxious and left the event. As participants had experiences like Kendall’s, they anticipated misunderstandings for future interactions and some took steps to mitigate potential confrontations. For example, Alec shared that he experienced sensory overload and stress when flying,

*“I always have an autism card on me, I give it to the passenger next to me and also the flight attendant as well so that they know that I have autism. And it's served me very well because, in the past, air travel didn't go very well when I was younger because I became panicked and afraid of air travel.”*

Writing as a communication strategy also resonated with other participants including Alana. When she was in a series of arguments with a close family member, she felt communication was *“better in writing. That way emotions don't get too high. When we're talking face to face, it's not good. So oftentimes we'll text or sometimes I'll write a letter.”* Some participants expressed explicit ways they wished they could influence others' emotions and behaviors during social interactions. For instance, when describing conflicts he experiences with parents and teachers, Chase expressed that he wished he had *“ice powers. I would ice their mouths. I'd keep people I don't like away from me. Freeze them out...Not in a negative way – more like a positive way; a fun way.”* In a similar vein of keeping negativity at a distance, David was bothered that, *“whenever someone tells me about how their day went, it's usually negative. I want to be positive and for them to be positive, too.”* By these actions, participants attempted to

predict and impact the social-emotional experiences of other people. These insights add to the potential role of affective computing in not just reflective affective states, but actively shaping affective experiences.

### ***Visual Representations of Emotions: Emotional Signals Between Social Partners***

The notion of how emotional experiences are socially constructed raises the issue of functionally similar vocabularies. Differences in vocabulary or variations of interpretation among people can add to the difficulty in establishing a mutual understanding of emotions. This can be especially relevant for autistic individuals since “63% of children with ASD meet criteria for a language disorder and even those with large vocabularies and strong verbal abilities often struggle to communicate their emotional struggles and experiences to others” (Kerns et al., 2015, p. 3476). Consistent with this tendency, during the visual representation of emotion activities participants regularly asked for definitions of descriptors (e.g., contempt, discerning) in the feeling wheel and the facial expression images.

Facial expressions, such as those in our visual representation, also did not resonate with all of our participants as predictable means of either expressing or perceiving emotions. Some participants described situations in which people questioned them about their emotions based on their facial expressions, which in turn created a feedback loop in which they were then uncomfortable for being questioned. A fairly common experience for the participants was that other people interpreted their baseline facial expressions as negative when the participants were actually feeling neutral. As Sarah shared, while looking at the facial expressions image,

*“I don't always show these facial expressions when I have a feeling. I feel like I usually have a pretty blank expression. I will smile and laugh when I'm happy... but I don't think I make these*

*faces all the time when I'm having these feelings...I notice that I tend to have the facial lines of sadness when I'm just neutral or when I'm concentrating...My concentration face looks sad, and I've often had people come up to me and say that I look sad.”*

In terms of reading emotions, they also do not always attend to faces due to sensory and social overload, as found in other research (Zolyomi et al., 2019). When they do attend to faces, the participants' interpretation of facial expressions varied widely during our visual activity. In essence, based on the participants' engagement with the facial expression image, the emotional signals between participants and their social partner would be ascribed different meanings by each person. This misalignment led to feeling emotionally disconnected from their social partners and having misunderstandings during communication and coordination activities.

## 5.14 Establishing Common Ground

In this section, I present findings from the “Common Ground” activity during the 15 pair interviews, during which the autistic participants and their trusted conversation partners described recent emotionally-laden interactions focused on the pair (or autistic individual and parents, in the cases where both parents were in the pair interview.) The types of interactions the participants described spanned arguments in which feelings were hurt, misunderstandings about instructions, difficult discussions about future plans, and anxiety-inducing social interactions with people outside the pair. This activity surfaced the ways that neurodiverse pairs describe how to establish common ground. As I described in Chapter 4 Methodology, according to Clark's Common Ground theoretical framework, interpersonal interactions can be conceptualized as joint activities centered around goals, which are both public (external) and private (personal). Each neurodiverse interaction pair will have their particular way of entering into an interaction,

broaching topics, coordinating their interaction, encountering friction in the interaction, addressing friction, and finally, closing the interaction. By analyzing the ways in which neurodiverse pairs establish common ground, and surfacing what they tend to keep private, this work can inform the design of communication and affective technologies that seek to scaffold neurodiverse interactions. In particular, this Common Ground research activity highlights key ways that their interpersonal communication is co-constructed and comprised of social, emotional, and sensory experiences.

I present the ways in which the neurodiverse pairs described establishing common ground. I focus my analysis on the following components of Clark's conceptual framework: (1) the roles they described enacting, (2) their description of their conversational moves and conversational acts, and (3) conversation outcomes. Note that my analysis is based on the conversation pairs account of the interaction and is not based on my direct observations. Therefore, my insights relate to how the pair remembered and described their interactions. The key insights are that: (1) both autistic and non-autistic individuals experienced what may appear to be incongruent internal and external states, (2) in cases in which the non-autistic partner had a strong emotional stance, the autistic individual tended to be focused on trying to understand the logic (or, in some cases, keep distant from) the emotions, and (3) the pairs tended to get "hooked" on the conflict, cycling through behaviors and statements and then, often, ending the exchange without a mutually-agreeable resolution.

The participants selected images to accompany their retelling of the interaction (Figure 17) and were allowed to select additional images from a web site ([theNounProject.com](http://theNounProject.com)) to augment the provided set (Figure 18). All of the images from the original set were used at least once by at least one participant. Participants added the following emojis that represent emotions:

three neutral emojis (one of which resembles the participant who chose it); a “meh” emojis, two exhausted emojis; a surprise emojis; and a “It wasn’t me” emoji, one proud emojis. The participants also added the following images representing actions and emotions: juggling, tornado, heartbreak, ran out of time, questioning, and idea.

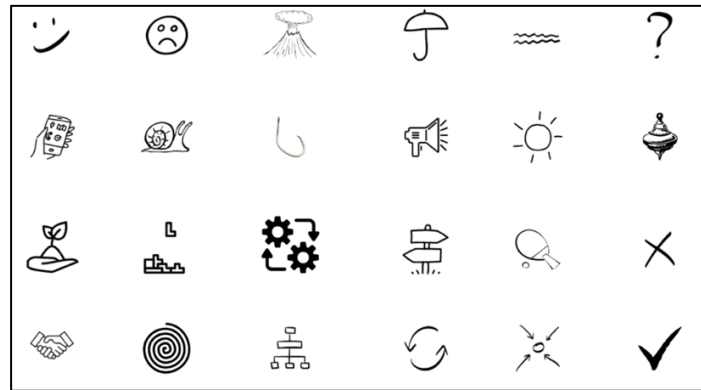


Figure 17: Common Ground visual language provided to participants

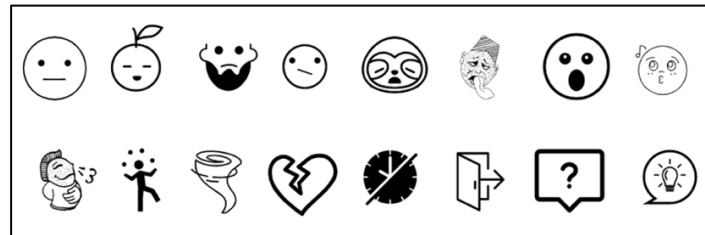


Figure 18: Images added by participants to the Common Ground visual language

First, I describe the range and meaning of roles described by the neurodiverse pair during the Common Ground activity. According to Clark’s framing, a role is not an identity, such as a son or spouse. Rather, a role is a position and is tied to a goal someone has during an interaction, such as being a leader or being passive. As the conversation pair described their interactions, they tended to articulate their roles when the interaction had some tension between what they were each trying to accomplish.

Here I examine two interactions in which roles were prominent. First, in the episode described by Daniel and his brother, Daniel intentionally tried to get a rise out of his brother by

making loud sounds while eating. This interaction, depicted in Figure 19, illustrated that Daniel began the interaction feeling calm (the word he attributed to the two wavy lines) both internally and expressing externally. Daniel’s brother expressed himself externally as happy (represented by the sun). As the interaction progresses, Daniel’s brother felt sad (frowny face) and then absolutely infuriated (volcano image). In response to “hooking his brother” (represented by the hook), Daniel felt happy (smiley face) that his brother was responding negatively. At the end of the interaction, Daniel returned to his calm state, whereas his brother left the room and attempted to brush off his frustration. This episode and common ground visualization illustrate (1) the roles of the brother (one as the “baiter” and the other as the “hooked”), (2) the stark difference in the internal and external emotional experiences of the brothers, and (3) a typical conclusion to their conflicts, in which Daniel’s smugly returned to his “*undisturbed day*” as his brother left the space and attempts to brush off the encounter.

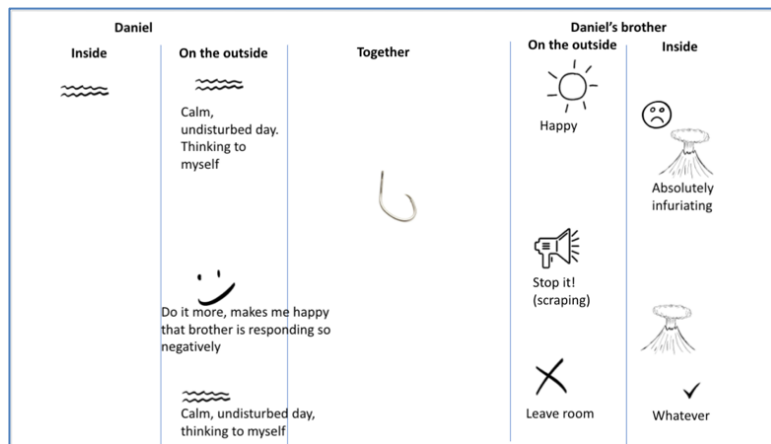


Figure 19: Diagram of interaction episode, as retold by Daniel and his brother

In the second example in which I highlight the roles of the participants, Emily and her boyfriend enacted the role of self-advocate and “questioner/resolution-seeker,” respectively. Their interaction (Figure 20) was about Emily desiring to spend more time at work-related



In both cases of Daniel and Emily, the images they chose for the middle swim lane, labeled, “Together,” (the hook and the ping-pong going around and around) reinforces the roles they were enacting and the dynamics of interaction, which they said later was fairly typical in their relationships overall. From these two examples, we see that the roles of the individuals were evident as they co-created the swim lane diagrams with each other and the researcher. This does not imply that during the interaction, they explicitly state these roles or their goals, but rather, by co-creating and reflecting on this activity, a layer of meaning is solidified or perhaps generated.

Second, I examine the types of conversational moves and conversational acts as described by the participants during the Common Ground activity. Conversational moves are the ways people engage and coordinate actions during an interaction, such as proposing topics and engaging on a topic. These moves keep the conversation going or hinder the flow of conversation. Conversational moves are an assemblage of communicative acts, which include discrete verbal and non-verbal communication. In the example of David and his brother, they were engaged in a back-and-forth as David made ate noisily (by scrapping his fork on his plate), as his brother yelled at him to stop to no avail. David’s moves hindered the flow of conversation (perhaps intentionally) and interaction, as his brother left the room. In the example of Emily and her boyfriend, their conversational dynamics in this interaction comprised questioning and providing rationale for decisions. This dynamic also hindered the conversational flow, as the pair ended the interaction by agreeing to disagree.

I now bring in another episode to examine for conversational moves and acts. Sam and his dad discussed a conversation in which his dad made a conversational move of confronting Sam about missing school (Figure 21). This confrontational stance immediately put Sam on the

defense, which then combined with multiple sensations, emotions, and thought processes as the interaction progresses. During the Common Ground activity, he used a flow chart diagram to indicate that he was thinking about various issues relating to his absence that he did not bring up with his dad during the interaction. He also recalled that his eyes were bothering him, surfacing a sensory experience that hindered the flow of conversation. The pair engage in conversational moves in which Sam raised an excuse, his dad refuted it, and Sam came to the realization that he does not have a valid excuse. Together, they recapped the situation and agreed upon a path forward, which concluded the interaction.

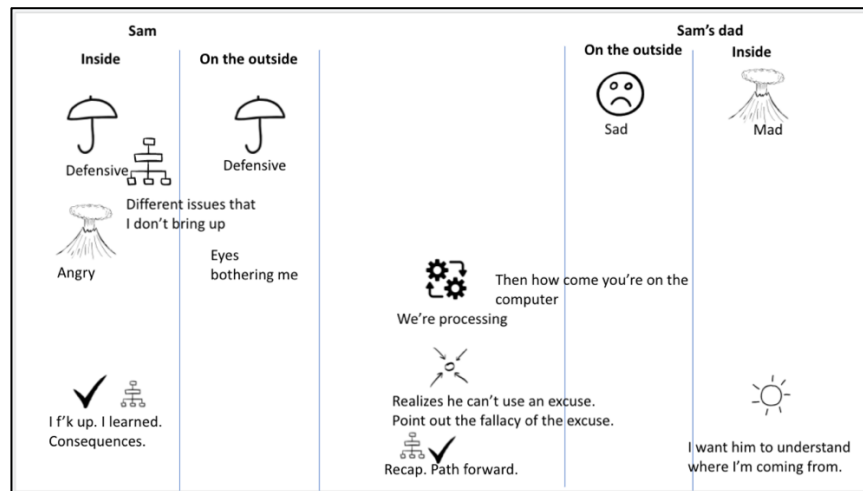


Figure 21: Sam and his dad retell an interaction episode

To consider another episode in which a young adult and his father have a confrontation, I next examine the episode relayed by Mitchell and his dad (Figure 22). Mitchell's dad had an intense explosive experience internally and externally, accompanied with yelling and leaving the room. P10's focus was on his internal state is cognitive, trying to understand why his dad is yelling and blaming him for something when he "*didn't do anything,*" having "*been in school half the day and you just came unglued on me.*" As indicated by the middle swim lane, the pair goes around and around. Mitchell's dad indicates that along with his anger is a fear that Mitchell

will follow in the footsteps of his older brother, which has led to difficulties. Mitchell’s dad leaves the room with no resolution, after which, Mitchell feels depressed and wishes he had never moved to live with his dad. He decides to “*just leave it where it is so I’m not getting in any more trouble.*” He turns to his cell phone as a way to distract himself and “*shrug it off.*”

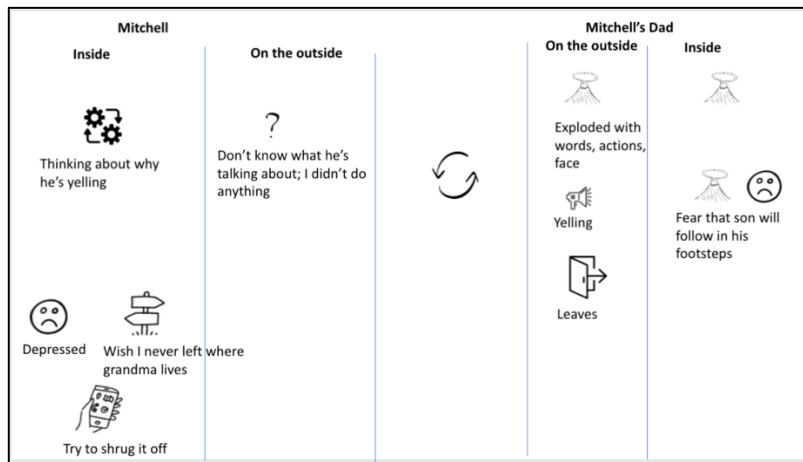


Figure 22: Common Ground activity for Mitchell and his dad

Last, I summarize the ways in which the neurodiverse pairs concluded their conversations. In the episodes described thus far, we see three different varieties of conversation endings: (1) an abrupt ending to the conversation with one person leaving the room, (2) agreeing to disagree, and (3) mutually agreeing upon a path forward. Other participants’ episodes involved another ending: not reaching a resolution, with some discomfort but not reaching a level of anger. As Mitchell demonstrated in his episode, when he experienced an abrupt end to a conversation, technology served as a means of handling the encounter and moving forward. Four autistic participants exhibited this socio-technical behavior, yet none of the non-autistic participants conveyed using technology in this manner.

Across all of the pairs, there are examples when (1) the internal state and external expression were congruent, and (2) when they were not congruent. This was the case for both

autistic and non-autistic individuals. As an example of the non-autistic individual having incongruent internal and external states, at the beginning of the interaction between Jack and his mom, Jack is surprised internally and externally; whereas his mother is feeling confused internally yet portraying “calm but guarded” externally (Figure 23).

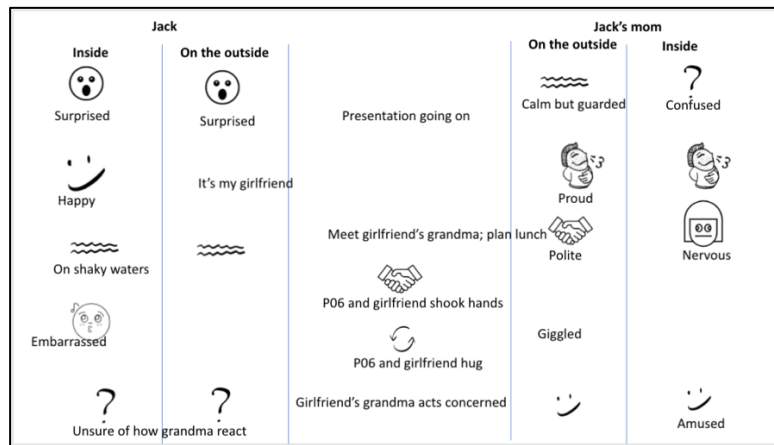


Figure 23. Interaction episode of Jack and his mother

As an example of the autistic individual experiencing different internal and external states, at the beginning of the interaction (Figure 24), Sarah is feeling confused internally (question mark) and reserved (umbrella) externally; whereas her boyfriend's internal and external states are congruent (happy face). Note that an internal state of being confused and an external state of being reserved are different states, but not necessarily incongruent. It can be natural to want to approach a situation hesitantly if one feels confused. This complexity demonstrates that emotional experiences are nuanced and can involve a mix of emotions connected to social goals.

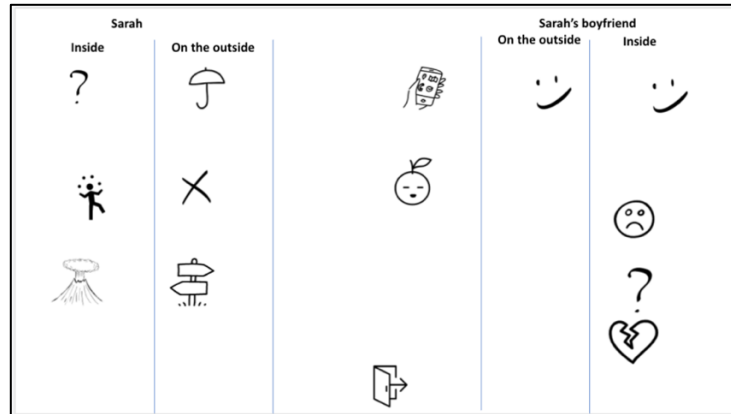


Figure 24: Sarah and her boyfriend diagrammed conversation

The Common Ground activity provided evidence for the following insights: (1) both autistic and non-autistic individuals experienced what may appear to be incongruent internal and external states, (2) in cases in which the non-autistic partner had a strong emotional stance, the autistic individual tended to be focused on trying to understand the logic of (or, in some cases, keep distant from) the emotions, and (3) the pairs tended to get “hooked” on the conflict, cycling through behaviors and statements and then, often, ending the exchange without a mutually-agreeable resolution. People can feel a mix of emotions and this may come across externally as a different or only one aspect of their emotional landscape. In other cases, people may want to put forward a certain persona due to the circumstances and hide their full range of emotions. Due to the complexities of social, emotional, and sensory experiences that surfaced during the Common Ground activities, I argue that affective technology cannot assume that people (autistic or non-autistic) express their true or full emotions externally through their facial expressions or actions.

## 5.15 Social-Emotional-Sensory Design Map for Affective Computing

Given the technology practices and what the individual and pair interviews surfaces about I about challenges with current approaches to affective technology, I argue that affective

computing design would be enriched by examining the intersection of social, emotional, and sensory experiences of autistic individuals. To formalize this examination, I present a social-emotional-sensory design map, depicted in Figure 25.

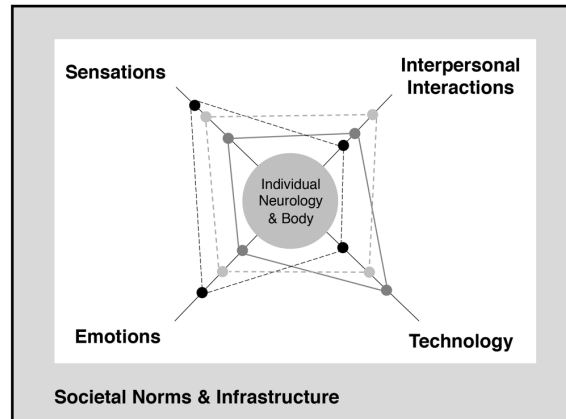


Figure 25. Social-Emotional-Sensory design map for affective computing. ©A. Zolyomi and J. Snyder.

By using the concept of a map, I point designers and researchers towards a rich site of exploration. I offer the term ‘design map’ as an alternative to other conceptual design frameworks, such as ‘design domain’ or ‘design space.’ The urban planner and educator, Schön, advocated for reflective design practices and defined design domains as rich descriptions of particular design settings in terms of concepts, words, language, and notation (Schön, 1990). A design domain typically represents a set of normalized and concretized practices, resulting from a formalization of a set of design problems and stakeholder groups. Similarly, a design space is a tool for design teams, often in technology and product design, that scopes a design exploration (e.g., (Card et al., 1990)). The dimensions of a design space are commonly bounded by (1) a limited number of dimensions, often depicted on a grid, and (2) the priorities and technology afforded to the product development team. In contrast, I use the term design map to describe a tool to be used to navigate a dynamic, non-normative, or less clearly delineated problem space. By depicting a set of influences with varying impact on a design space, a design map does not

represent an unequivocal definition, but rather captures a set of sliding measures to be considered during the design process. Similar to an equalizer or mixing board, I offer this tool as a means for designers to visualize the ways in which social, emotional, sensory, and technological factors impact the space in which they are working.

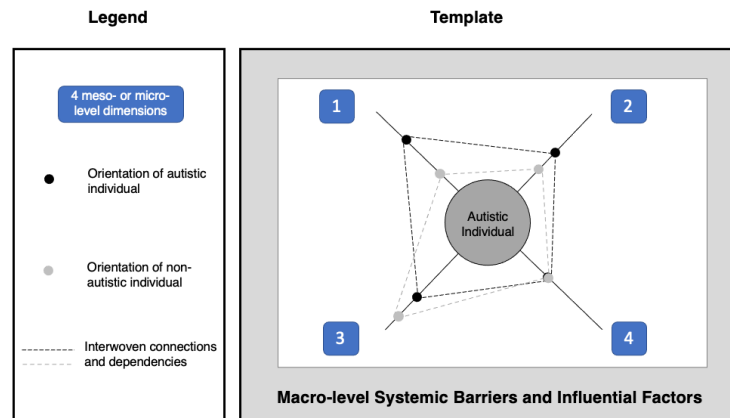


Figure 26. Legend and Template for Social-Emotional-Sensory design map for affective computing.

The social-emotional-sensory map depicts factors at a macro-, meso-, and micro-level that should be accounted for in the design of affective computing (Figure 26). The macro-level factors—depicted as the grey border—are societal and infrastructure barriers faced by disabled people, as described by the social model of disability. The design map is viewed within the lens of the social model of disability. The map centers the autistic individual with their particular neurology and physical body. Spokes extend from the center in four dimensions, which are: (1) emotional landscapes of individuals and groups, (2) communicative practices and social norms enacted by the social group (e.g., individual, dyads, small groups, groups, and communities), and (3) sensations in the environment or internal to individuals, and (4) technology use and influences.

This design map moves the focus of affective computing from the classical goal of segmenting and classifying the emotional experiences of an individual to creating constructed,

personalized models of emotional experiences. The social-emotional-sensory design map acknowledges people who experience emotions in different ways, creating an alternative to affective computing systems that presuppose or dictate normative measures and representations of emotion. Normative measures are a means to, as described by Sengers, “inadvertently disenchant affective experience, rendering it explainable and categorical, and, in the process, reducing its richness to the simple kinds of categories available to a computer” (Sengers et al., 2008, p. 348). The design map reimagines the connections between mind-body-emotions, allowing for unique expressions of interoception, including those that experience disconnections and mixed signals.

When creating or applying the map, the designers can consider the dimensions to be at either the (1) meso-level for analyzing groups and communities or (2) the micro-level of analysis for analyzing social practices of individuals, dyads, or small groups. The dots along the spokes depict the relative importance or emphasis along that dimension for different user groups, for example, autistic and non-autistic conversation partners. The emphasis of a particular dimension is due to salient factors in the socio-technical scenario, such as an individual’s skills, actions, goals, and sensitivities. The dots are placed according to a conceptual scale; a dot closer to the center means that dimension is less of a factor for that user group, as determined by research insights. For instance, the dark dot can represent an autistic individual with high sensory sensitivity and the grey dot represents a non-autistic individual with low sensory sensitivities. In that case, the dark dot is further from the center than the gray dot.

The map is dynamic in that the dots can move and slide along the dimensions, causing the overall web of factors to change shape. Consistent with radar maps, the elements along each spoke are connected, as shown with dashed and dotted lines in my map, to depict the interwoven

connections and dependencies between the dimensions within the given context. The flexible and variable nature of the map is necessary because the phenomena pointed to by the social-emotional-sensory design map are not set in stone, but rather, are dynamic, emerging from current experiences, perceptions, and activities of people—in our case, autistic adults. The setting occurs in a particular environment (virtual, real-life, augmented) at a particular time and place.

The design map serves to orient and establish common understanding among teams comprising designers, researchers, and developers. The map orients the team towards a phenomenon, reflecting the team’s current understanding of the phenomenon. At the beginning of a project, the team can tailor the map dimensions for a particular context of study, for instance, specifying that the “sensations” dimension occurs in a particular workplace environment. As the project progresses, the design map dimensions can shift to capture empirical findings and emerging themes. The team may determine that multiple maps are needed to reflect different categories of lived experiences or different design directions. I acknowledge that the social-emotional-sensory design map is emergent, and as is the nature of maps, is not the actual territory. I resist “reifying the map as unitary, fixed, coherent, or encompassing of all aspects of the territory” (Ellingson, 2017, p. 174). The map is a tool for a reflective design practice, which I used throughout my dissertation research and document throughout this manuscript. At the conclusion of the Design Study and Appropriation Study chapters, I provide examples of how to apply the design map to incorporate insights about stakeholders and context into design in a dynamic fashion.

# Chapter 6 Design Study

## 6.1 Introduction

The second phase of the Grounded Design research was a design study of interpersonal interactions of neurodiverse conversation partners. The design study further explored three themes that arose from the context study: (1) making interactions clearer, (2) making emotions more explicit and easier to share, and (3) increasing independence and agency during interactions. The design study investigated the following research questions:

- From the perspective of autistic young adults, what are the crucial elements of a face-to-face conversation that contribute to their social-emotional-sensory experience? (RQ3)
- In what ways can communication moves and emotions become clearer during face-to-face neurodiverse conversations, in ways that benefit the autistic individual? (RQ4)

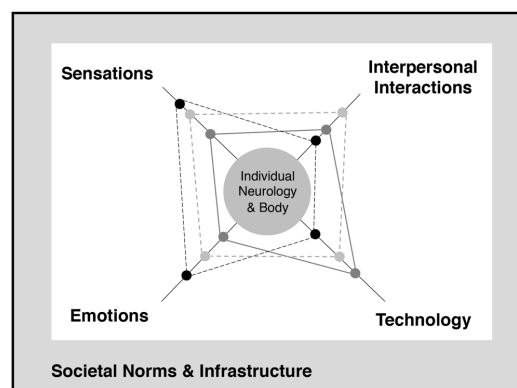


Figure 27 (for reference only; identical to Figure 25). Social-Emotional-Sensory design map for affective computing. ©A. Zolyomi and J. Snyder.

The research questions explore spaces to which the social-emotional-sensory design map (Figure 27) points, including: (1) the emotional landscape of autistic adults and their interpersonal

interaction partners, (2) communicative practices and social norms enacted by the group, and (3) sensations, constraints, and opportunities presented by the physical infrastructure and environment.

The design activities were centered around designing a game to support in-person conversations. Participants were asked to consider a proposition that *conversations are somewhat like a game*. And building upon this supposition, *what would a game be like to have conversations in ways that we want?* Using gaming as a structure throughout the remote design activities had three benefits. First, gaming was a familiar concept for participants, given that autistic individuals perceive play (Zolyomi et al., 2017) and game play (Finke et al., 2018; K. Ringland, 2018; Zolyomi & Schmalz, 2017) as beneficial to developing social skills, demonstrating expertise to others, and building community. Second, as the participants engaged in the design activities remotely, they would not have the benefit of an in-person design workshop. Their prior experiences playing games could serve as background knowledge for them to take into the design activities, such as understanding the role of player pieces, a game board, and game rules. Third, the research team could establish a theoretical basis for connecting game design concepts to common ground concepts, as described in the next section.

The goal of design activities were to generate game design ideas on one level, and on another level, to use the mechanics and paradigm of a game to probe the participants' underlying conceptions of what constitutes a conversation, what rules are they governed by, and what are the desirable interaction patterns. The activities were designed to be inclusive of the diversity of embodied emotional experiences and to surface potential moments in which technology could mediate upon and scaffold neurodiverse interactions.

## 6.2 Theoretical Framing for Considering Social Interactions as Game Play

As explored in the pair interviews, as people interact, they are trying to establish *common ground*, which is a socio-linguistic concept for co-creating meaning and understanding through interaction moves. As theorized by Clark, common ground is “the sum of their mutual, common, or joint knowledge, beliefs, and suppositions” (Clark, 1996, p. 93). Interestingly, one way Clark proposed to conceptualize common ground is to consider game play as a metaphor for social interactions. Clark argues that in any given moment, common ground is divided into (1) initial common ground, (2) current state of the joint activity, and (3) public events so far. He uses the game of chess to illustrate these divisions. The initial common ground is the presumptions players have about the rules and etiquette for chess, which allows them to interpret the chess board and pieces and place themselves physically at the game table. The current state of the activity is represented in concrete form as the game board and location of the game pieces that have not been captured. The public events so far is the record of the players’ moves up that led to the current state.

According to Clark, some social practices are well-codified (i.e., court proceedings) and some are uncoded. We learn social practices by examining communicative acts and ascribing meaning to them within the context of the joint activities. In interactions, these *communicative acts* include speech acts, signaling, and illocutionary acts--relating to the effect of the act (i.e., assertives, directives, commissives, expressives, effectives, verdictives). For individuals with autism, this social learning can be more difficult and non-intuitive when it comes to perceiving

the social acts of others, ascribing meaning, generalizing from one context to another, and executing social behaviors.

Turning now to game design, fundamental game play concepts have been theorized as follows. The game occurs within a specific frame of the game, in which a game setting is established. The *frame* “is what communicates that those contained within it are "playing" and that the space of play is separate in some way from that of the real world” (Salen & Zimmerman, 2004, p. 94). The *setting* is established by space and/or time, along with a material aspect, which can be physical, digital, or a combination. The participants bring into the setting information that they know, or can surmise, about each other. To engage in the interaction or game, all of the participants follow *rules of the game*. These include establishing the goal of the interaction, the pathways through the game, the ways to take turns or pass on a turn, etc. Predominantly, game play rules are concrete and often provided in a manual. In game play, the players interface with each other through these *game mechanics*, such as rolling the dice, moving a token, saying game-specific commands. “Meaningful play in a game emerges from the relationship between player action and system outcome; it is the process by which a player takes action within the designed system of a game and the system responds to the action. The meaning of an action in a game resides in the relationship between action and outcome” (Salen & Zimmerman, 2004, p. 34). An important component of meaningful play is that participants have *choices* and can readily observe the *consequences* and outcomes. “When a player makes a choice in a game, the system responds in some way. The relationship between the player's choice and the system's response is one way to characterize the depth and quality of interaction” (Salen & Zimmerman, 2004, p. 61).

### ***Integrated Framework for Design***

Using the metaphor of conversations as game play, we can connect theoretical constructs of common ground with concepts from game design. We integrate concepts from game design and common ground to generate a novel integrated framework. This framework is the basis for our design activities and analysis. We propose the following conceptual mappings:

- Social interaction partners → Game players
- Setting of the interaction (the boundaries, both physical and conceptual) → Frame of the game
- Grounding (establishing background) → Capabilities of the players and who is actively playing / who is out
- Social practices → Rules of the game
- Initiating → Initial configuration of the game board, game pieces, and rules for starting the game
- Roles people take on during the interaction → Roles players take on during game play
- Proposition → Setting up a choice in the game
- Engagement and coordination (the moves one makes to establish tasks, negotiate, accept / reject, clarify, reflect) → Making game moves, composed of game mechanics
- Communicative acts → Game mechanics
- Closing the interaction → Ending the game

In narrative form, mapping concepts from Common Ground and game play, we consider the interaction as establishing common ground, or in other words, establishing meaningful play. As an interaction begins, the participants gather in a common *setting* or the *frame of the game*. The participants engaging in *grounding* informed by knowledge about backgrounds, culture, what

they have in common, roles, and relationship dynamics. Roles can change as interaction progresses and power dynamics and motivations change. To construct their moves, participants engage in *communicative acts*, or in gameplay, specific *game mechanics*. Through the course of an interaction, the participants engage in a flow of activities: initiating, engaging in topics and rounds of turn-taking, interactions come into conflict or are in alignment. There can be a reshuffling of resources as the shift in power moves from player to player. Note that while in game play, rules are typically concrete, in social interactions, social practices can be more nebulous and harder to confine to a specific set of norms.

The sum of all these moves is establishing common ground or establishing meaningful play. It is valuable for participants to have interaction choices available so they are able to influence the coordination of activities and outcome of the interaction. Eventually, the interaction or game comes to a concluding state. The end state of a game is clearly defined and based on measurable and concrete factors. In contrast, the conclusion of an interaction emerges through the actions of the interaction pair and can end on uncertain grounds, with unspoken or unclear expectations of continued dialog and actions that extend beyond the setting of a specific interaction.

### 6.3 Operationalization of Theory for Design Activities

This dissertation uses *meaningful play* as a way to scaffold our design work so that we can learn more about how neurodiverse pairs establish *common ground*. The design activities were meant to externalize how the participants conceptualize the *setting* and players involved in their interpersonal interactions, as well as the *rules* they perceive in how interactions work. Through the design activities, we collaborated with the participants to devise ways to make *choices*, *actions*, and *outcomes* more explicit in social interactions, similar to how they are explicit in

games. I posited that this would enable autistic individuals to establish *common ground* in a more robust way. I operationalized this framework into participatory design prompts, as outlined in Table 8.

Table 8: Design activities based on the metaphor that social interactions are like games

Design Prompt	Description	Resulting Data	What this will tell us
<p><b>Theoretical concept:</b> As a social interaction begins, the participants gather in a common <i>setting</i> or the <i>frame of the game</i>. The <i>setting</i> is established by space and/or time, along with a material aspect, which can be physical, digital, or a combination. The participants bring into the setting information that they know, or can surmise, about each other. This <i>grounding</i> is informed by knowledge about backgrounds, culture, what we have in common, our roles, and our relationship dynamics.</p>			
Consider social interactions as a game you and your interaction partner are engaged in. What is an object that you can create to represent yourself and your partner?	<b>Design representations of the players:</b> Create game pieces for you and your interaction partner. What are ways that your game pieces can connect, engage, or maintain space?	Narrative and photos of design artifacts representing neurodiverse interaction partners	Aspects of self that they choose to emphasize or diminish; Ways that they observe, or wish to, connect, engage, and maintain space from their interaction partners.
What could you put / create for the space and pathways between you and your partner?	<b>Design the frame of the game:</b> Create a board game in which your interaction can take place.	Narrative and photos of game board	Game board shape & materials; Spaces and pathways between the players;
We come into a social interaction with how we are feeling, what is on our mind, and what we perceive about the other person.	<b>Design ways to establish grounding knowledge:</b> Ways for you to have more information or track information about the “place and space” your interaction partner is coming from (and for you to communicate yours). Emotional and sensory states and needs	Narrative and photos of design artifacts representing neurodiverse interaction partners	Information they find useful for grounding during interactions. Ways they externalize their internal emotions, sensations, and thoughts; ways they can observe that about others.
<p><b>Theoretical concept:</b> To establish meaningful play, participants have <i>choices</i> and can readily observe the <i>consequences</i> and outcomes. To engage in the interaction or game, all of the participants follow <i>social practices</i> or <i>rules of the game</i>. These include establishing the goal of the interaction, the pathways through the game, the ways to take turns or pass on a turn, etc.</p>			
During interactions, we often engage in certain ways, try to get certain things communicated. In terms of a game, what conversation moves do you make together?	<b>Design choices, consequences and outcomes:</b> Communicate your moves. (e.g., Moving tokens, levers, knobs, images to take turns, clarify ideas)	Narrative, board game elements, and photos of game mechanics and rules	Social interaction mechanics and rules; Ways that communication moves can be more explicit

If you think of interactions as a game, what are the rules that the players follow? What rules do you like and dislike?	<b>Specify rules of the game:</b> How do you move through the interaction? What are things your communication partner can do or have to make the interaction clearer?	Narrative, board game elements, and photos of game mechanics and rules	Social interaction mechanics and rules; Common patterns of movement and use of game elements
What are the wins and losses that occur during interactions? Is there a goal to your interaction game?	<b>Define the goal of the game:</b> What are you hoping to achieve or experience during the interaction?	Narrative, board game elements, and photos of “the end game”	Mental models of “the end game” / purpose / goal of social interactions
<b>Theoretical concept:</b> To construct their moves, participants engage in <i>communicative acts</i> , or in gameplay, specific <i>game mechanics</i> . In a social interaction, these <i>communicative acts</i> include speech acts, signaling, and illocutionary acts (assertives, directives, commissives, expressives, effectives, verdictives, etc.).			
Interactions can bring up emotions, both highs and lows, or neutral feelings. You can start to feel different things in your body. What emotions are you aware of and how could you and your partner share those?	<b>Create game mechanics and materials to share emotions and sensations:</b> Create physical, interactive representations of emotional states (of yourself and others). Use levers, knobs, images, etc. to supplement verbal discussion with interaction, emotion, sensory cues.	Narrative, board game elements, and photos of game mechanics and rules; physical representations of emotions and sensations	Explore emotion represented in physical forms ways that they want to manipulate, show, and hide emotions.

## 6.4 Method

Two design paradigms shaped the design study: *participatory design* and *research through design*. As I described in the Methodology chapter, participatory design engages the research population as designers, thus, incorporating their perspectives and values throughout the design process. Participatory design is especially useful in research involving marginalized communities, such as autistic adults, because (1) it brings their perspective into the design process, which helps counter assumptions and implicit bias about the community, and (2) it gives more power to the research population, thus shifting the power dynamics between the researcher, research population, and other stakeholders. For this study, autistic adults were invited to engage in a series of design activities, centered around the proposition that *conversations are somewhat*

*like a game.* And building upon this supposition, *what would a game be like to have conversations in ways that we want?*

The intention of this design activity was not to actually generate game design ideas, but rather, to probe the underlying concepts of what constitutes a conversation, what rules are they governed by, and what are the desirable interaction patterns? This framing of design is *research through design*, which “is an approach to conducting scholarly research that employs the methods, practices, and processes of design practice with the intention of generating new knowledge. (Zimmerman & Forlizzi, 2014, p. 1). This approach aligned with this dissertation because involves, in contrast to traditional design practice, is “more systematic and more explicitly reflective in its process of interpreting and reinterpreting a conventional understanding of the world” (Zimmerman & Forlizzi, 2014, p. 1). This chapter provides a detailed report of the design study and process in accordance with the principles of research by design.

### ***Recruiting and Participants***

The design phase occurred in Summer 2020 starting with an online survey sent to all participants of the context study. In keeping with the philosophy of Community-Based Participatory Research, this survey asked for their input on emerging design directions and welcomed input on how to engage with them for remote design. As a reminder, CBPR calls for sharing and gathering input on research plans and emerging findings throughout the research process. At this time, I also did a light-weight touchpoint with a representative from the UW LEND program and a representative from Ryther about emerging design directions, which they concurred with as interesting and relevant directions to explore further.

We also wanted to have a positive touchpoint with the participants during this uncertain time (COVID-19) to maintain community. Due to the 2020 coronavirus pandemic, the research team and participants across the state were under state-mandated quarantine starting in March 2020. To comply with university, state, and federal social gathering restrictions that began in March 2020, the research team reset our research plans to move from in-person to remote activities. Survey results were that participants confirmed the design directions were important. To participate in the upcoming design study, they needed a mix of rich communication channels (e.g., Zoom video calling) and low-bandwidth communication channels (e.g., email, postal mail). I also wanted to accommodate preferences for asynchronous and synchronous engagement. I put the participants into three tentative design groups (Slack, Zoom, individual via postal service) based on their preferred communication modalities.

In June 2020, I mailed participatory design kits to all 18 participants, even if they did not respond to my email or survey, in case someone was unable to respond to those inquiries, but still wanted to participate. I received email confirmation from eight participants that they had received the kit and wanted to participant. Since this number of eight did not meet my target of 12 participants, I conducted a second recruiting wave, as described in the “Participants and Recruiting” section in the Methodology Chapter. From the second wave, I recruited and screened six participants, which combined with eight participants from the original cohort, resulted in 14 participants in this phase (Table 9).

Table 9. Demographics of research participants in design study (n=13)

Attribute	Demographics
Age	18 – 33 (average 25)
Gender	5 female, 7 male; 1 non-binary

Attribute	Demographics
Location	United States, living in a rural, mid-size city (4) or living in large metropolitan city or suburbs (9)
Living arrangement	Live with parents (5); live alone or with roommates (7); live with spouse (1)
Level of education	Transition program for life and job skills at a community college (3); Master of Music (1), PhD in statistics (1), medical residency program (1), Bachelor degree (5); high school graduate (2)
Current employment	Employed in technology, music, and education fields. Internships with local retail shops (bakery, feed store, pizza restaurant, computer repair)
Shared design with	Friends (8), family (4), boyfriend (1)

### ***Pilot***

I piloted the design activities in three venues: (1) over Zoom, with 2 PhD students; (2) over Zoom, in a research lab meeting; and (3) two university courses. One course was undergraduate students enrolled in a Value Sensitive Design course. The design activities were conducted asynchronously. The students followed written instructions for the activities. They were asked to collect materials that they had available to them in their homes. This was in Spring 2020, which was during our state's quarantine, lock-down phase 1, protocols. We asked the students for feedback on how the remote design process went for them and if they had any barriers or complications to doing design work due to the pandemic quarantine. The second group that piloted the design protocol was a course on Accessible Design in the HCDE Master's program. I conducted the activity during their regular class, as a supplement to a guest lecture I gave on HCI and Cognitive Disabilities. The lecture and design activity was conducted over Zoom, with the course instructor and two teaching assistants in attendance. The main concern was providing adequate time for the activities, since the time seemed to go very quickly and we needed to give the students additional time to complete the first activity. We also wanted to give adequate time for students to report out the highlights of their design process and insights about conversations

as game play. Accordingly, I ensured there was buffer time in the Zoom co-design session to account for these considerations.

### ***Design Kits***

Participants were mailed design kits with design materials and handouts: (1) a welcome letter; (2) instructions, (3) a design kit inventory list, and (3) a design journal to complete. In the instructions, participants were asked to choose how to engage during the participatory design phase. I provided multiple avenues for communicating with me and other research participants (mailing the journal back to me; email; Zoom synchronous design meetups (see Appendix E for Zoom protocol), and Slack asynchronous design discussion forums). The participants were invited to join a Slack workspace that was dedicated to the research participants. They were given the option to join Slack to discuss ideas, ask questions, or merely observe the conversations if they desired. This asynchronous research approach was based on asynchronous remote community (ARC) research methods (Maestre et al., 2018). Alternatively, participants were invited to engage in the design activities without joining Slack. Our remote participatory design approach was beneficial to our participants' communication and cognitive styles, allowing them to (1) communicate in their preferred modality (writing, speaking, video calls), (2) engage in in-situ design (making the design process more relevant), and (3) engage at times and speeds that work for them.

Included in their design kits were materials they could use to complete the design activities (Figure 28). By sending all of the participants a common set of materials, we established a baseline for the materials they had access to while at home during the coronavirus pandemic. The instructions noted that they were welcome to also use materials from their home.

The kit included materials for creating 3D objects (tubes, Styrofoam balls, wooden dowels, pipe cleaners), flat surface for the game board (multi-colored construction paper), drawing supplies (markers, colored pencils, pencils), and materials to cut and attach elements (scissors, glue, tape, post-it notes). In the instructions, we invited them to gather materials from around their home to supplement the design kits. Some participants had worried that they are not good at drawing or were concerned that they were not doing well enough during the visual representation activity of the individual interviews. I wanted to express that drawing was not required and this was not a crafting activity. Therefore, in the examples of game pieces and game boards, I included examples of a game board made out of stones laid out on grass and another example of a game player piece that was a folded piece of paper in the shape of an animal and another example game player piece that was feathers glued together.



Figure 28. (a, b) Design kit supplies; ( c ) Design supplies packed as a kit, ready for shipping

The instructions began by introducing the idea that conversations are like playing a game. I asked them to take a minute to think of a game they like to play, then think about some ways that playing that game and having a conversations are similar. The instructions then presented four activities: (1) Game Pieces, (2) Game Board, (3) Conversation Choices and Rules, (4) Emotions and Sensations, and (5) Game Experimentation. Each activity had a brief description, design prompt, step-by-step instructions, and examples from the pilot studies. See Figure 29 for the content for Activity 1: Game Piece. (See Appendix D for the complete design instructions.)

## Activity 1: Game Pieces

Let's pretend that your own conversations are in the form of a game. Think of this game as a way to show:

- What you want to get out of the conversation
- How you want to feel during the conversation
- How you want other people to feel
- How you want your conversations to flow
- How you want to better understand the conversations

### Instructions

1. Think of a person that you have meaningful conversations with. This could be the person you did your Next Generation Autism Technology pair interview with. Or it could be a different person. We will call this person your "conversation partner".
2. In your design journal, answer the Planning questions about your game player pieces.
3. Create 2 game player pieces, one that represents you and another that represents your conversation partner.
  - a. Use materials, shapes and colors to show the person's personality and how they act during conversations.
  - b. The game pieces need to be a 3D object at least 2" tall. You can start with the cardboard rolls or some other physical object.

Here are some examples of what other people have created for their game players. These are just examples; your players will look different!



4. In your design journal, answer the Activity 1 Reflection Questions about your game player pieces.

Figure 29. Activity 1: Game Pieces content in the Instruction handout.

## Data Analysis

Data from the design study comprised video and photos of the participants' design artifacts, design journals with narratives about their design artifacts and design process. From the Zoom design session (with Sarah, Kendall, and Michelle), are the recorded video, screenshots, researcher notes, and research memo. Only one participant engaged via Slack; we exchanged messages and he submitted his photos on Slack. A few participants mentioned that they were not familiar with Slack and did not wish to use another platform for communication. This lack of engagement with Slack influenced my methodological decisions for the Appropriation study to use technologies participants have already been using during this research and to not expect

participants to maintain engagement with this research asynchronously over a long period of time. To analyze the data, I documented the type of materials used and my descriptions of the created artifacts. I collated the journal entries so I could compare them across participants. I coded the data for the following categories: common ground moves, available actions, impact of moves, and points of mediation. The mapping of these categories to the type of evidence and data sources across research phases are listed in Table 10. I used affinity diagramming to analyze this data for themes, such as the types of interactions afforded by the objects and the ways that the objects may complicate joint decision making and issues around physical comfort.

Table 10: Mapping of categories, evidence, and data sources from research phases.

Categories	Evidence	Data Source
1. Common ground moves	<p>How are they talking about common ground? How do they talk about moving in and out of common ground?</p> <p>Aspects of self that they choose to emphasize or diminish; Ways that they observe, or wish to, connect, engage, and maintain space from their interaction partners. Ways they externalize their emotions</p>	<p>Pair interviews: Information they find useful for grounding during interactions. How they initiate, coordinate, and close interactions. Ways in which technology is part of common ground actions.</p> <p>Common Ground visual activity: similarities and differences between internal/external for each person. Includes tech use.</p> <p>Game design: game player pieces</p>
2. Available actions	<p>Social interaction mechanics and rules; Ways that communication moves are materialized or characterized</p>	<p>Pair interviews: Patterns of communication, restrictions, consequences. What actions are afforded by technology?</p> <p>Common Ground visual activity: Patterns, boundaries, and barriers during the interaction</p> <p>Game design: Game choices and rules, game board boundaries and spaces</p>
3. Impact of moves	<p>The ways impacts are described. The ways in which participants drew on or incorporated</p>	<p>Pair interviews: points of friction, breakthroughs, decision making. How does tech impact agency and decision making?</p>

	social-emotional-sensory experiences in their descriptions of social interactions	<p>Common Ground visual activity: Changes in internal and external actions and emotions. Includes tech use.</p> <p>Game design: Game choices and rules, Mental models of “the end game” / purpose / goal of social interactions</p>
4. Points of mediation	Description of things, actions, feelings that they would want changed. Ways that they want to manipulate, show, and hide emotions.	<p>Pair interviews: What they would like to see changed; superpowers</p> <p>Common Ground visual activity: Points of intervention</p> <p>Game design: Opportunities to change the game play; Use of game elements to enhance social-emotional-sensory experiences.</p>

## 6.5 Findings

Based on this framework and analysis, I focus findings on insights that answer the motivating research questions regarding (1) the crucial elements of a face-to-face conversation that contribute to their social-emotional-sensory experiences; and (2) the design choices that the autistic participants made to make communication moves and emotions more concrete. The findings surface potential points of mediation and scaffolding for neurodiverse conversations. These points were situations in which the autistic participants wanted particular conversational moves, emotional experiences, and sensory experiences to be bolstered or altered.

***Game Design Categories: “Navigating Structured Topics” or “Co-Constructing Kinesthetic Experiences”***

I observed that the participants’ game concepts had some defining characteristics that led to broadly categorizing the games as either “navigating structured topics” or “co-constructing kinesthetic experiences.” In this section, I provide a sample of the participants’ game designs

concepts to illustrate how the games could be understood from the broad strokes of these categories.

In the “navigated structured topics” game concepts, the participants forefronted the types of topics to be discussed and the available moves were often explicit rules for how to discuss the topic and reach resolutions. The topics were often laid out in a structured format, such as a “*tree diagram of the topics*” (Michelle) with clear paths for moving through the topics (Figure 30).

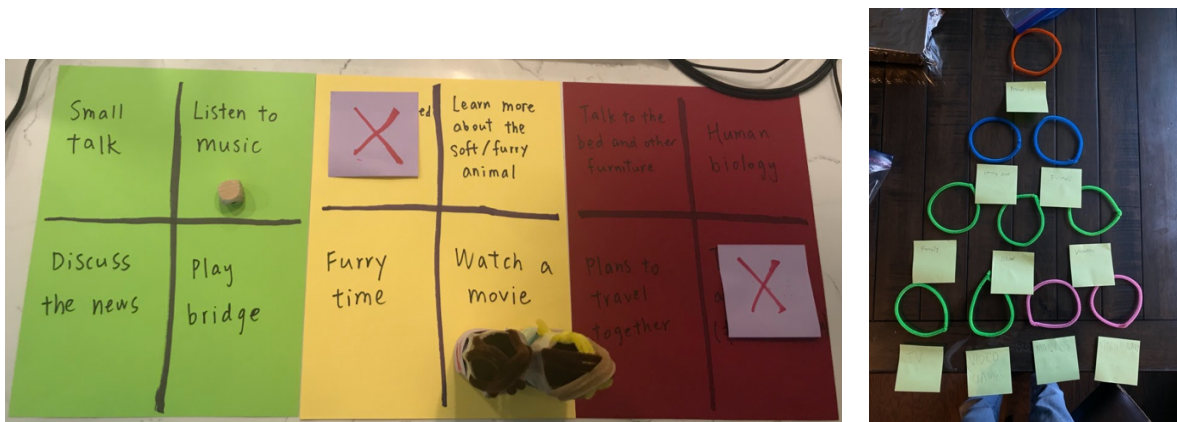


Figure 30. (a) Emily’s game board with topics laid out in a grid; (b) Rahul’s game board with topics organized as a tree.

As an exemplar of a “navigating structured topics” game concept, Alec designed a collaborative game that represented conversations he has with his brother-in-law. Alec described his game board as “*gigantic,*” allowing them to “*see the whole path, make quick changes, and fit our game pieces on it*” (Figure 31). He chose to design his game with his brother-in-law in mind because talking with him is “*relaxing and gentle. I feel safe with him because I know he will listen to my ideas and care what I think. Sometimes he likes to make things a little more complicated than I’m comfortable with, but he always stops to listen.*” The game player pieces Alec designed are comprised of cardboard tubes with pipe cleaners wrapped around and looping up. Alec describes that for his player piece, “*I am trying to show that there are two sides to me. There is a green side that is calm, peaceful, and nice. There is a red side showing that sometimes*

*I'm frustrated or angry.*” The pipe cleaners loop above the tube, signifying that his *“feelings go around and around in my head.”* Alec deliberately designed the other game elements, such as using *“hospital ‘pain level’ faces”* on it with a spinner to set to whatever *I’m feeling.”*



Figure 31: (a) Alec's board game (b) Game player pieces for Alec and his conversation partner.

In conversation together, Alec says that he and his brother-in-law are “in sync because we can see each other... We are also both pretty good at following a conversation and staying on topic... We have good intentions.” That positionality to each other is reflected in the design of the converging and diverging “stepping stone squares to land on.” Their “spinner faces” on their game player pieces “can see each other so each of us knows what the other is feeling.”

Each round of the game was based on a different theme, such as planning an upcoming trip. As their player pieces moved around the board, they collected “*issue cards*,” such as what to do on the trip (e.g., visit relatives), things to bring, mode of transportation, and type of food they will eat while traveling. When their player pieces landed on resolution spaces, the pair was tasked with discussing their point of view on the issue and collaboratively reaching a decision. Alec acknowledged that they would sometimes need to make concessions about the resulting decision. For example, if his brother-in-law “*made a persuasive case for visiting a gift shop and I*

wanted to go swimming, I might let him win on that issue, and I wouldn't tell him I was sad about it." In that case, they could change their "spinner face" to sad and exchange "goodwill gems." This exchange could inform the next resolution space, in which "we might give each other some slack and let the other one win on that new issue." In his description of his game, Alec emphasized the cooperative nature of his game and created game mechanics, such as goodwill gems to make cooperation explicit and balance his perspective that one can "win" or "lose" when trying to reach resolutions.

Next, in the category of "co-constructing kinesthetic experiences" game concepts, the participants' focused on the interactions of the player pieces and the joint formation of a conversation that evolved or moved over time. Interactions between player pieces involved some form of kinesthetic action, such as rolling a tube on the floor or winding their way around a Styrofoam ball (Figure 32).

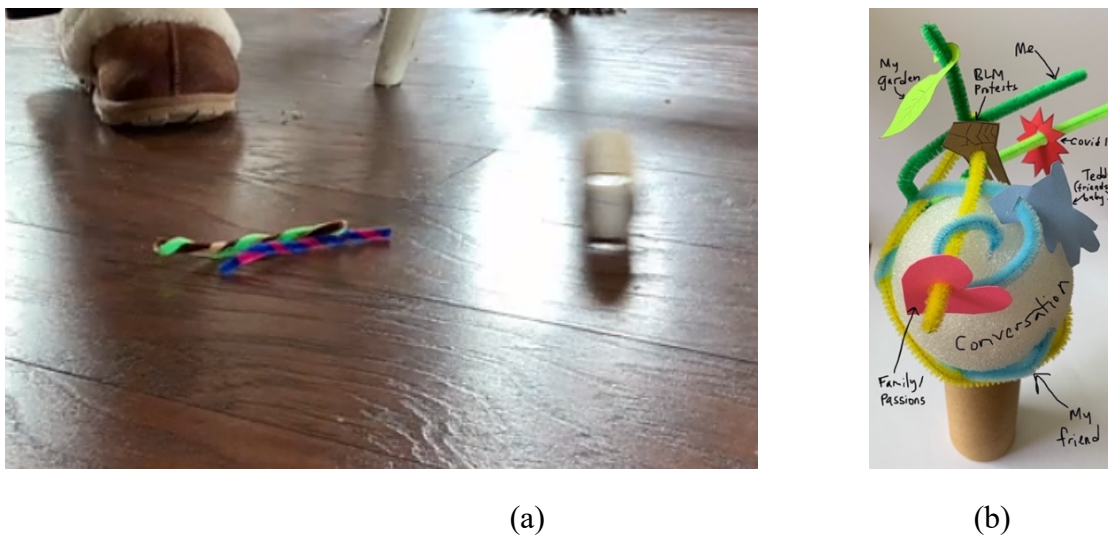


Figure 32. (a) Kendall's primary game action was putting the game player pieces (twister pipe cleaners) into a cardboard tube and rolling the tube on the floor; (b) Sarah's conversation is represented by the Styrofoam ball, around which are entwined the player pieces (pipe cleaner) and topics (paper cut-outs).

Charlie's game concept of building a "soup" conversation is a prime example of the "co-constructing kinesthetic experiences" game category. Charlie designed some of the most

elaborate player pieces of all the research participant's pieces (Figure 33). Charlie's self-representation is *"me as a drag queen because it shows my loud creative side and shows me as human, which is how I feel when talking to <their conversation partner>. I'm performing as a drag queen, but I don't have to perform (or mask) around him—so the drag is actually me having permission to play and be myself."* Charlie's conversation partner is depicted as a *"big eyeball with eye makeup because he sees me loud and clear."*



Figure 33. Charlie's game player pieces

Being fully seen by her conversation partner, in her unmasked, playful self, is important to Charlie as evident by her player pieces and in her game design. Charlie based their game design on the metaphor of creating soup, suggesting, *"the point of the conversation is to remain connected so keep making "soup" ... The game creates itself as we play, so it takes good communication on both our parts to play. We're each in control of putting in or taking out ingredients and that means we each can be casual about the game. It's a game where I assume we trust each other to make a good pot of soup together."* Charlie's game board comprised sketches of chairs on either side of a sketch of a big pot for cooking soup (Figure 31). Their game players take turns adding ingredients (a.k.a., topics) to *"this "soup" conversation"*, or alternatively, choosing a soup spoon to allocate quiet time for themselves.

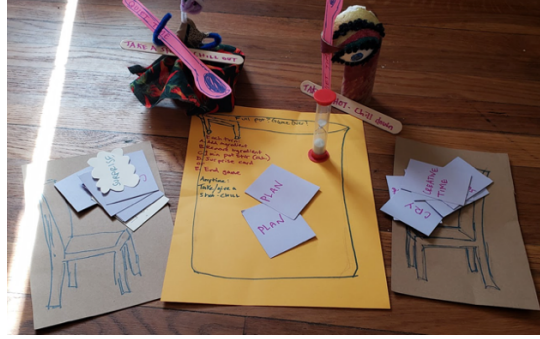


Figure 31. Charlie’s game of creating a metaphorical soup together.

Charlie placed value in building up a conversation with her conversation partner. The exact topics and sequence of topics are dependent on what they want to catch up on, what matters most is to have “*open space for thoughts (game pieces) to move around*” and for the “*game to take its own sort of path, rather than a clear beginning and end with a winner and loser.*” These values are evident in their use of soup as a metaphor for an evolving conversation, movable game board components, and game mechanics.

Although these two categories of games provided a way to compare and contrast the game designs, these categories are not concrete and a few of the games straddled both categories. For instance, Steve’s game concept included a structured set of topics as well as a strong kinesthetic aspect of game play (Figure 34).



Figure 34. Steve’s game design comprised spinning tubes representing conversation styles of causal, serious, factual, or funny.

The game board was not a flat surface, but rather, four cardboard tubes connected by rulers. This configuration allowed for a player to “*physically shift the game board*” to indicate

the type of conversation they want to engage in, which he specified as casual, serious, factual or funny. He provided the example of talking about rabbits, which could be discussed in, say, a funny way which is quite different than discussing them in a serious manner. Adding to the sensory experiences of the game, Steve noted that the game player pieces were cardboard boxes which could be opened to reveal game pieces and that *“the pipe cleaners are soft and can be touched if needing extra sensations.”* By attuning to particular types of physical movements and sensations, Steve specifies a multi-sensory conversation experience. In the following sections, I describe analytic themes that arose from the game design activities. These themes cut across both categories of game concepts.

***Theme: Rich Representations of Self and Conversation Partners***

Participants were instructed to create game player pieces to represent themselves and their conversation partner. In the game design, the participants represented themselves based on their personality traits and how they tend to feel they relate to other people. The resulting player pieces varied widely in how they were formed and the resulting objects. The player pieces ranged from a single pipe cleaner (Sarah) to elaborate 3-D figures constructed out of personal materials (Charlie). A common factor in the design of game boards and player pieces was choice of color. In designing their player pieces, several participants noted that they used materials with colors that matched to their personality. Sarah represented her *“kind, nice, and comfortable”* friend as a blue pipe cleaner, saying, *“blue is nice and yellow is nice and cheerful.”* In describing herself, Sarah said that, *“Green is me cuz I like green. I’m more like – more structured and logical.”* For Kendall, *“Green is the color of nature, and he’s all about nature.”* This shows that sometimes people chose an attribute of design, namely, color, because they are drawn to it and often attributed meaning to it.

In describing how they feel and perceive themselves in conversation with their partner, several participants emphasized feeling smart, logical and clever (Rahul, Tanish, Sarah); while others highlighted their playfulness and creativity (Emily, Charlie). In describing their conversation partners, participants appreciated that their conversation partners were kind (Rahul, Michelle) and humorous (Kendall, Rahul). Several participants stressed the importance of feeling comfortable and safe during their conversations (Sarah, Emily, Alec). They felt that their partners listened to them (Alec, Charlie, Emily) and they were easy to talk to (Charlie).

For all of the participants, they described that the relationship with their chosen conversation partner for this design study was a primary relationship in the lives. Participants described feeling more patient, present, and happy with these particular conversation partners than with other people (Alec, Daniel, Charlie). Some participants called out the importance of conversations as a way to “strengthen their relationship” (Emily) and share our “common humanity...bound together by a common thread of spiritual and physical unity” (Rahul). For both Emily and Rahul, it was important for them to physically attend to their conversation partners. Rahul noted that in conversations with his mother, “*matching eye contact, tone of voice, and pitch is crucial.*” Emily shared that she calls her boyfriend, “the furry animal,” and created her game pieces to reflect that he is more furry than she is. In her design journal, she included a photo of their arms to illustrate the differences in their body hair (Figure 35).



Figure 35. Emily's game pieces and game board and photo showing her and her boyfriend's forearms side-by-side.

Perceptions about themselves and their conversation partners were part of the grounding they did to begin to establish common ground. Trust was paramount to being able to enter into conversations feeling safe and comfortable. They had positive expectations about conversations with these trusted conversation partners who would “*listen to my ideas and care what I think*” (Alec), be truthful (Tanish, Steve, Charlie, Daniel) and forgiving (Daniel, Alec). Tanish shared that his mother “*understands me best and will guide me in the rhythm and flow of everyday conversations.*” This highlights that comfort in a conversation was attributed to trust in the relationship and in the flow of the conversation.

This activity of creating a physical representation of oneself and partner was a challenging task for some of the participants. This Steve said, “*I don't really think about myself during conversations. I am enjoying the conversation.*” He also used color to depict personality, yet his description of this was qualified with, “*The colors of the objects show the personality. The simplistic design is open to interpretation.*” For Laurel, she did not understand the instructions to create a representation of herself and her mother as game player pieces. (This is despite being an avid video game player, and therefore, familiar with game characters.) Her mother also did not understand this instruction, based on my phone call with Laurel and her mother. Laurel was blocked by this first activity of the design process, so instead of completing

the activities, we had a phone interview in which I asked her about her ideas for conversation rules, choices, and desired outcomes. We jointly ideated about how game mechanics, such as a timer, could help support a conversation. However, I do not include Laurel as a participant since she did not complete the game design activities. Another potential participant who responded with interest, received the kit, and then decided not to do the activities, also expressed that he did not feel that the activity was right for him. Perhaps, being with others during design would help these two individuals by seeing other people engaged in the activities, using materials, and the range and diversity of design artifacts. I reflect upon this further in the Discussion chapter regarding inclusive spaces in design.

***Theme: Perceptions of Available Actions During Conversations***

In their game designs, participants highlighted several key types of actions that were important to game play, and by extension, conversational moves. These key actions included choosing and changing topics of discussion, having clear rules for how the pair should interact, and having the ability to reveal or hide emotions.

First, in choosing topics, the participants' game board designs encoded their conceptualizations of topics of conversations they enjoyed. For some participants, they emphasized the straight-forward and focused nature of their conversations. For example, Tanish shared that, "*When we talk, it is always focused on the immediate practical tasks needed to be done as well as rules for given situations and opportunities to exploit.*" For Emily and her boyfriend, the game design revealed their day-to-day topics of conversation, including shopping, food, learning about big data, and job-related conferences. On the other hand, a few participants noted that they enjoy getting into "*deep discussions*" with their conversation partners about

politics, religion, and their life stories (Kendall, Daniel). Sarah and Charlie described how their relationship with their conversation partner and choice of topics were inter-related. As Charlie described, *“It helps me to have a topic to start with, but often we are catching up in our lives and that interests me, so it’s easy to fall into a rhythm where I feel in sync. My favorite is to remember things we have done or learned and feel connected well when we are both excited about planning something together or figuring out something.”*

Game designs included rules for how long to engage in a topic, ranging from, for example, “you have to say three different things about a topic” to “converse about the topic for 15 minutes or more.” Several participants shared that they find conversational dynamics, such as pause in the conversation, uncertainty about what to bring up next, and how to politely end the interaction. These concerns arose for one-on-one interactions and more-so in group interactions for some participants. Participants had design ideas for using visual objects as conversation cues. For example, Laurel suggested that people could pick from a stack of index cards with topic ideas. They could use timers to indicate to each other how much longer they wanted to remain on the topic or in the conversation. Michelle proposed that people in a group could take a physical cube or stick when they want to talk or handed it over to the person they want to hear from next.

Participants shared rules that they perceive as important in conversation dynamics and *“ideal rules that I would like to uphold”* (Daniel). The most common rules were about “staying on topic” and active listening, such as *“listen patiently”* (Daniel), *“don’t interrupt when others are talking”* (Rahul), and *“try to express that I’ve understood the person before saying my next piece of information”* (Charlie). The participants had rules about politeness, such as *“keep voices at a normal level”* (Rahul) and *“avoid sensitive words and subjects”* (Daniel).

A crucial, pervasive theme was for the conversation pair to establish and follow rules of consent regarding verbal conversation and physical interactions. At a fundamental level, Daniel articulated his right to not engage in the conversation at all, saying that for him, there “*are three basic choices per conversation: speak; don’t speak; and ignore.*” Charlie articulated the necessity of mutual agreement about conversation topics, saying, “*Since each ingredient comes one at a time they have time to talk about each ingredient before the next turn. It’s a soup they end up making together, but each person has a say in how they want it to be.*” Tanish expressed that “*you can always hide or withhold certain details. You can choose to focus on your points or the other points or find a nice balance. Alternatively, you can find common ground or choose to deflect from sensitive topics, or meet it head on.*” Emily’s game was explicit about negotiating topics, consent about comfort, especially when the topic of conversation could lead to physical closeness between the two of them.

Overall, in areas of verbal and non-verbal closeness, trust and explicit agreement to share was paramount. Another crucial component of establishing trusted common ground was the ability to choose how and when to share emotions. Sources of changes in their emotions during interactions were wide-ranging, as articulated by Daniel, “*Lack of communication and misunderstanding can cause frustrations and tempers to rise, as one example. Topic, words said and personal experience can cause all sorts of emotions as well.*” In Alec’s game, players could express their own emotions by “*adjusting the face on your piece if you are happy or sad.*” Also, players could respond to the other’s feelings, by, for example, “*giving the other player a goodwill gem if he helps you feel better, notices your emotion.*” Sarah imagined the use of dice to explicitly express emotions, especially as an alternative to masking—a term in the autism

community for hiding their autistic characteristics—by performing the body language and facial expressions expected by neurotypical social norms (Figure 36).

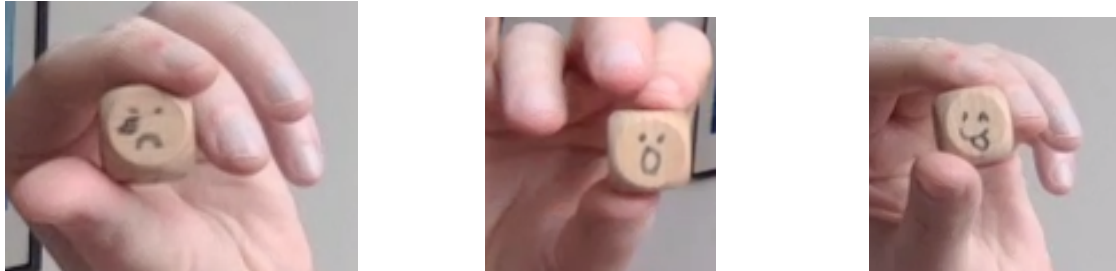


Figure 36. Sarah’s emoji dice

## 6.6 Experimentation and Reflection

In this section, I share how participants experimented with their game concepts with family and friends. I report on their closing reflections on the design premise that conversations are somewhat like a game.

The participants’ choices and reflections about experimenting and design can inform how designers and researchers can include autistic individuals in inclusive design spaces. Per activity instructions, the participants shared their game design with a trusted friend or family member and they selected parents, sibling, romantic partners, and friends. In collaboration, they experimented and adjusted the design (e.g., brainstorming topic choices, game board design, and game rules) according to their joint needs and preferences. Many of the participants reported that they enjoyed sharing their game and included their interaction partner in working through some of the design challenges they faced. After changing elements of the game together then playing through the game, Daniel reported that, “*The game served the purpose of stimulating social interactions extremely well, as not only did we converse, we also shared feelings and facts about each other that we did not know about before.*”

Some participants reported they had ideas for changes they desired for future game play, including making rules “*more concrete*” (Alec) and expanding game play, especially if they were to play with people other than their initial partner. For example, Alec wanted to ensure that the collaborative spirit of the game would be maintained even if he “*played with someone who was not being collaborative or helpful, there would probably need to be lots more rules about what to do when you disagree.*” Participants appreciated qualities of active listening and contributing ideas of their own in their design partners, indicating a comfort with a supportive and generative co-design style.

Last, I report on the participants reflections on ways that conversation are—and are not—like a game. Through the design activity, participants explored the proposition that conversations are somewhat like a game. In some regards, the participants felt there was some validity to this proposition. They noted that there are structural and mechanical similarities between conversations and game play. For example, both can be spontaneous or planned, and once they begin, the process has a beginning and end. There are shared expectations that turn-taking will facilitate “*a give and take (i.e., ‘turns’), a response to someone’s ‘move’*”(Charlie). Emily raised the issue of consent, a theme in her design, emphasizing that “*both parties have to be willing to continue for the conversation to happen... It is like playing tennis or ping-pong; the ball goes back and forth between each person.*”

Some participants shared that conversations and games are ways to learn about—and bond—with others. They reflected that relationships are strengthened by interactions when they demonstrate “*sportsmanship-like behavior*” which contributes to a “*healthy rivalry where friction shapes the people into better versions of themselves.*” (Daniel) It is through sharing

*“thoughts, feelings, and experiences [that you] truly connect with that person.”* (Tanish) When people engage in these ways, both people can be changed by the interaction.

On the other hand, participants offered important distinctions between conversations and game play. The overarching purpose of the two could be quite different with games being played for entertainment and conversations having the potential for higher stakes being *“based in reality with real consequences.”* (Charlie) Examples given included business negotiations, court hearings, and job interviews. Participants noted that types of interactions are governed by concrete social norms and protocols, such as the one-way conversation of a court hearing. In these context, the outcomes tend to be clear with people in winning and losing positions.

However, in everyday conversations, the outcomes are not as clear and *“you don’t always understand the goal.”* (Alec) Depending on the context, it is not desirable to aim for having a winner and loser, such as in the case of *“more flirtatious exchanges because that is not the right way to get to know a significant other.”* (Tanish) The process—such as when it is going to happen, agreement on topics, or when it is going to end—of an everyday conversation is not usually clear or agreed upon upfront. As Alec described, *“in a conversation you can’t always see the whole board so you don’t know where things are going and how close to “done” you are.* Conversations tend to be unpredictable due to *“lots of sporadicity, and you never know what can happen next.”* (Emily) Adding to the unpredictability are the *“unspoken rules and expectations.”* (Charlie).

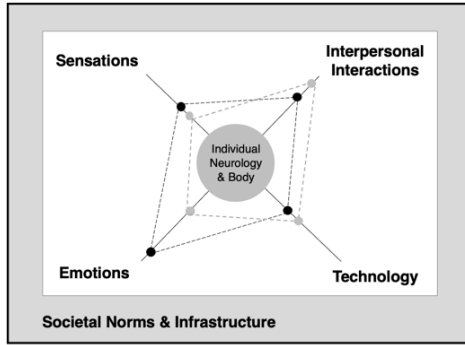
The factors noted above about the consequences and unpredictability of conversations contributed to feelings of vulnerability. Charlie notes that *“conversations can trigger certain responses like emotions or physical reactions.”* Contributing factors included confusion about

language (e.g., vocabulary), mismatch of humor (e.g., sarcasm), and feeling that mistakes would not be easily forgiven. However, with trust in their conversation partner and structure to the interaction—especially regarding consent—participants devised ways to reveal and process emotions. As Alec noted “*in a conversation, it’s sometimes easier to show your emotions and see the other person’s than in a game.*” (Alec) This points to the desire expressed by many participants for clear communication and direct interaction styles.

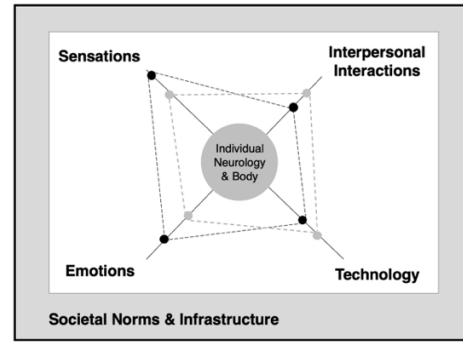
## 6.7 Implications to Design Themes

In summary, the design study provided empirical evidence of how participants conceptualize conversations as a complex process comprised of conversational moves and rules. Participants demonstrated a desire to balance structured interactions with bounded flexibility and choices in topics and emotional experiences. In the Discussion chapter, I synthesize insights about research questions explored in this phase. Here, I discuss the design outcomes that inform the next phase of Grounded Design, the appropriation study.

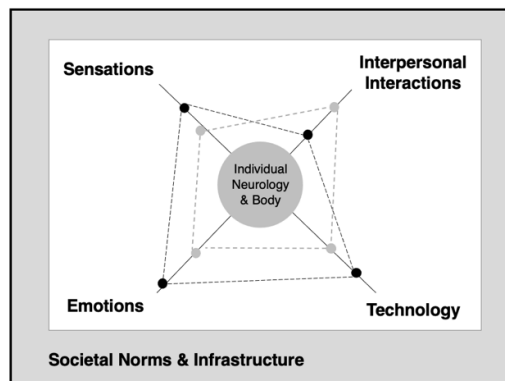
This design activity provided avenues for the participants freedom to choose which aspects of their social, emotional, sensory experiences were most salient to their individual neurology, body, and interaction styles. Thus, they explored the spaces of the social-emotional-sensory design map at will. In Figure 37, I demonstrate one way that the design map could be used to capture the relative emphasis the conversation pair places on different dimensions. In these instances, the dark circles and connecting lines capture the orientation of the primary participant. Likewise, the grey circles and connecting lines represent the orientation of the secondary participant.



(a) Alec



(b) Emily



(c) Sarah

Figure 37. Design maps capturing the relative emphasis participants placed on sensations and emotions within the context of the conversations for game design.

For most participants, the social aspects of game play served as the anchor point of their design map, with emotional and sensory aspects having focus at particular points in the game play. Many of the game designs in the category, “navigating structured topics” follow this model, such as Alec’s design which had an emotion spinner to capture changes in emotion (Figure 31 (b)). Notably, Emily’s “navigating structured topics” game had strong sensory elements in the game play topics and rules (Figure 30 (a)). Sarah’s “co-constructing kinesthetic experiences” game elegantly depicted the entwinement of the social and emotional connection with her conversation partner (Figure 32 (b)). She brought a deeper emotional element to her design with the addition of emoji dice to make emotional expressions explicit and relieve her masking efforts.

In the design maps, the placement of the markers on the technology axis are examples to indicate the role technology could play in the interaction. For instance, one person may be more inclined to use technology during the interaction. Alternatively, technology could be designed to proactively engage with one of the conversants, such as supporting the neurotypical person with tips for being more clear in their verbal and non-verbal communication. In another example, technology could support mutual understanding of each other's emotions as each individual intuitively expresses their emotions. In the next chapter, I further synthesize insights from the design study into the speculative design concept—an emotion translator—explored in the appropriation study.

# Chapter 7 Appropriation Study

## 7.1 Introduction

The third and final phase of the Grounded Design research was an appropriation study, during which participants critically examined and reconfigured an information technology artifact. The goals of the appropriation study were to explore (1) the ways that a neurodiverse dyad would use or reconfigure the technology artifact in a real-world scenario, and (2) their perceived values and potential harms of the technology artifact. In this work, the artifact was a speculative design concept implemented as a low-fidelity prototype. The speculative design concept emerged from the context study and was substantiated through participatory design. The concept was an “emotion translator”—a means of expressing one’s emotions as feels most natural and then, through technology mediation, having your emotion translated in a way that your conversation partner can understand and respond to. This design concept explored ways to augment a conversation, using imagery designed to represent emotional states that incorporated social and sensory elements. The concept also explored the idea of the co-constructed nature of emotional experiences, meaning that the conversation partners together developed the emotional tenor of an interaction. During this phase, the guiding research question was:

- Through engagement with a speculative design concept of an emotion translator, what does the pair desire to preserve, change, repurpose and convert? (RQ5)

Importantly, an appropriation study involves the social group using the technology artifact in real-world context of use. The context of use for this appropriation study was an online chat, a

technology participants reported in the Context study as using often on a variety of platforms including online forums, social media messaging (e.g., Facebook Messages), and mobile text messaging. Participants experienced social benefits of asynchronous, text-based computer-mediated communication (CMC) that aligned with prior research. As described in Chapter 3, HCI Research for Autism, common benefits for autistic individuals using these CMC technologies, as compared to face-to-face interactions, include reduced sensory processing, more control over the pacing of communication, and increased comprehension of communication. Participants described using text-based communication (e.g., texting, writing letters) to diffuse conflicts and playfully tease each other, even when having the option to speak face-to-face with their conversation partner.

The low-fidelity chat prototype had an asynchronous interface for configuring personal settings and a synchronous interface for real-time chat, which was supported by a “Wizard of Oz” researcher performing the emotion translation. Participants were empowered to edit, interact with, and guide changes to the behavior of low-fidelity chat interface. In real-time during Zoom sessions, I incorporated participants actions and verbal feedback into the prototype. As the appropriation sessions progressed, I assessed and prioritized feedback, and carefully made adjustments to the prototype. This approach of everyday adaptive design (Moran, 2002) allowed me to explore interpersonal social practices of neurodiverse dyads, as facilitated by an emotion translator.

## 7.2 Affective Computing Imaginaries: Emotion Translator

In this section, I introduce the information technology artifact for the appropriation study and the process by which it evolved. The artifact was a low-fidelity prototype for a speculative design

concept: an emotion translator. The premise of the emotion translator concept was that people express themselves according to their unique “emotion language” similar to how people have a native spoken (or signed) language. From the context and design studies, autistic participants described situations in which they had difficulty conveying their emotions to other people or wanting to conceal certain emotions or intense emotional states. They also described challenging conversations during which they did not understand another person’s emotions or they questioned the intention behind another person’s actions or words. This uncertainty led to social unease and misunderstandings. Both autistic and non-autistic participants expressed frustration at not being able to adequately express their emotions in ways that their conversation partner could understand. Neurodiverse dyads relayed interactions they had, even months prior, that they continue to discuss without full comprehension and resolution. During the context study, many participants expressed desires to have more seamless access to other’s emotions, perhaps through superpower mind reading skills. In the pair interviews, participants described many interactional moments during which their internal emotional state and thoughts were not fully expressed externally. During these interactions, the pair had misunderstandings about each other’s intentions, often leading to feeling hooked into established patterns of interactions that were not always beneficial in sustaining common ground. Therefore, the concept of an emotion translator could enable each person to fully express themselves according to their comfort level and desired way of expressing emotion. As a result, each person could feel fully heard and acknowledged; thus, building mutual empathy. By having an emotion translator available and knowing that the translator would do the work of translating to the other person’s emotional language, each person would be relieved of pressure to having to anticipate how their conversant may perceive and

interpret their emotional cues. They would not have the burden of trying to match their emotional expressions and interpretations to an unclear rubric and set of norms for emotional exchanges.

Drawing from these research insights, the research team engaged in speculative design, which explores preferable futures by opening up “possibilities that can be discussed, debated, and used collectively to define a preferable future for a given group of people” (Dunne & Raby, 2013, p. 6). Aligning with both speculative design and Grounded Design approaches to exploring the impacts of novel technologies, this phase of research brought emerging technology into the hands of the participants for critique, manipulation, and “the establishing of new social practices in light of new technologies” (Wulf et al., 2018, p. 139). The team envisioned *affective computing imaginaries*—new experiences people could have in which they felt safe expressing themselves and had capabilities to fully understand each other. We used the design prompt, “what if technology could...”, shared ideas, and collected compelling images from participants’ comfort objects and game designs from prior phases. We also drew from the lived experiences of our neurodiverse research team. We considered forms of digital and physical communication that augment in-person interactions, such as the Battleship game board and drive-through food order displays. We converged on a prominent emergent theme of technology-mediated conversations in which each individual could freely express their emotions and technology would facilitate sharing the emotions in a manner that could be fully received and understood. Taking inspiration from spoken-language translation services, such as Google Translate,<sup>8</sup> perhaps technology could provide emotion translation services to people during conversations. The emotion translator

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<sup>8</sup> <https://translate.google.com/>

concept allowed the research team and participants to co-design ways to augment a text-based conversation with information about their embodied emotional states.

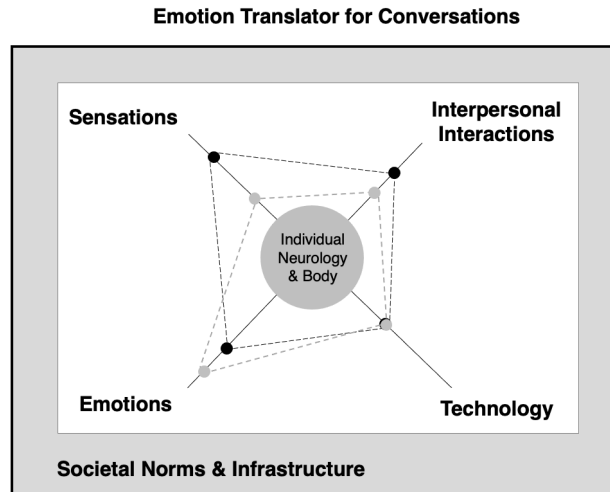


Figure 38. Design map depicting one framing of the emotion translator speculative design.

The emotional translator design concept can be framed using the social-emotional-sensory design map, as illustrated in Figure 38. As in the design maps constructed during the design study, the dark circles and connecting lines capture the orientation of the primary participant. Likewise, the grey circles and lines represent the orientation of the secondary participant. As the circles move towards the end of the dimension line, that indicates the need or use for that individual increases. For instance, the sensorial needs of the primary participant are greater than that of the primary participant in Figure 38. Reflecting on research insights from prior phases, this configuration of the design map shows a higher level of sensory attunement for the autistic individual and more dynamic emotional expressions from the non-autistic individual. The autistic individual may be more sensitive to sensory inputs and may have a more internally-focused experience during which they keep their emotions to themselves and do not express them externally as readily as their non-autistic partner. The interpersonal interaction dimension can be framed in terms of a heightened sense of social pressure, which is typically more intense

for autistic individuals than non-autistic individuals. The technology dimension holds both conversants in the same position since the emotion translator concept provides the same user interfaces and functionality to both users. In the Design Implications section below, I update the design map to incorporate insights from the appropriation study.

The research team envisioned the emotion translator as having a range of possible physical form factors. For example, the emotion translator could be software embedded in an Internet of Things (IoT) smart device, perhaps a commercial device people may already have in their homes such as an Amazon Alexa. On the other hand, the form factor could be specific for conversations in the form of a personal robot who could act as an intermediary in the conversation. Alternatively, we imagined an interactive game board powered by an Arduino electronics platform that could make conversational moves and emotions observable in ways other than human verbal and non-verbal forms, such as on a screen or with tangible objects. For three key reasons, the research team decided to manifest the design concept as a digital communication aid that would augment a chat app. First, as a digital software concept, we could focus participant appropriation on the core aspect of our speculative design—translating between conversants’ emotion languages. Second, by not bounding the software to a specific physical form, we allowed participants to imagine the potential value and harms for in-person and remote settings. Third, a software design allowed the team to present the concept to participants through online, remote interactions since we were still under COVID-19 social distancing restrictions.

To satisfy the goals of the appropriation study (to facilitate participant use and experimentation with a technology artifact within a grounded context of use), the technology artifact needs to be malleable, which requires having aspects that facilitate “transcend(ing) the intended purpose of software, supporting meta-activities like learning, troubleshooting, or

sensemaking with information technology tools in relation to a use case” (Wulf et al., 2018, p. 147). Salovaara and Isomäki summarized the necessary properties of appropriable technologies as openness, looking at data from multiple viewpoints, tailorabilities, configurational technologies or technologies as equivoques (Salovaara & Tamminen, 2009). We designed the emotional translator prototype with these properties in mind. I implemented the emotion translator as a low-fidelity prototype in Google Slides, which enabled the participants and researchers to enter text and manipulate images and the interface in real-time. The participants were familiar with Google Slides from earlier pair interviews, although I had performed the text input and image manipulation during that study. I chose to create a low-fidelity prototype because this level of fidelity helped participants understand that the artifact was a work-in-progress, as opposed to a more concrete medium- or high-fidelity models prototype. I next detail the prototype’s two interfaces: (1) a personal emotion grid, and (2) a simulated online chat during which users used personalized emojis that were translated by a “wizard” researcher.

### ***Emotion Translator: Emotion Grid***

Participants first interacted with the “emotion grid” interface of the emotion translator. Participants were invited to configure their emotion grid by populating it with images from two sets of customized visual icons that were licensed from visual artists. These images would serve as emojis for the chat interface. Emojis are images used in digital communication that “convey a wealth of emotions and concepts that otherwise would take many words to express” (Wiseman & Gould, 2018, p. 1). Each participant selected images from 32 images, shown in Figure 39 and 40 below. The goal was that the participant selects images that represent the types and range of emotions that they experience in daily life.



Figure 39: First set of images (from Poddar) in the “emotion picker”

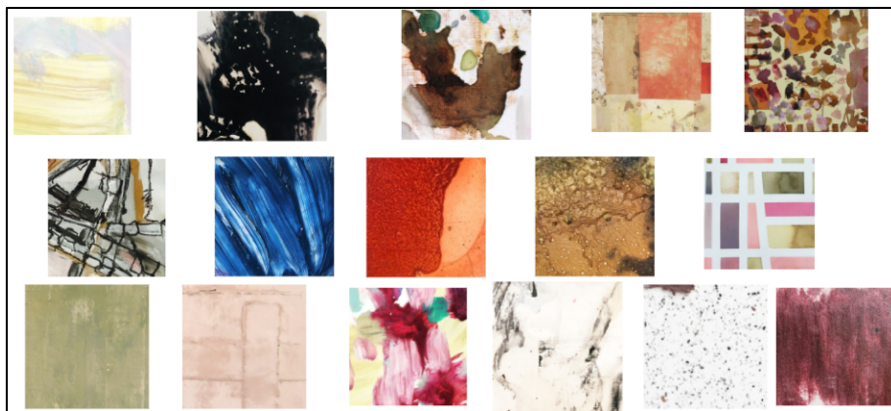


Figure 40: Second set of images (from Calladine) in the “emotion picker”

Based on the previous Grounded Design research activities, and as I discuss in the Context Study and Discussion chapters, I found that common representations of emotions, such as representing emotions as Ekman’s six basic emotions, did not adequately represent the emotional states of autistic adults. Common representations assume that people experience emotions as discernable distinct and unique emotional states with no overlap or mixing. The empirical evidence demonstrated that it was limiting to think of emotions as merely what is expressed through facial expressions. Rather, emotions could be embodied, rather abstract, and amorphous.

Thus, rather than use common representations of emotions and to provide the participants with images more aligned with our findings than the typical facial expression emojis, the

research team decided to curate images from visual artists. I chose two artists based on the following criteria: (1) their work evoked different qualities of emotions (e.g., environmental, social, colors) to align with our research interest in the social and sensory aspects of emotions, and (2) whose work was visually different from each other to provide distinct options to participants. The first artist, Rukmini Poddar “draws emotions” and focuses on “creating art that inspires thoughtfulness, introspection, and emotional wellbeing”<sup>9</sup>. I chose Poddar due to her visuals of human figures representing what she has coined “Obscure Emotions”—emotions “we feel deeply but cannot yet articulate or understand.” The second artist, Jacqueline Calladine,<sup>10</sup> is a textile artist who creates mixed-media artwork who has a series of artwork based on her experimentation with creating ink dyes from natural materials. I chose Calladine due to the range of colors, visual variety (e.g., patterns and color swatches) in her abstract artwork, which contrasted with Poddar’s human figures. I also selected Calladine for her natural dye technique which enriches digital images with underlying tactile, sensory qualities that connect with themes of this research. I had an independent Zoom video call with each artist to explain the Grounded Design research and my request to them, which was to select a set of at least nine images from their artwork that represented a range of emotions, including neutral emotion(s). The images could be photos of existing artwork or new pieces. During this meeting, I shared that Russell’s circumplex model of affect (Figure 41) has contributed to the theoretical framing of the research. I described that according to this model, affect was viewed as responses along two dimensions:

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<sup>9</sup> <https://dearruksi.com/> and <https://dearruksi.com/pages/obscure-emotion>

<sup>10</sup> <https://www.jkcalladine.com/>

pleasantness and activation. In theory, all possible emotional states can be mapped in this space according to their level of unpleasant—pleasant and deactivation—activation. I invited them, if it was a useful framework for them, to use this framework as a guide for selecting their images.

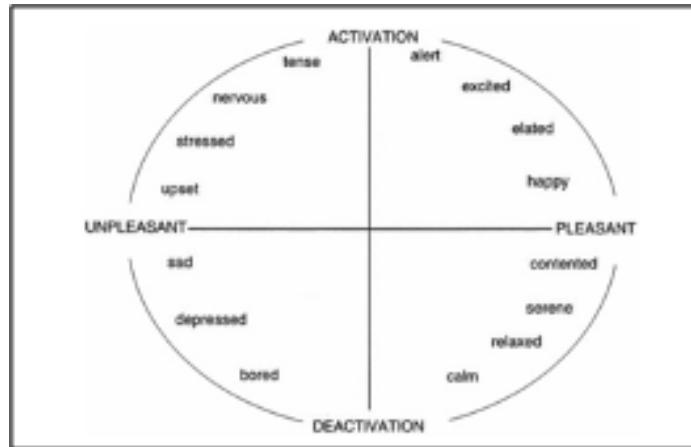


Figure 41 (for reference only, identical to Figure 1). Russell’s circumplex model of affect showing valence on the horizontal axis and arousal on the vertical axis.

I invited the artists to submit approximately 20 digital photos of their artwork, with each image representing their interpretation of a particular emotional state. The artists were paid for their time and their artwork was directly licensed through them. Poddar submitted the images shown in Figure 39. The image in the bottom row, at the far right position, was added later based on participant feedback, which I describe in Findings section below. Calladine submitted 45 images, of which I selected a subset of 16 to obtain variety in color, patterns, and textures (Figure 40). I originally selected 15, then added the image in the bottom row, far-right position when I added an image to Poddar’s set.

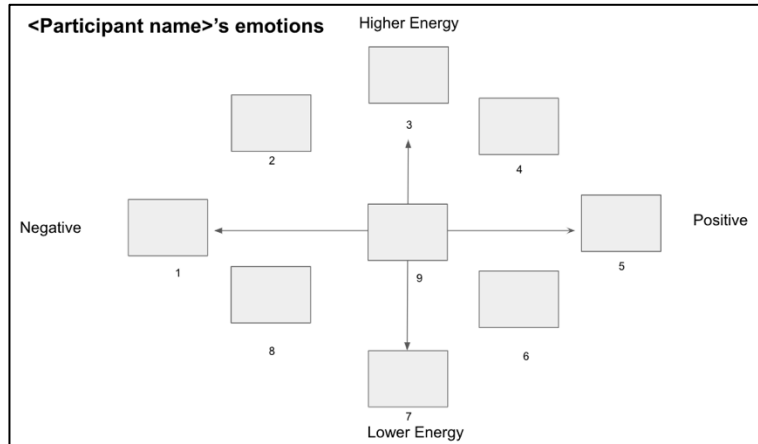


Figure 42: Empty “emotion grid” for participant to place emotion images according to how the images represents emotions along dimensions of negative to positive x-axis and lower energy to higher energy y-axis.

Along with the images, the important component of the ‘emotion grid’ was the layout and labels for the grid (Figure 42). The grid I proposed to the participants was based on the shape of Russell’s circumplex model of affect, with dimension labelled as negative-to-positive and lower energy-to-higher energy. During the appropriation study, the labels for the dimension end-points changed according to participant input, which I detail in the Findings section below. Note that for pilot and pair sessions, the emotion grid’s endpoints were not labeled. I left them unlabeled to not place any assumptions or constraints on how participants would interpret the two dimensions, such as implied by “low energy” or “high energy”. These participants were asked to label and explain the grid endpoints. I provided suggestions (high-low energy, small-big, angry-happy, and negative-positive). However, these participants had vastly different interpretations of the grid, such as the x-axis signifying time. This caused confusion during the synchronous session for participants and for the “wizard” emotion translator to perform a 1-to-1 mapping of emotions between two incongruent grids. We took time to resolve the confusion by discussing and proposing grid labels. However, to reduce confusion in subsequent interviews and time needed to re-do grids with congruent labels, I proposed grid labels based on Russell’s circumplex model of affect, in keeping with the intention of the grid structure and the use of that model by the artists.

### ***Emotion Translator: Chat Application***

For the purposes of the research, the necessary functionality of a chat app was for two people to be able to type, see and respond to each other’s typed messages, and select emojis. I

implemented a low-fidelity interface of this basic chat app using Google slides. Each slide represented a different screen that the participants could access that contained their personal emotion grids and the chat interface. The chat interaction was simulated with a Google slide showing the user interface elements (first name initial and text bubble) for the primary participant on the left side and the secondary participant’s elements on the right side, as shown in Figure 43.<sup>11</sup> The initial text bubble for each participant showed “type here” to indicate where the participant needed to place their cursor to type.

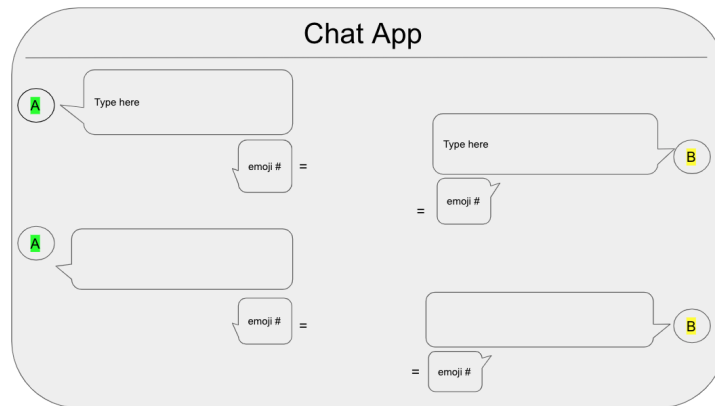


Figure 43: Chat template slide, customized for the session with Alec and his conversation partner, Bob (names are pseudonyms).

As the participants type in the chat app, they chose an emoji from their emotion grid that corresponded to what they just typed. The participant could look at their emojis, which were laid out according to their emotion grid (example shown in Figure 44).

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<sup>11</sup> Note that the first initial of each person’s name is highlighted in a different color. The prototype had a consistent color-coding for the emoji borders. This color-coding treatment was added to the interface after the first appropriation interview.

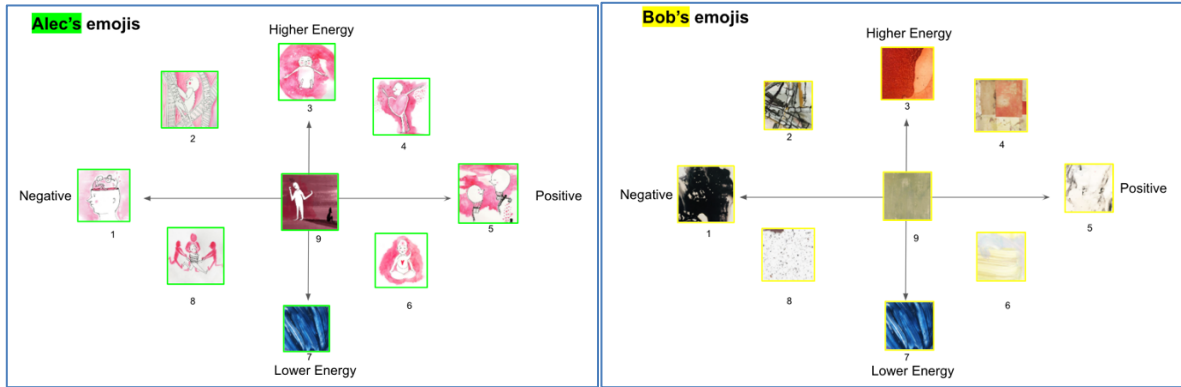


Figure 44: Example of emoji set for a participant (Alec) and his conversation partner (Bob).

The speculative functionality of an emotion translator was conveyed using a Wizard of Oz technique in which a researcher acts as a “wizard” to simulate the envisioned interactions (Dow et al., 2005). When a participant said or typed an emoji number, a researcher (1) pasted the emoji into an emoji speech bubble, and then (2) pasted their partner’s corresponding image based on emoji number. For example, based on Alec’s and Bob’s grids shown in Figure 44, when Alec chose image #5, the wizard copy-and-pasted Alec’s image 5 (two figures) and Bob’s (an abstract black-and-white image) side-by-side (Figure 45).



Figure 45: Example of mapping the primary participant’s image for the positive and middle-energy spot on the emotion grid.

### 7.3 Method

This study started with recruiting participants from prior phases, then asynchronous configuring of each participants’ emotion grid, and Zoom sessions during conversation as dyads experimented with the chat prototype.

## ***Recruiting and Participants***

I began recruiting for the appropriation study in February 2021 by emailing participants from the design study. In an attempt to reconnect with Spokane Community College IMAGES program students who I had been unable to reach during the design study, I emailed the instructors of the IMAGES program to inquire about student availability and well-being during the COVID-19 pandemic. I recruited seven participants, including two from IMAGES, and collected data in February and March 2021. Primary participants then invited trusted conversation partners of their choosing, which could be the same or a different partner invited to the context study pair interviews or involved in design. Both primary and secondary participants configured personal emotion grids and interacted with the chat app prototype during their pair Zoom sessions. Summary descriptions of participants in the appropriation study are provided in Table 11. I conducted a pilot session with one conversation dyad, an undergraduate student in the Informatics department of my university and that student's younger sister.

Table 11. Demographics of research participants in participatory design phase (n=14; 7 pairs)

Attribute	Demographics
Age	19 – 33 (average 25)
Gender	3 women, 3 men; 1 non-binary
Location	United States; living in a rural, mid-size city (2) or in large metropolitan city or suburbs (5)
Living arrangement	Before COVID-19: Live with parents (4); live alone or with roommates (3)
Level of education	Transition program for life and job skills at a community college (2); Master of Music (1), PhD in statistics (1), medical residency program (1), Bachelor degree (1); high school graduate (1)
Current employment	Employed in technology and music fields. Internships with local retail shops (bakery, feed store, pizza restaurant, computer repair)
Conversation partner	Instructor (2), family (2), boyfriend (2), friend (1)

### ***Configuring Emotion Grids***

Participants first interacted with the “emotion grid” independently and asynchronously, prior to the Zoom interview. When I confirmed the participant’s Zoom interview schedule, I informed them that I would be asking them to independently complete a short 15-minute activity prior to the Zoom call. Five days prior to their Zoom interview, I emailed the participants a link to their individual emotion grid Google slide deck. In the deck were instructions for completing their emotion grid, as summarized in Table 12 below and detailed in Appendix F.

Table 12: Step-by-step instructions for participants to configure personal emotion grids.

Step	Instruction	Details
Emotion Grid – 1	Select 9 images that represent the types of feelings they have during conversations.	They were invited to use all images from one slide, or to mix-and-match images from both slides.
Emotion Grid – 2	Place chosen images on the emotion grid.	
Emotion Grid – 3	Answer questions	1. Why did you choose the images you did?  2. Was there anything missing from the set of images you were looking for?

Prior to each Zoom session, I copied their completed emotion grids (Figure 42) into the chat prototype so they could easily access them. I also created new slides based on their grids to stylize their chosen images as emojis to use in the chat activities (e.g., Figure 44).

### ***Interacting with Chat Prototype***

The participants interacted with the chat prototype during a synchronous Zoom session with me and another member of the research team. I introduced the other researcher as a note-taker. There

were two team members who performed as the wizard and they each attended approximately half of the sessions. After introductions, I provided a brief recap of research activities thus far since participants had been part of prior phases. Each participant and researcher opened the Google slides for the chat prototype and I shared my screen in Zoom. I explained that their cursor would be labeled by Google as “anonymous animal of some type” because of how Google labels people using a shared Google slide without being logged into a Google account. Then, I walked the participants through each activity, moving the slides and asking them to move, on their computer, to the slide in which they would type into the chat interface. The chat activities are listed in Table 13 below and detailed in the Appendix G.

Table 13: Chat activities during Zoom session

Activity	Description	Details
Chat – 1	Use chat interface to say hello and tell each other about your day’s activities.	No emojis; getting familiar with typing into Google slides using the chat user interface
Chat – 2	Discuss primary and then secondary participant’s emotion grid.	Ask if it was easy or difficult for them to complete the grid, and what made it easy or difficult. Ask which image was selected first and how did they proceed selecting images. Ask for meaning of the images.  After sharing both, ask for reactions to each other’s grids and if there were any surprises.
Chat – 3	Use chat interface to discuss a hot topic. After each typed message, select an emoji from their emotion grid to accompany their message.	The pair first selected a hot topic, which I described as a topic you have a difference of opinion on or to role play two people who have

	Emotion translator was active and displaying the original and translated emoji's side-by-side.	different opinions. (All participants chose topics they had an actual difference of opinion on.) I provided examples: what genre movie to watch; favorite types of video games; whether schools should re-open during COVID-19.  After the chat concluded, I explained the Wizard of Oz step and asked for their reaction to that functionality.
Chat – 4a	Review the hot topic conversation, but shown as if the emotion translator made the translated emoji more prominent than the original emoji.	For activity 4, we experimented with (a) making the original emoji small and placed at the edge as if only in the view of the person who sent it, and (b) only showing the translated emoji (deleting the original emoji)
Chat– 4b	Review the hot topic conversation, but shown as if the emotion translator removed the original emoji and only showed the translated emoji.	

After each step, I asked the participants for their perceptions of the experience, what they would like to change and why.

***Appropriation Study Analysis***

The appropriation study data comprised participant emotion grids, written responses to emotion grid questions, chat app activity (text and emojis), video recording of Zoom interviews, and researcher notes taken during the Zoom interviews. After each interview, the “wizard” researcher and I debriefed about our impressions of the participants’ engagement with the prototype and discussed emerging themes.

To assess the appropriation of the technology artifact, I conducted inductive analysis modelled on prior work that examined the appropriation of technology designs and artifacts (Jacucci, 2006; Kim et al., 2013; Salovaara, 2007; Salovaara & Tamminen, 2009; Vaida & Mynatt, 2005). In these studies, researchers (1) examined how particular features provided the mechanism by which participants could appropriate the technology, and (2) primarily conducted inductive analysis to formulate emergent themes. Inductive analysis is an appropriate approach since, as Salovaara et al. state, the “existing literature on appropriation does not contain definitions for appropriability metrics, but suitable measures are linked to a system’s usefulness in various settings, and its configurability with other systems in the use contexts. (Salovaara & Tamminen, 2009, p. 12). For example, Vaida & Mynatt collected video snapshots of participants’ use of shrugging gesture as evidence of using gestures to convey emotional intent. Similarly, I collected participants’ emoji in position #9—the neutral position in the emotion grid—and display them together (Figure 48) to amplify the diversity of interpretation of neutral emotion.

Kim et al. proposed a taxonomy based on “cases of appropriation,” in which technology artifacts were appropriated by study participants (Kim et al., 2013). Their taxonomy had three dimensions. First, the “seriousness” of appropriation as indicated by the extent of “changes in the share of the appropriated object from the design, lasts longer than easy appropriation, and results in more necessary needs” (Kim et al., 2013, p. 4). Second, the “unexpectedness of the appropriation” captures the “distance between the designed context (of use) and the actual context” (Kim et al., 2013, p. 4). Last, the third dimension, “novelty”, refers to the uniqueness of the appropriation. However, this taxonomy has not been verified in subsequent studies; therefore,

I took modeled my analysis on this taxonomic approach but allowed the appropriation themes to emerge from my data (See Table 14, which includes appropriation codes).

Table 14: Categories and Themes from Inductive Analyses

Category	Themes	Data to which these codes were applied
Selection of images		
	Forms versus abstract	Table 12, Emotion Grid-1
	Ease of image selection	Table 12, Emotion Grid-1
	Interpretation of images	Table 12, Emotion Grid-1, 2, 3
Emotion taxonomies		
	Structure versus elusiveness	Table 12, Emotion Grid-2; Table 13, Chat - 2
	Dimension number and labels	Table 12, Emotion Grid-1; Table 13, Chat - 2
	Accessing emojis during chat	Table 13, Chat-3
Chat actions		
	Augmentation of written text (video comments; emojis)	Table 13, Chat-3
	Turn-taking with emojis	Table 13, Chat-3
	Interpretation of emoji behavior and meaning	Table 13, Chat-3, 4a, 4b
Perceptions		
	Perceived value of technology mediation; insights about conversation partner; meaning ascribed to functionality	Table 12, Emotion Grid-1, 2, 3; Table 13, Chat-1,2, 3, 4a, 4b
	Potential harms of technology mediation; potential losses of connection	Table 12, Emotion Grid-1, 2, 3; Table 13, Chat-1,2, 3, 4a, 4b

Appropriation		
	Structure versus flexibility	
	Desired personalization	
	Meaning ascribed to functionality	
	Reconfiguration	
	Unexpectedness (distance from original concept)	
	Connections to established practices	

Within a chat of a hot topic (Table 13, Chat-3), I coded chat exchanges, as defined by one back-and-forth exchange between the pair (chat message + emoji, and the chat message + emoji in response). I analyzed the messages and emojis as they were generated by the participants, meaning the order of message and emojis mattered. These analysis techniques are based on Goodwin’s principles of interaction analysis, a method used in systematic investigation of talk-in-interaction during daily activities (C. Goodwin, 1999). Goodwin’s interaction analysis technique details an “embodied participation framework” composed of body positioning, artifacts, gestures, gazes, and linguistic markers. In my analysis, interaction analysis is primarily based on text and emojis captured in the chat interface, supplemented with (1) the participants’ body positioning, gestures, and gazes visible within the Zoom camera and (2) movements of the mouse and keyboard cursor in Google slides. By accounting for a variety of verbal and nonverbal cues during the chat exchange, we analyze not only the written messages and selected emojis, but also, for example, a pause in typing during which the dyad had a verbal exchange before typing resumed. I analyzed the messages and emojis in the order they were generated by the participants, meaning the order mattered, as it does in conversation analysis techniques

(Jefferson, 2004; Ochs, n.d.). Rather than generating a notated transcript as in tradition conversational analysis, I used the written and visual record of the completed chat to strategically select chat exchanges for deeper analysis, referring to video recordings and researcher memos for related data.

As the participant sessions continued, common themes emerged regarding interpretation of images, tensions between structure and elusive emotion taxonomies; accessing emojis during chat, intuitiveness of emotion translation, and perceptions of value and harms (Table 14). The mapping of thematic categories (Table 14) to the type of evidence and data sources across research phases are listed in Table 15. This is based on Table 10 in the Design Study chapter, updated here to include the appropriation study.

Table 15: Cumulative mapping of categories, evidence, and data sources from all Grounded Design research phases.

Categories	Evidence	Data Source
1. Common ground moves	<p>How are they talking about common ground? How do they talk about moving in and out of common ground?</p> <p>Aspects of self that they choose to emphasize or diminish; Ways that they observe, or wish to, connect, engage, and maintain space from their interaction partners. Ways they externalize their emotions.</p>	<p>Pair interviews: Information they find useful for grounding during interactions. How they initiate, coordinate, and close interactions. Ways in which technology is part of common ground actions.</p> <p>Common Ground visual activity: similarities and differences between internal/external for each person. Includes tech use.</p> <p>Game design: game player pieces</p> <p>Appropriation: Choice of conversation topic, personal emoji grids, use of emojis during chat, appropriation actions.</p>

<p>2. Available actions</p>	<p>Social interaction mechanics and rules; Ways that communication moves are materialized or characterized</p>	<p>Pair interviews: Patterns of communication, restrictions, consequences. What actions are afforded by technology?</p> <p>Common Ground visual activity: Patterns, boundaries, and barriers during the interaction</p> <p>Game design: Game choices and rules, game board boundaries and spaces</p> <p>Appropriation: typed messages in chat, choice of emojis, verbal and nonverbal exchanges over Zoom</p>
<p>3. Impact of moves</p>	<p>The ways impacts are described. The ways in which participants drew on or incorporated social-emotional-sensory experiences in their descriptions of social interactions</p>	<p>Pair interviews: points of friction, breakthroughs, decision making. How does tech impact agency and decision making?</p> <p>Common Ground visual activity: Changes in internal and external actions and emotions. Includes tech use.</p> <p>Game design: Game choices and rules, Mental models of “the end game” / purpose / goal of social interactions</p> <p>Appropriation: sharing of emotion grids, typed messages in chat, choice of emojis, appropriation actions</p>
<p>4. Points of mediation</p>	<p>Description of things, actions, feelings that they would want changed. Ways that they want to manipulate, show, and hide emotions.</p>	<p>Pair interviews: What they would like to see changed; superpowers</p> <p>Common Ground visual activity: Points of intervention</p> <p>Game design: Opportunities to change the game play; Use of game elements to enhance social-emotional-sensory experiences.</p>

		Appropriation: personalized emotion grids, sharing of emotion grids, choice of emojis during chat, appropriation actions
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To maintain a prototype that evolved in response to participant appropriation, the research team captured ideas from participants and brainstormed ways to reflect their ideas in the emotion grid and chat prototype interface, text labels, emojis, and wizard translation behavior. After each interview, I grouped potential changes into one of the following categories: (1) critical issues—points of confusion in the purpose or fundamental functionality of the prototype, (2) concern or idea to probe in future session, or (3) idea to track for broader analysis. In preparation for the next interview, I addressed the critical issues by making continual, relevant changes to emotion grid slides and / or chat prototype slides. I detailed this experimentation and evolution in the Findings section below.

## 7.4 Appropriation Study Findings

The appropriation study explored the research question: through engagement with a speculative design concept of an emotion translator, what does the pair desire to change, repurpose and convert? I observed that the pairs appropriated all components of the prototype: the emotion grid, the chat interface, and the emotion translation functionality. Participants took unexpected actions during asynchronous (Table 12, Emotion steps) and synchronous activities (Table 13, Chat activities), including guiding the researcher and wizard researcher through words, gestures, and mouse movements during Zoom sessions. The main change participants suggested involved the behavior of the emotion translator. Their appropriation actions and verbal feedback raise important issues about embedding assumptions into emotion-related features in communication

technology. In addition, many participants resisted the proposed structure of the emotion grid and altered the structure to produce unexpected and novel configurations. These findings reveal factors for designing affective computing, including careful consideration of the initial configuration user experience, facilitating sharing about the meaning ascribed to affective images, and balancing tensions between structure and flexibility in using affective functionality.

### ***Diverse Rationale for Image Selection***

No two participant emotion grids were alike. Variation was succinctly rationalized by Kyle, who, when asked what he thought about the differences between his grid and his partner's grid (Table 13, Chat-2) said, "*everyone is different.*" The human form images were selected much more than the abstract forms. The human forms resonated with the autistic participants because the figures were "*literally figures in situations that are expressing emotions*" (Sarah). The human forms had faces, which were "*better to show emotion and energy*" (Alec). The forms were more relevant to emotions, whereas the abstract "*color swatch*" images were considered "*more ambiguous*" (Sarah). Sarah also appreciated that she "*could pick multiple emotions for one image.*" This demonstrates that the abstract images evoked emotions but were more open to interpretation of a diverse set of possible emotions. Emily said that she started with "*the non-human images,*" then realized "*they did not represent energy.*" She considered energy as being a human attribute and did not equate the abstract images as having this human attribute.

The most diverse selection of images within a pair was Alec and his partner, who was the only participant to select all abstract images (Figure 46). Coincidentally, they both selected the same abstract blue image for position 7, lower energy, midway between negative and positive.

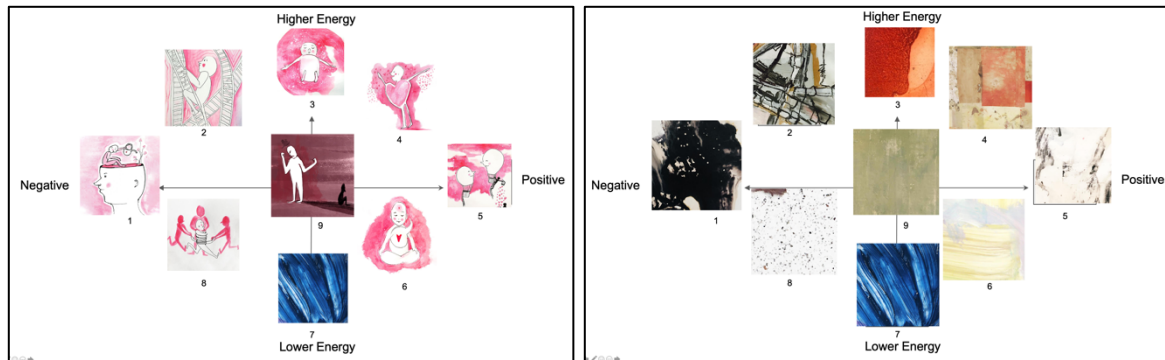


Figure 46: Emotion grids of Alec and his conversation partner

Participants expressed strong opinions about the interpretive nature of images, which could lead to misunderstandings about emotional states when shared during chats. Participants shared personal connections they felt with the images (Table 13, Chat-2). The majority of participants said that it was easy to select images. They said that the images “*represent how I feel,*” and to Mitchell, “*how my life has been.*” Mitchell placed himself in the situations of the human forms in the images. For instance, the first image he selected was “*the guy look back at his shadow (#1). I came from a dark childhood and I’m not going look back. I move forward*” (Figure 47).

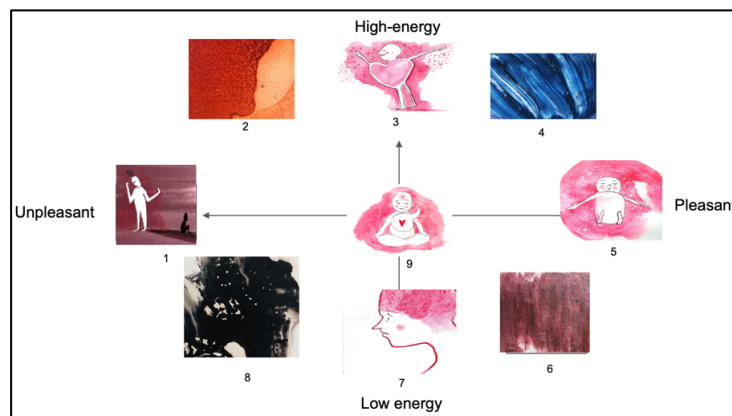


Figure 47: Mitchell’s emotion grid with a mix of human forms and abstract images. His selection of images reflect life experiences.

Unprompted by researchers (during Table 13, Chat-2)., many participants organically examined each other’s center image (# 9) in their emotion grids, noting similarities and differences. Figure 48 below shows image # 9 for each primary participant in the top row and for

their respective conversation pair in the bottom row. Some participants referred to this image as the neutral emotion. However, this was not always the case; some participants viewed the grid as being a conversation cycle (Laurel’s mom) or representative of emotions they felt throughout life (Mitchell). This insight has implications for design because it demonstrates that autistic people have different views of what a neutral or baseline emotion feels and looks like. Other marginalized population are likely to have emotional experiences for which a normative, straight-line, middle-state of a baseline emotion is not representative. For example, Snyder found that people with bipolar disorder conveyed their baseline emotional states, moods, and behaviors as visually situated outside the middle-ground x-axis or as oscillated in a range rather than as a single line (Snyder, 2020b). Therefore, affective computing technologies should not dictate how users should represent or experience neutral or baseline emotional states.

Primary participants							
	Sarah	Emily	Alec	Mitchell	Kyle	Laurel	Charlie
Secondary participants							

Figure 48. Images in position 9 for all participants. The pairs are in the same column. Note that Mitchell and Kyle had the same conversation partner (their instructor), thus, his yellow abstract image appears twice in the bottom row.

After discussing their mutual images for neutral, Sarah shared that “I like being able to figure out what the discrepancy is and that helps me. Helps me figure out where people are coming from. If he says neutral, I should just get it. But I’m not used to it.” The emojis served as an avenue for learning about other people’s perspectives and emotional expressions. I propose that these are unique conversation moves afforded by the emotion grid.

### ***Interpretation and Reconfiguration of Emotion Grid Structure***

All participants used the proposed grid layout and labels during their asynchronous activity (Table 12, Grid steps). However, during the Zoom sessions (Table 13, Chat activities), the majority of the participants reconfigured or expressed resistance to the structure of the grid (Sarah, Mitchell, Kyle, Charlie, Laurel). As a result, the emotion grids changed their graphics, including layout, grid labels, and the number and positions of images.

First, the labels for the grid dimensions were often questioned and debated by participants. For the pilot and first pair session, I left the grid labels empty and asked the pair to label the axis (Table 12, Emotion Grid–2). I gave examples from which they could choose (high-low energy, small-big, angry-happy, and negative-positive). Sarah chose negative-positive and high-low energy because “*They seem like basic foundations for different emotions. But I feel like there should be more dimensions.*” Taking a different approach, her partner labeled the x-axis as “interaction starts-interaction ends” (from left to right), and the y-axis as “emotions at the end-emotions at the beginning” (from top to bottom). Without suggested labels, the dyad had vastly different interpretations of the grid. Since the “wizard” functionality relied on mapping each pair’s images—matching images in position #1 to indicate a positive emotion, for instance—I anticipated that the “wizard” functionality would result in inherently mis-matched emojis. Therefore, during the Zoom call, after sharing how they approached their grids, I invited Sarah’s partner to align his grid labels to hers. To achieve improved alignment for subsequent dyads, I labeled the grid axes as “low to high energy” (on the x-axis) and “unpleasant to pleasant” (on the y-axis), in keeping with the Russel circumplex model of affect.

Some participants, both those who were autistic and non-autistic, added a temporal aspect to the grid and interpreted the grid as a cycle (Mitchell and Teri). As shown in Figure 47 above, Mitchell viewed the emotions as starting positive then cycling downward to a negative outcome, saying that *“I can grate a conversation then it can go down the drain.”* Mitchell expands on the connections between the images and his emotional life experience as follows:

*“The colors represent my rage and my mood; ones with the bodies represent how I’d look like when I’m in a good mood or bad mood. Image 9, I’m at peace. Image 2 represents me going from a sad day into a better day. Image 5 is me trying to stay as calm as possible but it slowly translates into me wanting to close up from the world. Image 6 is me closing up from the world; not wanting to talk to people. Image 8 is a link from 1 to 7. And image 7 is doubting the choices I did in the past.”*

Upon listening to Mitchell’s explanation (Table 13, Chat–2), his conversation partner said that it was insightful for him to learn about how Mitchell *“internalize[d] the shapes and colors to mean something to him. I had a hard time making meaning of those [abstract images] in context of the chart. They still don’t mean much to me.”*

Several participants found it difficult to make clear distinctions between all positions on the grid, especially in-between positions (2, 4, 6, and 8) that did not anchor endpoints. For example, Kyle selected the same image for multiple positions (Figure 49).

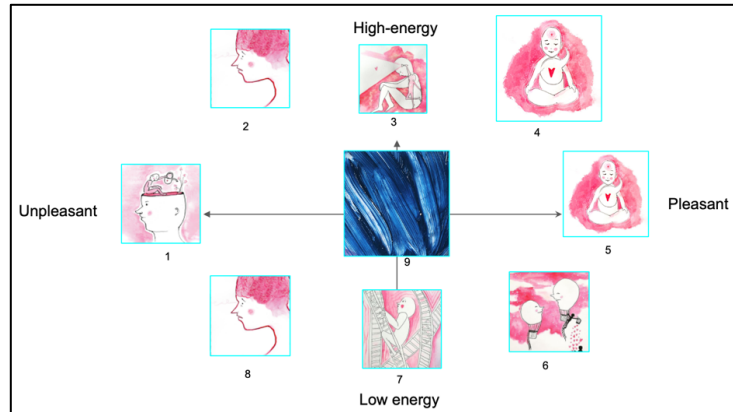


Figure 49: Kyle used the same image in positions 4 and 5, and 2 and 8.

In another example, Charlie described how they found the grid conflicting, explaining that “*Structure is helpful until it is not. I think abstractly but I need structure. I need context. I need examples. Then I could assign an emotion to it. Or the emotions are overlapping and always move and changing.*” Charlie converted their grid from fitting into the proposed structure to overlapping groupings of images (Figure 50.) This was a more representative depiction of the fluid and ambiguous nature of how they experienced and attempted to define emotional states.



Figure 50. Charlie’s converted grid into groupings

During the Zoom session, several dyads converted their grid into linear layouts (Mitchell, Kyle, and Laurel), such as the grids of Kyle and his partner (Figures 51 and 52). The linear layout aligned the dyads’ conceptual understanding of the grids, aided in the “wizard” mapping, and made it easier for the dyad to select emojis in-real time. Mitchell preferred one dimension, saying it “*makes more sense. It shows how I could have bad attitudes and slowly progresses into*

a better one.” Linear layouts helped to disambiguate the two axes that these participants viewed as incongruent or competing with each other. This difficulty with the two-dimensional grid was exacerbated during the chat because “*there are four criteria you are picking from in real-time*” (conversation partner of Mitchell and Kyle, their instructor).

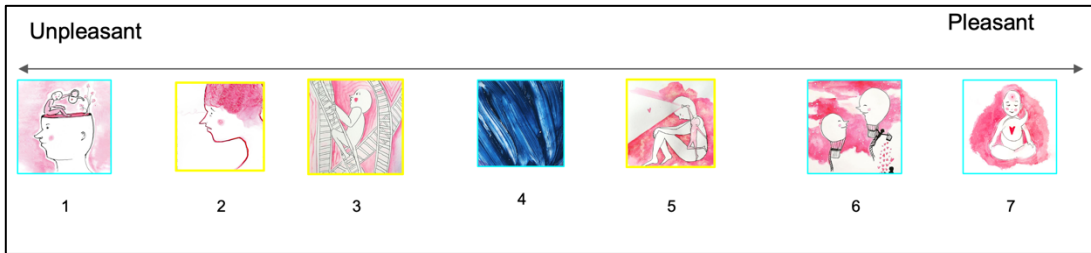


Figure 51. Kyle's reconfigured linear emotion grid.

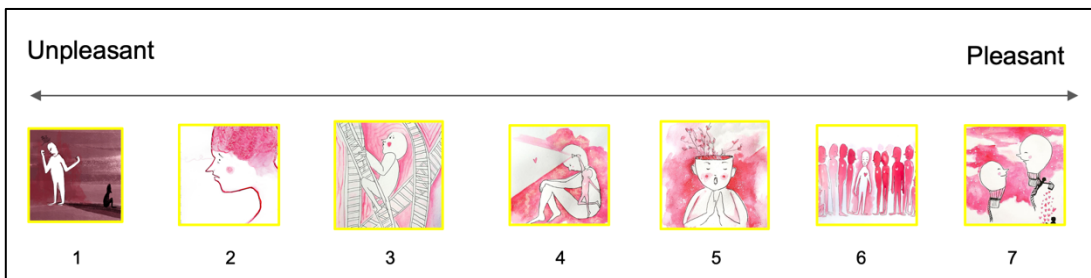


Figure 52. Kyle's partner's reconfigured linear emotion grid.

When converting the grids, the participants demonstrated agency over the grids and images. For instance, Kyle took the opportunity to make a linear grid and remove the redundant images he has used in his original grid. Laurel and her mother used the time to share their interpretation of grid labels and possible number of images per dimension (Figure 53). Three participants noted that their choice of images changed from their original selection a few days ago. Mitchell took an unexpected step while reconfiguring his grid because his emotions “*depend on the day*” he is having. Through their appropriation actions, participants demonstrated the dynamic nature of how people feel and express emotions.

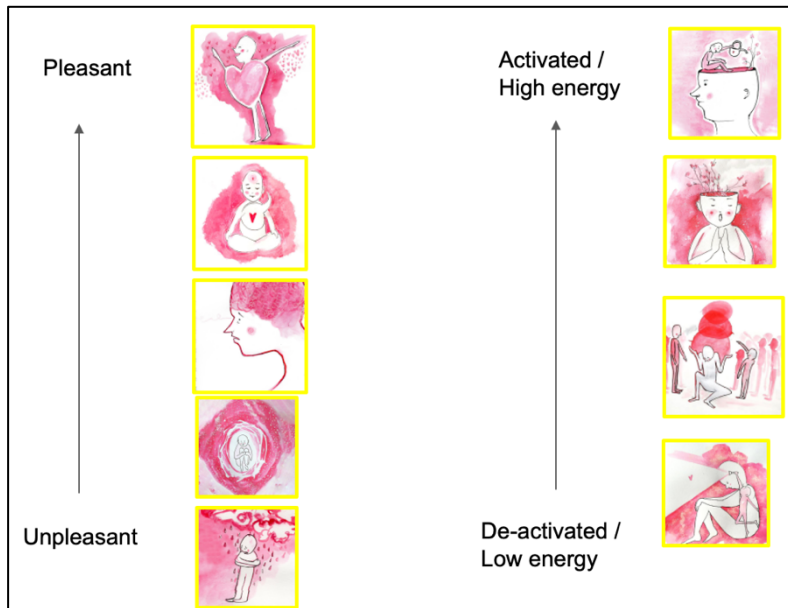


Figure 53. Laurel's reconfigured grid as linear lines for two spectrums: unpleasant to pleasant and de-activated / low energy to activated / high energy.

As they engaged in the chat and used these emoji's (Table 13, Chat-3, 4a, 4b), Mitchell's conversation partner said that hearing his explanation first gave him more insights into Mitchell's use of the images, saying, "*if I hadn't just sat and listened to him, I wouldn't have understood.*" The examples in this section substantiate my proposal introduced in the section above, because new conversational moves were afforded by using and jointly reflecting on the emotion grid. New conversational moves were also afforded by using the emojis while in conversation.

### ***Appropriation of Chat App and Emotion Translation***

Throughout the study, the participants spontaneously took unexpected actions while using the chat app (Table 13, Chat activities). Table 16 below lists the key changes made to the chat app based on participant actions and feedback.

Table 16: Design modifications incorporated into chat app in response to participant appropriation (Table 13, Chat-1, 3, 4a, 4b)

Category	Design Change	Rationale
Visual treatment		
	Color-coded names, speech bubbles and emojis	Visually connect speech bubbles and emojis to each user
	Placed images into speech bubbles to mimic the standard visual look of emojis used in common chat apps	Consistent with current technology user experiences.
Selecting emojis		
	User can make emoji selection with either voice or typing an emoji number	Typing emoji allowed users to stay in typing-mode, rather than switching to speaking to the researcher
	User to respond to partner's emoji with an emoji of their own (rather than going straight to written response)	Allow for response that acknowledges, validates, reactions to partner's emotion. Align with behavior of common chat apps.
	User can choose 1 or 2 emojis (Figure 54)	Feeling more than 1 emotion
	User can select emoji from partner's set	Not finding emoji in their own set, so selects from partner's
Emotion translation functionality		
	Added equal sign between emojis to indicate that they are equivalent.	Clarify that the images are mapped to each other
	Experiment with transparency of emoji mapping. Include conditions of (1) showing both emojis mapped together; (2) putting the user's emoji under their initial and the translated emoji in the "common area"; (3) showing only the translated emoji	Probing participant preferences for showing translated emoji only or mapped to original emoji

With a low-fidelity prototype and wizard researcher, we were able to adjust the look-and-feel of the prototype in real-time. For instance, Alec immediately asked if he could choose two images (Table 13, Chat-3), saying, “*Just like someone asks for vanilla bean and French vanilla [ice cream], I can feel 2 emotions.*” In response, the wizard elongated the emoji bubble and stacked Alec’s emojis and the mapped emojis in his partner’s emotion language (Figure 54).

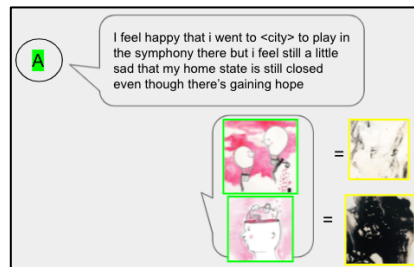


Figure 54. Sample of Alec and Bob’s chat. Alec chose two emojis (left, green border) per message stating that he felt more than one emotion. left with green border. The “wizard of oz” researcher provided emotion translator functionality by mapping Alec’s emojis to Bob’s (right, yellow border).

While chatting (Table 13, Chat-3), participants desired more space for emojis in the chat app to allow them to reply to each other’s emojis (Figure 55). This was particularly important for participants who often “*communicate with emojis*” and when they use an emoji, “*they get an emoji back.*” (Mitchell’s partner).

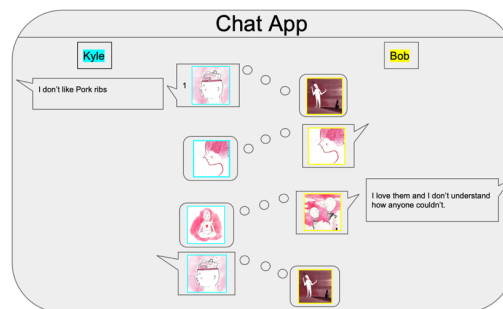


Figure 55: Chat app design change to allow for an emoji in response to an emoji. The emojis in call-out boxes point to the user that sent the emoji. Emojis in squares (with no call-out arrows) are the translated emojis.

Next, I describe our experimentation with the emotion translator functionality and participant responses. The original design was for the wizard to map the emoji from one user’s emotion language to their partners (Figure 56).



Figure 56: Emily's emoji (left) translated to her partner's emoji (right)

When participants first encountered the emotion translation in the chat (Table 13, Chat-3), several participants understood the meaning of the emotion mapping within the first page of chat messages as evidenced by their comments on what they were observing. They typically commented in cases in which the dyad's emotion grids had obvious differences (e.g., Figures 57 and 58).

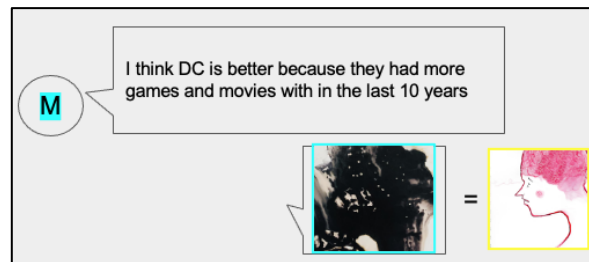


Figure 57. Mitchell's abstract image translated to partner's human form language.

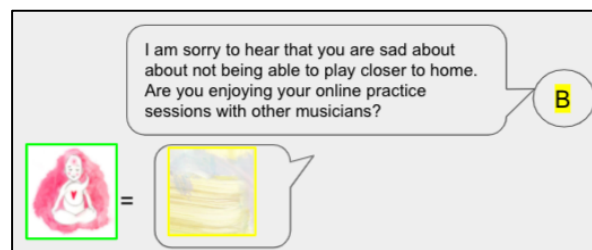


Figure 58. Alec and Bob's translated emoji's. Bob verbally commented on noticing the translation, to which Alec concurred.

Upon reflection, Bob said, *"I was a little confused by the pictographs [human forms]. I had a hard time assigning emotions to them. When I see Alec's translated to mine, I get it more. I don't have to look at grid. When I see the two together, in black and white, it is easier to translate into my mapping."* To which Alec responded, *"Our system is totally different but it*

*accomplishes the same end thing. It's almost like depending on the situation, which system will work for the situation."*

On the other hand, many participants did not pick up on the meaning of the mapping in real-time. Some noted that they were focused on what they were typing, had too much to think about, were thinking about their emotions, or were otherwise not able to decipher the meaning of the layout of the emojis. For the latter case, participants voiced several issues how why it was hard to discern the translation. In at least two instances, participants made fresh interpretations of the images within the context of the chat topic. For instance, Emily's chat was about whether it was safe to begin eating in restaurants again since COVID-19 pandemic restrictions were being eased. Upon seeing her partner's emoji (Figure 56 b), she interpreted it as people having a feast and pointing at someone. Her partner's intention, however, was that he felt worried about the situation.

All of the participants understood the intent of the emotion translator after I explained the functionality and we walked through examples in their chat. Overall, all participants responded positively to the concept, saying that it was a "*cool idea*" (Sarah) that provided visual reinforcement of emotions that would be helpful for them to avoid misunderstandings. A common theme was the desire to learn more about each other and viewing these emojis as "*an invitation for further exploration*" (Charlie). Sarah anticipated that emotion translation would help ease the effort she puts into understanding conversations, saying:

*"Neurotype has a lot involved in how people interact. Autistic people communicate directly and say what's on their mind. Neuro-typical people - it's a social game, let's lie about how we feel. It can be a fun game. The emotions I feel, is what I say. People will assume I am playing the game.*

*They think I mean the opposite and not being straight forward. I think this is why autistic people are misunderstood....It takes effort to understand if you communicate differently.”*

Sarah raised reasons why the communication styles of autistic and non-autistic people lend themselves to misunderstandings. Laurel’s conversation partner said that, her mom, this idea could help them avoid some misunderstanding and even though she did not find the particular images resonate with her emotions, *“I would love to see art that better represents emotions. It’s not just for autism, everyone could use this.”* In response, Laurel agreed, adding that she *“just wants [my mom] to interpret them the way I see them.”*

Although the design concept was positively received, there were important concerns about potential harms. Several participants noted that different interpretations of novel emojis opened an opportunity to misunderstand the images and (by extension) the emotions of their partner. The challenges of the grid structure could lead to misunderstandings if, for instance, one person considered a position on the grid to be for anxiety and the other person saw it as anger. Charlie suggested addressing this lack of definition by having a *“way that all the emojis are clearly defined for each person.”* Both conversants could access to a common reference with emojis and definitions. This reference could be used in conjunction with the playful interaction that some participants enjoy when observing their partner use new emojis and then eventually learning about them and adopting them to *“mirror them in interaction so we can get along better”* (Sarah). In addition to Charlie’s design modification described above, participants had other specific design ideas and provided feedback that I have translated to design ideas (Table 17).

Table 17: Emergent design ideas from Appropriation study

Category	Design Change	Rationale
Grid structure		
	Allow for overlapping emotions; allow for “ever changing” emotions	Emotions are dynamic and not discrete
	Provide example situation to contextualize grid	Emotional experiences depend on social and environmental context
	Provide definitions for what images mean	People can chose different emotions for same spot on grid. People can choose same image for different spots on the grid.
Choice of personalized emojis		
	Provide different image sets	More options for colors (e.g., not all pink human forms); image sets did not resonate with all participants; include more emojis to include expressive emojis (e.g., very upset)
	Include images or notation for sarcasm and other forms of language (e.g., rhetorical question, jokes)	Discrepancy between words and intent difficult to discern
	Include emojis with “stimming” movement (e.g., hamster dancing)	Convey embodied feelings
	Compatibility with emojis on current platforms	Built knowledge about meaning of existing emojis
	Include memes	“ <i>A meme can be a whole emotion</i> ” (Sarah) Memes are common and meaningful form of online social interactions
Sharing about communication styles		

	Let dyad try each other's emoji set	Support perspective taking; see if each prefers using the other's images
	Include fun emojis	Support different styles of conversation (e.g., silly)
Selecting emojis in real-time		
	Allow chat to begin with exchange of emojis.	Use emojis as a conversation starter ice breaker
	Help people interpret each other's behaviors (e.g., stimming, eye movements, distracted by things in environment)	Do not want behavior to be misinterpreted
Conversation support		
	In-person version of emotion translator	Real-time, face-to-face conversations require more processing than asynchronous, remote interactions. People often misinterpret flat affect as being uninterested or stressed.
	Support for in-person group settings	Harder to process what to say than when one-on-one. Social discomfort may increase in groups.
	Support for new social environments	Support adjusting to new social situations
	Provide prompts for what to say in conversation	Unsure how to start conversation or keep conversation going

These reflections and design ideas highlight existing challenges of navigating social norms from autistic and non-autistic perspectives. Several dyads shared that they do have misunderstandings in daily interactions and are striving to achieve mutual understanding. They expressed that trust is required to be vulnerable with each other and that as they disclose more with each other, there is greater risk of being hurt. Ultimately, any technology-mediation for

neurodiverse conversations needs to respect desired levels of disclosure and provide ways to bolster the trust the pair has worked hard to establish.

## 7.5 Implications for Design

The appropriation study revealed new conversational moves around building mutual understanding of emojis. Both autistic and non-autistic participants appreciated opportunities to inquire about discrepancies into emoji selections. These dialogs helped them understand each other's perspectives and their mutual learnings contributed to the dyad building common ground. From this perspective, the emotion translator became a resource for action for the neurodiverse dyad (Salovaara, 2007). Affective computing and communication technologies could be intentionally designed as a resource for action; for instance, by using emojis as an avenue for joint discovery motivated by people's desire to learn about each other.

Reflecting on the findings, I offer an updated design map (Figure 59) that is based on the map in this chapter's Introduction. This map is more descriptive than the initial map and is specific to the findings of this Appropriation study. Important factors have been called out in the Societal Norms & Infrastructure framing, as well as in the four dimensions.

### Emotion Translator for Conversations

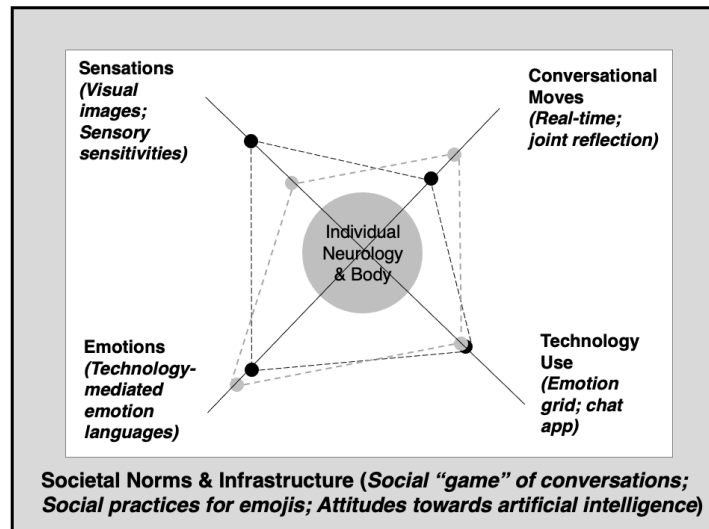


Figure 59. Design map depicting one framing of the emotion translator speculative design.

In the Societal Norms & Infrastructure framing, the design map highlights three crucial themes that arose regarding neurodiverse conversations within the broader societal context. First, autistic individuals describe having awareness of, and difficulty navigating of a type of “social game” with non-autistic individuals. As described by participants in this study and substantiated by related work (e.g., (Davidson & Henderson, 2010; Zolyomi et al., 2019), intentions of non-autistic people can be unclear and obscured by discrepancies between language and emotions (e.g., sarcasm). Second, the map reveals that autistic individuals engage in existing social practices using emojis. Their learning and knowledge of existing emojis for communication platforms, such as emojis available on Android phones, should be leveraged and recognized as a preference for some users as they are potentially presented with more sophisticated affective computing technologies, such as Emotion AI embedded in video calling. Third, individual and societal attitudes towards the role of artificial intelligence should also be accounted for in the design of affective computing. In this study, some participants were wary of artificial intelligence making errors in translation and dictating too many constraints for their emotion

language. Their apprehension is aligned with related work on perceived harms of artificial intelligence and emotion (Andalibi & Buss, 2020).

In the four dimensions, appropriation of an emotion translator prototype revealed considerations for the particular type of interpersonal interaction—conversations, the range of sensations both individuals can experience, and the use of emotion translation technology as conceptualized and prototyped in this study. The technology circles remained balanced between the two conversants since they both have access to the emotion grid and chat app. The translation functionality remained active for both participants, although participants experimented with how much of the mapping functionality they would be exposed to (by sometimes seeing their own emoji mapped to their partners, or seeing just the translated emoji).

Regarding the interpersonal dimension, the map now focuses on conversational moves that occur during conversations. The original concept of the emotion translator was a tool that would be available for trusted conversation dyads. However, participants eventually proposed that the emotion translator would add value to communication with larger groups and people with whom they are not comfortable. Another update to the map was to indicate a temporal component to the interpersonal interaction. Participants asynchronously prepared for conversations and then engaged in real-time chat while on Zoom, which allowed the participants to see each other and talk verbally while typing in the chat. The Google slides provided a visual history of their interactions and the outcomes of their appropriation actions. Conversation dyads and researchers engaged in joint reflection using a variety of modalities, including speech, gestures, typing, and pointing the mouse cursor to elements on the slides. Therefore, I observed that the dyads built common ground before, during, and after conversations. Likewise, designers of affective computing could lay the groundwork for establishing common ground even before

the dyad engages in conversation and facilitate joint reflection before, during, and after conversations.

Last, the updated design map highlights that the emotion translator offers an enriched visual experience to both conversants. The customization and real-time availability of personalized emojis attuned them both to the role of emojis and meaning ascribed to images with human forms and abstract colors and patterns. Both individuals could experience sensory sensitivities, although they were more likely to be experienced by the autistic individual as shown by the dark circle positioned farther along that dimension. In this map, the sensation dimension connects to the Societal Norms & Infrastructure framing via the social practices of using emojis. Users of affective computing may want to mix and match new emojis or representations of emotions with emojis they are familiar with from their current communication tools.

In summary, working with the social-emotional-sensory design map gives designers a format for highlighting important aspects of the design and considering the dependencies between the overall framing and the four dimensions. In the next chapter, I situate insights from the Appropriation study within this Grounded Design research and related work.

# Chapter 8 Discussion

In this dissertation, I have examined affective computing through the lens of autism. The phenomenon of autism—with its unique expressions of cognitive, sensory, and social styles—offers the research community valuable perspectives for designing inclusive communication and affective computing technologies. This research has confronted a crucial concern in technology design: how can we design affective computing that is inclusive of autistic ways of being and does not exacerbate inequities formed by neurotypical social norms and infrastructural barriers. As technologists encode social norms into affective computing, communication technologies, artificial intelligence, and virtual reality, etc., it is imperative that they design experiences that are comfortable for autistic individuals, rather than perpetuate socio-technical burdens typically placed upon disabled people.

This chapter summarizes my theoretical and empirical contributions to our understanding of the social practice of neurodiverse conversions and use of technology at the intersection of social, emotional, and sensory experiences of autistic adults. This work contributes (1) a social-emotional-sensory design map that describes neurodiverse socio-technical phenomena and serves as guides for future designs and (2) a speculative design concept and prototype that explore ideas about how people conceptualize emotions and how visual representations of emotions may contribute to establishing common ground during conversation. This work provided evidence of how autistic young adults (1) conceptualize conversations manifest as game design concepts, and (2) appropriate an emotional translator artifact. Together, these techniques present a durable

methodology for broadly improving affective technology design and technology-mediated communication among neurodiverse pairs.

My research was conducted using the framework of grounded design, which defines three types of iterative and cumulative studies: context, design, and appropriation (Phase A, B, and C in Table 18, respectively). Each study in this dissertation was motivated by particular research questions and resulted in (1) process outcomes—conceptual insights and building of community relationships; and (2) outputs—artifacts and deliverables generated by the research team and participants. This table provides a structured format for communicating this work as a design case study, which is an important mechanism for sharing knowledge in the grounded design framework. Design case studies allow for highly contextualized studies to be compared and contrasted among other Grounded Design research. This analytical comparison “encourage(s) the transferability of insights in a non-positivist design-research paradigm” (Wulf et al., 2018, p. 36). Thus, this dissertation serves as a case study to be included in Dr. Snyder’s future research investigating the design of technology for marginalized populations.

Table 18: Mapping of Grounded Design phase, research questions, process outcomes, and outputs.

Phase	Research Questions	Process Outcomes	Outputs
A: Context Study	RQ1: During daily interpersonal interactions, how do autistic young adults conceptualize and share emotions and sensory experiences?	(1) Understanding of social, emotional, sensory and technological factors in daily lives of autistic young adults, particularly during neurodiverse interactions.	(1) Empirical evidence of how social, emotional, sensory, and technological factors intersect.  (2) Analytic codebook for interviews and common ground visualization activity.
	RQ2: In what ways do autistic adults use or respond to digital	(2) The perceptions and critiques of autistic young adults of current visual representations of	(3) Initial design themes for affective computing for autistic young adults.

	technologies within the context of their social, emotional, and sensory experiences?	emotion in affective computing.  (3) Engagement with autism community members to provide input into research goals and design.	(4) Design map for affective computing.
B: Design Study	RQ3: From the perspective of autistic young adults, what are the crucial elements of a face-to-face conversation that contribute to their social-emotional-sensory experience?	(1) Understanding of how autistic young adults envision current and ideal conversations.  (2) Understanding of embodied ways in which autistic young adults engage in design.  (3) Creation of community-based participatory research activities to engage autism community during COVID-19 pandemic.	(1) Empirical evidence of autistic young adults' conceptions of conversations.  (2) Analytic codebook for common ground and game design framework.  (3) Conversation game design artifacts created by autistic young adults.
	RQ4: In what ways can communication moves and emotions become clearer during face-to-face neurodiverse conversations, in ways that benefit the autistic individual?	(4) Learnings from design study reflected in refined design map for affective computing.	(4) Refined design themes for affective computing for autistic young adults.
C: Appropriation Study	RQ5: Through engagement with a speculative design concept of an emotion translator, what does the pair desire to change, repurpose and convert?	(1) Understanding of how neurodiverse dyads engage in appropriation of an affective computing design concept.  (2) Creation of remote appropriation protocol to engage autistic participants during COVID-19 pandemic.  (3) Learnings from appropriation study reflected in refined design map for affective computing.  (4) Understanding of what	(1) Empirical evidence of neurodiverse conversation dyads appropriate a technology artifact for their emotional and conversational styles.  (2) Final analytic codebook to analyze common ground for neurodiverse dyads.  (3) Low-fidelity prototype to be appropriated by neurodiverse conversation

		information autistic research participants want at the conclusion of co-design research.	dyads.  (4) Design implications for affective computing that account for social, emotional, and sensory experiences of autistic young adults.
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In the remainder of this chapter, I discuss outputs and process outcomes of this dissertation and then present broader implications for designing technology for neurodiverse communities. First, I discuss the empirically-based insights that address the dissertation research questions. Next, I summarize the outcomes and implications for design: the affective computing design themes, design map, speculative design concept, and design artifact. Then, I discuss implications for conducting research with autism communities based on my process and methodological choices. Last, I discuss limitations, future work, and broader impacts to how researchers in the field of human-computer interaction can design technology that is inclusive of neurodiverse communities.

### 8.1 Summary of Research Insights

In this section, I present a summary of research insights that address the dissertation’s research questions. I situate findings in my theoretical framing of autism presented in Chapter 2 and HCI related work presented in Chapter 3.

The context study (Table 18, Phase A) demonstrated that autistic young adults have complex, layered, and situated emotional experiences that are influenced by (1) their internal sense of self, (2) their perceptions of external—social and physical—worlds, and (3) social relationships and interaction norms. Autistic young adults reported difficulty identifying and

describing their emotional experiences, even with visual aids and visual representations of emotions common in social-emotional therapy, education, and affective computing systems. Participants' interpersonal interactions were constructed from a combination of social, emotional, sensory, and technological factors. Those factors did not act in isolation. For example, as autistic young adults interacted with different social groups—including in technology-mediated interactions—they adjusted their communication styles, modulated their sensory inputs, and worked to establish comfortable emotional boundaries.

In the design study (Table 18, Phase B), participants developed game concepts based on the metaphor that conversations are somewhat like games. They designed game elements, such as game player pieces and game boards, that represented their conversations with a trusted conversation partner. Participants' game artifacts identified crucial communication moves, expressions of emotion, and sensory needs during interpersonal communication. For example, their designs demonstrated that mutual trust, and continuous emotional, social, and physical comfort, are crucial for establishing common ground. Emotional comfort was composed of validating emotions, respecting when someone wanted to withhold emotions, and forgiving social blunders. Social comfort was established by having clear expectations of the purpose and details of the interaction—including timing, length, and tone of the conversation. Participants desired a balance of structure and flexibility in the interaction, such as having consistent and fair rules of interaction with choices of topics to discuss. Participants also desired physical comfort, including the freedom to seek or avoid sensory inputs, respect sensory boundaries, and establish rules of consent for physical contact.

The appropriation study (Table 18, Phase C) demonstrated how neurodiverse conversation partners interrogated, used, and reconfigured an emotion translator prototype—a

concept that emerged from the prior studies. This speculative design concept explored ways to augment a conversation with imagery designed to represent emotional states using social and sensory elements. The design concept also explored how the exchange of visual imagery contributed to the co-creation of the emotional tenor of a conversation. Participants took a range of appropriation actions including: (1) resisting and reconfiguring the emotion grid; (2) making literal and situated interpretations of emojis; and (3) selecting multiple emojis together to represent the confluence of emotions they were feeling. During appropriation, participants used in-person and digital resources available to them, such as speaking with each other aloud over the Zoom audio channel while typing in the chat prototype; typing on each other's computer; and selecting from each other's set of emojis. Although this study was conducted online, participants noted that an emotion translator could be useful when communicators are co-located as well, especially given their current socio-technical behaviors such as texting each other while home together and sharing written letters about topics that were difficult to discuss. These uses of technology align with related work investigating the use of technology for co-located scenarios of digital game play (Keating & Sunakawa, 2010; Zolyomi & Schmalz, 2017), co-working, and attending remote school. Thus, these social practices could generally be used to improve work and school life for co-located as well as remote neurodiverse pairs.

These findings provide (1) empirical evidence of the connections between the social, emotional, and sensorial experiences of autistic young adults and (2) forefronts the emotional work autistic young adults engage in during neurodiverse conversations. These insights align with and build upon Alper's notion of inclusive sensory ethnography—built upon empirical evidence of autistic *children*—which “account(s) for how the internal senses shape participation in and exclusion from daily uses of media and technology, as well as for natural variations in

human ability to organize sensations coming from the body and the mediated environment” (Alper, 2018, p. 3561). However, by focusing on emotional experiences, my dissertation provides empirical evidence not previously deeply studied in autism-related HCI research. Thus, this project contributes connections between negotiating social practices of conversations and managing sensorial experiences. These research insights demonstrated how autistic adults and their conversation partners engage in embodied, participatory sense-making, which as theorized by De Jaegher (De Jaegher, 2013), involves a variety of psychological and cognitive aspects, such as emotion, knowledge, mood, background, norms, and concepts. As a result, this work contributes rich descriptions of sense-making of *neurodiverse dyads*—not just autistic individuals in isolation—as the pair establishes and maintains common ground.

## 8.2 Implications for Design

In this section, I summarize the Grounded Design outputs—deliverables and artifacts—related to design. I discuss the affective computing design themes and the resulting speculative design concept of an emotion translator; the use of the design map; and implications for the design of affective computing and communication technologies.

### ***Design Themes and Speculative Design Concept***

During the context study, three design themes arose: (1) making interactions clearer, (2) making emotions more explicit and easier to share, and (3) increasing independence and agency during interactions. The emotion theme (#2) was substantiated by the design study and was also closely connected to the research questions as we had articulated to our Community Based Participatory Design collaborators at the onset of our research activities. As is the nature of Grounded Design,

these decisions impacted the capabilities of the design artifact and the participants' activities during the appropriation study. Thus, the integrity of our research was maintained by the iterative, analytical processes of Grounded Design, including the cumulative codebook for Common Ground (Table 15 in the Appropriation chapter). If we had chosen to focus on a different theme or made different design choices when envisioning a speculative design concept, the artifact and appropriate findings would yield different insights. This is an opportunity for future research to explore an alternative design theme or speculative design concept for emotions. Further research could investigate the connections between the three design themes, such as identifying and amplifying factors that impact independence and agency for neurodivergent individuals—factors which encompass clear communication and freedom of emotional experiences (Rossetti et al., 2008).

As summarized in the research insights section above, participants found the concept of an emotion translator compelling. The material manifestation of the concept as an online chat with emoji mapping was a particular incarnation of the concept; however, there are many other manifestations that could be explored, such as using physical computing to provide a multi-modal, embodied emotional experience. Our design focused on a dyad and participants conveyed that an emotion translator as potentially valuable in larger social groups and among people that are not as well-known as conversation partners chosen for the study. By envisioning future uses and making design suggestions, participants engaged in design moves for technologies not yet in existence. This is not an easy feat for research participants to confidently provide feedback during research and design of emerging technologies (e.g., related to human-robotic interactions, Zamfirescu-Pereira et al., 2021). This work contributes a Grounded Design framework to engage participants over a period of time, slowly building up mutual understanding of their lived

experiences and then moving into co-design to imagine new pathways for design. By engaging in multiple research activities together over time, researchers and participants build common ground and learn ways to effectively and more comfortably engage in research activities. This work also demonstrates how to engage with participants in design activities that are multi-layered in their purpose. The game design activities gave participants concrete activities within a familiar context of gaming. However, the theoretical basis of examining common ground as mapped to game design concepts allowed me to analyze their game activities in terms of common ground. This type of theoretical framing for design could be useful for other design explorations of emerging technology.

Our speculative design concept of an emotion translator could be an avenue of exploration for other research exploring nonverbal communication in conversations. For example, Sobel et al. (2017) researched communication practices of people with disabilities that affect their speech and expression of nonverbal communication. As users of augmentative and alternative communication (AAC) devices, their expressive communication is constrained by the capabilities of the AAC device, which typically converts symbols or text phrases to spoken text. In their research, Sobel et al. identified the need to communicate emotion and mediate communication flow. For communicating emotion as output from an awareness display, Sobel et al. chose to convey emotions using emoticons (text-based emojis) and graphical emojis since they are known to users and viewed as socially acceptable. However, they note that emoticons and emojis are normative displays of emotional states and perhaps not as expressive as other design concepts, such as abstract color animations. This dissertation offers an alternative path for research to explore what an emotion translator would look like and act in their research context. The social-emotional-sensory affective computing design map could be a useful tool to orient

explorations of highly personalized expressions of emotions, in which the technology mediates or translates between users.

### ***Evolution of the Social-emotional-sensory design map for affective computing***

In this section, I discuss using the design map as a tool for identifying, scoping, and imagining affective computing.

In addition to my empirical findings, this dissertation has produced a design tool for affective computing: the social-emotional-sensory design map (Figure 60). The design map originated during the context study as a way to capture the intersection of social, emotional, and sensory experiences of autistic young adults.

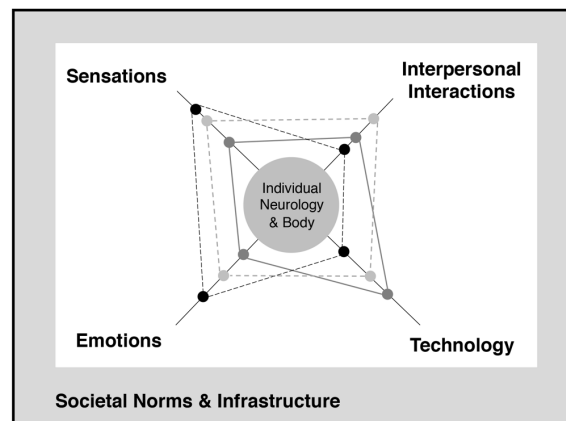


Figure 60 (for reference only; identical to Figure 25). Social-Emotional-Sensory design map for affective computing. ©A. Zolyomi and J. Snyder.

As detailed at the conclusion of my Context Study chapter, I used the term “map” to emphasize that it was intended as a tool to navigate a dynamic and non-normative problem space. The notion of a design map is a counter to design spaces, which are used in design practice to clearly delineate a problem space. The map centers the autistic individual with their particular neurology and physical body. The social-emotional-sensory map depicts factors at a

macro-, meso-, and micro-level that should be accounted for in the design of affective computing. The macro-level factors are societal and infrastructure barriers faced by disabled people, as described by the social model of disability. The four dimensions of the map represent micro-level analysis of: (1) emotional landscapes of individuals and groups, (2) communicative practices and social norms enacted by the social group (e.g., individual, dyads, small groups, groups, and communities), and (3) sensations in the environment or internal to individuals, and (4) technology use and influences.

As described at the conclusion of the Design Study and Appropriation Study chapters, I applied the design map as a conceptual tool to capture and reflect upon design of affective computing that emerged from each particular study. The final iteration of the design map (Figure 61) is specific to the evolution and appropriation of an emotion translator for neurodiverse conversations.

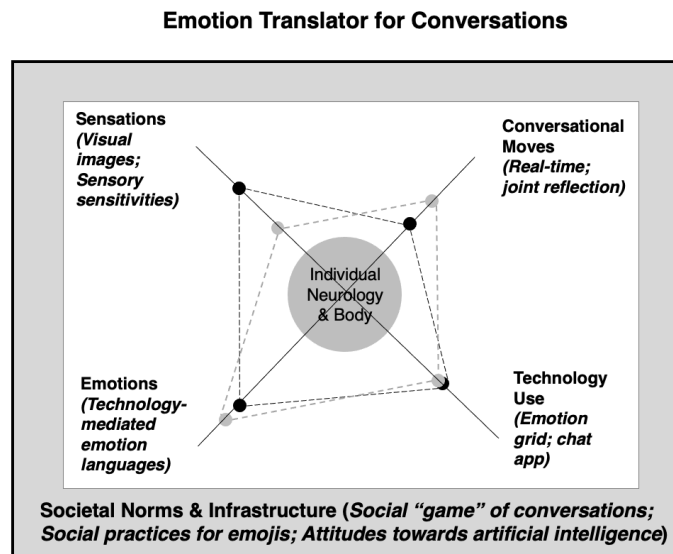


Figure 61 (for reference only, identical to Figure 59). Design map depicting one framing of the emotion translator speculative design.

This design map moves the focus of affective computing from the classical goal of segmenting and classifying the emotional experiences of an individual to constructing personalized models

of emotional experiences. The social-emotional-sensory design map acknowledges that people experience emotions in different ways and presents an alternative to affective computing systems that presuppose or dictate normative measures and representations of emotion. One implication of how we typically approach interaction design in HCI is that the experiences of the people using the technology are highlighted by the map, giving them space and autonomy to establish particular social norms that work for the group. Establishing group norms, such as explicitly managing conversation flow, confirming interpretations of emotions, freely stimulating and exhibiting (and embracing) non-normative behaviors, can be a way to create needing autonomy from pressures of broader social norms. A second implication to HCI design is to consider the social group as a whole, especially when designing for marginalized populations. Researchers often explain that they are foregrounding the perspective of the disabled person, but I argue researchers would ultimately satisfy their intention more readily by separating understanding the perspective of disabled person from designing technology interventions. Interventions can also be made on the social group as a whole or on the non-marginalized people of the group.

To see how the design map supports a shift from normative views, let us construct an imagined affective wearable device designed according to this approach. Our imagined affective wearable device is a fictional alternative to currently available wearable devices that show pre-determined emotional states through a daily log populated with emojis. In contrast, our imagined wearable device is highly contextualized, situating an emotion *event* within a *particular location*, *timeframe*, and *social activity*. The user of this device may have difficulty identifying and expressing their emotions in this context. Our imagined affective wearable device also scaffolds the user's interpretation of affective experiences. Prior affective computing research has highlighted the importance of co-interpretation of affect, which our work supports, although

prior work has focused on joint interpretation between humans and machines (Sengers et al., 2008). In contrast, our work highlights the importance of emotional *co-construction* of affect within a social group. Importantly, this act of co-construction applies not only to the present interaction but interpretations of past experiences and anticipation of future ones. Therefore, our imagined affective wearable device would help the wearer make connections between *patterns of social-emotional-sensory experiences*. The device could support the wearer by working through emotional experiences that they view as difficult, rather than the device automatically classifying experiences as positive or negative. An extension, the wearable could include an application that scaffolds verbal (e.g., scripts or prompts) and non-verbal communication according to the preferences and strengths of members of the social group. The design map also allows for the reconstruction and reconfiguration of emotional experiences through individual and shared memory, which can be aided by affective technology. Some technologies have considered ways to support the recall of emotional memories (McDuff et al., 2012). Our imagined affective computing device would be an emotionally-supportive tool for autistic adults as they recall and anticipate social-emotional experiences.

### ***Implications for Design of Affective Computing, Emotion AI, and Communication Technologies***

This section builds upon my description of an imagined affective wearable device, and research insights, to highlight implications for the design of affective computing and communication technologies more broadly. By examining the social practices exhibited by neurodiverse dyads, designers can enhance user experiences of communication technologies by making communication moves and emotions clearer during face-to-face and remote neurodiverse conversations. These technologies can mediate the navigation of topics, taking of turns, rules of conversation, and available conversational moves, while validating emotional and conversational

choices. Technologies can also facilitate kinesthetic movement and provide avenues for processing of sensory information, as desired by autistic individuals. In addition, this work illustrates how an upcoming conversation could be scaffolded by technology prior to, during, and after a conversation. By phasing the interaction across time, participants engaged in asynchronous and synchronous activities. Having time to process an interaction and selecting from multiple modes of interacting have been shown to enhance digital communication experiences of autistic adults (Burke et al., 2010). Also, revisiting an interpersonal interaction and iterative collaboration has been found to build common ground among collaborators (Convertino et al., 2007). Thus, I argue that affective computing technologies also provide flexible opportunities for configuring, using, and reflecting upon interactions.

The entwinement of social, emotional, and sensory factors complicates normative views of emotions upon which affective computing technologies are predominantly built. For example, take the notion of baseline emotions. Affective systems tend to assume a neutral baseline state and facial expression and then categorize emotional states based on observable deviations from that neutral state. However, participants in my study discussed that their baseline emotional state could be non-neutral and instead, happy, sad, or anxious. Also, their description of feeling neutral was not an in-between or equilibrium state as depicted by affective systems. Rather, they described their neutral emotional state and facial expressions as being congruent with concentration, blank expressions, or not showing their feelings through their facial expressions. These affective behaviors may be associated with alexithymia—difficulty perceiving and expressing emotions—and perhaps with traumatic experiences with long-term implications for how individuals experience and express emotions (Robinson, 2018). Socially, other people tend

to misread their neutral or blank facial expressions, causing some participants to put effort into making their facial expressions adhere to societal norms.

Insights such as these can improve the visual style, textual descriptions, taxonomy, and automatic detection and categorization of emotional states used in affective computing and communication technologies. For example, the range of visual representations and taxonomies of emotions can be expanded to offer nuanced expressions of neutrality. Emotion AI systems can account for personalized baseline emotions, such as anxiety, and gauge emotion intensities or detect other emotional states from those personalized baselines. Systems should be aware that a person's seemingly anxious, flat, or sad affective cues do not necessarily match how the person is actually feeling. The person may want to conceal and not be fully transparent about their emotions in that moment. Interfaces for emotion AI systems can be non-judgmental in how they convey or contextualize emotional states typically considered as "negative" states since the AI system may be misinterpreting the emotional state of the individual and since the person, even if feeling that type of emotion, may not desire to have their emotional states questioned or altered.

To create AI systems that respect neurodiverse user needs, Emotion AI systems can operate with notions of consent and transparency. Systems should respect a person's desire for levels of consent, meaning, systems can allow the user to make adjustments to how the system works based on the individual's level of comfort in the interaction, allowing the user to hide and reveal emotional states and receive emotional states according to their comfort levels. The system themselves being transparent about its own emotional literacy capabilities. For instance, the system could convey that it is able to detect basic emotions but not nuanced emotions. The system could state its limitations, such as not being able to detect non-verbal cues that are outside the camera view. Ultimately, due to the potential for misreading and misinterpreting

emotions—which causes the user cognitive and emotional dissonance—the user should be given control and enabled to use the system without emotion AI capabilities activated. Further research can explore designing affective computing that is trauma-informed, meaning it is respectful of difficult and painful emotional experiences and helps individuals establish emotional boundaries and consent both between humans-and-technology and within the social group.

Given that many types of artificial intelligence technologies include affective models and that these technologies are often seamlessly into platforms and applications, individuals unknowingly engage with affective computing, such as chatbots. Similar to our participants' concerns about privacy, agency, and potential harm of these systems, the general population wants these systems to be more accountable to their concerns and values (Andalibi & Buss, 2020). As highlighted by Andalibi and Buss, when emotional information is encoded, stored, and shared by affective computing systems, we must recognize that emotional data is highly sensitive. For example, my participants raised concerns about being targeted for emotional manipulation and exploitation. Further research is needed to explore protections to emotional data and experiences of autistic and other vulnerable populations.

As highlighted by participants, social issues remain—regardless of the potential benefits of technology. As described by my participants, neurotypical people play a “social game” which can be frustrating at times and sometimes intriguing. The social game can be difficult for neurodivergent individuals to decipher when, for instance, there are discrepancies in what someone says and the person's underlying emotion (e.g., when using of sarcasm, during which the literal words usually do not match the emotion or intention behind the statement). Paying attention to interactions during which there are intentional discrepancies could improve trust and mutual understanding. Therefore, a fundamental goal of designers of affective computing and

communication technologies needs to be support for neurodiverse conversation dyads as they establish and sustain trust. This work involves cultivating the emotion, social, and physical comfort described in the summary of research insights above.

### 8.3 Implications for Design of Inclusive and Universal Technology

This dissertation offers a perspective on designing technology that is inclusive for both autistic individuals and to broader, mainstream, populations. In Chapter 3, I posed the question: what does it mean to provide accessible technology for autistic users? In the context of mediated interpersonal conversations, this dissertation argues that technology should scaffold the conversation as a whole, not just the conversational moves of the autistic individual. The design map is one tool for viewing the design holistically and not assuming the technology is on the autistic individual. This dissertation also argues that technology in the context of neurodiverse conversations should support various dimensions of communication—verbal, non-verbal, sensorial, and internal emotional states. Again, this richness is depicted in the design map. Thinking more broadly about technology design for autistic individuals, I argue that the whole experience of the individual needs to be taken into account. The core accessibility needs, such as speech output or executive functioning and organizational support, need to be provided. But the use of these capabilities are not done in isolation. The user is speaking *with* someone. They are organizing activities for their daily lives, which are not lived in isolation. This work draws from the concept of interdependency in disability work (Bennett et al., 2018) that acknowledges that people’s lives are entangled, and that by understanding our mutual dependence, we can achieve new socio-technical ways to meet both individual and group goals. By considering the needs of

the social group and within the context of the social practice, technology designs can be richer, more nuanced, and more rewarding.

Another aspect to consider in the design of technology for autistic individuals is to consider various roles that the individual takes, or may want to take, during a social practice. Rather than designing technology assuming the individual needs help, assistance, or a set of normative goals, the technology should allow the individual to take on various roles in the interaction. This requirement for technology design stems from the research insights about autistic individuals as initiators of conversations, negotiators, listeners, clarifiers, etc. Also autistic individuals may be proactively wanting to learn more about their conversation partner, which was demonstrated in this dissertation by autistic young adults describing their interest in building emotional literacy skills. They proactively sought out information about perceiving and expressing emotions from books, videos, and films. Some participants enjoyed learning about how their friends use emojis so they could understand their point of view and adopt similar communication styles. These insights about how autistic individuals engage in information seeking and social-emotional learning reframes the goals and behaviors of autistic individuals. These insights also alter how HCI researchers should view the role of technology and media for the autism community. Current HCI work tends to position technology as an assistive tool to augment abilities of autistic individuals. However, by considering technology as an information source for social-emotional learning, autistic individuals can be viewed as empowered learners and distributors of knowledge for others in the community.

This dissertation supports the principle of “curb-cuts”—aspects of the built and technological environments (e.g., cross walk curb-cuts) that provide access for disabled people and benefit society as a whole—and the universal benefits of technology designed for disabled

people (Petrick, 2019). By studying socio-technical experiences through the lens of autism, this work identifies user needs that are crucial for autistic individuals and may be inherent in everyone depending on the context. This concept is not new to this dissertation; researchers have described how interventions for people with disabilities can help the greater population and support this notion in their work. For example, Picard supports this notion in her work on affect awareness, in which she highlights benefits for mainstream populations (Picard, 2000). Burke et al. has similarly extended this lesson as applied to computer-mediated-communication specific social skills training for autistic adults (Bernstein et al., 2013; Burke et al., 2010). In my research about video calling practices of autistic adults, we proposed the development features (e.g., audio filtering techniques) that could make video calling more comfortable for everyone. In this dissertation, insights about social, emotional, and physical comfort illuminate challenges for autistic individuals that likely affect other disabled people and neurotypical people to a lesser degree and in specific contexts. For example, users of alternative and augmentative communication devices, such as Sobel et al.'s research described above, could benefit from alternative means of expressing social, emotional, and physical comfort due to the limiting bandwidth of AAC communication. Designers of embodied conversational agents can also examine these factors to assess, for instance, the design of the agent's bodily behaviors (e.g., indicating the agent wants to request feedback by making eye contact and raising eyebrows) that should allow for neurodivergent communication styles. By designing for communication preferences and styles of the particular human in human-AI agent communication—even perhaps style matching (Aneja et al., 2021)—the individual is more likely to feel emotionally connected.

## 8.4 Implications for Research Methodology

In this section, I reflect upon this work's grounded design process. I summarize our methods, offering examples of best practices for other researchers and designers of inclusive technology.

By following a Grounded Design framework, this dissertation generated knowledge as each study progressed. Each study built upon the previous phases and concepts that emerged were validated and refined. Thus, the research team embarked on Grounded Design knowing the research questions, plans, and overarching protocols, but not the design concept or the form or capabilities of the design artifact. This approach necessitated placing the human at the center of the design process and making sure the research insights led the way to the next step. This approach is counter to research and design approaches that center a technology. Thus, this work was able to meet its commitments to the autism community to foreground the perspectives of autistic individuals and their lived experiences.

There were, however, some situations in which Grounded Design was difficult to apply in the circumstances of this dissertation. First, Grounded Design requires a multi-phase research process, which is a significant commitment for a research sample, especially a marginalized population. This required participants to commit to a multi-phase research without full understanding of what would be required of them other than the broad descriptions of research interviews and co-design activities. This can be especially challenging for autistic individuals who tend to prefer structure and predictability. Another challenge in implementing Grounded Design was the nature of appropriation, which typically involves placing technology in the hands of a community of practice. To study interpersonal interactions at a micro-level, releasing technology "into the wild" was not feasible for this dissertation. The interactions needed to be

observable and traceable, without requiring the research participants to log or journal the details of their interactions. Thus, the research team adjusted the parameters of the appropriation study to be of shorter time for using the artifact, but at a higher resolution of observation. This type of mapping of appropriation activities to unit of analysis was not accounted for in the Grounded Design framework.

Last, the interviews, design activities, and appropriation methods and protocols needed to be designed to be inclusive to communication, sensory, and cognitive styles and needs of a diverse research sample. The research team approached this need with a design mindset, meaning, by conceptualizing the research activities themselves as designed interactions between the researcher and participant. In qualitative HCI research, the interview is a foundational method meant to enable the researcher “to delve deeply into social and personal matters” (DiCicco-Bloom & Crabtree, 2006, p. 315). The researcher “co-create[s] meaning with interviewees by reconstructing perceptions of events and experiences” (DiCicco-Bloom & Crabtree, 2006, p. 316). During interviews, design, and appropriation, the interviewer and participant are ideally both in a flow of expressing ideas, while reflecting and responding to emerging information. These interactions depend on how they draw upon their communication, cognitive, and emotional skills. In this dissertation, I modified the traditional HCI methods, with a focus on the following dimensions and the goal of facilitating open communication.

**Dimension 1: Communication Modalities:** The researcher and participant will have different communication strengths and styles. They can operate from different cultural and social norms. One may be an extrovert and the other an introvert. During an interview or design activity, they must bridge their communication styles by relying on verbal, auditory, and visual modalities. As the interviewer asks the participant questions, the participant relies upon their auditory abilities

to follow her line of questioning. At other points, a combination of modalities is used, requiring the individual to switch being modalities.

Examples of using a variety of communication modalities in this work are providing visual schedules during interviews; facilitating remote design via Slack, Zoom, and postal mail; and establishing phone, Zoom, and web-based communication during Appropriation sessions. This dissertation explored ways that non-verbal forms of communication, namely visual imagery and physical objects, can open avenues of communication and elicit deeper research insights. Research interview protocols used visual representations of emotion, swimlane diagrams to diagram conversations, and game design as a design metaphor. The prescribed turn-taking of the activity allowed the primary participant to have an opportunity to express their ideas. In essence, these methods entailed the researcher facilitating collective sensemaking of the neurodiverse dyad. Group sensemaking benefits from facilitation and formalized documentation and modeling processes, which can be supported by digital tools (e.g., collaborative hypertext systems (Conklin et al., 2003)). Future research could explore collective sensemaking for neurodiverse pairs for research and daily lives.

**Dimension 2: Emotional and Cognitive Comfort:** Both participants are working with their natural cognitive styles and regulating their emotions. There is likely some level of uncertainty for both people. Despite giving consent to be interviewed, the participant may feel nervous about meeting the expectations of the researcher. Likewise, the researcher may be wondering how the interview will go and may feel pressure to generate research insights. They may benefit from more structure and physical prompts to scaffold the interview, or perhaps an allowance and acceptance of a sense of play and an openness to perceived failure. The challenge is to find a middle ground that creates more open dialog and exchange of information.

Despite the challenges of adjusting research methods at the onset of the COVID-19 pandemic, conducting remote interviews and design enabled more modes of engagement. By participating in their home environment, participants had access to their usual resources for physical, emotional, and cognitive comfort. They could engage in the design activities according to their communication styles, such as live Zoom sessions or independent, asynchronous engagement. An unexpected benefit was that the research team received more information about participant spaces and social groups. These benefits align with those found by Bennet and Rosner who, in their research, position disabled people as designers, noting their strengths in drawing upon abilities, perspectives, and resources (Bennett & Rosner, 2019). In this dissertation, research participants were invited to be co-designers in novel autism technology. As my research activities with my co-designers came to a conclusion, they expressed an interest in learning the outcomes of this multi-phase research. I prepared a community report (Appendix H) whose audience is the research primary and secondary participants and the autism community, especially organizations involved in our Community-Based Participatory Research (CBPR). This community report serves to provide participants and CBPR collaborators with evidence of work in a manner that extends beyond academic boundaries. Research participants requested a summary of the research, expressing interest in understanding more about the purpose of the research, findings, and shared experiences and opinions with other participants. The report underscores the important role of autistic young adults as research participants and co-designers. The project provided an avenue for participants' capacity building, which was a valued outcome of the research among participants. For instance, one participant updated her resume to include her role as co-designer in this project. This substantiates the notion that when CBPR is integrated

with participatory design methods, “methods can be a means of data collection as well as an opportunity for capacity and skill building in the community” (Racadio et al., 2014, p. 52).

## 8.5 Limitations and Future Directions

This work had several limitations that should be considered. First, this work did not represent the full diversity of the community of autistic young adults. For instance, all participants in our research communicated verbally, thus our work does not include the perspectives of non-verbal autistic individuals. Future work could explore the emotional experiences and communication of non-verbal autistic individuals, including those who use augmentative communication tools. To deepen our understanding of language in connection to emotions, future work could examine the vocabulary and metaphors available to verbal, non-verbal, and autistic individuals who experience selective mutism (Steffenburg et al., 2018).

Another methodological limitation is that we selected four specific visual representations of emotions based on criteria regarding source (autism therapy and affective computing) and realism (realistic to iconographic). A range of different images could have been chosen to meet these criteria, or the criteria could be altered for another dimension, such as gender and race matching that of the participant. Future work could select other specific images or alter the selection criteria, which may result in different insights from the participants.

Some people will be hesitant to use AI-driven technologies and others will be open to it, or perhaps oblivious to it. This is an area of potential harm that designers and other technologists need account for, such as giving options to turn off AI-driven capabilities while keeping the core communication capabilities intact. This is in keeping with other accessibility guidelines for

supporting technology to operate seamlessly even if advanced functionality (such as JavaScript-enabled web content ) is turned off (WebAIM, 2020). However, this division in technology capabilities is not a best practice because it often presents a divergent user experience for disabled and non-disabled users, with the disabled users often received a deprecated user experience. Therefore, future work should investigate ways to make AI-based options available to all users with customizations that allow users to adjust, restrict, or eliminate AI-driven functionality. Crucially, the default configuration mode would provide equitable user experiences for all users and not degrade the user experience for users who choose not to enable AI-based functionality.

My future work will continue to reveal the burden placed upon—and the hidden work done by—disabled people, especially people who are cognitively disabled and neurodivergent. My research will produce conceptual models, design tools, design guidelines, research method adaptations, and technology prototypes that probe social and infrastructural barriers faced by disabled people. More definition is needed around what it means for technology to be “cognitively accessible.” One reason is that the foundational principles of accessible technology (providing multi-modal access to digital interfaces and content) is insufficient for people with cognitive disabilities. Also, although adapting interfaces is a promising direction for cognitive disabilities, we have not established which aspects of the interaction, interface, and content should be adapted, and how. There has also not been sufficient work comparing adaptability versus custom-built interactions in terms of providing adequate access for individuals with cognitive vulnerabilities. My future work will use collaborative design methodologies to establish theoretical framings and empirically-grounded principles for designing and creating technology that is accessible for people with cognitive disabilities.

Accessibility research should continue engaging in community-based participatory research. The current set of research methods in HCI embed assumptions about the ways in which communities being researched participate and interface with researchers. Future work could investigate more ways that qualitative research methods can be more inclusive and level the balance of power being researcher and participant. Future work could also design and validate adaptations to qualitative research methods to create avenues of communication that are respectful of individual cognitive, sensory, and socio-emotional experiences.

## 8.6 Conclusion

Affective computing seeks to embed emotional awareness into computing systems, including wearables that track emotions and health chatbots that promote wellbeing. Technologists have pursued different techniques for computationally modeling affective responses and emotions by training machine learning algorithms on body language and biometric data. My dissertation uses Grounded Design research to challenge assumptions and stereotypes embedded in affective computing and communication technologies. My research provides empirical evidence that the affective experiences of autistic young adults can diverge sharply from the theoretical, computational, and visual models encoded in therapy, media, and affective computing systems. Findings show that technology influences how autistic individuals learn about, emulate, and enact affective responses and emotional states. This work revealed burdens placed upon—and the hidden work done by—autistic adults in our neurotypical-oriented society.

This work explored affective computing user scenarios and imaginaries to effectively and respectfully mediate on neurodiverse conversation dyads in support of autistic individuals. Through physical, reflexive design, participants highlighted crucial communicative acts,

including (1) individual and joint decision-making; (2) clarification of language and emotions; and (3) embodied sense-making around identity, relationships, and shared information. The speculative design concept of an emotion translator demonstrated ways that novel affective computing could act in support of the social group by facilitating the respectful and nuanced co-construction of social, emotional, and sensory experiences.

The goal of this work is to contribute to HCI research and design of more ethically-sound and representative technologies. This work argues that, by examining the embodied and co-constructed nature of emotions, affective computing would more richly support the affective experiences of autistic adults, and other marginalized groups perceived as having non-normative emotional experiences due to communication, cognitive, and cultural differences, including people with aphasia or dementia. I introduced a social-emotional-sensory design map to guide designers in creating more diverse and nuanced affective computing interfaces that are enriched by accounting for neurodivergent users. In practice, applying the design map for affective computing carries with it a commitment to design affective computing that explicitly supports diverse, non-normative expressions and perceptions of emotion. The design should account for ethical considerations to protect privacy, vulnerabilities, and disclosure, especially given that the data is even more vulnerable because it captures personal, emotional states and information about location, social groups, and infrastructure. This dissertation is a step towards making affective computing more inclusive—and crucially, not introducing harm—by accounting for situated and embodied emotional experiences of autistic individuals.

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# Appendices

## Appendix A: Recruiting Flyer




### NextGen Autism Technology

*Imagining the next generation of technology for neurodiverse communities*

We are recruiting autistic adults for a research study. We are designing new ways technology could be used when collaborating with other people.


If you participate, you will be asked to attend four sessions. You will be paid for each session. (\$275 total)

#### Our Technology Design Process




*Discover*

**Session 1:** One-on-one interview (2 hours, \$75)  
**Session 2:** Interview with trusted friend (1 hour, \$50)



*Brainstorm*

**Session 3:** Small group brainstorming session (2 hours, \$75)




*Evaluate*

**Session 4:** Online diary about using prototypes in your daily life (2 hours over the course of 4 weeks, \$75)

You are invited to join if you are:

- On the autism spectrum
- 18-30 years old
- Can meet in Seattle or the Eastside
- Available from Oct. or Nov. 2019 until Spring 2020

 Email the University of Washington researchers at [vsrs@uw.edu](mailto:vsrs@uw.edu) to sign up or find out more.

This research has been approved by the UW Institutional Review board.

Image: Recruiting flyer for research, which we referred to as the “Next Gen Autism Technology” study

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## Appendix B: Context Study Individual Interviews – Interview Script

The overall purpose of this interview is to establish a relationship, build rapport, and learn about a participant's experiences during their social interactions at work and daily lives. We want to understand their socio-technical experiences related to their sensory processing and emotional awareness.

### Preparation

During the screening interview, we requested that the participant bring:

1. Show and Tell: Bring an object that they use for comfort and stress relief (e.g., fidget cube; photo of weighted blanket) and / or documents for tracking and releasing stress (e.g., spreadsheet; doodling patterns on a paper)

Bring following materials to the interview:

- Consent forms: 2 forms per participant (one for their records)
- Visual Schedule (main activities and timeframes; indicate when the participant will be able to do Show and Tell)
- Compensation: \$75 per participant for each interview
- Form that participant signs to confirm compensation was received
- Laptop (charged) with power cord
- iPad (charged), apple pencil (charged), USB cable to connect iPad to laptop
- Paper and pencils/pens for backup in case technology fails

### Introduction (5 minutes)

Greetings, consent, start recording.

- Thank the participant again for his/her time and introduce yourself, then provide a high-level description of what the interview session will entail.
  - For our research study, we want to learn about the social interactions of autistic adults. The purpose of today's session is for us to get to know each other a bit and learn about your everyday experiences that are influenced by your social interactions, emotions, and sensory processing. What I mean by sensory processing is your reactions to sensory inputs like bright lights or repetitive sounds; sensory experiences can also arise internally, out-of-balance or perhaps feeling disconnected from your body.
- To explain more about the background of our research, this project is being conducted in close consultation with the autism community, such as a local group for autistic adults in Seattle and organizations that provide services to autistic youth and adults.

- It is important to us to collaborate with the autism community. My team and I are neurotypical - not autistic. And we are technologists, not clinicians. We design technology and are interested in the many ways that people are using technology to better understand themselves and collaborate with others.
  - We are specifically trying NOT to ask questions like clinicians, so if you are getting that feeling please let me know. We are more interested in learning about your personal experience than your diagnosis.
- My dissertation is on the role of technology in the lives of autistic adults. Over the course of several sessions, we hope to work together with our research participants to uncover ways that technology could facilitate more comfortable social interactions.
  - We generally use the terms “autistic” and “person on the autism spectrum.” Is that the terminology you prefer? [If participant has a preferred term, aim to use that throughout the remainder of the interview in place of whatever the script reads.]
- Do you have any questions so far?

Obtain verbal consent:

- Next, I will review the research consent form with you. We are required to obtain your verbal consent by the University of Washington research ethics office.
- Go over the statement quickly but completely. End with, “Do you give us consent to move forward with this interview?”
- Great. As we talk today, we want you to feel comfortable skipping any questions you prefer not to answer. Also, if you want a short break, just let us know. If you decide you want to end the interview, you can tell us so.
- You will receive an Amazon gift card for \$75 via email after this interview.

Ask for verbal permission to record.

- I will be jotting down a few notes while we talk, and I’d also like to record our interview so I can review our discussion a bit more carefully later. Is recording this interview okay with you?

**Background** — general personal details, with a focus on autism and how it relates to sense of self/identity (~ 10 minutes)

1. I’d like to just start out by learning a little bit about your daily activities. Are you currently in school, working, or between jobs?
  - a. What are the main activities for you in a typical week?
  - b. Why did you choose this course of study / work?
2. Are there certain adjustments you make at school / work that you connect with being autistic?
3. When do you come to know that you are autistic?
  - a. Did you have an early intuition about being autistic?

- b. Do you have an official diagnosis, or are you self-diagnosed?
  - c. Do you share being autistic with other people?
  - d. How do you describe being autistic to other people?
4. What are aspects of being autistic that you appreciate? Has that changed over time?
  5. What's the most frustrating part of being autistic? Has that changed over time?
  6. Can you tell me a little bit about what drew you to our study?

### **Sensory and emotional experiences (10 minutes)**

From our previous research studies and reading other studies, we have been learning that sensory processing can be a part of the autistic experience. So next I want to ask you questions about your sensory sensitivities; if you have difficult memories about sensory processing, please feel free to share as much or as little as you feel comfortable.

1. Do you consider yourself to be hyper- or hypo- sensitive to sensory inputs? Or neither?
  - a. What sensory inputs do you have the strongest reaction to or that you miss or seek out? (e.g., external: light, sounds, touch, taste, smell; internal: proprioception (connection to mind-body), balance, gut)
  - b. What does this sensory experience feel like in your mind and / or body? (e.g., pain, headaches, kinetic and motor challenges, attention, ability to talk)?
  - c. Do you have an emotional response to it?

I'd like to understand more about how your emotions come into play during sensory experiences and, more broadly, your interactions with other people I have an understanding that there are different aspects to emotional awareness, including understanding your own emotional states and also reacting to other people's emotions. your own emotions and also understanding the emotion emotions of other people.

1. Thinking first about your own emotions, do you ever have difficulty understanding and conveying your own emotions?
2. What is your experience like decoding your own internal emotional states?
  - a. When did you explicitly become more attuned to your internal emotions??
  - b. How have you learned to better distinguish between emotions?
  - c. Can you describe what different emotions feel like in your mind and / or body?
3. How do you convey your emotions to others?
  - a. Verbally? Non-verbally?
  - b. Do you prefer different modes of communication in different circumstances?
4. Now, let's talk about reacting to other people's emotions. Do you find it difficult to identify other people's emotions?
  - a. Do you find certain people more difficult to understand, emotionally?
  - b. Are there specific situations that are more emotional for you and other people?

- c. What is the impact to you and your relationship when it is difficult to understand their emotions?

Ok, now that we have talked about your sensory and emotional experiences, I am curious how these factors influence each other.

1. Do you think there is a connection between how you respond to sensory inputs, your emotions, and your social interactions?
  - a. If so, how would you describe the connections and how they influence each other?
  - b. If not, do you see them as separate experiences that don't impact each other?
2. Where is a place that you feel most comfortable in, where you can engage in what you are doing with other people?
3. Where is a place that you feel very uncomfortable and it is hard to engage?
4. Let's talk a little more about a specific experience you've had so we can understand this interaction (or lack of interaction). You mentioned [experience] in which your social interaction, emotions, and sensory sensitivities came into play. Can you describe what that felt like to go through that? Was there a trigger? Do you classify that as sensory or emotional, or all put together? How did it impact you?
5. What actions do you and others take during these experiences?
6. How do these experiences impact your ability and desire to engage in future activities?

### **Sensory and emotional well-being practices (Show and Tell) (10 minutes)**

1. During the screening interview, we invited you to bring examples of objects or written processes you use to balance your sensory and emotional experiences. Do you have anything you'd like to show me?  
**Take photos of documents, with the permission of the participant.**
  - a. Walk me through how you use this? Can you tell me about how and when you started using these techniques?
  - b. In what situations and places do you use these techniques?
  - c. What have you gotten from [insert well-being technique]?
  - d. What have you not liked about [well-being practice]?
  - e. Do you talk about or share these techniques with others? If yes, with whom, why, and what's been the impact?
2. Are there other ways that you self-soothe or calm down when things seem overwhelming or you feel over-stimulating? How do you find comfort?
3. Do you find it helpful to stim or fidget?
4. Do you talk about or share these techniques with others? If yes, what, with whom, why, and what's been the impact?

5. Does technology play a role in this? In other words, do you think that technology is a tool for self-soothing? (e.g., organizational tools, use of technology to watch videos or listen to music or podcasts)
  - a. In what situations and places do you use these technology-focused techniques?
  - b. What have you gotten from [insert technology-focused technique]?
  - c. What have you not liked about [technology-focused technique]?
  - d. Do you talk about or share these techniques with others? If yes, with whom, why, and what's been the impact?

### **Visualization Representation of Emotions (~20 minutes)**

Now we are going to move into a joint brainstorming activity. There are 3 activities I will walk you through about visual representations of emotions. First, we will look at 2 examples of how emotions are represented and ask for your feedback on them. We will ask you to mark them up with changes or additions you think would make them more relevant and accurate for you. Then, we will ask you to create your own visual representation

Feel free to share the thoughts that come to your mind; your suggestions don't have to be 100% complete or concrete. I'll be recording what happens on the iPad, so don't worry about losing anything or being precious with what we make, ok?

1. Getting comfortable with the technology: Show the participant a few of the tools: eraser, lasso, pen, and ink tools, how to undo. (hand over Apple Pencil and orient iPad to the participant)
  - a. 4m tutorial video on this step here: [video link](#)
  - b. Allow participant to play with pencil on blank "sheet" of paper in GoodNotes.
  - c. IF PARTICIPANT SEEMS HESITANT: ask them to do the following tasks:
    - i. Write the word "bat"
    - ii. Erase the "t" in the word "bat" and turn it into the word "ball"
    - iii. Draw a circle around the word ball
    - iv. Move the circle to someplace else on the page
    - v. Zoom in and erase just the letter "b," so that it says "all" inside the circle
    - vi. Zoom out so you can see the entire page again
- START iPad recording now.

Ok, let's start the first activity. Here is an example of a traditional way emotions have been represented.

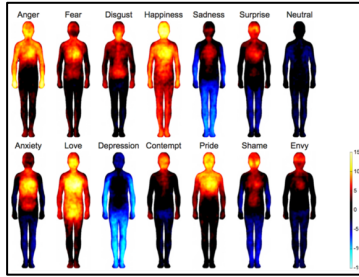


Image 1: Location of emotion in body

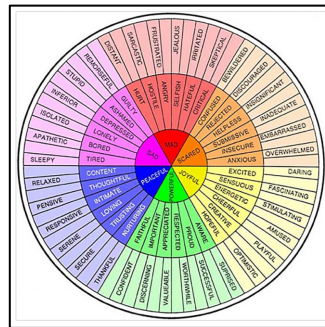


Image 2: The Feeling Wheel

1. Does looking at this visual representation make you think about your relationship with emotions?
2. Do any of the elements on the representation resonate with you - meaning, fits with how you think about emotions? If so, please indicate those elements on the image and write down why as well.
3. Do some elements not resonate with you? Please indicate those elements on the image and make a note about it.
4. Can you walk me through what you marked up in the image?
5. (When finished) Is there anything missing? Are you satisfied that marking it up shows what you like and don't like about this representation?

Ok, let's move onto the 2nd activity. Here is an example of a newer technology being used to convey information about emotions.

This band can sense your heart rate, breathing, and sweat levels. It transforms this information into an emotion. There is an app that shows what your emotion was at different times in the day.

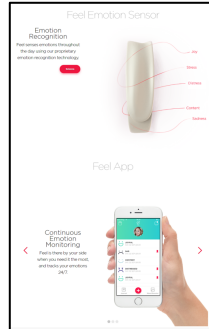


Image 3: Feel emotion sensor and app

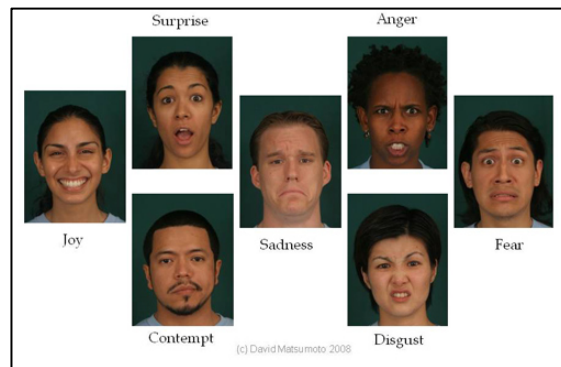


Image 4: Facial expressions

1. Does looking at this visual representation make you think about your relationship with emotions?
2. Do any of the elements on the representation resonate with you - meaning, fits with how you think about emotions? If so, please indicate those elements on the image and write down why as well.
3. Do some elements not resonate with you? Please indicate those elements on the image and make a note about it.
4. Can you walk me through what you marked up in the image?
5. (When finished) Is there anything missing? Are you satisfied that marking it up shows what you like and don't like about this representation?
6. What was that process of marking these images up and brainstorming like for you?

Ok, now that you've seen and given us feedback on two visual representations, we have one final activity. We would like you to draw your own visual representation that shows how you conceptualize emotions. Please draw the visual and annotate it with text.

1. Can you walk me through your visual representation?
2. What does the visual convey about your relationship with emotions?
3. What's most important here?
4. Is there anything you're not sure how to represent?

5. Is there anything missing?
6. Are you satisfied with this visual representation?
7. Does looking at this visual representation make you think about your relationship with emotions?
8. What was that process of making this visual representation like for you?
  - Turn off iPad recording

**Closing** - Opportunity to share any other thoughts or ask questions (5 minutes)

- Those are all the questions I have — but is there anything else you'd like to tell me about, anything you thought of while we've been talking and would like to share? Could be anything at all. We can even go back to the visualizations, if you'd like.
- We would appreciate being able to talk with someone you interact with in some of the situations we have talked about today. We want to understand their perspective and perhaps challenges with some of these same types of issues. Is there someone whom you are comfortable having a joint session with us?
- We'll also send email to set up session 2 with your friend.
- Any questions for me before we conclude the session?

**Conclusion**

- Turn off any recording equipment + save recorded files. Turn off voice recorder
- Compensate the participant and obtain required information on form acknowledging they received compensation.
- Invite the participant to get in touch any time with questions in the meantime.

## Appendix C: Context Study Pair Interview – Interview Script

### Preparation

1. Establish a date and time for each pair to be physically together and able to log onto a computer for a video call.
2. Ask for their preferred video call application and username (Google Hangouts, Skype, or Facetime).
3. Ask them to have their microphone and speaker working.
4. I need to have a screencast application installed and working on my laptop.
5. Send the consent forms to both the primary and secondary participant prior to the interview so they can read them ahead of time if they want to.
6. Tell the primary and secondary participant that they will both receive a \$50 Amazon gift card, via email, after the interview. I will not be able to compensate them in other ways (e.g., I cannot provide cash or other types of gift cards).

### Introduction (5 minutes)

Greetings, consent, initiate recording:

- Thank the participants for their time and introduce yourself, then provide a high-level description of what the session will entail
  - For our research study, we want to learn about the social interactions of autistic adults with their friends, co-workers, and family. I interviewed <the primary participant> in <Nov/Dec> and learned about their everyday experiences. We talked about their social interactions with other people, and their thoughts about expressing emotions. We talked about whether or not they have sensory sensitivities to things like loud noises or strong smells.
  - In this interview, I'll ask you some background questions about your relationship and the activities you do together. And then we will do two activities together.
- Obtain verbal consent:
  - Next, I will review the research consent form with you. We are required to obtain your verbal consent by the University of Washington research ethics office.
  - Go over the statement quickly but completely. End with, "Do you each give me consent to move forward with this interview?"
  - Great. As we talk today, we want you to feel comfortable skipping any questions you prefer not to answer. Also, if you want a short break, just let us know. If you decide you want to end the interview, you can tell us so.
  - As a thank you, you will each receive an email with an Amazon gift card for \$50.
- Ask for verbal permission to record

- I will be jotting down a few notes while we talk, and I'd also like to record our interview so I can review our discussion a bit more carefully later. The recording will not be shared beyond the research team. Is recording this interview okay with you?
- Start the voice recording and screen recording (SnagIt) now.

**Background** (5 minutes) — general information about their relationships and the nature of their joint activities and interactions. In what ways does autism influence their interactions? Do they use technology to facilitate their interactions?

Ask primary participant:

1. (skip this question if they are family): Since you selected <secondary participant> to join you for this interview, please tell me how you meet <secondary participant> and how long you have known each other.
  - 1.1. Why did you select <name> to join you for this interview?

<Ask question of each person, one after the other>:

2. <primary participant>: What types of activities do you like to do with <name>?
  - 2.1. <secondary participant>: From your point of view, what types of activities do you like to do with <name>?
3. <primary participant>: Are there activities you would like to do more together?
  - 3.1. <secondary participant>: From your point of view, are there activities you would like to do more together?

### **Interpersonal communication** (10 minutes)

These next set of questions are for both of you to discuss and answer together.

1. How would you describe the ways you communicate with each other?
  - 1.1. How do you know what the other person is feeling?
  - 1.2. How do you know if you had a misunderstanding between the two of you?
2. How has your ways of communicating with each other changed over time?
3. Do you communicate with each other using technology, like texting or phone calls?
  - 3.1. What works well about using technology to communicate?
  - 3.2. What does not work well?
4. Together, come up with three things about how you behave or think in **similar** ways. For example, these can be things you both find funny or ways you react to situations. Can you give me examples from real-life?
  - 4.1. When was this really striking to you?
  - 4.2. Were there times that this difference/similarity really impact your communication?

5. Now, together, what are three ways in which you behave or think **differently**? Can you give me examples?
- 5.1. When was this really striking to you?

**Activity: Common Ground Visualization** (20 minutes)

Launch Google Slides to create their Common Ground Visualization.

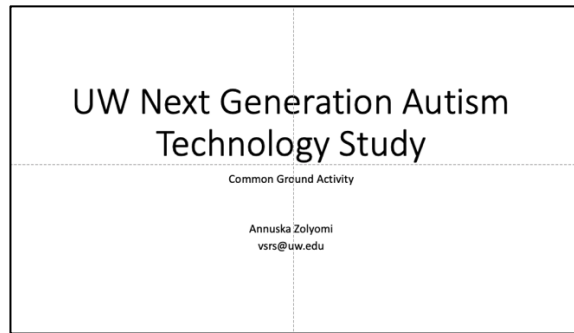


Image: Title slide

Now we are going to do an activity together we are calling “Common Ground”. You will, together, recall a recent interaction with each other.

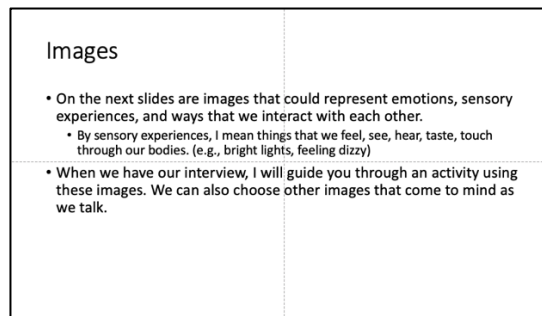


Image: Introduction to images slide

On the next slides are images that could represent emotions, sensory experiences, and ways that we interact with each other.

By sensory experiences, I mean things that we feel, see, hear, taste, touch through our bodies. (e.g., bright lights, feeling dizzy)

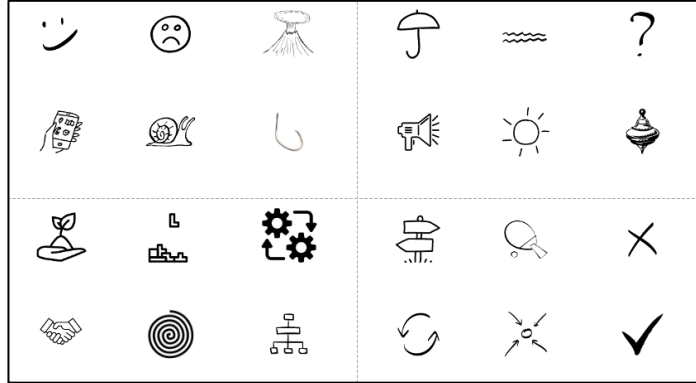


Image: Visual vocabulary slide

I'll be creating a visualization about that interaction. The purpose of the visualization is to show the dynamics of your interaction, like the feelings behind the interaction, points of understanding or misunderstanding, and the various ways you try to be on the same page with each other. We are using an idea called "Common Ground" for this activity - which basically means that our interactions are not only what we say aloud to each other, but also the deeper meaning of our words, actions, emotions, and how we feel in the physical space.

I will guide you through an activity using these images. We can also choose other images that come to mind as we talk.

<p>Example discussion</p> <ul style="list-style-type: none"> <li>• I'll ask you and your interview partner to think of a recent interaction you had with each other.</li> <li>• I'll ask you to describe it to me, including significant emotions, sensory experiences, and your goals and ways of interacting.</li> <li>• The following slides show an example of a discussion between Ethan and Tom. The visual representation builds up over several steps, which I'll walk you through.</li> </ul>	
--	--

Image: Slide to introduce to example discussion

Ethan		Tom	
Inside	On the outside	On the outside	Inside
☀️	🌊	👥	😊
🌋	✖️	🚶	☹️
☂️	🌐	☀️	😊
	🔍		

Image: Slide 1

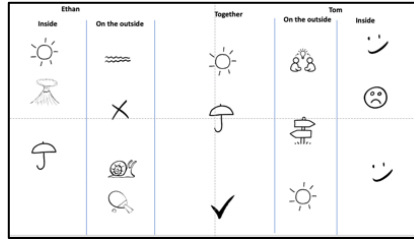


Image: Slide 2

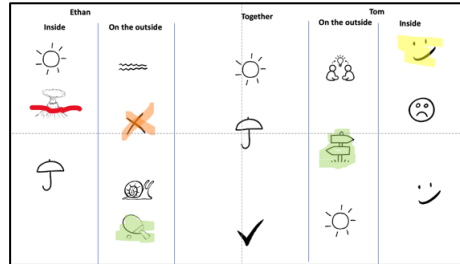


Image: Slide 3

I'd like you to come up, together, with an example of a recent conversation you had that raised some different opinions, goals, or difficult emotions. Examples of these types of conversations can be sharing difficult news, talking about a controversial topic, or trying to reach a decision.

Talk together about potential examples and let me know which one you pick to tell me about.

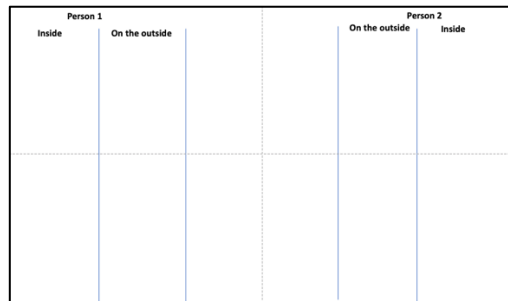


Image: Blank template slide

Let's talk through the dynamics and emotions during this discussion. We have 15 minutes for this activity.

6. You are going to take turns describing what you said, thought (may be words or an image you saw in your head), and felt. And then the other person will describe what they said, thought, and felt. Tell me what you said, but not every detail. When you were questioning, confused, emotional responses.
7. Who started the interaction? Where were you?
8. What did you first do?

- 8.1. What did you say or do?
- 8.2. Select an object that represents what first happened. This is your “token” or “game piece”
9. Ok, now <other participant>, how did you respond? Select an object that represents your response.
10. Continue through the interaction. Prompts:
  - Why did you choose that image / object?
  - How strong was your statement / emotion on a scale of 1-5? (1 = low; 5 = high)
  - How were you feeling?

### **Reflection on Decision Making Visualization activity (10 minutes)**

<Ask question of each person, one after the other>:

1. <primary participant>:What parts of the conversation do you feel work really well?
  - 1.1. <secondary participant>: How about from your point of view?
2. <primary participant>:What parts do not work well for you?
  - 2.1. <secondary participant>: How about from your point of view?
3. <primary participant>: How well does this represent a typical conversation?
  - 3.1. <secondary participant>: How about from your point of view?

### **Characteristics about their interpersonal communications (10 minutes)**

(each person answer on a piece of paper and hold it up to the camera first)

<Ask question of each person, one after the other>:

1. <primary participant>:If you could choose a superpower to use when you are interacting with <partner name>, what would it be?
  - 1.1. <secondary participant>: How about from your point of view?
2. Do you think there are ways that technology could help you have that superpower?

### **Closing - Opportunity to share any other thoughts or ask questions (5 minutes)**

- Those are all the questions I have — but is there anything else you’d like to tell me about, anything you thought of while we’ve been talking and would like to share? Could be anything at all.
- Ok, if you think of anything else you would like to tell me, you can email me.
- Later tonight, I will email both of you a link to your Amazon gift card.
- The next phase of my research will be a design workshop with <name of primary participant>. I hope that you are interested in being a part of the workshop. We will have about 4-6 people on the autism spectrum in the workshop. We will do activities to brainstorm ideas for how technology could make communication and working together

more effective. Everyone will be paid \$75 for participating. Do you want to be in the workshops?

- Great, I will contact you around March to schedule the workshops.
- Any questions for me before we conclude the session?

### **Conclusion**

- Address gratuity. Thanks again and goodbye for now!
- Turn off any recording equipment + save recorded files.

## Appendix D: Design Study – Activity Instructions

### Introduction

We are going to explore one main idea for all of our design activities. This idea is that:

*Conversations are like playing a game*



Chess



Jenga



Animal Crossing

Take a minute to think of a game you like to play. I like to play Chess, Jenga, and Animal Crossing. Then think about some ways that playing the game you like to play and having conversations are similar. Here is my list:

- There are certain people involved in a conversation, just like there are certain players in a game. In Chess, there are two people. In Jenga and Animal Crossing, more than two people can play.
- In both conversations and games, people take turns. In Chess and Jenga, people take turns in order. In Animal Crossing, someone can talk a lot and show someone around. The idea of “taking turns” is less clear.
- In both conversations and games, there are rules to follow and choices you can make about what to do. In Jenga, the only move you can make is pulling out a piece. You get to choose what piece. In Animal Crossing, you have lots of activities to choose from.
- Eventually, both conversations and games come to a close. Chess ends at checkmate. Jenga ends when the stack falls down. In Animal Crossing, the game ends when someone decides to log off!

## Activity 1: Game Pieces

Let's pretend that your own conversations are in the form of a game. Think of this game as a way to show:

- What you want to get out of the conversation
- How you want to feel during the conversation
- How you want other people to feel
- How you want your conversations to flow
- How you want to better understand the conversations

### Instructions

1. Think of a person that you have meaningful conversations with. This could be the person you did your Next Generation Autism Technology pair interview with. Or it could be a different person. **We will call this person your “conversation partner”.**
2. In your design journal, answer the Planning questions about your game player pieces.
3. **Create 2 game player pieces**, one that represents you and another that represents your conversation partner.
  - a. Use materials, shapes and colors to show the person's personality and how they act during conversations.
  - b. The game pieces need to be a 3D object at least 2” tall. You can start with the cardboard rolls or some other physical object.

Here are some examples of what other people have created for their game players. These are just examples; your players will look different!



4. In your design journal, answer the Activity 1 Reflection Questions about your game player pieces.

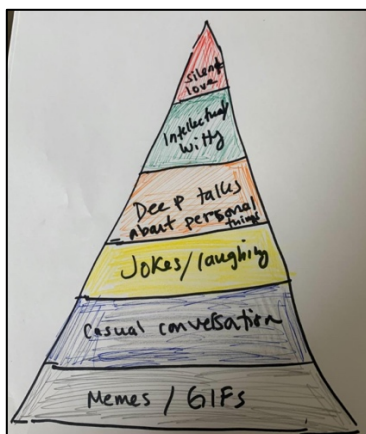
## Activity 2: Game Board

Every game takes place within a specific setting. The setting holds the game players, game actions, and all the game elements. In this activity, you will create a game board for you to put your game pieces on, move throughout the interaction, perhaps taking pauses, moving closer or further apart.

### Instructions

1. Think of a physical board that could be next to or between you and your partner when you talk face-to-face.
2. In your design journal, answer the Activity 2 Planning questions about your game board.
3. **Create a game board** for your game player pieces to move around on during a conversation.
  - a. Your game board must be a flat surface where your pieces can move around.
  - b. Use materials, shapes and colors to represent the spaces and places of your conversation.
  - c. Your game board may have different areas for different types of activities and game elements.

Here are some examples of what other people have created for their game boards. These are just examples; your board will look different!



4. In your design journal, answer the Activity 2 Reflection questions about your game board.

### Activity 3: Conversation Choices and Rules

In conversations, we share ideas, opinions, and feelings. We have different choices we can make about when to talk, what to say, and what to do. We may try to figure out what the other person wants. We may listen closely to each other or barely at all. In this activity, we will show different choices and maybe conversation rules that you experience or observe.

#### **Instructions**

1. Think about a particular recent conversation or conversation topic that is meaningful to you.
2. In your design journal, answer the Activity 3 Planning questions about your conversation choices and rules.
3. **With your game player pieces and game board, create different ways to keep track of the state of the conversation (your game). You will want to create new game elements (like tokens) or use objects from your design kit (like dice or cards).**
  - a. Show how your game begins. Who starts it? How does it start in your game setting?
  - b. Your game must have at least 4 choices or rules.
  - c. Show how your game players mark progress through the game.
  - d. Show how your game uses different game elements to take turns, make choices, and follow rules. (You can use things like game tokens, dice, steps along the game board, levels, knobs.)
  - e. Show how your game ends and how you determine the outcome of the game.
4. In your design journal, answer the Activity 3 Reflection questions about your game choices and rules.

Here are some examples of what other people have said about game choices and rules for their conversation game. These are just examples; your list of choices and rules will be different!

- Only 1 person talks at a time. They hold a ball while they are talking.
- If someone interrupts someone talking, they move their player piece back 1 space.

## Activity 4: Emotions and Sensations

During conversations, we can sometimes feel different emotions and physical sensations come up. Conversations can change your emotions, making you feel more relaxed or stressed. Or, you may feel exactly the same even when you are having a difficult conversation! In this activity, you will create ways to think about, show, and recognize emotions and sensations in yourself and your conversation partner.

### Instructions

1. Think about...
  - a. Do you tend to show emotions during your conversations?
  - b. Do you feel physical sensations during conversations or when you are thinking about a conversation happening?
  - c. Do you respond to sensations like bright lights and loud noises? Or you find some environments more safe than other places to have conversations?
2. In your design journal, answer the Activity 4 Planning questions about conversation choices and rules.
3. **Create ways in your game to show emotions:**
  - a. Each game player piece needs to show emotions somehow. Make this personal to you and your conversation partner.
  - b. Each game player piece needs to respond to emotions of the game players
  - c. In your game, have a way to indicate when someone is having an intense response to a sensation or a strong need for more sensations.
  - d. In your game, what happens when there is a change of emotions and sensations? For instance, you can have progress, conversation topics, or pathways through the game change.
4. In your design journal, answer the Activity 4 Reflection questions about emotions and sensations.

Here are some examples of what other people have said about game choices and rules for their conversation game. These are just examples; your list of choices and rules will be different!

- If someone shares how they feel about something, they get an extra bonus card.
- If someone wants to pause the conversation because they feel upset, all players take 1 minute in the relaxation area of the board game.

## Activity 5: Game Experimentation

Congratulations, you have designed the basic elements of a game!

The game is probably not a complete game with a full set of rules and elements, but you have built the basics. In this last activity, you will share your game elements and ideas with your conversation partner or someone whom you can talk with either in-person or remotely (which I know may be limited during this quarantine period.)

### **Instructions**

1. In your design journal, answer the Activity 5 Planning questions about game experimentation.
2. **Share your game design to a conversation partner.**
  - a. Explain the game player pieces and game board. Show them your list of game choices and rules, and how that shows up in the game play. Show them how the game includes ways to show emotions and physical sensations.
  - b. Ask them for their ideas of how conversations can be like playing a game.
  - c. Try using the game players, rules, and tracking a conversation together. You could play with the game elements while you talk about something you want to decide together (like what to have for dinner) or something that you want to share (like how you are doing during quarantine).
  - d. You will probably get ideas for things to change about your game or to add to your game. Write down these ideas or make the changes as you go along.
3. In your design journal, answer the Activity 5 Reflection questions about emotions and sensations.

Yay, you finished all the design activities!

1. Email your photos or videos to Annuska (unless you already shared them on Slack). Call Annuska if you need more information.
2. In the pre-addressed, stamped envelope, mail Annuska your design journal.

Thank you! Your work is an important part of our research.

## Appendix E: Design Study – Zoom Session

This is the outline of the Zoom design sessions for participants who chose to do their design activities synchronously with myself and other participants.

Topic	Time Duration
Settling in: Introduction, logistics, and ice-breaker	10 minutes
Annuska to introduce the design setting: In-person interpersonal communications. Introduce using game play as a metaphor for establishing common ground.  If you were to consider in-person interactions as a game, what does this game entail? What is the goal of your game? Does someone win? Think of a person you have meaningful in-person interactions with. Now, imagine if, for the next two weeks, your conversations take place using a game framework you designed.	5 minutes
Activity 1:  Prompt: Consider social interactions as a game you and your interaction partner are engaged in. What is an object that you can create to represent yourself and your partner?  Task: <b>Design representations of the players:</b> Create game pieces for you and your interaction partner. What are ways that your game pieces can connect, engage, or maintain space?	15 minutes
Activity 2:  Prompt: What could you put / create for the space and pathways between you and your partner? Are there wins and losses? What's the end-state of the game?  Task: <b>Design the frame of the game:</b> Create a board game in which your interaction can take place.	15 minutes
Break	10 minutes
Activity 3:  Prompt: During interactions, we often engage in certain ways, try to get certain things communicated. In terms of a game, what conversation moves	15 minutes

<p>do you make together? If you think of interactions as a game, what are the rules that the players follow? What rules do you like and dislike?</p> <p>Task: <b>Specify rules of the game:</b> How do you move through the interaction? What are things your communication partner can do or have to make the interaction clearer?</p> <p><b>Design choices, consequences and outcomes:</b> Communicate your moves. (e.g., Moving tokens, levers, knobs, images to take turns, clarify ideas)</p>	
<p>Activity 4:</p> <p>Prompt: Interactions can bring up emotions, both highs and lows, or neutral feelings. You can start to feel different things in your body. What emotions are you aware of and how could you and your partner share those?</p> <p>Task: <b>Create game mechanics and materials to share emotions and sensations:</b> Create physical, interactive representations of emotional states (of yourself and others). Use levers, knobs, images, etc. to supplement verbal discussion with interaction, emotion, sensory cues.</p>	15 minutes
<p>Activity 5:</p> <p>Prompt: Are there wins and losses? What's the end-state of the game?</p> <p>Task: <b>Outcome:</b> What determines when the interaction is over?</p> <p>Prompts: What is the end state of the game? What was created together? How do you carry things beyond the game setting that need to be continued?</p>	15 minutes
<p>Group reflection</p>	10 minutes

## Appendix F: Appropriation Study – Emotion Grid Instructions

This is the outline of slides used during the Appropriation Study for Emotion Grid slides, which were completed by participants asynchronously, prior to their Zoom session.

**Slide 1:** Welcome Title slide

**Slide 2:** Description of the session to come.

Our interview is on <date> at <time>.

- During that interview, I will ask you to use a pretend chat app.
- In the app, you will be able to use custom emojis.
- Please select your custom emojis by following instructions on the next slides.

**Slide 3:** Instructions

Selecting images to be your emojis during a chat

- Look at the images on slides 6 and 7.
- Choose 9 images that represent the types and range of feelings you have during conversations.
- You can select all your images from slide 7, all from slide 8, or mix and match images from both slides.
- On slide 5, place your images on the 9 spots on the grid. The ends of the arrows are labeled:
- “Higher Energy” to “Lower Energy” go from up to down
- “Negative” to “Positive” go from left to right

**Slide 4:** Notes

- Contact Annuska if you have any questions about this activity.
- This activity will likely take about 15 minutes.
- Please complete this activity before <date of interview> at <one hour prior to interview start time>.

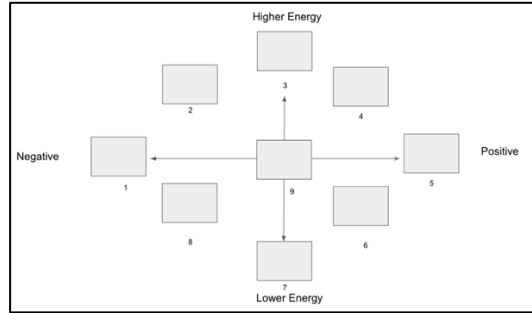


Image: **Slide 5:** Emotion grid



Image: **Slide 6:** First set of images

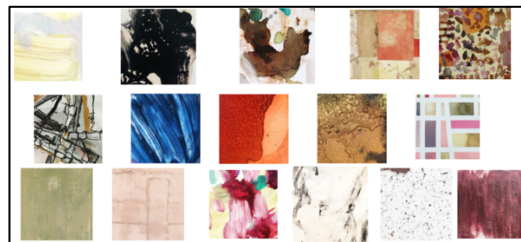


Image: **Slide 7:** Second set of images

**Slide 8:** Questions

Please write here on this slide the answer to these questions:

1. Why did you choose the images you did?
2. Was there anything missing from the set of images you were looking for?
3. Why did you name the grid labels that you decided on? (*P02 and pilot, only*)

**Slide 9:** Thank you

Please email Annuska to let her know you are done with this activity.

## Appendix G: Appropriation Study – Chat App Session

This is the outline of slides used during the Zoom sessions, during which participants appropriated the Chat prototype.

**Slide 1:** Welcome Title slide

**Slide 2:** Goals

Goals for this research interview:

- Have you try out a pretend “chat app”
- I want to know what you think of it - what you like and do not like.
- We can change how it works as you try it out.

**Slide 3:** Activities

1. Try out “chat app”
2. Share emojis
3. Role play a hot topic
4. Personal hot topic
5. Closing: overall thoughts about the emojis

**Slides 4 - 8:** Activity 1: Try out the “chat app”

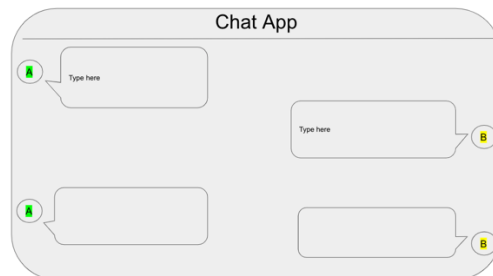


Image: Chat template slide for P04 (Note initial of primary participant is in green; initial of secondary participant is in yellow. Colors are consistent for emoji borders in subsequent slides.)

**Slide 9:** Activity 2: Share emojis section slide

**Slide 10:** <Insert emotion grid from primary participant>

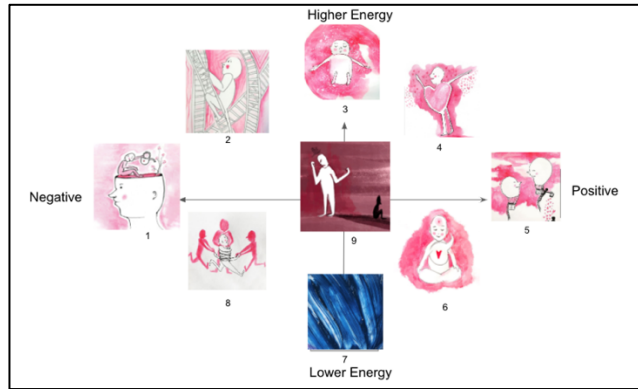


Image: Emotion grid for P04

Slide 11: <Insert emotion grid from secondary participant>

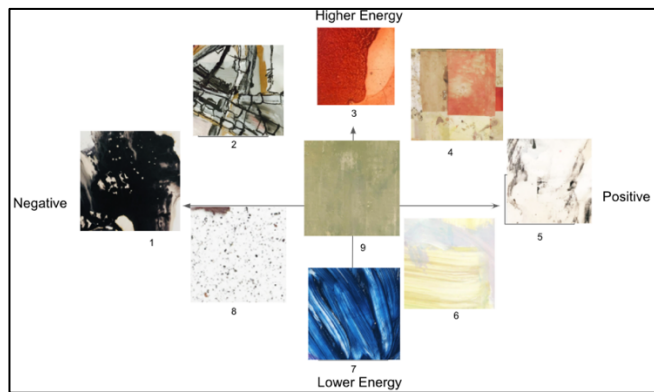


Image: Emotion grid for P04 conversation partner

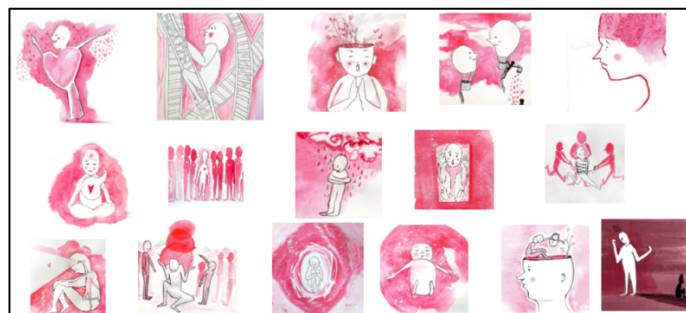


Image: Slide 12: First set of images

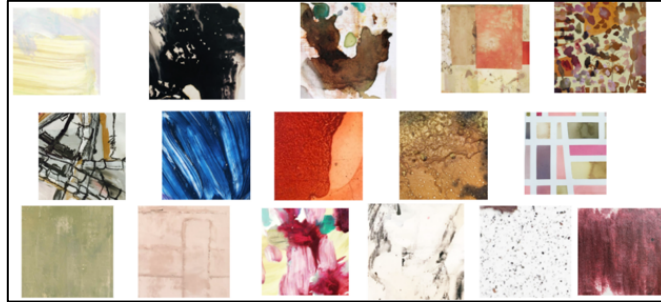


Image: **Slide 13:** Second set of images

**Slide 14:** Activity 3: Role play chat 1

**Slide 15:** Emojis for Chat section slide

**Slide 16:** <Insert emotion grid from primary participant, with participant name and images stylized as emojis>

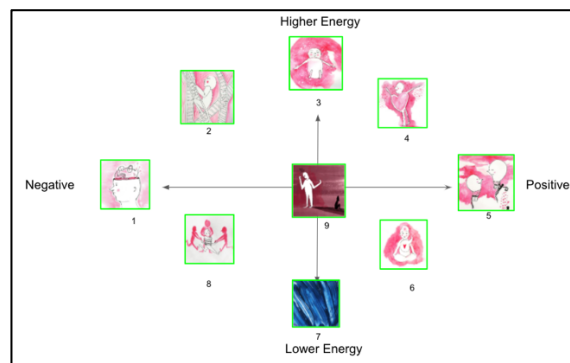


Image: Emoji grid for P04 (Note green border for primary participant's emojis)

**Slide 17:** <Insert emotion grid from secondary participant, with participant name and images stylized as emojis>

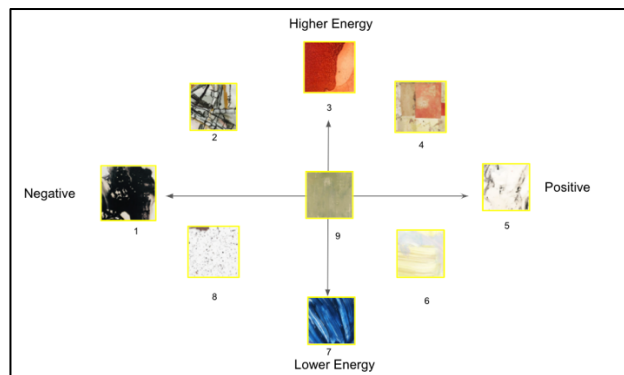


Image: Emoji grid for P04's conversation partner (Note yellow border for primary participant's emojis)

**Slide 18 – 24:** Chat app template slides

**Slide 25:** Activity 3: Role play chat 2

**Slides 26 – 30:** Chat app template slides

**Slide 31:** Overall thoughts section slide

**Slide 32:** Questions

1. Did anything help you express your feelings?
2. Did anything make it harder to express your feelings?
3. Did anything help you understand each other's feelings?
4. Did anything make it harder to understand each other's feelings?

**Slide 33:** Thank you slide

# Appendix H: Community Report for Next Generation Autism

## Technology Study

**Audience:** Research Participants and Community-Based Participatory Design Collaborators

The research team from the University of Washington Information School have concluded the Next Generation Autism Research study. We are pleased to report to the community what we learned from the research.

### **Research Activities**

The goals of the research were to understand the experiences of autistic young adults in their daily lives, especially their interactions and conversations with other people. We invited autistic young adults to be in interviews, do design activity, and try out a new technology concept. In some of the activities, the autistic young adult invited a trusted conversation partner to be part of an interview, design activity, or technology experiment. The autistic young adults created imaginative games to show what they think about how conversations should go. They created game pieces, game boards, and wrote out rules for good game play that would support conversations. They tried out an online chat tool with a new set of emojis. They gave the research team valuable feedback on how they experience emotions and what they want to know about other people during conversations so that everyone can be on the same page.

### **Research Findings**

1. We learned that autistic young adults and trusted conversation partners want to establish common ground—they want to understand what each other is trying to communicate. They want to have harmony and reach their goals. Sometimes, understanding emotions is

very difficult and it is hard to always know what the other person is feeling, or sometimes the other person's feelings can be confusing. Sometimes during conversations, the conversation pair can get stuck or hooked on a conflict or misunderstanding. It's not always clear how to resolve issues or to know what the exact outcome of a conversation was.

2. There are many ideas that the autistic young adults shared with the research team about ways to improve conversations. They wanted decision-making process to be clear and fair, whether it is consensus or individual decision-making. They wanted people to communicate clearly and directly, so that words and actions fit together. They wanted to have more boundaries around emotions and physical sensations.
3. Ultimately, during conversations, people can work together to find ways to make sure everyone is comfortable. This can mean making the conversation interaction and expectations clear, respecting emotional and physical boundaries, and trying to understand each other's point of view.

### **Recommendations for People Creating Technology**

Future technology can do a lot to help people feel more comfortable in conversations, especially when people are talking about difficult topics and feelings are involved. From this research, we recommend that technology designers and developers do the following:

1. For creating technology that supports conversations, help make conversations clearer between people. Help people establish a consistent and predictable pattern of communication, like taking turns and moving from topic to topic. Give people a way to

clarify vocabulary, instructions, and intentions. Give people a way to address any sensory sensitivities, such as avoiding bright lights and annoying sounds.

2. Encourage people to express themselves, through words, emotions, drawing, writing, technology, media, and physical movement.
3. For creating technology that wants to recognize or express emotions, do not assume all people experience emotions in the same way. There are many shades of emotions and ways that people express them. Be respectful of how people share and show emotions.
4. Finally, include autistic individuals in research about what people want from technology.

### **Thanks!**

We are so thankful to the 24 autistic young adults who participated in our research over the past 18 months! Even during the COVID-19 pandemic and quarantine, the research participants did interviews and design work. We also thank the autistic self-advocates and autism organizations who provided input on our research goals and approach. Those organizations and individuals are connected to the UW Autism Center, UW LEND program, Spokane Community College IMAGES program, Seattle SquarePegs, and Ryther. We also thank the National Science Foundation for funding this project through Dr. Jaime Snyder's CAREER award.

### **Contact Information**

- Dr. Annuska Zolyomi, [annuska@uw.edu](mailto:annuska@uw.edu)
- Dr. Jaime Snyder, [vsrs@uw.edu](mailto:vsrs@uw.edu)

# VITA

Research Areas: human-computer interaction, human-centered design, accessible technology

## Education

2021 PhD, Information Science  
University of Washington, Information School  
Dissertation Title: *Grounded Design of Affective Computing Accounting for Social-Emotional-Sensory Experiences of Autistic Adults\**  
Advisor: Jaime Snyder  
Committee: David Hendry, Julie Kientz  
*\*Nominated by the Information School for UW Graduate School Distinguished Dissertation Award*

2014 Master of Science, Human Centered Design and Engineering (HCDE), UW

1994 Bachelor of Science, Industrial Engineering, UW

## Professional Experience: Academic

2020-21 Part-time Lecturer, Computing and Software Systems, University of Washington Bothell

2020-21 Pre-Doctoral Lecturer, Information School, University of Washington Seattle

2019-2021 Graduate Research Assistant, Visualization Studies Research Studio led by Jaime Snyder

2019 Research intern on the Microsoft Research (MSR) Ability team

## Professional Experience: Technology Industry

2013-Present Good Labs LLC

Launched a small business providing user experience consulting services with a specialization in accessible, inclusive experiences. Clients included Microsoft, Amazon, Easter Seals, and Joan Ganz Cooney Center at Sesame Workshop.

1998- 2013 Microsoft

Senior Accessibility Strategist, Program Manager, and Product Planner in Windows, Accessibility Business Unit, Trustworthy Computing, and MSN. Created and delivered training to product groups on research, design, and technical implementation to make products usable for people with disabilities. Delivered product functional specifications, user research, competitive research, and design prototypes (Ease of Access Center in Windows Vista). Contributor to the Microsoft Accessibility Standards and the World Wide Web (W3C) Web Accessibility Initiative guidelines. Creator of Microsoft Imagine Cup (IC) Accessibility competition. Co-creator / co-captain for Accessible Education Tablet IC competition. Co-captain for User Interface Design IC competition. 2008-2012. Launched the Microsoft Inclusive Research Lab.

1995-98                      Accenture

Technology consultant doing systems analysis and development for telecommunications and technology industry clients including AT&T Wireless, Microsoft. Designed and prototyped first-generation internet applications.

## **Teaching Experience**

### *Instructor*

2020 - 2021 Part-time Lecturer, Usability and User-Centered Design (CSS 473), Computing Software and Systems, UW Bothell

2020 - 2021 Pre-Doctoral Lecturer, Accessible Technology and Inclusive Design (INFO 498), Input and Interaction (INFO 463), Information School, UW

2006-07                      Instructor for personal computing and digital photography courses for older adult students, OSHER Institute for Lifelong Learning, UW

### *Teaching Practicum*

2020 "Values in Designing Neurodiverse Social Interactions", Value Sensitive Design (INFO 464), UW

2017 "Prototyping with Arduino", *Prototyping Studio* (HCID 521), UW

### *Teaching Assistant*

2019 Information Systems Analysis and Design (INFO 380), UW

2018 Informatics Capstone (INFO 490), UW

2017 Prototyping Studio (HCID 521), Master of Human-Computer Interaction and Design, UW

### *Guest Lectures in User-Centered Design*

“Co-Designing Sensory-Aware Technology”, *Explorations in Human Centered Design* (HCDE 210), UW, 2019

“User-Centered Design for People with Cognitive Disabilities”, *Accessibility and Inclusive Design* (HCDE 598), UW, 2019

“Design Methods for Inclusive and Accessible Technology,” *Design Methods* (INFO 360), UW, 2019

“Designing for Accessibility”, *Usability and User-Centered Design* (Computing & Software Systems, CSS 478), UW – Bothell, 2019

“Designing for Accessibility”, *Integrated Media and Design Capstone* (Interactive Media Design, IMD 481), UW – Bothell, 2018

“Designing Inclusive User Experiences”, *Perspectives in Assistive Technology* (ENGR 110/210), Stanford University, 2012

### *Guest Lectures in Technical Implementation*

“Great Engineers Build in Accessibility”, *Collaborative Software Design* (INFO 461), UW, 2018

“The Goals and Complexities of Designing Inclusive, Cutting-Edge, Technology Solutions”, *Computer Science and Engineering* (CSE 590), UW, 2012

## **PUBLICATIONS**

### **Journals**

[j1] **Annuska Zolyomi**. 2018. Where the Stakeholders are: tapping into social media during value sensitive design research. *Ethics and Information Technology Journal*, Springer.

### **Conference Papers: Peer-Reviewed, Archival**

[c14] Annuska **Zolyomi** and Jaime Snyder. 2021. Social-Emotional-Sensory Design Map for Affective Computing Informed by Neurodivergent Experiences. *Proc. of ACM on Human-Computer Interaction*, Vol 5, CSCW1, Article 77 (April 2021), 1-33.

[c13] Begel, Tang, Andrist, Bernett, Carbary, Choudhury, Cutrell, Fung, Junuzovic, McDuff, Rowan, Sahoo, Waldern, Wolk, Zheng, **Zolyomi**. 2020. Lessons Learned in Designing AI for Autistic Adults: Designing the Video Calling for Autism Prototype. *Proc. Of ACM ASSETS Computers and Accessibility 2020*, 1-6. (acceptance rate: 30%)

[c12] **Annuska Zolyomi**, Andrew Begel, Jennifer Frances Walden, John Tang, Mike Barnett, Edward Cutrell, Daniel McDuff, Sean Andrist, Meredith Ringel Morris. 2019. Managing Stress: The Needs of Autistic Adults in Video Calling. *Proc. of ACM on Human-Computer Interaction*, Vol 3, CSCW (Nov. 2019), 1-29. (acceptance rate: 31%, **Best Paper Honorable Mention Award** – top 5%)

[c11] **Annuska Zolyomi**, Anne Spencer Ross, Arpita Bhattacharya, Lauren Milne, and Sean Munson. 2018. Values, Identity, and Social Translucence: Neurodiverse Student Teams in Higher Education. *ACM Human Factors in Computing Systems (SIGCHI)*, 1-13. (acceptance rate: 26%)

[c10] **Annuska Zolyomi**, Anushree Shukla, and Jaime Snyder. 2017. Technology-Mediated Sight: A Case Study of Early Adopters of a Low Vision Assistive Technology. *Proc. Of ACM ASSETS Computers and Accessibility 2016*, 220-229. (acceptance rate: 22%, **Best Student Paper Award** – top 2%)

[c9] **Annuska Zolyomi**, Ankitha Bharadwaj, Jaime Snyder. 2017. Let's Play (While Far Away)! Using Technology to Mediate Remote Playdates for Children with Autism. *Human-Computer Interaction International (HCII)*, 415-432.

[c8] L.A.E. Boyd, K. Rector, H. Profita, A. Stangl, **A. Zolyomi**, S. Kane, G. Hayes. 2017. Understanding the Role Fluidity of Stakeholders During Assistive Technology in the Wild. *Proc. SIGCHI Conference on Human Factors in Computing Systems (CHI 2017)*, 6147-6158. (acceptance rate: 25%)

[c7] Hala Annabi, Karthika Sundaresan, and **Annuska Zolyomi**. 2017. It's Not Just About Attention to Details: Redefining the Talents Autistic Software Developers Bring to Software Development. *The 50th Hawaii International Conference on System Sciences (HICSS)*, 5501-5510. (acceptance rate: 47%)

[c6] **Annuska Zolyomi** and Marc Schmalz. 2017. Mining for Social Skills: Minecraft in Home and Therapy for Neurodiverse Youth. *HICSS*, 3391-3400. (acceptance rate: 47%)

[c5] **Annuska Zolyomi**. 2017. Challenges of Constructing a Multiple-Perspective Domain Analysis of Neurodiversity. *Advances in Classification Research Online*, 28(1), 11-13.

[c4] **Annuska Zolyomi**, Joseph Tennis. 2017. Autism Prism: A Domain Analysis Examining Neurodiversity. *Proc. of the North American Symposium on Knowledge Organization (NASKO)*, 1-34.

[c3] Meredith Morris, **Annuska Perkins**, Catherine Yao, Sina Bahram, Jeffrey Bigham, Shaun Kane. 2016. With most of it being pictures now, I rarely use it:

Understanding Twitter's Evolving Accessibility to Blind Users. *Proc. SIGCHI Conference on Human Factors in Computing Systems (CHI 2016)*, 1-12. (acceptance rate: 23%)

[c2] Camille Cobb, Ted McCarthy, **Annuska Perkins**, Ankitha Bharadwaj, Jared Comis, Brian Do, Kate Starbird. 2014. Designing for the Deluge: Understanding & Supporting the Distributed, Collaborative Work of Crisis Volunteers. *ACM CSCW*, 888-899. (acceptance rate: 27%)

[c1] Shaun Kane, Meredith Morris, **Annuska Perkins**, Daniel Wigdor, Richard Ladner, Jacob O. Wobbrock. 2011. Access Overlays: Improving Non-Visual Access to Large Touch Screens for Blind Users. *ACM Symposium of User Interface Software and Technology (UIST)*, 1-10. (acceptance rate: 25%)

### **Extended Abstracts and Posters: Archival, Refereed**

[p5] **Annuska Zolyomi**, Ridley Jones, Tomer Kaftan. 2020. #ActuallyAutistic Sense-Making on Twitter. *ACM SIGACCESS*.

[p4] **Annuska Zolyomi**, Taylor Gotfrid, Kristen Shinohara. 2019. Socializing via a Scarf: Individuals with Intellectual and Developmental Disabilities Explore Smart Textiles. *ACM SIGCHI*.

[p3] **Annuska Zolyomi**, Anne Spencer Ross, Arpita Bhattacharya, Lauren Milne, and Sean Munson. 2017. Value Sensitive Design for Neurodiverse Teams in Higher Education. *ACM SIGACCESS*.

[p2] **Annuska Zolyomi**, Anushree Shukla, and Jaime Snyder. 2016. Social Dimensions of Technology-Mediated Sight. *ACM SIGACCESS*.

[p1] **Annuska Perkins**, Tira Cohene. 2006. The impact of user research on product design case study: accessibility ecosystem for Windows Vista. *ACM SIGACCESS*.

### Workshop Papers: Refereed

[w4] **Zolyomi, A.** 2019. Neurodiverse Technology-Mediated Collaboration: Co-Design Towards Enhancing the Agency of Autistic Adults, *Consortium for the Science of Socio-Technical Systems (CSST)*.

[w3] **Annuska Zolyomi** and Marc Schmalz. 2018. Clay for HCI Research: Creating and Interpreting Forms. *Disruptive Improvisation Workshop*, ACM SIGCHI.

[w2] **Annuska Zolyomi**. 2016. Connecting Tinkerers: Enriching Maker Communities through Neurodiversity. *Autism and Technology Workshop*, ACM SIGCHI.

[w1] Lund, A., **Perkins, A.**, Kurniawan, S., Nacke, L. 2011. *Accessible Games Special Interest Group (SIG)*, ACM SIGCHI.

### **Book, Magazine, and Newsletter Contributions**

[b3] **Annuska Zolyomi**, Jaime Snyder. 2018. Early Adopters of a Low Vision Head-Mounted Assistive Technology. Special Interest Group on Accessible Computing (SIGACCESS), Newsletter Issue 122.

[b2] Technical Contributor for Microsoft Corporation. *Engineering Software for Accessibility*. Microsoft Press (2009).

[b1] Jennifer Linn, **Annuska Perkins**. 2008. Accessibility 101, Code Magazine, 5(4).

### **Media Coverage**

[m1] A DARPA Sarcasm Detector Is Good [<https://gizmodo.com/a-darpa-sarcasm-detector-is-good-1846991265>]  
By W. Kimball  
[www.gizmodo.com](http://www.gizmodo.com). May 2021

### **Awards and Honors**

2019 Best Paper Honorable Mention Award. Annuska Zolyomi, et al. Managing Stress: The Needs of Autistic Adults in Video Calling. *ACM CSCW*. Publication [c12].

2019 ACM ASSETS Doctoral Consortium Grant

2017 Best Paper Honorable Mention Award. Zolyomi, et al. Technology-Mediated Sight: A Case Study of Early Adopters of a Low Vision Assistive Technology. *ACM ASSETS*. Publication [c10].

2017-18 Fellow, Leadership Education in Neurodevelopmental and Related Disabilities (LEND), UW.

2017 Harlan Hahn grant (\$2,000), Disability Studies Department, UW.

2015-17 Top Scholar Award, Graduate Opportunities and Minority Achievement Program (GO-MAP), UW.

2014 Patent granted for “User experience customization framework”, US 8732661.

2009 Patent granted for “Personalization of user accessibility options”, US 7554522.

2009 Patent granted for “Icon for a portion of a display screen (Windows Vista Ease of Access icon)”, US D606091.

2009 Patent application for “Three-State Touch Input System), US 20110138284.

2000-10 Five Microsoft Ship-It Awards for contributing to the release of MSN and Windows products.

## **Contribution to Technology Industry Research and Standards Organizations**

Industry coalition member, Cloud4All and Global Public Inclusive Infrastructure; funders included the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and the European Union, 2011-13.

Advisory Board member, *National Center for Technology Innovation (NCTI)* funded by the U.S. Office of Special Education Programs (OSEP), 2007-10.

Working Group Member, Web Accessibility Guidelines, Web Accessibility Initiative (WAI), World Wide Web (W3C), 1999-2001.

## **Federal Grant Referee**

“Technology in the Works” Grants for collaborative research projects that explore innovative assistive technologies that can provide greater access for students with disabilities. National Center for Technology Innovation – Office of Special Education Programs (OSEP), 2007-10.

## **Invited Talks**

2021 Digital Equity Panel, Inclusify By Design University of Washington

2018 “Technology-Mediated Lived Experiences of #ActuallyAutistic Individuals”, *Human Factors and Ergonomics Society Symposium*.

2013 “Demonstration of Wearable Fabric Technology”, *Kennedy Center Leadership Exchange in Arts and Disability (LEAD)*, John F. Kenney Center for the Performing Arts, Washington D.C.

2012 “Designing Effective Technologies Through the Use of Personas”, Research Webinar, *Assistive Technology Industry Association (ATIA)*.

2012 “Digital Rights and Markup for Digital Books” and “Panel on Accessibility and Inter-operability”, *Computers Helping People with Special Needs (ICCHP)*.

2011 “Accessible Touch Screen Interactions”, Demonstrated Surface Touch Overlays. *Technology and Persons with Disabilities Conference (CSUN)*.

2010 “Research on Emerging Technologies: A Panel Speaks About Research Funded by NCTI”, *CSUN*.

2009 “Inclusive Innovation at Microsoft: Windows 7 and Silverlight”, *Software Development for Enhancing Accessibility and Fighting Info-exclusion (DSAI)*.

2007 “Creating usable interfaces for people with disabilities”, *Puget Sound World Usability Day*.

2006 “Built-in Ease of Access Coming in Windows Vista”, *CSUN*.

## **Invited Research Workshops**

Microsoft Research Faculty Summit, *Ability Team*, 2019.

Autism Research Workshop, *Autism at Work*, 2019.

Digital Storytelling Fellows, UW, 2017.

Workshopped my paper on Neurodiverse Teamwork in Higher Education, *Value Sensitive Design: Charting the Next Decade*, Lorentz Center – Leiden, The Netherlands, 2016.

Expanding Accessibility Research, *UW Computer Science and Engineering / Microsoft Research Summer Institute*, 2016.

## **Doctoral Consortia**

**Zolyomi, A.** 2019. “Neurodiverse Socio-Technical Collaboration: Co-Design Towards Enhancing the Agency of Autistic Adults”, *ACM SIGACCESS conference (ASSETS)*.

**Zolyomi, A.** 2019. “Designing to Improve the Agency of Autistic Adults in Technology-Mediated Collaboration”, *UW Design-Use-Build (DUB)*.

## **Service to Profession**

### *Conference Peer-Reviewer*

International Conference on Affective Computing & Intelligent Interaction (ACII) 2021

ACM Computer Human-Interaction (CHI): 2016, 2017, **2019\***, 2020

ACM Interaction Design for Children (IDC): 2019, 2020

ACM IDC Work-In-Progress: 2021

ACM Tangible, Embedded and Embodied Interactions (TEI): 2019

ACM Computer Supported Cooperative Work (CSCW): 2018, June 2020, Oct 2020, April 2021

Hawaii International Conference on System Sciences (HICSS): 2017, 2018

Educational Research and Reviews (ERR): 2017

ACM User Interface Software and Technology (UIST): **2014\***

**\*Special Recognition for Exceptional Reviewing**

### *Journal Reviewer*

Springer Higher Education: 2020  
Autism Policy and Practice: 2019  
Springer Journal of Ambient Intelligence and Humanized Computing: 2018  
ACM Transactions on Accessible Computing (TACCESS): 2018

### *Event Organization*

Co-organizer of “Non-Ableist Data Science Workshop: Exploring Data Science and Inclusion” co-sponsored by Taskar Center for Accessible Technology, UW eScience Institute and Paul G. Allen School of Computer Science & Engineering, 2020

Co-organizer of Neurodiversity Knowledge Structures session for workshop on “Involving Participants in Identifying Issues in Multi-Dimensional, Multi-Perspective, and Multi-Viewpoint Knowledge Structures”, *Association for Information Science and Technology (ASIS&T)* Special Interest Group on Classification Research, 2017

Co-organizer, *Accessibility and Gaming*, ACM CHI Special Interest Group, 2011

Producer, *Puget Sound World Usability Day*, 2011-12

## **Departmental/University Service**

### *Leadership Positions*

PhD student representative, Information School Research Committee, UW, 2018-19

Treasurer, Doctoral Student Association, Information School, UW, 2017-18

### *Volunteer*

Co-developed and presented learning module, “Critical Thinking to Increase Community Voices in Data for Social Justice,” UW-CAMP Dare to Dream Science Academy for high school students, UW, 2020

Member, Diversity Welcome Committee, Information School, UW, 2015

## **Community Involvement**

Interactive electronic textile skirt co-created with a textile artist, “Interactive” exhibit, Venues for Artists in the Local Area (VALA), 2014.

Organized digital, do-it-yourself Maker workshops for elementary and middle school students; partnered with Sparkfun Educational Outreach, 2013.

Created and delivered introductory course on Arduino computer prototyping, *Ryther* (agency serving neurodiverse youth and young adults), 2012-13.