LITERACY ENTANGLEMENTS IN A SIGNIFICANT DISABILITY CONTEXT

by

WISNU AGUNG PRADANA

(Under the Direction of Usree Bhattacharya)

ABSTRACT

This interdisciplinary inquiry engaged in posthuman thinking on literacy entanglements of a multilingual individual with Rett syndrome, a rare neurological condition resulting in significant disabilities in speech and functional hand use, among others. Drawing from in-situ observations, interviews, and a focus group discussion with the individual, her parent, her literacy teacher, and her babysitter, the study posed two central questions: "How is a child with Rett syndrome entangled with other human and non-human interactants during literacy activities at home?" and "What are the larger implications of these entanglements for inclusive language and literacy education practices?" The findings demonstrated dynamic interconnectedness between the actants in shaping the individual's language and literacy experiences. The study proposed language and literacy teachers, teacher educators, and scholars turn the gaze to the non-human elements and their entanglements in language and literacy and interrogate the assumed boundaries that marginalized certain ways of knowing, doing, and becoming literacies.

INDEX WORDS: Posthumanism, Critical Disability Studies, Literacy, Significant Disabilities, Rett Syndrome, Augmentative and Alternative Communication

LITERACY ENTANGLEMENTS IN A SIGNIFICANT DISABILITY CONTEXT

by

WISNU AGUNG PRADANA

B.Ed., Universitas Sanata Dharma, Indonesia, 2013

M.Ed., University of Georgia, 2019

A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PHILOSOPHY

ATHENS, GEORGIA

2024

LITERACY ENTANGLEMENTS IN A SIGNIFICANT DISABILITY CONTEXT

by

WISNU AGUNG PRADANA

Major Professor:	Usree Bhattacharya
Committee:	Ruth Harman
	Rachel Rose Cagliani

Electronic Version Approved:

Ron Walcott
Vice Provost for Graduate Education and Dean of the Graduate School
The University of Georgia
August 2024

DEDICATION

Dengan menyebut nama Allah Yang Maha Pengasih lagi Maha Penyayang.

For my ancestors, family, and those who will come after me.

ACKNOWLEDGEMENTS

The stars have finally aligned. From the bottom of my heart, I would like to express my gratitude to all those who supported me during my graduate studies at UGA. My success in reaching the pinnacle of education would not have been possible without the support of my kindhearted and selfless family and friends in the U.S., Indonesia, Australia, and Vietnam.

To Dr. Bhattacharya, thank you so much for your unending support during my time pursuing my master's and doctoral degrees. Even in your busy schedule, you always made sure you were there for me. It certainly would have been a difficult journey if it weren't with you. Your care and guidance have been the cornerstone of my academic success. I will never forget the warmth and care of your family, especially when I lost my father in the midst of the pandemic. Thank you for pushing me to be the best version of myself and allowing me to grow at my own pace. I am forever in debt to you.

To Dr. Ruth Harman and Dr. Rachel Cagliani thank you for your insights during the preparation and writing of this dissertation. Notably, your questions and suggestions really pushed me to think beyond the boundaries.

To Kalika, you are such a beautiful, strong, and intelligent girl. Words cannot express how grateful I am to be entangled with you through my studies at UGA. During my not-so-easy doctoral journey, you have always been a source of inspiration and joy. I am always amazed by the brilliance, patience, and strength you have shown since the first time I saw you in the classroom in 2017. Believe me, there is nothing you cannot conquer with the brilliance, patience,

and strength you possess. It is indeed a blessing to know you as a person beyond being the child of my doctoral advisor.

To Baba, Sally, and Sofia, thank you for sharing your stories and wisdom with me. I learned so much from you beyond the scope of my research. I will always cherish the moments we shared during my data collection time. Thank you for allowing me to know you and trusting me with your stories.

To my father, mother, sister, and brothers, terima kasih untuk kasih sayang dan semua doa yang dipanjatkan untuk aku setiap hari. Untuk bapak, khususnya, I miss you with every breath I take. Thank you for your unceasing love, support, and comfort until this very second. Sampai jumpa lagi di ruang dan waktu yang izinkan-Nya.

To my friends: Ji, Shuang, Yixuan, and Saurabh, thank you for the countless hours we spent together writing, presenting, chatting, and hanging out. Thank you for being so understanding and supportive during my time in the U.S. You are all my chosen family. To my best Indonesian buddies: Tiara, Pungki, Titus, Vena, and the Indonesian Student Community at UGA (Habib, Zaki, Ummu, Mas Dedi, Nasir, Sarah, Kak Elsye, Taki, Ulfa, Marvin, Kezia, Samara, Samantha, Rosari, Bang Is, Ci Winne, Ci Olin, Adi, Mas Avry, Andhika, and others), thank you for our shared time, food, and laughter during my 7-year stay in Athens.

To Fulbright, thank you for the opportunity to earn my master's degree in a country that I previously could only see on television and in my schoolbooks. This path eventually led me to earn the first PhD in my family. Thank you for making my dream, as well as the dreams of my family and ancestors, come true. During the preparation of this work, the author collaborated with Grammarly and ChatGPT as non-human elements to improve the readability of his original writing.

TABLE OF CONTENTS

Page

LIST OF EXCERPTS AND NARRATIVES

Page

LIST OF ILLUSTRATIONS

Page

LIST OF FIGURES

Page

CHAPTER 1

INTRODUCTION

Excerpt 1

"No, no, no, don't use it. You speak.": The Boundaries of Speaking

Instrumental music of 'Rasa Sayange' (Feelings of Love), a popular folk song from the Maluku Islands in Indonesia was playing in the background during the first of three-day celebrations of International Disability Day, held by the Ministry of Social Affairs of Republic Indonesia. On the stage, Aldy, a talented painter and student with autism and speech difficulties was standing next to the minister.

> "Now I ask you to speak, without your tool. You speak, Aldy," said the minister followed by directing her microphone to Aldy.

Aldy looked down with no sounds coming out of his mouth. His left hand was on his chest, rubbing and playing a button of his purple batik shirt. He then touched the microphone held by the minister and turned it down slowly.

The minister responded to Aldy's gesture by moving the microphone back up to his mouth and continued persuading him to speak by mouth. Aldi once again touched the microphone and turned it down. The minister then moved his left hand toward Aldi's hand on the microphone, asking him to keep it down and let her hold the microphone for him.

> "You can speak, sayang [love]. I…", the minister said softly, prompting him to continue her sentence.

Aldy closed his eyes and vocalized softly, trying to say "Saya (I)" for the minister.

"C'mon, Aldy, you speak," asked the minister.

Aldy then looked behind where his mom was patiently standing, witnessing his child being pressured to speak by a minister whose scope of responsibilities included ensuring accessibility and inclusivity of more than 27 million people with disabilities in the nation. Shortly after, he reached the communication tool that his mom had been holding for him.

"No, no, no, don't use it. You speak," said the minister.

> The pressure to speak by mouth continued until Aldy could vocalize a whole sentence of "Aldy wants to preserve the nature," which described his painting. This interaction lasted for approximately five minutes, in front of hundreds of audiences in the room and those who streamed the celebration over the internet, in the year of 2021, three years before this dissertation is written.

The pressure to speak by mouth experienced by Aldy on a celebration of International Disability Day above exemplifies the overt ableism that many individuals with disabilities experience in the country known as the world's largest archipelago. As a transnational Indonesian scholar in language and literacy education, born with monocular vision, who has closely worked with other individuals with disabilities and families in both the United States and Indonesia, witnessing such blatant ableism from the person most responsible for ensuring accessibility, inclusivity, and the welfare of individuals with disabilities in the nation is heart-wrenching.

With over 275 million people scattered across almost 17,000 islands, Indonesia still grapples with the fulfillment of rights and inclusivity for well over 27 million people with disabilities. Indonesian students with disabilities have historically been educated in separate schools known as Sekolah Luar Biasa (SLB) or Special School since the country gained independence in 1945. It was only after the country ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2011 that the government began promoting inclusive education for students with disabilities to be included in mainstream schools.

Over a decade after the ratification of CRPD, the implementation of inclusive education in the country is still far from expected. Children with disabilities in Indonesia are less likely to attend and complete school across all educational levels than children without disabilities. At the primary school level, those with functional difficulties in communication, self-care, and cognition had the lowest completion rates, with only 36%, 24%, and 24%, respectively

(UNICEF, 2021). Many children with disabilities in Indonesia are also malnourished and stunted. They face increased risks of child protection, higher rates of sexual abuse, and are less likely to be registered at birth (UNICEF, 2021).

In the so-called inclusive classrooms, many of these children experience bullying from their peers (Napitupulu, 2023) and a lack of access to accessible instruction. Sunardi et al. (2011), for example, found that out of the 186 inclusive schools they surveyed, only 2% had enough instructional resources for students with autism, 4% had adequate resources for students with speech and hearing difficulties, and only 23% had the necessary resources for students with intellectual disabilities. In short, the availability of resources, including instructional media and assistive tools, remains severely limited in many Indonesian inclusive classrooms. These students are forced to adapt to the mainstream ways of learning and being despite their documented disabilities, just like Aldy being forced to speak by mouth despite his speech difficulties.

In Aldy's case above, his lived experience as a person with speech difficulties, his entanglement with his assistive tool and mother, and his ways of communication are rendered illegitimate, 'abnormal', and invisible. To the minister, Aldy did not 'speak' – his silence, body movement, hand gestures, and tool-mediated communication were dismissed as meaningless. 'Speaking', in such an anthropocentric mindset, holds no alternative meaning other than producing intelligible sounds in a language using one's own oral cavity organs.

Discourse about disability in Indonesia tends to circulate around personal misfortunes and challenges. The practice of shackling individuals with psychosocial disabilities, for example, is still found in some areas of Indonesia. In Bali, one mother chained her son with a psychosocial disability for more than 10 years. She described that:

> "We took Ngurah to more than 40 traditional healers where they poked him with a stick and put herbs in his eyes, but it didn't work. We didn't know what to do. When Ngurah kept getting lost, the local police and community blamed and put pressure on us. We felt ashamed so we decided to chain him" (Human Rights Watch, 2020, n.p.)

Such discourse about curses, diseases, limitations, social burdens, and misfortunes for having a disability is not unique to the Indonesian society context. In many parts of the world, people historically perceive individuals with disabilities as *non-humans* (Goodley et al., 2014). They are continuously portrayed as "lacking, inept, incompetent, inferior, in need, incapable, degenerate, uneducated, weak, ugly, underdeveloped, diseased, immature, unskilled, frail, uncivilized, defective, and so on" individuals (Siebers, 2010, p. 23).

Many people grapple with fathoming disability phenomena and 'appropriate' discourse about the ways of being, doing, and becoming of individuals with disabilities (Siebers, 2010; Ferri & Connor, 2014; Beneke & Cheatham, 2020). In the U.S., for example, the term 'intellectual disability' has experienced at least 18 changes in the last 60 years, encompassing terms such as 'cognitive delay' and 'learning disability', which suggests both changes in social attitude and metacognitive grapple (Berkson, 2006; Metzler, 2016). In the context of education, students with disabilities have been described as unruly subjects who need to be 'fixed', 'cured', and 'excluded' (Erevelles, 2000). In 2017-2018 academic year, the U.S. Department of Education (2021) reported that 56.9% of preschool students served under IDEA were expelled from school. Similarly, Gilmour et al. (2019) also found that numerous students with disabilities are not accessing the existing school curriculum – the average reading gap between students with and without disabilities was about 3.3 years of reading growth.

In literacy studies, specifically, the engagement of individuals with disabilities in literacy activities has been perceived through deficit-oriented lenses that highlight their deviation from the unquestioned 'normal' axis of literacy engagements (Bhattacharya & Pradana, 2022). These phenomena prompted me to reflect on our collective metacognition of disability and its intersection with education, especially language and literacy education. I wonder:

1. What constitutes a 'human'? Who gets to label and be labeled as a human and a non-human?
2. How does the prevailing construction of humans devalue the diverse ways of languaging and literacy engagements of individuals with disabilities?
3. How can we expand our understanding of humans to account for the diverse ways of being, doing, and becoming literacy and languaging of individuals with disabilities?

The Gap in Disability Construction

Disability is an inherent facet of human civilization. Portrayals of individuals with disabilities can be found in numerous classic literatures, folklores, temple reliefs, films, and books across the globe. In Greek culture, some prominent gods and goddesses are portrayed with disabilities. For instance, Larunda, a nymph and daughter of the river god Almo, is portrayed as non-speaking after Zeus ripped out her tongue for being loquacious and spreading rumors about his infidelity (Mishra & Abhiramis, 2021). Meanwhile, Tiresias, a prophet, suffered blindness as a curse for displeasing Hera, Zeus' consort, during their argument. Some sources also suggest that his blindness was a consequence of glimpsing Athena's naked body (e.g., Loraux, 2014; Rocco, 2016).

In other parts of the world, such as Indonesia, depictions of individuals with disabilities were found in ancient literary scripts, known as 'naskah kesustraan,' as well as in Hindu and

Buddhist temples in Java. On a relief panel of the 9th-century Shiva temple in Prambanan, Central Java, for example, individuals with disabilities were intricately carved onto solid volcanic rocks by the people of the Sanjaya Dynasty around 850 CE. They were portrayed as royal servants, advisors, and individuals possessing magical powers, serving the kings, sultans, and sunans of Java. Meanwhile, in the ancient literary scripts, such as the 14th century literary scripts of Kitab Korawacrama and Kitab Rajapatigundala, various conditions such as mental illness, intellectual disability, albinism, blindness, mutism, limping, deafness, and kyphosis (hunchback), were described as some consequences of norm violations and supernatural forces. Kitab Rajapatigundala specifically outlines that those who transgressed societal norms were cursed by the king, leading to enduring suffering from disabilities and diseases throughout their lives (Kasiyati, 2008).

Such depictions of individuals with disabilities as symbols of evil, curses, savants, and beings with magical powers persist today. From well-known canonical English literature, such as Moby Dick (Melville, 1851) to contemporary pop culture in North America and Europe (Goldstein & Tessa, 2021; Botha & Harvey, 2022), Asia (Diffrient, 2017; Al-Zoubi & Al-Zoubi, 2022), and Africa (e.g., Lipenga & Ngwira, 2018; Olaiya, 2013), individuals with disabilities are continuously characterized as the figures in between or semi-humans. Their physical representations are often framed as subhumans (evils, curse) or the superhumans (magical figures, gods). Their being in the world has consistently been within the spectrum of humanness, yet they have never been fully recognized as 'humans.'

The prevailing static narratives portraying individuals with disabilities as 'not-quite-humans' are partly sustained by the tendency of disability studies and studies involving individuals with disabilities to base their logical explorations on the traditional Vitruvian model

of the human body that endorses Eurocentrism and self-centered individualism. The model represents a very chauvinistic imagined perception of the human body and humanity (Hańderek, 2021). It exclusively symbolizes a European healthy male body as the ideal representation of human (Braidotti, 2013), which insidiously renders women, individuals with disabilities, LGBTQ people, and persons of color as defective and secondary individuals. Additionally, the model champions individualism which manifests in the existing medical perspective (also known as the medical model) of disability. This viewpoint sees disability as a personal tragedy caused by the functional limitations of one's own body, highlighting individual impairment rather than acknowledging the negative consequences resulting from the intersection of disabilities with the ableist social environment and attitudes. The perpetuation of disability as the "misfit" (Garland-Thompson, 2011, p. 594) contributes to ongoing stigma and poses significant daily challenges for individuals with disabilities.

Additionally, current explorations of disability tend to portray disability as a static lived experience rather than a process of becoming. For a long time, individuals with disabilities have been perceived as aberrations, deviants, half-humans, disturbances, and threats to society. Due to their 'ambiguities', they have been confined to asylums (Segrest, 2020), restrained with chains and wooden beams (Hunt, 2021), and segregated from mainstream classrooms (Fenning & Johnson, 2022). Mainstream disability studies have predominantly approached these phenomena from the perspective of crip vs able bodies, often neglecting an inquiry into the boundaries (or the unruliness of these boundaries) of humanity that contribute to the ingrained notions of human vs. non-human, able vs. crip bodies, superior vs. inferior, and 'us' vs. 'the others.' The boundary, as argued by Hańderek (2021), "simultaneously unites and divides what lies beyond it, thus creating a liminal space, a space of what lies between, and a space of ritual passage, change, and

entrance into the sphere of the other" (p. 17). It possesses significant political and cultural gravity, making people conscious of the socially marked and unmarked phenomena that impact our social positions in perceiving the legitimacy of being for those within and outside these boundaries. It is this concept of separateness or agential cuts (Barad, 2003, p. 815) between subject and object, individualism, and its repercussions on the prevailing pathological perspective of disability that motivates me to approach this study from an educational standpoint.

I argue that a critical oversight in the understanding of disability lies in the lack of exploration of the dynamic assemblage of individuals with disabilities and the power of their entanglement with other humans and non-humans. An assemblage, as described by Bennett (2005), is a circumstantial grouping of heterogeneous living actants (humans and nonhumans; organic and mechanic; nature and culture). It signifies dynamic processes of construction and deconstruction; an ongoing process of assembling, arranging, and organizing things (Bodén, 2013). The omission of knowledge that highlights the hybridity and entanglement of their bodies with their environment perpetuates the epistemic injustice of viewing disability as a non-human phenomenon.

The language and literacy of individuals with disabilities, especially, have long been regarded as defective, secondary, and illegitimate due to their deviation from the 'normative' ways of languaging and literacy engagement (Bhattacharya & Pradana, 2022). This perception has contributed to the marginalization of their communicative abilities, portraying their language use and literacy practices as others, non-'standards,' and non-humans. It is essential to challenge these biases and recognize that there is no such thing as 'disordered' language – it is the social disordering of their bodies that leads people to perceive their language as disordered (Henner & Robinson, 2023). A new paradigm, or episteme in Foucault's (1966/2005) term, that offers a new

perspective of the human body is needed to foster a more inclusive and equitable understanding of disabilities and disability experiences. This paradigm should emphasize the diverse ways of being, doing, and becoming, acknowledging and celebrating the richness of these varied expressions within the spectrum of human experience.

The Epistemological Shift Toward Entanglements

What you are about to embark on is an exploration of disability phenomena in its intersection with language and literacy from the perspective of posthumanism. In this study, a 'phenomenon' is understood as an observable event, the smallest unit of analysis, and an epistemological shift to the interconnection and dynamic relationship of various humans and non-human elements (Barad, 2007). As an observable event and unit of analysis in literacy research, an example of a phenomenon can be the intra-actions between a child, a parent, the book they are reading, the illustrations and colors of the story in the book, the chair they are sitting on, and the lights in the room they are in during a story reading activities. Meanwhile, as an epistemological shift, a phenomenon is a turn towards the actions, doings, and relationality of humans and non-human actants in a phenomenon.

In this study, I seek to steer away from the conventional approach of determining hierarchies and separations in a phenomenon. Barad (2007) refers to this alternative approach as the "performative" turn (p. 135). Therefore, in this study, my focus lies in unveiling how each human and non-human element exerts agency, performs, and intra-acts with one another instead of identifying a specific superior entity(ies) and emphasizing its dominant roles within a phenomenon. By turning to the entanglements of humans and non-human elements, I endeavor to shed light on the dynamics of intra-actions between human and non-human elements and how they shape the language and literacy experiences of a child with significant disabilities.

This study explores the literacy entanglements of a multilingual seven-year-old individual with Rett syndrome during her literacy activities at home. It focuses on unfolding two interrelated research questions, namely:

1. How is a child with Rett syndrome entangled with other human and non-human interactants during literacy activities at home?
    a. Who and what are the interactants that are part of the child language and literacy activities?
    b. What role do these interactants play in navigating language and literacy activities for the child?
2. What are the larger implications of these entanglements for inclusive language and literacy education practices?

Significance

This study delves into the entanglements of humans and non-human elements in the literacy experiences of an individual with Rett syndrome named Kalika. By taking a close examination of the linkages between humans and non-human elements during Kalika's literacy activities with her babysitter (Sofia), father (Baba), and literacy specialist/teacher (Sally) at home, this study aims to illuminate the roles of humans and non-human elements and their entanglements in shaping Kalika's language and literacy experiences.

The emphasis on entanglement in this study offers a segue for literacy scholars, teachers, and therapists to broaden their ideological perspectives on literacy and literacy practices. Specifically, it provides an opportunity to reimagine literacy and literacy education within the framework of the new materialism paradigm, which emphasizes the interdependencies of students with other humans (parents, siblings, peers, teachers, therapists) and non-human entities

(classroom space, technology, instructional materials). A few questions that I would like literacy scholars and educators to ponder with me while exploring this study are:

1. How can we create an educational environment that values the entanglements of the students with other life forms?
2. How does the shift toward entanglements help us deconstruct our existing conceptions of language, literacy, and disability which have been informed by Humanist ableist ideology?
3. And how does the shift toward entanglements facilitate us to reimagine futures of the classrooms that are inclusive to all bodily representations and abilities?

Conceptualization of Terms

This study bridles literature and concepts from posthumanism, language and literacy, critical disability studies, and Augmentative and Alternative Communication (AAC). To achieve clarity across different disciplines of study, the following section elucidates my conceptualization of specialized terms that I am using in this study.

Actant. An actant is a metaphysical concept that denotes "any entity that modifies another entity in a trial" (Latour, 2004, p. 237). Actants can be either humans or nonhumans possessing the efficacy to produce and alter phenomena within assemblages. In this study, actants encompass all human and non-human entities that could directly impact Kalika's engagement during her literacy activities. These entities may range from an eye-tracking AAC device, Sally, Sofia, Baba, a dining table, food residues under a dining table to window shields within a given setting.

Assemblage. Assemblage is a new-materialist concept that pays homage to Deleuze and Guattari's theorization of agencement or arrangement (see Phillips, 2006). Assemblages are the

"ad hoc groupings of diverse elements, of vibrant materials of all sorts" (Bennett, 2010, p. 23); they are open-ended systems of network of heterogeneous actants that create novel lifeworlds. For Bennett (2010), everything is a mosaic of diverse bodies that work together forming a new phenomenon that "is distinct from the sum of the vital force of each materiality considered alone" (p. 23). This implies that each member of an assemblage produces something beyond itself. Therefore, comprehending an assemblage cannot simply be derived from understanding the agency of its members alone, as each agency contributes to the creation of an unpredictable union. In this study, assemblages are understood as arrangements of humans and non-human elements within a phenomenon. They work in concert for specific roles during literacy activities of Kalika with Sally, Baba, and Sofia.

Augmentative and Alternative Communication (AAC). AAC refers to all methods of communication used by individuals with complex communication repertoires due to a range of temporary or permanent conditions, e.g., diseases, syndromes, injury, trauma, and developmental cognitive and linguistic disability (Beukelman & Light, 2020). AAC is classified into two, i.e., the unaided AAC and the aided AAC. Unaided AAC includes the communication modality that fully relies on the use of the body, such as gesture, eye contact, finger spelling, facial expression, and formalized manual signing (e.g., American Sign Language). For those with preserved mobility or hand use, the individuals may also communicate through body proxemics. These include approaching the desired objects, such as books or cutleries for expressing an interest in reading and eating, or coming into a particular place, such as a bedroom for expressing an interest in going to bed (see Dada, 2021). Aided AAC, in contrast, is a type of complex communication repertoires that employs external tools or materials. Examples of aided AAC

include picture board communication, flashcards for communication, and electronic speech-generating devices (SGD), e.g., Tobii Dynavox, Accent™.

Entanglement. Entanglement, in quantum physics, is a phenomenon in which two particles share a deeply interlinked state. The state of one particle can influence the state of the other(s), even when they are widely separated. In this study, entanglement is conceptualized as the interconnected relationships of actants within a phenomenon. This concept emphasizes the intricate relationships and mutual influences among these components, where the properties or behaviors of one element are inherently linked to those of another (Barad, 2007).

Fixation. Fixation is a temporary pause the eye makes on an area of interest. In reading, fixation signifies the individual's visual attention and processing of information in an area of interest, such as a word, a phrase, or a picture (Holmqvist et al., 2011). In this study, fixation refers to a momentary pause in eye movements that Kalika makes on an area of interest on her AAC device screen or pageset for at least 0.8 seconds.

Intra-action. Barad (2007) contends that "individuals do not preexist their interactions; rather, individuals emerge through and as part of their entangled intra-relating" (p. x). In other words, intra-action is the inherent nature of actants that are inseparable from each other. This perspective acknowledges the dynamic process of a phenomenon, where actants do not exist independently but emerge through their entangled intra-relating. This term contrasts with 'interaction' which suggests subject-object duality and signifies the social interactions of people (Barad, 2007). 'Intra-actants,' therefore, is a term that describes the intra-acting actants within an assemblage or an entanglement.

Phenomenon. A phenomenon is an observable event within a specific context or system that arises from the intra-actions and entanglements of various actants. It is not a static

occurrence engineered by humans as in laboratory experiments, but rather a dynamic manifestation shaped by the continuous interplay of human and non-human elements within a context or a setting. In this study, a phenomenon may include Kalika's complex communication repertoires and their intra-action with humans and non-human elements during literacy activities (e.g., story reading, homework, and learning to read sessions), Kalika's significant disabilities and how her ways of being, doing, and becoming literacies are disordered in anthropocentric perspectives, or creative collaborations between humans and non-human elements to mediate the teaching of literacy for Kalika. Additionally, a phenomenon is also understood as a signal of an ethico-onto-epistemological shift towards the interconnection and dynamic relationships of various elements that are intra-acting within a specific observable event (Barad, 2007).

Rett Syndrome. Rett Syndrome is a rare neurodevelopmental spectrum condition that is instigated by the mutation of a nuclear protein MeCP2 (methyl-CpG-binding protein 2) in the X-chromosome (Amir et al., 1999). Mostly found in the brain, lung, and spleen, MeCP2 regulates brain development and the transcription of mammal's neuron profile to be silenced or overexpressed (Karaca, Brito, & Oliveira, 2019). The mutation causes impairments in expressive language functions (Clarkson et al., 2017; Marschik, et al., 2012), fine motor skills (Kaufmann, Percy, Clarke, Leonard, Naidu, 2017), and ambulation (Hallemans, et al. 2019). The hallmark feature of Rett syndrome is the presence of repetitive hand-washing, hand-wringing, and hand-mouthing behavior (Kerr, Montage, & Stephenson, 1987; Stallworth et al., 2019; Matson, Dempsey, & Wilkins, 2008) which profoundly hinders many individuals with Rett syndrome to manipulate and explore objects using their hands. The gross motor skills of individuals with Rett syndrome vary according to the type of mutation, age, and comorbid conditions, such as progressive scoliosis, bradykinesia, and neurological impairments (Downs et al., 2016). Rett

Syndrome occurs almost exclusively in female births (1:10.000-15.000) and the population is heterogeneous (see Coleman 1988; Lazuardi et al, 1989; Herini et al., 2005; Demeter et al., 2000).

Structure of Dissertation

This dissertation is organized into five distinct chapters, each contributing to a comprehensive exploration of the entanglement phenomena within the context of disability, language, and literacy. In this chapter **(Chapter 1)**, I outline the background and rationales for investigating Kalika's more-than-human literacy entanglements. Additionally, I establish crucial terms and parameters for my posthuman investigation. I argue that the existing anthropocentric perspective in disability studies perpetuates dehumanizing narratives and portrayals of individuals with disabilities in contemporary society. The epistemological shift toward the entanglements marks the beginning of a reconsideration of boundaries between humans and non-humans, persons and non-persons, independence and dependence.

Chapter 2 of this dissertation delves into my theoretical framework and a review of pertinent literature on critical posthumanism intersecting with the study of disability, literacy, and AAC. This section discusses critical posthumanism as the philosophical lens I adopt to explore the entanglement phenomenon and the posthuman turn in literacy. Employing diffractive reading (Barad, 2007), I also review the literature on the current subjecthood of individuals with disabilities from various disciplines, including anthropology, history, critical disability studies, education, and philosophy. A central argument emphasized in this chapter is that disability studies and investigations involving individuals with disabilities have been significantly shaped by the Vitruvian model of 'human.' Such anthropocentric gaze overlooks the long-standing

interconnectedness of individuals with disabilities with other humans and non-human elements in their environments, including during their processes of being, doing, and becoming literacy.

Chapter 3 elucidates the research methodology, methods, and procedures I employed to shed light on the entanglement of human and non-human elements during Kalika's literacy activities at home. This chapter also encompasses participant and setting descriptions, data sources, along with the mode of thinking I adopted in this dissertation to support my posthuman investigation, i.e., diagrammatical thinking. Relevant supplementary documents mentioned in this chapter, such as the prompts for interviews and focus group discussions with all human participants, are available in the List of Appendices.

Chapter 4 details the results of my exploration into the entanglement of human and non-human elements in Kalika's literacy practices with her babysitter (Sofia), parent (Baba), and literacy specialist (Sally). In this section, I specifically focus on addressing the first research question and elaborating on three major themes of entanglement observed during Kalika's literacy activities at home. These themes are addressed in distinct sections: *Part I: Thinking with Space and Its Intra-Acting Actants*, *Part II: Thinking with Actants in Complex Communication Repertoires*, and *Part III: Thinking with the Assemblages of Humans and Non-Human Elements in Literacy.* Each section commences with a reconstructed narrative drawn from my observations, field notes, and interview and focus group discussions with my participants, followed by discussions of the findings.

Chapter 5 provides discussions, conclusions, and directions for future research. It wraps up my exploration of more-than-human literacy entanglements in a significant disability context and also discusses the larger implications of these entanglements for inclusive language and literacy education practices in the home and beyond.

CHAPTER 2

LITERATURE REVIEW

> Humanity is neither an essence nor an end, but a continuous and precarious process of becoming human, a process that entails the inescapable recognition that our humanity is on loan from others, to precisely the extent that we acknowledge it in them.
>
> (Davies, 1997, p. 132).

This chapter explains my philosophical entry points into the investigation of the entanglements of humans and non-human elements in the literacy of an individual with significant disabilities. It presents the results of my diffractive reading (Barad, 2007) on individuals with disabilities from the fields of philosophy, history, language and literacy education, and assistive technology. This chapter is divided into four sections, namely *Posthumanism, Posthuman Turn in Literacy, Posthuman Disability,* and *Implications of Anthropocentrism in Education.* The first section explicates the philosophical lens I adopted in this study and explains some key principles in posthumanism, namely the agency or vitality of human and non-human actants as well as the interconnectedness or entanglement of the actants. Following this, I offer a literature review on the posthuman turn in literacy and the ways humans and non-human elements are entangled in literacy. The third section of this chapter lays out a historical trace of individuals with disabilities across different geographies and the ways their bodies have been perceived as aberrant due to the dominance of humanism. This section aims to support my earlier claims on the importance of turning into human and non-human entanglements in disability explorations or also known as posthuman disability studies. Finally,

the last section covers the implications of humanism, also known as anthropocentrism, in education.

Posthumanism

The Demise of Human

Posthumanism represents a philosophical perspective that underscores the entanglements between human and non-human life. This epistemological, ontological, and ethical shift "signal[s] the crucial recognition that nonhumans play an important role in natural cultural practices, including everyday social practices, scientific practices, and practices that do not include humans" (Barad, 2007, p. 32). While sharing overlapping histories, principles, and entry points with other 'after-human' philosophies that challenge the anthropocentric perspective of humans, such as animal studies (Wolfe, 2003), new materialism (Coole & Frost, 2010), and political ecology (Bennett, 2010), posthumanism stands out for its unique focus on the posthuman 'subject' and its rejection of humanist philosophies of subjectivity (Braidotti, 2013a). This philosophy draws inspiration from post-structuralists, the anti-universalism of feminism, anti-colonial phenomenology, as well as ecology and environmentalism. Braidotti (2013) contends that these critical perspectives share a "sustained commitment to working out the implications of posthumanism for our shared understandings of the human subject and of humanity as a whole" (p. 46).

In general, posthumanism encompasses both a philosophical ontology and a novel conceptualization of the human subject (Nayar, 2014). As an onto-epistemological condition, it explores the phenomena of hybridized life forms involving both human and non-human entities. According to Barad (2007), it represents "an approach that understands humans as part of nature and practices of knowing as natural processes of engagement with and as part of the world" (p.

331). The entanglements of humans, nonhumans, and the environment prompt scholars to question the existing boundaries of humanness, challenging portrayals of humans as self-determining, coherent, and superior entities in the world.

Meanwhile, as a novel conceptualization of humans, posthumanism provides scholars with a means to scrutinize the taken-for-granted understanding of humans as the primary reference point for all things in the world (Braidotti, 2013a). It involves the "radical decentering of the traditional sovereign, coherent and autonomous human to demonstrate how the human is always already evolving with, constituted by and constitutive of multiple forms of life and machines" (Nayar, 2014, p. 2). The philosophy rejects humanism's tendency to position humans as autonomous, conscious selves and the most elite elements in the world. Instead, it views humans as part of a network of connections, linkages, and entanglements with other forms of life in the world. The philosophy fundamentally opposes ableism and embraces diverse representations of human bodies and other life forms. By placing less emphasis on ability, Nayar (2014) argues that posthumanism "calls for a radical rethink of species uniqueness and the boundedness of the human" (p. 4)

Proponents of the theory contend that the traditional conception of the human within the framework of humanism embodies a Eurocentric utopia. In this anthropocentric paradigm, Europe positions itself as the all-encompassing authority and consciousness of humanity worldwide. It projects itself as the universal, value-neutral standard and idealized essence from which the legitimacy of others (both human and non-human) is expected to be derived. Such ingrained practices operate by instating a narrow Eurocentric viewpoint regarding the normative human nature, constricted to the attributes of a male, heterosexual, urban, and able-bodied 'Man,' as depicted in da Vinci's Vitruvian Man (Braidotti, 2013; Nayar, 2014). As Braidotti

(2013) contends, the conception of human in humanism is inherently 'he' – "he is white, European, handsome, and able-bodied" (p. 24)

In other words, the prevailing ideology of 'universal' humanism is, nevertheless, "a system of *differentiation*" (Nayar, 2014, p. 12, emphasis in the original) designed to rationalize acts of injustice and marginalization against those who do not meet the criteria for the 'standard' human. Eurocentrism further perpetuates its dominance as the normative orientation of humanity by stigmatizing alternative representations as aberrant, derogatory, negative, abnormal, and subhuman. Braidotti (2013) argues that this phenomenon leads to the active (re)production of binary identities and hierarchies between the human and non-human, as well as the delineation of bios- and world in our understanding of existence. In other words, the Eurocentric paradigm within existing humanistic epistemology renders certain bodies as more than others, such as "more mortal than others" (Braidotti, 2013, p. 15); more human than others; more vital than others; and more dependable than others. Posthumanism introduces a new worldview to decenter the anthropocentric ideal by appreciating the multidimensionality of being and doing for all humans and non-human entities; it seeks a more inclusive way of conceptualizing humanity and life.

The Interconnectedness of Humans and Non-Human Elements

A fundamental tenet of posthumanism is the understanding of being, often denoted as a "non-unitary subject" (Nayar, 2014, p. 8) or "monism" (Braidotti, 2013, p. 56). This perspective challenges the longstanding humanism's separation of mind-body, nature-culture, organic-mechanic, and body-object distinctions. Posthumanism rejects the notions of independence; it underscores interconnectedness and interdependencies among all and between human and non-human actants. It considers "embodiment as essential to the construction of the environment (the

world is what we perceive through our senses) in which any organic system (such as the human body) exists" (Nayar, 2014, p. 9).

At the heart of this non-unitary conception is the argument for the primacy of the non-human self-organizing vital force, or zoe. Braidotti (2013, p. 60) defines zoe as "the dynamic, self-organizing structure of life itself… that cuts across and reconnects previously segregated species, categories, and domains." It represents the force of vitality in human and non-human actants, mediating the embodied and embedded process of relations between and among these actants. Braidotti (2013) contends that zoe is not an exclusive property of humans but rather a universal aspect of matter to which both humans and other entities belong.

Braidotti's conception of zoe aligns with some principles of Bennett's (2010) vitality and Barad's (2006) agency. In her influential book 'Meeting The Universe Halfway,' Barad (2007) defines agency as the "ongoing reconfigurings of the world" (p. 141), denoting a process of change through the dynamics of 'doing' or intra-activity among interactants. Barad (2007) argues that agency is not an inherent attribute of humans or non-humans and is unrelated to intentionality or subjectivity in the humanist sense. Consequently, according to Barad (2007), agency is not a matter of choice that perpetuates subject-object duality, positioning humans above non-humans. Instead, it is an aspect of ongoing construction and deconstruction.

Understanding vitality or agency in a posthumanist sense encourages a reevaluation of our notion of 'life' from the perspective of co-dependency, mutual relationships, and interrelatedness among humans and non-human entities. Furthermore, this perspective emphasizes the philosophy's inclination toward symbiotic relations rather than competitions, dominations, and exploitations of humans over other forms of life.

Posthumanist scholars posit that all entities in the world are intelligent and immanent unto themselves. These entities possess a relational capacity to coexist in the world, mediating the fusion of the vital and the material, termed 'vitalist-materialism' (Braidotti, 2013). Some epistemological consequences of adopting this vitalist-materialism linkage in posthumanism include the demise of the traditional conception of the human as the measure of all things, the emergence of the hybridity of humans and non-human others, and the proliferation of theories that challenge the universality of Eurocentric 'man' as the orientation of humanity (e.g., postcolonial theory and feminism).

In this new paradigm, the human is understood as an entity beyond the limited conception of bios-; instead, it is "an assemblage, co-evolving with other forms of life, enmeshed with the environment and technology" (Nayar, 2011, p. 4). Furthermore, posthumanist scholars view humans and non-human elements as dynamic and nomadic entities or "subjects-in-process" (Braidotti, 2019, p. 36). Therefore, unlike humanism, subjectivity in posthumanism is not an independent, exclusive, static, and monolithic property of humans (Barad, 2007). Posthuman subjectivity is conceptualized as a dynamic and synergistic negotiation process between humans and all matters in the world; it is a situated and grounded collective process of becoming, a continuum of the relational nature and culture intra-action (Barad, 2007). For Braidotti (2013), a posthuman subject is "a relational subject constituted in and by multiplicity, that is to say a subject that works across differences and is also internally differentiated" (p. 49). This ecological view of becoming rejects the long-established unitary conception of individualism in humanism, where the human is thought to be the static and sole intelligent self-governing entity of the planet.

The zoe-centric worldview in posthumanism provides a valuable avenue for scholars to delve into the bonding of humans with tools/technology beyond the linear functionalism of the machine to humans (i.e., the benefits of the machine to humans). The shift to interconnection or entanglement and the demise of the traditional conception of human epistemologically destabilize the unequal relationship of humans with machines and enable scholars to investigate new modes of subjectivity resulting from the interconnection between humans and technology. This phenomenon, also known as 'becoming machine' in Deleuze and Guattari's (1983) works, reimagines humans as bio-technologically mediated subjects or "figures of mixity" (Braidotti, 2013a, p. 97) or "dynamic hybrids" (Jöns, 2006, p. 559) supported by the non-hierarchical vitality of humans and machines.

As Deleuze and Guattari (1983) argued, "not man as the king of creation, but rather as the being who is in intimate contact with the profound life of all forms or all types of beings…" (p. 4). In this new paradigm, machines and the environment are no longer perceived as subordinate entities to humans, and the conception of humanity itself transcends purely biological boundaries. This understanding of subjectivity as an assemblage aligns with Braidotti's (2013a) argument: in the exchange of relational power between humans and technology, technology "both captures and processes forces and energies, facilitating interrelations, multiple connections, and assemblages. They stand for radical relationality and delight as well as productivity" (p. 92). In other words, their entanglement is not driven by either one's needs or lacks but by the equilibrium of relational space created by the assemblage itself (Deleuze & Guattari, 1983). Therefore, non-human elements are not understood as imitations or metaphors for particular human capacities; posthuman scholars believe that in the assemblage of humans and non-humans, non-human entities carry their own political effects that work in mutual

interdependence or alliance with humans in creating symbiotic human and non-human fusion or hybrid.

The Entanglements of Individuals with Disabilities with Non-Human Elements

Multiple studies in the fields of critical disability studies, AAC, and phenomenology have demonstrated the imbrication of individuals with disabilities with their assistive technology. In the field of AAC, for example, McCord and Soto (2004) reported that one of their participants described the tool as "my talker" (p. 216). Another participant in the same study was also observed to smile and hug the tool when asked about the benefits of the tool for her. Similar responses were noted in Sigafoos et al. (2004), where a participant smiled and giggled when teachers searched for their aided AAC tool. Participants in Clarke et al. (2001) expressed a desire for a more personalized tool, mentioning that they would like to have a design and a voice that were unique to them. In other studies, researchers also reported ambivalent relationships that individuals experience with their devices. In McCall et al. (1997) and McCord and Soto (2004), for instance, individuals commented that their devices were confusing, slow, uncool, boring, too difficult, too heavy, 'look stupid', and embarrassing.

The bonding between individuals and assistive technology has indeed been explored by scholars in various fields, including phenomenology and posthumanism. Merleau-Ponty (2012), in his seminal work 'Phenomenology of Perception,' illustrated the embodiment process of subjects and objects by describing how a walking cane becomes an integral part of an individual with visual impairment. He argued that "the cane's furthest point is transformed into a sensitive zone, it increases the scope and the radius of the act of touching and has become analogous to a gaze" (Merleau-Ponty, 2012, p. 144). Similarly, for wheelchair users, Papadimitrou (2008) described the embodiment process of the wheelchair with the body as 'en-wheeled', i.e., "a

comfortable style in and through which the chair is experienced as an extension and integral part of the lived body" (Papadimitrou, 2008, p. 699). A similar conclusion was also drawn by Gibson et al. (2012), who argued that for wheelchair users, their walking aids are an integral part of their body: a wheelchair user "is not 'in' her chair nor does she 'use' her chair, rather she is her chair, but sometimes she isn't" (Gibson et al., 2012, p. 1896). Such a process of object embodiment has also been investigated by researchers across different disciplines. In the fields of cognitive sciences and experimental psychology, Iriki et al. (1996) and Maravita (2004) explored the human relationship with tools in their environment, such as forks, clothes, and rakes. They found that humans have the plasticity of body representation in the brain (body schema) that can help them treat external tools as part of their body.

Posthuman Turn in Literacy

The posthuman turn in literacy wrestles with the long-standing human-centric gaze in literacy. The turn highlights the mutually constitutive relationship of humans with non-humans to interrogate the ontology, epistemology, and axiology of the existing conception of 'literacy' that has privileged certain ways of knowing, doing, and becoming literacies (see Kuby et al., 2019). In literacy education research, specifically, this turn gives rise to new philosophical and methodological approaches for exploring literacy pedagogy beyond the traditional human-to-human relational perspective, such as teacher-student or adult-novice interaction. It aims to shed light on the significant involvement of non-humans (such as the internet, computers, artificial intelligence, books, stickers, buildings, and sounds) and their entanglement with humans in the processes of teaching, learning, and experiencing literacy within educational spaces. Consequently, this shift mediates changes in the current constructs of literacy engagement which have long upheld the notion of an autonomous biological self and independence. Within this

paradigm, a learner of literacy is (re)conceptualized as a dynamic assemblage of human and non-human forces with the capacities not only to make sense of a text but also to relate, produce, and reconfigure the text itself. This (re)orientation of the subjecthood of the learner calls for a (re)investigation of what qualifies as literacy, literacy engagement, literacy goals and trajectory, and the evaluation/assessment of literacy (Kuby et al., 2019).

While there is limited but growing scholarship in posthuman literacy, several scholars have paved the way for investigating human-non-human monism in literacy. Schulte (2019), for instance, illustrated how the untimely death of a bird became a narrative site for the children of a small preschool in central Sweden. By thinking and listening with the materials, namely the dead bird, the children in Schulte (2019) engaged in discussions and speculations about life, death, and the bird's potential before finding it lying motionless at the playground. Schulte (2019) argued that “posthumanism and its potential literacies in early childhood are, more than anything else, about creating a sense of hope and buoyancy for the other” (p. 79).

Another study by Harwood and Collier (2017) explored the entanglement of children with sticks in the forest, describing the agentive power of the stick to co-shape meanings and literacies with the children. As the authors argued, the stick was not a passive element in human and non-human entanglement; its affordances invited the children to act and react in certain ways. For the children, the sticks served as “weapons, magic helpers, seatbelts, boundary markers, art representations, ladders, tools to write and draw with, and much more. The stick was also a friend, carried and cared for by the child” (Harwood & Collier, 2017, p. 344).

Lastly, MacRae (2020) examined the hand movements of young children as they played with toys in the sand tray. The posthuman analysis of hand movements highlighted the ways the children, toys, and sand were bound and reciprocal to each other’s forces. MacRae (2020) argued

that when the hands and the toys were in contact, they were influencing each other: “As hands touch things, they are animated by what they touch, and simultaneously things are animated through the give and take of pulls and pushes of desire expressed as kinetic force” (p. 90). MacRae (2020) concluded that attending to the hand movements of children and their entanglement with the environment offers scholars new ways of reconceptualizing early literacy beyond the limited conception of verbal language.

Posthuman Disability Studies

Centuries of Othering and Dehumanization of Bodies with Disabilities

The subjecthood of individuals with disabilities has long suffered degradation through practices of dehumanization and othering. In European history, the subtle exclusion of individuals with disabilities from the spectrum of humanness is evident in numerous ancient Greek and Roman poems, plays, folklore, mythology, paintings, and statues, where individuals with disabilities (e.g., progeria and Cockayne Syndrome Type II) were portrayed as inhumane entities – freaks, oddities, beasts, or creatures with magical powers (Felton, 2012a). The Roman Empire, in particular, was notorious for its horrific treatment of individuals with disabilities. Not only were individuals with disabilities referred to as ‘monstrum’ by the Romans (Capewell et al., 2015), but they also established the teraton agora (monstrosities market), where individuals with disabilities were materialized and commodified as collectible items, objects of amusement, and slaves (Barton, 1995). Similarly, infanticide for children with disabilities was commonly practiced by Spartans, who reportedly screened infants and left those deemed weak and deformed “exposed to the elements and left to die” (Barnes, 2018, p. 52).

Such practices of dehumanization of individuals with disabilities continued and transformed into multiple ideologies, assumptions, policies, and practices in later centuries. This

includes Francis Galton's (1883) Eugenics, the establishment of disability asylums (see Segrest, 2020), the Nazi Aktion T4 euthanasia program that murdered almost 300,000 people with disabilities in 1939-1941, and the ongoing systematic exclusion of individuals with disabilities from mainstream classrooms in the U.S., UK, Australia, and other global regions.

Similar to the construction of whiteness ideology (see Batchelor, 2000), the latent (re)production of disability ideology is not a naturally occurring phenomenon. The enactment of the 'standard' or 'desired' quality of body took sustaining collective acts of fetishization of certain types of bodies and relegation of other types of bodies to the background. In this paradigm, neurotypical bodies are set as a value-neutral standard to discern the human versus the non-human others. This particular case can be seen in the transformation of disability labels, which suggests not only a genealogy of disability but also the subtle practice of othering individuals with disabilities. The analysis of labels across different languages is useful because languages not only represent the speakers' mental structure but also reflect certain ideologies, beliefs, values, and the history of the phenomena being described. The term 'intellectual disability' in U.S. English, for example, has changed from natural fool in the medieval age to 'feeblemindedness', 'idiotism', 'imbecility', 'fatuity', 'simple-mindedness', 'mental defect', 'mental retardation', 'mental deficiency', 'mental handicap', 'mental subnormality', 'developmental delay', 'developmental disability', 'cognitive delay', 'cognitive impairment', 'learning disability', 'intellectual impairment', and 'intellectual disability' in the last 60 years (see Berkson, 2006; Metzler, 2016).

Similarly, in Indonesian language, the terminology of 'disability' has evolved from 'cacat' (defect) to 'difabel' (differently abled) in the last eight decades. Suharto et al. (2016) argued that these changes of terminology were influenced by the socio-political gravity and

reform in Indonesia. During the New Order Era (1966-1998), for example, the term ‘cacat’ was euphemized to ‘tuna-‘ (which literally means ‘without,’ ‘loss,’ ‘lack of’) as the cabinet of Indonesian government was dominated by Central Javanese people who were famed for their culture of subtlety and modesty (Suharto et al., 2016). Since then (i.e., the Reformation Era [1998-present]), Indonesian people have used various terms to describe individuals with disabilities as the country has become more open, democratic, and liberal to globalization and other cultures outside Indonesia. Some of the words that are currently used by Indonesian people to describe individuals with disabilities are ‘tuna-,’ ‘penyandang disabilitas’ (individuals with disabilities), ‘orang berkebutuhan khusus’ (individuals with special needs), and ‘kaum difabel’ (differently abled people) (Suharto et al., 2016).

Titchkosky (2011) argued that these terms and their changes “represent concepts used to notice and orient self and other” (p. 5); the terms work not only as a label for certain individuals, but also to perceive and make sense of their bodies. While the act of (re)naming the disability phenomena might signify the changes in values and social attitudes of the people, the multiplicity and fluidity of the labels also suggest a conceptual grapple that the society has struggled for decades to make sense of the disability phenomenon (Suharto et al., 2016). Furthermore, it is also worth noting that all the labels of disability in both languages (English and Indonesian language) have gravitated toward the impression of brokenness, deficiency, inferiority, and subordination of the disability population from the able bodies.

In many parts of the world, such as India (e.g., Saini & Kapoor, 2020; Edwaraj et al., 2010), Indonesia (e.g., Riany et al., 2016), Kenya (Bunning et al., 2017), and Korea (e.g., Hwang & Charnley, 2010), the practices of othering individuals with disabilities are evident in how people perceive the phenomenon of disability. In Indonesia, perceptions of disability are deeply

influenced not only by political power but also by religious, educational, and cultural backgrounds. The Javanese people of Indonesia are particularly cautious about the genealogical line of a person, as reflected in their principles of ‘bibit,’ ‘bobot,’ and ‘bebet’ when finding a spouse or a community leader.

‘Bibit,’ which literally means ‘the seeds’ in Javanese and Indonesian languages, is the first criterion for an ‘ideal’ person in society. It refers to the lineage of descent or origin, including the family’s genetics, health history, disability, and deeds in the past. The importance of ‘bibit’ or origin in Javanese people’s lives is also reflected in many of their proverbs and wisdom, such as “Ngelingana bibit kawite, ngelingana tembe mburine,” which means “remember your/the origin, and remember the consequence it entails.” ‘Bobot,’ or ‘intellectual weight,’ refers to the background of education, profession, and level of expertise in religion. Meanwhile, ‘bebet’ comes from the Javanese word ‘bebedan,’ which means ‘to wear a long batik cloth from the hip to ankle.’ The interpretations of ‘bebet’ in society include the persistence and tenacity of a person, as well as their dignity, prosperity, and appearance.

The triad of ‘bibit,’ ‘bobot,’ and ‘bebet’ is used by society to evaluate available candidates and select the one they deem the most ‘ideal’ person. In this context, disability is perceived as a marked phenomenon; its presence in one’s ‘bibit’ evokes lack, pity, fear, and hesitation in society regarding the person’s legitimacy as a human and their ability to have roles in society and family. Moreover, their ‘bobot’ and ‘bebet’ are also affected by the prolonged exclusion of individuals with disabilities from mainstream classrooms (Widayanti & Fletcher, 2022) and discriminatory practices in workplaces (Lessy et al., 2021).

Some professionals (medical practitioners, teachers, and religious leaders) in Handoyo et al. (2021), for example, expressed fear and hesitation about endorsing marriage and/or

parenthood for individuals with intellectual disabilities due to concerns about the possibility of passing down the disability to future generations. In fact, 'not being able to marry' was the most frequently reported type of discrimination by persons with leprosy-related disabilities in van Brakel et al., (2012). These individuals often end up marrying another person with a disability because non-disabled individuals are afraid of having descendants with disabilities.

In addition to being perceived as a 'monstrum,' an inheritable sickness, or disease, people around the world also conceptualize disability as a destiny or life test from God. Some parents and communities in Israel (Nov-Klaiman et al., 2022), Pakistan (Mirza et al., 2009), Jordan (Alqatarneh et al., 2022), and Tanzania (see Stone-MacDonald, 2012) view disability as God's will. The people of Lushoto in Tanzania, in particular, describe disability as part of God's plan, where children are seen as "fulfilling a role for God" (Stone-MacDonald, 2012, p. 404). Meanwhile, some parents in Israel (Nov-Klaiman et al., 2022) and Jordan (Alqatarneh et al., 2022) express that having children with disabilities is a form of a faith test from God and an integral part of the Almighty's plan that they cannot avoid. Similarly, Indonesian parents in Tucker (2013) also express that their children's disability is an ordeal or a lesson from God that they must accept. People in these countries tend to view disability as a means to become spiritually closer to their God and deepen their understanding of patience, sincerity, and compassion toward other human beings.

Additionally, disability is commonly attributed to supernatural causes and past lives. In many countries in Asia, people associate disability with bad karma, curses, and sins resulting from the wrongdoings of parents during pregnancy (e.g., engaging in criminal activities, gambling, killing sacred animals), misdeeds of the family in the past, and disrespectfulness of

parents toward their own parents or the elderly (Riany et al., 2016; Tucker, 2013; Handoyo et al., 2021).

For instance, Indonesians' understanding of disability as karma can be traced back to some classic stories in their Javanese shadow puppet tradition called Wayang. Wayang is a traditional form of storytelling primarily used to disseminate orders of rulers to society, spread Javanese wisdom, and convey teachings of Hinduism and Islam from the 5th to 15th centuries. Three popular Wayang characters described with physical disabilities are Drestarastra (blind), Pandu (albino and torticollis), and Widura (anisomelia) in the story of Mahabharata. All of their disabilities are portrayed as a result of the curse from the 'ajian' (magical power) that their father (Prabu Kresna Dwipayana, also known as Abiyasa) received from his predecessor and the misdeeds of their mothers.

In some regions in other culturally diverse countries, such as India (Saini & Kapoor, 2020) and Kenya (Barbareschi et al., 2021), people also associate disability with ancestral karma or witchcraft curses. In Kenya, it is believed that certain types of disability, such as intellectual disability and blindness, are caused by the jealousy and hatred of someone who cast a spell with the help of a witch. Some participants in Barbareschi et al. (2021) even expressed fears of assisting individuals with disabilities because they assumed that the curse might be "somehow passed on" (p. 7) to them. Similarly, in some parts of India, disability is also perceived as a curse or an outcome of wrongdoing committed by parents or ancestors in the past (Benjamin-Thomas, 2022; Saini & Kapoor, 2020). For instance, a majority of mothers in Vellore, South India, perceived intellectual disability to be caused by consanguineous marriage (Edwardraj et al., 2010).

Disability as a Quasi-'Human' Phenomenon

Rose (2003) suggested that the understanding of disability in the past is part of our present consciousness about the phenomenon. The long tradition of othering individuals with disabilities in many of the world's cultures has resulted in the existing dehumanizing practices toward individuals with disabilities and the metacognitive struggle of our contemporary society with the phenomenon of disability. From folklore and classic scriptures written in the 5th century BCE to contemporary movies and films, individuals with disabilities have been characterized as either sub-humans or super-humans (hereafter the semi-humans).

As sub-humans, they have been abysmally constructed as sick, tragic, diseased, mischievous, villainous, and threats to society. This portrayal is particularly evident in major canonical English literature, such as 'Moby Dick' (Melville, 1851) and Shakespeare's 'Richard III' (1592-1594), where individuals with hearing loss, arthritis, cataracts, muscle atrophy, and short stature were described as treacherous, warped, ruthless, disgusting, and evil creatures (see Margolis & Shapiro, 1987). The people of India are also noted to have some classic scriptures featuring disabled characters who have long been falsely portrayed as evil and villainous. Manthara, for example, is a maidservant of Queen Kaikeyi in the epic of Ramayana, which is also famous in other countries, including Indonesia. She is described as the hunchbacked villain due to her role in perpetuating the exile of Lord Rama, an incarnation of Vishnu, the God of protection in Hinduism. Verma (2021) argued that the malicious portrayals of disabled characters in classic Indian scriptures have been "unidimensional, sexist, and one that caters to the upper-class male gaze and patriarchal worldview" (n. p); the villainy perspective has subtly promoted stigma, biases, and prejudice toward disability, especially female Indians with disabilities.

On the other hand, individuals with disabilities have also been portrayed as powerful and magical entities. Roman patricians and emperors, for example, were avid collectors of individuals with congenital disorders. Garland (1995) reported that persons with short stature, ostrich heads, and three eyes had been treated as the "ideal companions and confidants" (p. 49) of the Roman emperors, just like some sacred animals (cats and lions) for the Egyptian pharaohs (Felton 2012b). Similarly, in Indonesian wayang, some characters with disabilities are also portrayed as trustworthy, helpful, patient, and wise figures. Gareng, for example, has strabismus (cross eyes), short stature, and limping legs; he is noted as one of the most loyal servants of the Pandawa, i.e., the five knights in Kakawin Bhāratayuddha, an Old Javanese poetical rendering of the Indian epic of Mahabharata. In Javanese culture, Gareng symbolizes honesty, humility, and wisdom. Some individuals with disabilities, especially those with short stature, albino, and limping legs, also have a special status in past and present Javanese kingdoms due to their wisdom and the assumed magical power they have (Sunarto, 2012).

The Sultanate of Yogyakarta (1755-present) and the Sunanate of Surakarta (1745-present), for example, regard select individuals with disabilities as Abdi Dalem Palawija*,* i.e., the loyal servants and companions of the Sultan. Their special status in the sultanate and the sunanate can be seen from the many royal traditions and ceremonies, such as the crowning of the Sultan and Sunan where Abdi Dalem Palawija (e.g., short stature, albino, limping legs) walked preceding the royal dancers, princes and princesses, the Sultan or the Sunan, and the royal consorts as well as the commemoration of the Prophet Muhammad, SAW. In the past, the Sultan and the Sunan also dedicated a special housing area called Palawijan around their Keraton (the palace) and houses of the royals for individuals with disabilities and their families who served as Abdi Dalem.

In recent times, individuals with disabilities continue to be portrayed both as the threat and the heroes in popular films, graphic novels, comic books, newspapers, and advertisements. Studies by Conn and Bhugra (2013) and Goldstein and Tessa (2021), for example, found that depictions of individuals with autism spectrum disorder in major American movies and TV shows range from being freaks, childlike persons, and mentally ill figures to savants, healers, gods, and heroes. The semi-humanness of individuals with disabilities is also seen in newspaper reports and advertisements (Ismail et al., 2022) as well as in popular blockbuster movies, such as 'Iron Man,' 'Star Wars,' and 'Captain America' (see Fahn, 2020; Tankard, 2022; Shaholli, 2022), where individuals with disabilities were represented as humanoid figures that reflect both peculiarity and inspirational imagery of the individuals.

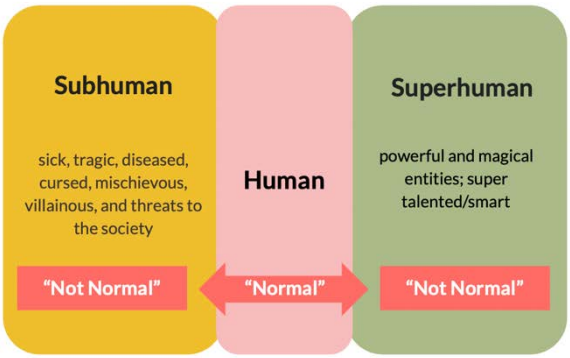

Figure 1. Spectrum of Humaness of Individuals with Disabilities

In other contexts, such as in the Arab world (Al-Zoubi & Al-Zoubi, 2022) and Asia (e.g., Diffrient, 2017), the same phenomena of semi-humanness of disability are also found in the many local productions of movies, films, and books. McRuer (2018) argued that such attempts to render the inspirational imagery of disability or "cripspiration" (p. 58) is a manifestation of austerity of representation. He posited that cripspiration sought to shift the pathological disability image by capitalizing and promulgating some 'inspirational' narratives of individuals with disabilities (or the supercrip) who successfully overcome their struggles and hardships of

disability. This phenomenon stands in direct opposition to the social model of disability that conceptualizes disability as a dynamic and relational phenomenon. Through cripspiration, disability is projected as a monolithic personal obstacle where the onus to conquer the challenge is on each individual with a disability, not the society nor the broken social justice system of the society (McRuer, 2018).

In the current neoliberal capitalist world, individuals with disabilities are considered both as a menace and a benefit to society. They are conditioned to be the "undefined, ambiguous people" (Murphy, 1990, p. 131) who are neither dead nor fully alive, sick nor well, out of nor within the society, to-be-looked-at and not-to-be-looked-at (see Murphy, 1990; Garland-Thomson, 2002; Erevelles, 2011). While they are deemed to be a threat and parasite to society due to their lack of economic productivity (Barnes, 2018), they are also an invaluable resource for biotechnological and medical breakthroughs and a profitable business market for capitalism. The development of access technology for individuals with disabilities (e.g., AAC, prosthetic limbs, and hearing aids), for example, is one of the largest burgeoning industries in the world where disability phenomenon is at the epicenter of the interdisciplinary research and product innovations (see Lee, 2016; Fahn, 2020). Puar (2017) described such social phenomena as 'maimed' where disability is purposefully maintained in a state of suspension or debilitation by foreclosing them from the social, cultural, and political access for the capital profit of able bodies. Indeed, as Albrecht (1976 in Barnes, 2018) argued, disability is essentially also a business – it is a direct outcome of a capitalistic system of economy that views the body from its use/productivity value. This ideology results in the stigmatization of diverse bodily conditions and the commercialization of rehabilitation and disability.

Visual representations of disability in the mainstream media and arts have been powerful in the inculcation of disability as the non-human others in our deeply visually oriented society. Foucault (1980) argued that vision is a surreptitious and subtle form of power. He described seeing (or the gaze) as an interiorized system that "has had great importance among the techniques of power" (Foucault, 1980, p. 155), "it records and totalizes; it gradually reconstitutes immanent organization" (Foucault, 1973, p. 121). The act of seeing becomes an important modality of body surveillance whose end goal is to make everybody docile and become overseers of their own bodies. The powerful role of vision, i.e., the act of seeing and the established visual culture and orientation, makes the politics of body representation in public discourse salient. This influence is evident in the practice of marking bodies and defining personhood within a society. The well-established narratives and practices of semi-humanization of individuals with disabilities through vision modality in our society have insidiously catapulted disability phenomena as an "outlaw ontology" (Wrigley, 1996, p. 95), a conundrum that outlaws the existing conception of 'normality' of bodies.

The history of disability is in part a history of visual display within the able-body world (Garland-Thomson, 2002). Since centuries ago, the phenomenon of disability has been constantly conceptualized as a visual reminder for able-bodied persons on how persons at the border of humanness look like – their bodies are marked as semi-humans; they are monsters, heroes, and hybrids; they encapsulate the physical and metaphysical tragedy, failure, suffering, vulnerability, pity, laughter, terror as well as the adulation, inspiration, amazement, and admiration (Garland-Thomson, 2002). Their very existence and lived experiences are extraordinary to the gaze of the ableist world; their bodies are conspicuous, but they are visually aberrant as they do not conform to the standard notion of how the human body is 'supposed' to

look. Therefore, the semi-humanness of disability functions as a borderline "to preserve and validate such privileged designations as beautiful, healthy, normal, fit, competent, intelligent – all of which provide cultural capital to those who can claim such status, who can reside within these subject positions" (Garland-Thomson, 2002, p. 74-75). Such acts of rendering the bodies of individuals with disabilities at the border of humanness have resulted in many dehumanizing and unequal treatments towards individuals with disabilities, including their erasure of rights to live (see Alford [2021] on how Peter Singer, a renowned Princeton bioethicist and philosopher, advocated the elimination of fetal or newborn life with intellectual disability as one of the ways to alleviate global poverty) as well as their ongoing barriers to accessing the quality health care, public service, and general classroom. In the following section, I will explore the practice of othering of individuals with disabilities in education.

Implications of Anthropocentrism in Education

Individuals with disabilities face the longest and most arduous road to quality education. A report on disability gaps in educational attainment and literacy from the World Bank and the Global Partnership for Education (2017) reveals that students with disabilities are being left behind by global efforts to improve education opportunities for all. Their analysis shows that children with disabilities in 19 developing countries are less likely to be enrolled in school than nondisabled children. They also found that the primary school and secondary school completion rates for students with disabilities in those countries are just about 48% and 33%, respectively.

In Indonesia, students with disabilities face significant challenges in their pursuit of inclusive and quality education. Historically, these students have been confined to special schools. As of 2021, The Ministry of Education and Culture (Kemdikbud) reported the existence of 2,250 Sekolah Luar Biasa (special schools) with 144,621 students identified with disabilities

attending primary to senior high schools. Further, the Ministry of National Development Planning (Bapennas) (2021) further reported that 27.74% of individuals with disabilities in Indonesia did not finish elementary school; 13.02% of the population never go to school; and only 5.12% of individuals with disabilities in Indonesia attended college.

In developed countries such as the U.S., U.K., and Australia, students with disability were also at a higher risk of dropping out and losing instructions. A study by Losen et al., (2021), for example, found that students with disability across all grades in the U.S. lost twice the instructional days due to suspensions than nondisabled students. In the U.K., the rate of school expulsion of students with disability was six times higher than nondisabled students during the 2017-2018 school year; and this trend has steadily risen in recent years (see Daniels et al., 2019; Department for Education, 2018; Martin-Denham, 2020). Meanwhile, in the state of New South Wales Australia, 40% of the students receiving school suspension and exclusion in 2019 were students with disability (Baker, 2019); and the vast majority of students enrolled in flexible learning programs (FLPs), i.e., a government program for students who are considered to be disengaged in the general education classroom, across all states in Australia are students with disability (Thomas & Rayner, 2021).

Students of color with disability have the highest risk of exclusion through school suspension and expulsion. In the U.S., Black students have consistently made up the largest population served under the Individuals with Disabilities Education Act (IDEA) for various types of disability, especially emotional disturbance, intellectual disability, developmental delay, and specific learning disability for decades (Sullivan & Bal, 2013; Skiba et al., 2005). They are "three times as likely to be labeled mentally retarded, two times as likely to be labeled emotionally disturbed, and one and a half times as likely to be labeled learning disabled,

compared to their white peers" (Parish, 2002 in Annamma et al., 2013, p. 3). Research by Robinson and Norton (2019) also found that Black students are disproportionately represented in 75% of the states for the speech or language impairments category each year. Together with Hispanic, American Indian/Alaska Native, Asian, and Two or More Races populations, Black students consistently make up the biggest body of students who are labeled with disability and receive out-of-school suspension, in-school suspension, referral to law enforcement, expulsion, corporal punishment, and school-related arrest (see Connor et al., 2016; U.S. Department of Education, 2018; Yu et al., 2021). Fenning and Johnson (2022) expressed that the disparities of exclusion of students with disability and those of color from the general education classroom in the U.S. were consistently found across two different generations, from the 1972-1973 school year to the 2017-2018 school year, regardless of the existence of federal laws that regulate education for individuals with disabilities (e.g., Section 504 of the Rehabilitation Act of 1973 and IDEA).

The nexus of disability and semi-humanness in education is present in the ways schools discipline and segregate diverse bio-physical conditions from the general education classroom. Through covert Eugenic practices, schools sort, classify, and examine students' bodies, and make sure that the diverse bodily representations of students conform to the adopted 'standards' of look, behavior, and intelligence or they are eliminated. The Eugenics principles manifest in some existing schooling practices, including the use of standardized testing (e.g., IQ test and behavior assessment), the administration of a one-size-fits-all curriculum and learning approach, the implementation of suspension and exclusion of individuals with disabilities, the longstanding underfunding of IDEA, the overly used Euro-American canon and the lack of textbooks that represent individuals with disabilities and persons of color, the coercive implementation of zero-

tolerance approach, as well as the development of inaccessible educational buildings (see Skiba & Williams, 2014; Baker, 2017; Titchkosky, 2011).

In the previous decades, pervasive Eugenic practices were exercised overtly by the government or the monarch to proliferate the ambit of 'standard' human beings and engineer the uniformed human bodies, e.g., the Nazi Aktion T4 euthanasia program (Campbell, 2000). Nowadays, however, the ruler or the government plays "a less direct and de-centered role in the governing of 'disability'" (Campbell, 2000, p. 308) and the elimination of disruptions entailed from its existence. The gatekeepers of education are now the educational institutions themselves and the standard operations they implement, which include the insidious assessments and quality control practices administered by the school administrators, teachers, and special educators to assess and diagnose any potential challenges that students with 'anomalous' bodies might pose to the general classroom. In this paradigm, surveillance over bodies at the border of humanness is non-consciously at work. Everyone acts as their own overseer; they police each other's bodies and value their bodily representations based on the adopted standards of corporeal 'fitness' within the community.

This phenomenon resonates with Foucault's conception of power through his renowned panopticon analogy. Foucault (1980) argued that "in the Panopticon each person, depending on his place, is watched by all or certain of the others" (p. 158). He continued that the most effective and efficient system of surveillance and disciplining bodies requires neither physical violence nor material constraints – it instead only requires "an inspecting gaze, a gaze which each individual under its weight will end by interiorizing to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself" (p. 155). This panoptic surveillance system constitutes schools as an extension of government surveillance where the

socialization of norms and values of the dominant community is enforced and the dissonance from the standards is eradicated. The use of this system conceals the deeply ingrained institutional ableism in schools, and instead highlights the anomalous being and doing as a menace to combat. Foucault named this form of scrutiny as the 'pedagogization of children' (Foucault, 1981).

In such a vicious system of surveillance, families are often situated as the morality judge of their own decision to either allow their children to be excluded from the general classroom (partially or fully; temporary or permanently) or 'insist' on having their children being the "detractors" (Baker, 2017, p. 148) in the general education classroom. Such deceitful autonomy of choice is often nebulous yet life-changing for the family and the students with disability. Parents, especially those of culturally and linguistically diverse backgrounds, are often unaware of their rights, legal resources, and the long-term consequences that entail from the choices they make to their children's lives. Among the Latinx family (i.e., the largest ethnic minority group in the U.S.), for example, Bravo-Ruiz and Flynn (2022) argued that the families' lack of knowledge on the U.S. special education system leads to the disempowerment of parents to advocate for their children's rights to inclusive education. While participation of the family in the Individualized Education Program (IEP) development process is legally mandated by IDEA, many of the culturally and linguistically diverse families reported that they were baffled by the legal and scientific jargon and received little to no support from the schools regarding the resources of special education (Larios & Zetlin, 2022). Multiple studies on the parents' satisfaction with the IEP process have also consistently shown high levels of stress, frustration, and dissatisfaction among culturally and linguistically diverse families (see Fish, 2008; Zeitlin & Curcic, 2014; Rossetti et al., 2021). This dissatisfaction has resulted in a continuous decrease in

the family's participation in the special education process throughout the decades (Fish, 2008; Salas, 2004).

Years of research have continuously highlighted the detrimental effects of school suspension and exclusion on the mental health, identity development, and prolonged educational attainment of students with disability. Goldman-Mellor et al. (2016) and Martin-Denham (2020), for example, argued that suspension and exclusion of students with disability significantly impact their educational outcomes and pose severe implications for their transitions to adulthood. A study by Christle et al (2007) also found a positive relationship between the rates of school suspension and exclusion and school dropouts. Cholewa et al (2018) added that those who receive transient school isolation are 4.7 times more likely to be dropped out of high school than those who do not. Adverse childhood experiences from school suspension and exclusion have also been found to correlate with the increased risk of involvement in the juvenile justice system and prolonged truancy. Black students with intellectual disability, especially, are significantly more likely to be referred to the juvenile justice system and receive unfair exclusionary discipline actions and grace compared to other students with disability and nondisabled students (Mendoza et al., 2020).

Lastly, the suspension and exclusion of students with disability from the mainstream classroom also affected their self-concept and identity development. Murphy (2022) reported that children aged 6-16 perceived their special education needs as a shame and disability as a stigma. In the context of Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD), for example, students mentioned that they felt embarrassed about their learning needs. For many of the students, this misconception had previously prevented them from seeking help from the professionals. Students also reported that schools tend to have low empathy and

sensitivity towards their disability; schools view the coping mechanisms of their disability as misbehaviors where the use of punitive measures is needed. Murphy (2022) argued that such coercive treatments for disability had tremendously impacted the learning, social, educational, emotional, and familial development of the students. It is also important to note and highlight that the students' conception of disability as a shame and stigma of disability does not exist in a vacuum; they are made up and continuously propagated by overt and covert ableist practices in the larger social contexts that fuse differences of bodily representations with tragedy and inferiority.

Despite the fact that school suspension and exclusion have resulted in more adverse effects than positive outcomes, educational institutions continue to implement the removal of students from their classrooms as a way to discipline unruly bodies. This approach fundamentally shows a deep and intricate relationship between education and the medical model of disability that views the aberration of being and doing as an individual student problem. Therefore, the government and schools' approach to remediate the inequality of educational attainment or "education debt" (Ladson-Billings, 2006, p. 3) for students with disabilities tends to be personal curative instead of institutionally restorative. While studies have continuously reported the longstanding grapple of school personnel in understanding the dynamic disability phenomena and providing fair and inclusive teaching (see Round et al., 2016; Hauerwas & Mahon, 2018), educational institutions unceasingly view disability as an individual disease to cure, and isolation bodies as a way to 'rehab' the anomalous being and doing. Secondary school teachers in Round et al. (2016), for example, expressed their concerns about the inclusion of students with disability in the mainstream classroom and the detrimental effects of the inclusion towards nondisabled students. Many of the teachers in the study also view the inclusion of

students with disabilities as an additional burden to their duties as teachers. In such a phenomenon, students with disabilities are situated and treated a menace and disease to the general education classroom, because the very existence of their bodies in the mainstream classroom disrupts and disarms the imagined standard representation of human learners.

In this section, I have laid out the philosophical backdrop and review of literature for my dissertation. I began the chapter with discussions on posthumanism and its key principles that guide the exploration of entanglement in this study, namely the agency or vitality of human and non-human actants as well as the interconnectedness of actants. I then explained posthuman in its intersection with two disciplines relevant to this dissertation, namely literacy studies and disability studies. I end the chapter with discussions on the implications of the human-centric gaze or anthropocentrism in education to highlight the importance of turning into human and non-human entanglements in disability explorations. In the next chapter, we discuss the methodology, methods, and data sources of this dissertation.

CHAPTER 3

METHODOLOGY

> To think is to experiment, but experimentation is always that which is in the process of coming about—the new, remarkable, and interesting that replace the appearance of truth and are more demanding than it is.
>
> (Deleuze & Guattari, 1994, p. 111).

This study is designed by following the posthumanism paradigm in postqualitative research. Posthuman research decenters humans as the sole legitimate figures capable of producing knowledge in a study. This indicates that posthuman research does not exclude the role of humans in shaping knowledge (Ulmer, 2017). Instead, the methodology highlights the longstanding intertwining relationship of humans with non-human elements, and endeavors to include what has been understood as the peripherals in research, i.e., the non-human elements (Bodén, 2013). Posthuman research requires new ways of seeing, thinking, and understanding phenomena. To mediate such needs, St. Pierre (2019) argued that rather than focusing on the established methods, researchers are encouraged to engage with creative and experimental ways of doing research to provoke new ways of thinking and understanding phenomena. Proponents of this non-representational paradigm view that standardized methods impede creativity and "do little more than provide a false sense of security that knowledge is stable, or even knowable" (Ulmer, 2017, p. 838).

While there are no methodological prescriptions on how to organize posthuman research, Ulmer (2017) posited that posthuman research must be able to produce situated, material,

interconnected, processual, and affirmative knowledge. *Situated knowledge* means that posthuman research does not claim universal knowledge. Rather, the research provides "a necessary means of partially translating experiences" (Ulmer, 2017, p. 836) of a person or a population within a particular context. Therefore, knowledge is always perceived to be something grounded in local formations. *Material knowledge* means that posthuman research attends not only to the ways humans produce knowledge but also to how the non-human elements (e.g., plants, furniture, nature, animals) provide an understanding of the phenomena that are being investigated. This means that posthuman research is also a radical onto-epistemological shift from humanism; it aims to spotlight what non-human elements can offer to the construction of our understanding of the world (Bodén, 2013). Next, posthuman research produces *interconnected knowledge* that explains how humans and non-humans are entangled, forming a mutual trans-species interdependent relationship. Posthuman research must also provide *processual knowledge* where the processes of becoming and knowing (i.e., the process ontologies) are fostered. In this sense, posthuman research views knowledge as something dynamic, messy, and uncertain. Lastly, posthuman research also emphasizes *affirmative knowledge* which leads to innovative, critical, imaginative, and creative ways of research and interpretation of the phenomena.

Posthuman methodology comes with some challenges. Ulmer (2017), for example, argued that posthuman research can be unsettling for many scholars as they embark on different ways of experimentation to generate knowledge. This may cause researchers to frequently experience self-doubt, hesitation, trepidation, and uncertainty during research (Ulmer, 2017). Additionally, the lengthy process of thinking and working with data and theories throughout the research can be time-consuming for researchers. Therefore, researchers should consider time

management strategies to navigate the complexities of posthuman research. Lastly, Vannini (2015) also noted the danger of engaging in new ways of doing research. She argued that "non-representational scholarship is borne out of a disorderly will to experiment and to fail" (p. 324). This requires researchers to be more skeptical of its consistency, efficiency, and applicability, among others.

In the field of education, multiple posthuman research has been done in various contexts through thinking with technology (Bodén, 2013), animals (Sjögren et al., 2015), water (Pacini-Ketchabaw & Clark, 2016), movements and sounds (Hackett & Somerville, 2017), and leaf blower (Flint, 2022). Bodén (2013), for example, examined school absence software to unravel the entanglement of educational settings with gender, social practice, and materialistic components in three Swedish schools. By thinking with colors (i.e., red, green, and blue) in the school absence software, Bodén (2013) illustrated the ways in which the materials or non-human elements – such as colors and software – operated with discourses of absence and narrative of good and bad students. Sjögren et al. (2015) analyzed the intertwining relationship of humans and animals among teacher instructors. They found that the understanding of the human and nonhuman's intertwining relationship affects the instructors' attitudes toward a sustainable environment and education. Meanwhile, Hackett and Somerville (2017) explored the potentiality of adopting a posthuman lens in reconceptualizing emergent literacy practices of children. By listening to and observing the human/children and non-human sounds and movements (e.g., sounds of drums, vocalization, jiggle, feet and hand movement), they illustrated the "synergy" (Hackett & Somerville, 2017, p. 380) or entanglement of the human and non-human which creates affective responses that influence one another. Their study concluded that meaning and world are always entangled; and the understanding of the human-nonhuman entanglement offers

new ways for literacy scholars to explore literacy beyond the anthropocentric framings (Hackett & Somerville, 2017). Lastly, Flint (2022) offered a methodological entry point of the investigation of whiteness in the higher education context through thinking with a leafblower. By listening to the sound of a leafblower, she reflected on the phenomena of commodification of lawns (e.g., lawn maintenance, machinery, chemical fertilizers, pesticides) in the U.S., and argued that such practices in the U.S. higher education are far from being value-neutral; they subtly manifest the desire of white American people to ideality, uniformity, control, and homogeneity of society.

This study employs the posthuman method as a way to highlight and explore the entanglement of humans and non-humans in a significant disability context. The following research questions guided the exploration in this study:

1. How is a child with Rett syndrome entangled with other human and non-human interactants during literacy activities at home?
    a. Who and what are the interactants that are part of the child's language and literacy activities?
    b. What role do these interactants play in navigating language and literacy activities for the child?
2. What are the larger implications of these entanglements for inclusive language and literacy education practices?

Human Participants

This study explores the entanglement of four human participants, namely an individual with Rett syndrome (Kalika), a parent (Baba), a babysitter (Sofia), and a literacy specialist (Sally), with non-human elements during literacy activities at home. Additionally, there was one

supporting participant, i.e., the individual's mother (Ma) that was involved in some observations. All five human participants in this study were recruited through convenience sampling.

Convenience sampling is a non-probability sampling strategy that uses the researcher's convenient pool at hand (Marshall & Rossman, 2016; Bhattacharya, 2017). Kalika, the child participant in this study, is the only daughter of my PhD advisor, whom I have known and worked with since I started my master's degree in 2017. Prior to conducting this dissertation, I had established a relationship with Kalika and the family in multiple different projects on her language and literacy engagement in school and home contexts. Building upon this longstanding relationship, I decided to conduct extensive research on Kalika's disability experiences from a posthuman perspective for my dissertation. I perceive Kalika's lived experiences as a complex disability experience that provides me with an avenue to understand disability and literacy from multiple aspects. This is due to her significant disabilities caused by Rett syndrome and Kalika's powerful entanglement with other humans and non-human elements.

Another factor influencing my decision to work with Kalika was the enduring relationship I had cultivated with her and her family over the years. This privilege allows me to engage more effectively with Kalika and her family, gain a richer perspective and understanding beyond the context of this research, and facilitate a more participatory approach to the research process. All five human participants in this study were recruited through my personal connection with Kalika and her family.

Kalika. Kalika is a multilingual 7-year-old child attending a primary school (Grade 1) at an inclusive coeducational public elementary school in the southern United States. She was born to an Indian-American woman and a Jewish-American man who both work as university professors at a large R1 public university in the southern United States. Being raised in a

multicultural family, Kalika speaks English and Bangla. Additionally, she is an avid reader. Within a month, she could read more than 40 children's books on various topics including religions and world folklore. Kalika has also loved listening to music since she was little. She enjoys a variety of music genres, particularly those with upbeat rhythms and songs in languages, such as Punjabi, English, Hindi, French, and Spanish. One of her favorite songs is the 1970s French song 'Mammy Blue'.

Figure 2. Sample of Kalika's Pageset About Herself

Kalika started losing her speech and developed accommodative esotropia or eye crossing at the age of 24 months as well as a decreased muscle tone and repetitive hand clapping, which profoundly hindered her from manipulating and exploring objects using her hands, at the age of 26 months. Kalika was officially diagnosed with classic Rett syndrome at the age of 2.5 years old in June 2018. Having lost her speech and purposeful hand use, Kalika communicates multimodally using her gaze, body movements, facial expressions, vocalizations, and eye-tracking AAC devices. She has two eye-tracking AAC devices: one is a Windows-based Tobii i-13, which she has used since her third birthday in December 2018, and the other one is a TD Pilot built on an iPad Operating System (iPadOS).

In terms of specifications, Kalika's Tobii i-13 weighs about 5.5 pounds with a 13.3-inch screen (thus, Baba called this device 'the big Tobii'), while Kalika's TD Pilot weighs 4.4 pounds with a 12-inch screen. The TD Pilot device is also equipped with a partner window on the back of the device that enables interlocutors to see Kalika's speech in written form. All the devices use TD Snap Language software developed by the same manufacturer of the devices, Tobii Dynavox. The software includes pagesets of icons, words, numbers, letters, phrases, and expressions for a variety of communication purposes. Figure 2 illustrates Kalika's pageset that she uses to introduce herself to others. Using this pageset, Kalika can exchange various information with her interlocutors, such as her name, age, date of birth, and the languages she speaks. Kalika's AAC device mediates communication in English. However, to support her multilingualism, Kalika's mother (Ma) also manually added words and phrases in Bengali on her device so she could speak to her maternal grandparents who live in India.

To support her mobility, Kalika has three mobility chairs, namely an activity chair that is mainly parked in the family's dining room, a standing activity chair in the playroom, and a wheelchair in front of her house. At home, Kalika mostly uses an activity chair for activities around the dining table. Other tools she is entangled with daily include the big Tobii, the TD Pilot eye-tracking AAC device, a pink armbrace to mitigate her uncontrollable repetitive hand movements, eyeglasses, G-Tube for feeding, and adaptive shoes. Kalika has her own phone that she uses to listen to her favorite songs and an iPad to have a virtual meeting with Sally and watch her favorite show, 'Sesame Street.'

Baba. Baba (a Bengali word for Dad) is Kalika's father. He was born into a Jewish family and is proficient in various languages such as Hebrew, French, German, Turkish, Arabic, and English. His multilingualism originated from both his studies at college and his immersion in

communities where these languages are spoken. For instance, he acquired Hebrew from his father, who used to speak basic Hebrew to him when he was little, while his mother communicated with him in English. On the other hand, he developed proficiency in German, French, Turkish, and Arabic through academic learning at college and studying abroad in countries, such as France, Egypt, Morocco, and Turkey. Currently, Baba serves as an assistant professor of French literature at an R1 public university in the southern United States. He perceives language as a gateway to "access different cultures" (Baba, Interview 1). He enjoys listening to music and delving into literature from diverse cultures, which fundamentally shapes his approach to language teaching. With Kalika, Baba reads a variety of children's books before bedtime. One of their favorite books to read is 'East of the Sun and West of the Moon,' a classic Nordic folk story about the journey of a young girl to rescue her prince, which they have read six times in total (Field note, July 8). The family regularly visits the county's library 1-2 times a week and borrows many children's books as well as books on world cuisines.

Sofia. Sofia is Kalika's babysitter. She is a white American undergraduate student pursuing a degree in communication sciences and disorders at the same university where Baba and Ma work, as well as where I am pursuing my doctoral degree. Studying speech disorders, she learns about human communication repertoires, including the use of Augmentative and Alternative Communication (AAC), and therapies for those with aphasia. Sofia and Kalika have known each other since June 2023. Before babysitting for Kalika, Sofia had never encountered individuals with Rett syndrome or had experience assisting someone who uses an eye-tracking AAC device. She found herself learning about these aspects during her babysitting time with Kalika, which typically occurs two days a week or five hours per week. As a babysitter, Sofia's responsibilities include feeding Kalika, reading books to her, and playing with her. Throughout

the data collection period of this study, she was only observed using Kalika's TD Pilot AAC device during her interactions. Sofia's sessions typically last two to three hours (120-180 minutes) per meeting.

Sally. Sally is a white American literacy specialist/teacher based in a big city in the Midwestern region of the U.S. She has over 45 years of experience working with individuals with complex communication repertoires, including those with Rett syndrome and autism. As one of the experts in the field, she has served students internationally and managed a global e-learning platform for parents, educators, and therapists of Rett syndrome students. Sally has been Kalika's literacy specialist since 2022. The entanglement between Sally, Kalika, and the family began in the summer of 2022 when the family had a series of "contentious IEP meetings" (Baba, Interview 2) with a school. IEP (Individualized Education Program) is a formal written document for a student with disabilities who receives special education services in schools. It is a blueprint for the student's education program developed collaboratively by involving parents, teachers, therapists, specialists, and, when appropriate, the student themselves.

An acquaintance of the family suggested inviting Sally as a specialist to help the parents advocate for Kalika to have a place in a collaborative classroom rather than being confined solely to a special education setting. Since then, Sally has worked with Kalika and the family to develop Kalika's literacy virtually. Leveraging Kalika's Tobii i-13 AAC eye-tracking device, the internet, and various digital apps, such as Voice Dream (a text-to-speech reader), Sally is able to teach Kalika and fully control her eye-tracking AAC device from a distance. This includes tracking Kalika's eye gaze, screen-recording the sessions, downloading the recordings, and pausing the pageset to move to another pageset. Throughout the data collection period of this study, Sally only used Kalika's Tobii i-13 (the big Tobii). She argued that it was the only device

that could be controlled remotely (Sally, Interview 1). Kalika's literacy sessions with Sally occur for one hour (60 minutes) every Saturday afternoon.

Ma. Ma (a Bengali word for Mom) is Kalika's mother, an Indian-American woman, and a multilingual speaker proficient in English and Bengali. Ma grew up in New Delhi, India, and has lived in different countries for study and work, including the Netherlands, Indonesia, Canada, and the U.S. Currently she holds the position of associate professor of language and literacy at the same university where Baba works. In this study, Ma also serves as the PhD advisor of the author. As a supportive human participant, Ma engages in some of my observations of Kalika with Sally, Baba, and Sofia, and contributes specific background information about Kalika when necessary. To maintain research integrity and mitigate potential conflicts of interest, Ma refrains from participating in other data collection activities, such as interviews and focus group discussions.

Design and Methods

This qualitative research is a single instrumental case study that focuses on investigating the literacy practices of an individual with Rett syndrome with her parent, babysitter, and educational therapist. Bhattacharya (2017) defined a single instrumental case study as a type of case study that "focuses on a unique, information-rich situation, concern, or problem and selects a bounded system as a case to study" (p. 110). There are a few reasons why a single instrumental case study was chosen for this dissertation:

First, case study facilitates an in-depth examination of an individual, program, event, policy, or any other phenomenon for relatively short periods of time (Bhattacharya, 2017). This study explores a specific phenomenon, namely the entanglement of an individual with Rett syndrome with her parent, babysitter, literacy specialist, and non-human intra-actants during

literacy activities at home. The specific context and the small study population in this study provide an opportunity for me to focus intently on the phenomenon, carefully observe the interactants involved in the entanglement, understand the roles they play, as well as gain in-depth perspectives on how the entanglements are formed and their implications for Kalika's language and literacy. Additionally, data collection of this study spanned five months from July to November 2023, which is relatively shorter than other types of qualitative study, such as ethnography and oral histories. Case study offers the flexibility for me to conduct research within such a specific population within a concise timeframe.

Second, case study allows versatility in incorporating diverse perspectives, data collection methods, and interpretive strategies (Marshall & Rossman, 2016; Bhattacharya, 2017). As described earlier, posthuman scholars are non-representational (Ulmer, 2017) – they are eclectic, open to different modes of thought and approaches in research, and eager to seek alternatives to methodological conformity. This is done to generate new ways of understanding phenomena as well as diffractions in normative thoughts and arguments. This study employs multiple qualitative data collection methods to capture arrays of participants' perspectives and gather a more nuanced description of their entanglement with each other. This involves the use of visual elicitation interviews (Copes et al., 2018), participant-generated drawings (Rose, 2016), and a combination of virtual and face-to-face observations along with a focus group discussion. Additionally, the study also experiments with a combination of coding, narrative writing, and collage in data analysis to generate more innovative, imaginative, and critical interpretations of the phenomena being investigated.

Third, case study is not interested in discovering the 'correct' or generalizable interpretation of facts. Rather, it aims to present one with the most compelling and possible

interpretation of a phenomenon (Bhattacharya, 2017). As argued in the first chapter, the purpose of this study is not to provide a generalizable and universal conclusion on how entanglement occurs and matters in literacy activities. Instead, this study aims to provide a thorough examination of how humans (i.e., Kalika, Sofia, Baba, and Sally) intra-act with non-humans in this study, forming a dynamic entanglement that shapes and mediates the language and literacy experiences of an individual with Rett syndrome. This study endeavors to offer an alternative perspective on how researchers can examine disability phenomena and literacy by turning toward materiality and more-than-human entanglements. The turn to materiality and entanglement, I contend, challenges the prevailing disordering perspective on the repertoires of language and literacy of individuals with disabilities and destabilizes anthropocentrism and the medical perspective in disability studies that inherently champion individualism over interconnection among human and non-human elements. Additionally, it provides a nuanced understanding of disability experiences as a dynamic process of becoming instead of a monolithic lived experience.

The following section delineates the methods I employed to collect data from Kalika, Baba, Sofia, and Sally and the non-humans involved in their entanglements.

Data Sources

Observation

Observation is a crucial aspect of qualitative research (Marshall & Rossman, 2016). In this study, nine face-to-face observations and two virtual observations were conducted from July to September 2023. Table 1 in Appendix A lists the date and length of all observations as well as the human participants involved. These observations, totaling 24 hours of video-recorded sessions, cover various literacy events of Kalika with Sofia, Sally, and Baba. Literacy events, as

Heath (1982) describes, are “any occasion in which a piece of writing is integral to the nature of participants’ interactions and their interpretive processes” (p. 93). In other words, any observable activity or episode that involves literacy (i.e., a piece of writing from Heath’s perspective) is considered a literacy event. In this study, the events that I particularly focus on during Kalika’s activities with Sofia, Sally, and Baba include storybook reading, learning alphabets and sight words, playing board games, and finishing up homework from school that took place in the dining room, living room, and the playroom.

The purpose of these in-situ observations is to capture the complex nuance of human-non-human interactions within Kalika’s literacy entanglements. By immersing myself in the same environment as my participants, I am not only able to see the complex relationality among Kalika, Sally, Sofia, and Baba, but also generate other sources of insights from the environment through my senses, including the olfaction (smell), tactition (touch), and audition (hearing). These factors include capturing the non-human aspects that may affect their intra-actions and shape Kalika’s literacy experiences. Examples include the room’s brightness that influences Kalika’s view of her AAC screen, the noise from the blending machine used by Baba or Ma while preparing food for Kalika during sessions with Sally and Sofia, the difference in weight between the big Tobii and the small Tobii, the sturdiness of the dining table used by Kalika and Baba during sessions with Sally, the pitch of Kalika’s cries when she refused to engage in literacy activities with Sally and Sofia, and the various music played during her literacy activities. I contend that such detailed observations are needed to capture relevant assemblages that are involved in Kalika’s literacy. Assemblages, Bennett (2010) argued, are “ad hoc groupings of diverse elements, of vibrant materials of all sorts” (p. 23). They are both human and non-human elements that are involved in and shape the formation of an entanglement. These

include human and non-human objects in an environment, research instruments, disability, ableism, class, and gender that can play roles in Kalika's language and literacy development.

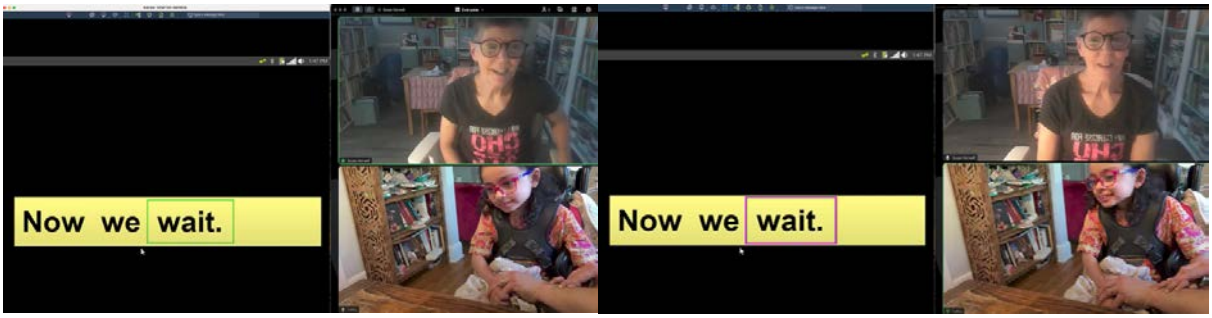

Figure 3. Eye-Tracking Recording

In addition to direct observations at Kalika's house, my observation data also includes five hours of Kalika's eye-tracking recordings gathered during her session with Sally. Obtained from Sally, these data are the screen recordings of Sally's computer – they capture Kalika's eye-tracking AAC device page, Kalika's face, and Sally's face (see Figure 3). These data are employed to specifically observe Kalika's eye movements and fixations on her AAC device pagesets and determine her visual engagement during her session with Sally. The green rectangle in Figure 3, for example, illustrates an area of interest on the pageset that Sally wants Kalika to specifically see as she reads the sentence. Meanwhile, the pink rectangle indicates a successful fixation of Kalika's eyes on the target area of interest. Fixation, Holmqvist et al., (2011) argued, is a momentary stop that eye makes on an object or area of interest. In reading, fixation signifies the individual's visual attention and processing of information in the area of interest. Together with the hours of in-situ observations, the total observation data in this study is 25 hours.

During my in-situ observation, I am aware that my presence and the presence of my research tools (e.g., iPad, tripod, wireless microphone) may discomfort my participants, especially Kalika who may find my iPad distracting and remind her of her favorite show to watch (Ma, field note, August 15). As Marshall and Rossman (2016) argued, among the common

challenges that researchers need to consider during observations include mitigating participants' discomfort and managing a relatively unobtrusive role of the researcher. To alleviate discomfort and obtrusion during observations, I decided to maintain distance from my participants, place my iPad and the tripod in another room or behind an object, and cover them with a piece of cloth (Figure 4). During Kalika's session with Sally in the dining room, specifically, I observed their interaction from the living room and placed my iPad and tripod in the kitchen. Both of these rooms are connected to the dining room with no door so I could still see and hear their interactions clearly.

Figure 4. Covered iPad and Tripod During Data Collection

To further alleviate discomfort, my observation schedule was also determined by the participants' time availability and convenience. Working with individuals with significant disabilities like Kalika requires me to be mindful of the dynamic of their health, therapy schedules, and changes in routine. During the process of data collection, there were times when the scheduled observations and other data collection activities were rescheduled to another time. For example, my scheduled visit on November 2 was canceled because Kalika "had a really rough day lots of crying and being upset" due to her field trip and being away from Baba who was traveling to another state (Ma, field note, November 2). Therefore, two to seven days before

the visit, I would text Ma and Sofia to ask if I could come to the house and if they would be willing to be observed by me. Meanwhile, Sally requested me to inform her about the observation a few minutes before her session began with Kalika. This practice was done to preserve my participants' agency in the research, protect their privacy, and respect their personal boundaries.

Interview

In addition to a series of direct observations, I employed two 60-minute video-recorded semi-structured interviews with Sally, Baba, and Sofia and two 30-minute video-recorded story-reading mediated interviews with Kalika. These interviews are aimed at achieving a deeper understanding of the phenomena from my human participants' perspectives beyond mere observation. I offered two modes of interviews, namely face-to-face and virtual, to accommodate their schedules and differences in time and location, especially for Sally who lived in a city in a different state. Table 1 in Appendix A lists the date, mode of interview, venue, participant, and length of all interviews I conducted with my participants. Protocols and questions for interviews with Baba, Sally, and Sofia can be found in Appendix B.

Interviews with Sally, Baba, and Sofia. The first round of interviews with Sally, Baba, and Sofia was intended to get to know them better, share the overall purpose and design of my study, and have discussions on their relationship with Kalika. While the phrasing of the questions is different from one participant to the others to better connect and reflect their roles in Kalika's literacy, all questions are geared towards exploring their understandings of Kalika and Rett syndrome, their experiences in engaging with Kalika, their perceptions of Kalika's communication, and their opinions on the roles of humans and non-human elements during Kalika's literacy activities.

In addition to having them answer my questions, I also asked them to watch a short clip of observation from their literacy session with Kalika that I randomly selected from a list of observation videos I had collected (see Table 2 Appendix F). With Sofia, for example, I asked her to watch a clip of her session with Kalika, because she had never been involved in Kalika's session with Sally and Baba. Likewise, with Sally and Baba, I assigned them to watch a clip of one of their Saturday sessions with Kalika, because the two of them were never present during Kalika's session with Sofia. Following this activity, the participants were invited to narrate the video they watched using their own words and share their thoughts on the roles of themselves, other humans, and non-human elements in the video.

The purpose of this activity, also known as visual elicitation (see Freedman & Siegesmund, 2023), is to stimulate dialogue and obtain more nuanced information on their entanglements with Kalika. By watching the videos, participants were not only given a specific context for them to discuss but also allowing them to have a view of the sessions from my perspective. Following each interview, I transcribed the recordings, printed the transcription, reviewed, and preliminary coded the transcripts. Lastly, I selected segments from each interview transcript where the interviewees specifically talked about their entanglements with Kalika, their roles, and the roles of the non-humans within the entanglements. These segments were then compiled into three different documents based on the interviewees' roles. The compilations of the segments would then be used as a tool in my second interview with them.

The second interviews were organized face-to-face on campus where Baba, Ma, Sofia, and I work/study and virtually. These interviews were organized to serve two purposes. First, to ask for clarifications from the initial interview. After reviewing the transcript, I encountered some points that needed further clarification from my participants. With Baba, for example, I

specifically asked how and when he and Ma met Sally. Meanwhile, with Sally, I asked further questions about the applications she used to teach and prepare the materials for Kalika. Second, to extend conversations on the role of the non-human elements and their entanglements with the humans during Kalika's literacy session. Having reviewed and preliminary coded the first interview, I realized that most of my questions in the first interview focused on the roles of humans within the entanglements. Therefore, for the second interview, I wanted to have time to specifically explore their perceptions on the roles of the non-human elements in the entanglements and the ways the non-human elements matter in the entanglements.

In organizing the second interview, I engaged in guided conversations with my participants rather than structured queries. Guided conversation is an interview technique where questions in the interviews are fluid rather than rigid (Yin, 2018). This technique facilitates researchers to probe more information from the participants using questions they prepared earlier and questions that organically come out during the conversations to gain more fluid and natural responses from the participants.

The second interview consists of two activities, namely transcript reading and drawing activities. For the transcript reading activity, I instructed my participants to read the three select segments of transcripts from the first interviews, beginning with their own interview transcripts followed by whichever transcripts they preferred. To provide convenience to my face-to-face interview participants (Baba and Sofia), I printed the transcripts using three different colored papers and titled each transcript with the roles of the interviewees. This was done to make it easier for them to locate specific information on the transcripts. I also printed my prompt on a piece of paper so that my participants could always refer to it back in case they missed my instructions. Meanwhile, for Sally who had a virtual interview, I uploaded the transcripts on a

Google Doc and organized them according to the following order: Directions of activity – Sally's transcript – Baba's transcript – Sofia's transcript.

Figure 5. Set Up for Face-to-Face 2nd Interview Involving Drawing Activity with Sofia

I provided each of my participants with a maximum of 15 minutes to review all transcript segments. During their reading, I asked my participants to specifically focus on the roles of the non-human elements and their entanglement with the humans in the transcripts. They were specifically instructed to underline or highlight statements that they agreed with, that resonated with their experiences, or that they found interesting. Additionally, they were asked to mark any parts where they disagreed or found conflicting with their own opinions. After they finished reading, I guided the conversations to focus on the roles of the non-humans in the entanglement and what new insights they learned from other adult participants' transcripts by sharing with me what they underlined and marked on the transcripts.

By inviting my participants to review segments of the collected data, I enhanced their entanglement with the study to talk more about what they and other participants' said, raised concerns, and provided corrections of language and clarifications (Mero-Jaffe, 2011). When reading her own transcript, for example, Sally informed me that I made an error in the name of

the application she used to prepare learning materials for Kalika. She then corrected the transcript and also showed me the application she meant at the end of the interview. Importantly, by reading their own transcripts and reading other participants' transcripts, the participants were able to gain perspectives on the entanglement from other participants prior to the focus group discussions. This opportunity facilitates each participant to establish a foundation for mutual understanding of the entanglement before the upcoming focus group discussion in the following week.

Following the transcript reading activity, I invited my participants to draw an illustration of their entanglement with Kalika and other human and non-human intra-actants in the study. All participants, except Sally who lived in a different state, were provided with stationery to draw (Figure 5). These include crayons, markers, pencil colors, watercolor paints, and brushes, as well as drawing pads. Before they began drawing, I invited them to tell me what they knew about entanglement followed by reading them the question on the prompt paper to guide their drawing, i.e. *"How does the entanglement between humans and non-humans during Kalika's literacy activities look like to you?"* The participants took about 5-10 minutes to complete their illustration of entanglement. After that, I began the guided conversations using open-ended questions that focused on their entanglements and the roles of the non-humans, such as *"Tell me about your drawing", "What did you draw in the entanglement and why?"*; and *"What elements did you draw first and the last and why?"*. Additionally, I also invited my participants to reflect on their drawing experiences and showed them how other adults perceived their entanglements with Kalika and other humans and non-human elements. These guided conversations mediated in drawing activity served as a catalyst for me to have in-depth dialogues with my participants beyond formal questions and answers sessions, and established a stronger rapport with them.

Drawing activity was especially chosen for it not only facilitates my participants "to convey contents that words can only approximately represent" (Lapenta, 2011, p. 202), but also because it helps mediate my participants' reflexivity on their profound entanglement with other humans and non-humans in Kalika's literacy development (Mulvihill & Swaminathan, 2020).

Interview with Kalika. In addition to interviewing the adults, I extended an invitation for two video-recorded interview sessions to Kalika. Her participation in this study was particularly crucial, not only because she and her literacy experience constitute the nucleus of the phenomena under observation but also due to the prolonged exclusions of individuals with disabilities, especially those with speech difficulties, from research about themselves (see Feldman et al., 2013; Taylor & Balandin, 2020). This exclusion often stems from societal stigmas surrounding their intelligence and expressive capabilities (Tager-Flusberg & Kasari, 2013; Clare, 2017), strict human research protocols (Boxall & Ralph, 2011), and a scholarly inclination to prioritize verbal accounts as the primary data in research. By inviting Kalika to share her experience of her entanglement with other human and non-human intra-actants, I aim to provide a model of inclusive research that embraces the multiplicity of participation of individuals with disabilities in research beyond being an object of observation.

After consultations with Ma on what strategies I could use to interview Kalika, I decided to incorporate story-reading activities into my interviews with Kalika. There are some considerations on why I chose to interview Kalika through story reading. First, story reading is one of Kalika's favorite activities. From the observations and interviews with Baba, Sally, and Sofia as well as insights gained from my previous engagement with Kalika in various research projects with Ma, I learned that Kalika engaged in story-reading activities every day with her parents, Sofia, Sally, therapists, and teachers at her school. By integrating my interview

questions through story reading, I provide a familiar activity for Kalika to engage in a question-and-answer session about the book and her relationality with the characters in the story.

Figure 6. Instruments for Interview 1 with Kalika

Figure 7. Baba Selecting a Song to Dance with Kalika; Elsie's Dancing With Her Daddy

Second, story reading facilitates multimodality of communication beyond verbal communication. The context of the story as well as the incorporation of the visuals, gestures, and other modalities of communication during story reading activity facilitates understanding of children, particularly those with literacy and communication challenges as well as individuals with intellectual disabilities (Anderson & Balandin, 2011). In Kalika's case, the illustrations in the book we read helped contextualize my questions on her perceptions of her AAC device, activity chair, music, as well as other human participants (Baba, Sally, Sofia). By integrating story reading into the interview with Kalika, the goal is to cultivate a more comfortable

environment for Kalika to engage in a dialogue with me and provide responses to my interview questions.

Lasting around 30-45 minutes each, the face-to-face interviews with Kalika were mediated through story-reading activities involving a children's book titled 'Dancing with Daddy' by Antira Schulte (2021). The selection of this book was intentional to reflect Kalika's profound disabilities and entanglement with the non-human elements. Elsie, the main character in the book, is a girl with Wolf-Hirschhorn syndrome, a rare chromosomal condition resulting from a missing piece of the short arm of chromosome 4 due to the partial deletion or monosomy of the chromosome. Elsie is entangled with various accessibility tools in her daily life, including an activity chair, AAC tools, and a feeding tube. Elsie also loves music and dancing with her father, which I found similar to what Kalika loves to do with her father (see Figure 7).

Figure 8. Interview with Kalika

My interviews with Kalika took place in the playroom of her house. Accompanied by Sofia, I posed approximately 10 questions, including questions that are designed to make the story-reading fluid and engaging, such as "*Which dress do you think Elsie will choose? Pink or Red?";* and *"How about you, do you like Pink or Red?"* To value Kalika's multimodal communication beyond her facial expression, body language, and gestures, I prepared a few alternative media for Kalika to answer my questions, namely the cutouts of pictures and symbols

as well as her eye-tracking AAC device. The cutouts of pictures and symbols, specifically, were prepared to accommodate her preference for answering the questions through touch. I decided to incorporate this strategy after observing Kalika's session with Sofia on August 24, 2023, where she answered Sofia's questions on addition by touching and approximating her body to the flashcards.

To create the cutouts, I first reviewed the questions that I would ask Kalika during the story reading and identified some answer options to the questions. Next, I located pictures and symbols to represent the answers, namely the pictures of Sally and Sofia as well as the symbols for *"yes", "no", "red",* and *"pink"* (Figure 6). This process included consultation with Ma on how the symbols were represented on Kalika's AAC device system to provide familiarity for her. After that, I arranged the pictures and the symbols on a word document, arranged the layout to ensure that the size was big enough for Kalika to see, printed them, and cut them out individually.

In addition to the cutouts, her eye-gaze AAC device was incorporated to accommodate her preference to answer my questions using her gaze. This method was primarily used in the second interview with Kalika to facilitate more diverse responses beyond the cutouts of pictures and symbols. Learning from Sally's technique in eliciting Kalika's responses to open-ended questions, I helped Kalika locate specific pagesets of words/phrases that may answer the interview questions. For example, to answer my interview questions on what she felt about her AAC device, I helped her find a specific pageset that listed adjectives of feelings, such as *"fantastic", "happy", "good",* and *"bad."* My interview prompts and questions to Kalika can be found in Appendix C.

Focus Group Discussion (FGD)

A 60-minute video-recorded focus group discussion was conducted with Baba, Sally, and Sofia to conclude the series of data-gathering activities in this study. The purpose of the discussion was to gain collective understanding and insights of the participants on 1) Kalika's entanglements and the roles of the humans (Baba, Sally, Sofia) and non-human elements in shaping her literacy experiences; 2) challenges in helping Kalika with her language and literacy development and how their entanglements could address those challenges; and 3) inclusive education. Additionally, this focus group discussion was organized to foster Kalika's support network or entanglement among the humans. During my one-on-one interviews with each participant, I realized that Sofia and Sally did not know each other and how they had been supporting Kalika. Therefore, this focus group discussion also served as an opportunity for them to connect, listen to each other's opinions, and talk about how they could support each other in developing Kalika's literacy.

I began the FGD by asking the participants to introduce themselves and their roles in supporting Kalika's literacy development. This was then followed by showing them their drawings of entanglement from the second interview and briefly explaining how the human and non-human elements in their drawings have been shaping Kalika's literacy experiences. After that, I asked the group to provide answers to my questions and listen to each other's responses. Additionally, I encouraged the participants to ask each other questions and discuss how they, as a group, could strengthen the established entanglement to further support Kalika's literacy development. The questions and protocol for this focus group discussion session can be found in Appendix D.

Field Notes and Memos

Marshall and Rossman (2016) argued that in qualitative studies, the researcher is an instrument. Therefore, in addition to the observations, interviews, and focus group discussions, I also employed field notes and memos to record descriptions of events, settings, short dialogues, and recurring patterns and behaviors observed during the data collection process. These documents also serve as a growing record of my emotions and self-reflections on what I sense and wonder about the observed phenomena. They include details as simple as *"Ask Baba how the family knew Sally," "What is Kalika's relationship with the cats?",* titles of books that Kalika reads with Sofia (see Appendix E), or a collage of the dining table layout created from used magazines (see Appendix G).

Throughout the study, I created 11 field notes that correspond with each of the observations in Kalika's house. Initially, I jotted down the notes and created the memos using an unruled notebook for practical reasons. I carried this notebook every time I visited Kalika's house and wrote down my reflections and important observations on it. Following the completion of each observation, I retyped and uploaded all the notes and memos digitally onto UGA OneDrive for accessibility and preservation of data. These documents serve as a crucial source of data that complements information gathered from the observation, interview, and focus group discussion video/audio recordings. Before beginning a new observation, especially, I would re-read my entries to see if there were things I needed to specifically observe or ask the participants for clarifications. This practice helps me ensure that I cover all information needed for this study as well as deepen my thinking on the observed phenomena.

Data Analysis

Mode of Thinking: Diagrammatical Thinking

In analyzing my data, I adopted a diagrammatical mode of thinking. Diagrammatical thinking "seeks to disrupt conventional ways of thinking about human and nonhuman interactive spaces or networks" (Freeman, 2017, p. 9). It concerns the strategy of seeing humans and non-human elements in the data as emerging assemblages, moving away from interpreting them based on pre-established conceptions as separate entities. Unlike categorical thinking which tends to see things based on preconceived categories, e.g., characteristics, materials, and class, diagrammatical thinking is interested in understanding how the seemingly separate things overlap, entangle, and form a dynamic matter. For example, rather than seeing the dining table in Kalika's house simply as an isolated table or a piece of furniture in the dining room, researchers employing diagrammatical thinking would ask: "How is this object related to Kalika and the family?"; "What makes this object more/less than a table when it is entangled with other furniture in the room or with the family?"; "What kind of new object(s) will this object become as a result of the entanglements?"; and "What kind of changes will this object bring to other objects in the entanglements?" To think diagrammatically in research, Freeman (2017) argued, "require[s] thinking differently about the nature of things, and the relationship between things" (p. 99). It encourages researchers to step away from the essentialist categories and speculate how a thing emerges or changes from its preconceived class when they are entangled with another thing(s). This strategy of seeing and understanding data offers an avenue for researchers to think of research as a space of creative and innovative experimentation.

In this dissertation, diagrammatical thinking serves as a cognitive strategy to help me examine the entanglement that emerges from the interactions among the humans and non-human

elements in literacy in a significant disability context. Diagrammatical thinking is especially helpful in providing three principles that guide my thinking in this dissertation:

First, *to refrain from the dominant assumption that humans are the only entities with agency in the data*. This was done through iterative readings of posthuman literature throughout the study and diffractive reading of literature across disciplines. To diffract, Barad (2006) posits, is to disrupt the linearity in knowledge production that tends to repeat one after another. The strategy is derived from a quantum physics phenomenon called diffraction that describes the unique behavior of waves, such as light, sound, or water waves when they encounter an obstruction or opening (Barad, 2006). An example of diffraction in everyday experience includes the ripples of water created by a speedboat traveling through a gap in walls or a jetty, which results in a pattern of new waves. Diffractive reading thus entails reading and re-reading insights across different theoretical schools to engender new ripples of interpretations and thoughts from data.

In this study, my diffractive reading entails a careful review of literature from the fields of critical disability studies, posthumanism, and literacy throughout the process of crafting this dissertation. In the literature review section (Chapter 2), especially, I explored the phenomena of disability from multidisciplinary angles to provide not only the theoretical background of this study but also the historical overview of the disability and its interconnection with the marginalization of students with disabilities as well as their ways of languaging and becoming literacy. Similarly, during data analysis, I supported the process by re-reading the posthuman theories I adopted in this study.

Second, *to think with both the humans (Kalika, Baba, Sally, Sofia) and the non-human elements in the data*. As a scholar who has been trained and worked within the humanist

paradigm, I found myself easily inclined to focus on what humans do among themselves, what they do toward non-human elements, and what happens to them afterward in the data. Meanwhile, as Ulmer (2017) posits, posthuman research "move[s] toward material ways of thinking and being" (p. 836). It seeks to understand phenomena as more than just human phenomena. Realizing my anthropocentric inclination in research, I feel the need to have an explicit commitment in my data analysis to locate the non-humans in the data and think with them in terms of how they express their agencies or power in the entanglement. As McCoy (2012) argued, "matter is not a formless blob that is given shape by our imaginings of it. It is not inert substance waiting to be discovered and described. It acts; matter pushes back… Forces are produced. Momentum. Counterforces" (p. 764). Therefore, the purpose of this strategy is to have a moment to shift the focus away from the central figure of human participants as the most exclusive and independent entity in Kalika's literacy entanglements and knowledge production. The exploration of the non-humans and examination of their roles in the data provides a pathway to understanding how they have always been present and entangled with Kalika, Baba, Sally, and Sofia in shaping Kalika's literacy experience.

Third, *to attend to the ways the humans and the non-humans are entangled and how the entanglements are formed*. Thinking diagrammatically provides an avenue for researchers to tune into the interrelation of seemingly different entities and to view them as emerging assemblages or becomings. By thinking diagrammatically, I set a mental strategy throughout my data analysis process to perceive everyone (Kalika, Baba, Sofia, Sally) and everything (the non-human elements) as actors with forces within an open and fluid entanglement. Thus, during my data analysis process, I endeavor not only to identify who and what the actors are but also to examine the linkages between them and how their linkages come to matter. Such endeavor prompts me to

think in creative and innovative ways to help me see the unpredictable or the unthought human and non-human entanglements during Kalika's literacy activities.

Data Management and Analysis

As described earlier in this chapter, in posthuman studies, there is no prescribed research design and method of analysis. Instead, posthuman studies encourage researchers to "think with theories and matter in the world (i.e. students, schools, teachers, writing, books, art supplies, plants, digital tools and so forth) in order to create a new (theories, literacies, methodologies, and...and...and...)" (Kuby & Rowsell, 2017, p. 287). The freedom to experiment and think with data in posthumanism led me to engage in some eclectic data analysis strategies, such as constructing narratives (see Holley & Colyar, 2009; Pepper & Wildy, 2009) and collage-making (see Holbrook & Pourchier, 2014) in addition to inductive coding method (Saldaña, 2021). As Amanda Coffey and Paul Atkinson (1996) argue: "There is no single right way to analyze qualitative data; equally, it is essential to find ways of using the data to think with" (p. 2). The multiplicity of data analysis techniques in my study not only helped me in thinking with the data and weaving them with posthuman readings but also mediated my process of reflexivity as a researcher. There are four main procedures for analyzing data in this dissertation.

Data Review and Storage. The process of data analysis began with reviews of data sources from the observations, interviews, focus group discussions, and field notes to give me a bird's-eye view of my data terrain. This was accomplished by re-reading my field notes and memos, rewatching the videos, reviewing the photos, and writing brief notes about the data. The insights gained from this process were then transferred to a table containing the information of the wealth of data I have for this study (see Table 2 Appendix F). This table acts as a 'table of

contents' of my data that helped me navigate and locate specific resources I needed during the writing process of this dissertation, including the selections of photos and videos.

All data collected from my participants were stored safely in a password-protected UGA OneDrive folder that can only be accessed by me and my doctoral advisor (Ma). To back up my data, I also store the data on an external hard drive and my personal password-protected computer. To ensure confidentiality, I assigned pseudonyms to all participants except Kalika as per the family's agreement which is reflected on the approved Institutional Review Board (IRB) report of this study.

Transcriptions. Transcriptions of videos of observations, interviews, and focus-group discussions were done after the completion of each data collection process. To expedite the process of transcription, I used a digital transcription platform called Otter.ai. The platform utilizes machine learning algorithms to transcribe spoken words from the videos into written text. To transcribe using the platform, I first uploaded the videos on the system. Then, the system would convert the videos I uploaded into audio files and generate verbatim transcripts of speech from the participants from the audio files within 15-30 minutes depending on the length of the audio. Once the data were preliminarily transcribed by the machine, I reviewed and edited the transcripts to ensure the accuracy of the words and information based on their corresponding audio data. Afterward, I downloaded the polished transcripts from the platform and uploaded them to the aforementioned storage systems and personal devices.

Besides providing time efficiency, working with this machine learning also prompts me to wonder about my relationality with the non-human elements in the research process. With Otter.ai., specifically, it intrigues me to reflect on their essence as a non-human element and their roles as a non-human transcriber or collaborator in my research. As a machine, Otter.ai. does not

remain static. Instead, it grows and evolves with the data that I uploaded onto their system and the edits I made to the transcripts. For example, in the first few videos I uploaded to their system, Otter.ai did not recognize the speakers involved in the interactions – it assigned my participants' names as 'Speaker 1,' 'Speaker 2,' etc. As I trained the machine by editing the transcript and assigning pseudonyms, Otter.ai processed the alterations and autonomously associated them with participants' speeches based on the acoustic features of their voices.

One of the striking aspects during my intra-action with Otter.ai is that the machine did not recognize Kalika's AAC voice despite the multiple training I gave to it. It kept lumping her speech into other participants' speeches, rendering her verbal communication non-present in the transcript. Additionally, the machine also did not transcribe Kalika's gestures, facial expressions, eye gaze, cries, laughs, and vocalization. The absence of Kalika's complex communication repertoires in the transcripts intrigued me to further reflect on Kalika's presence in my data and to ponder the notion of speech and communication in the transcription process, especially in research involving individuals who rely on AAC. It also challenged me to think of alternative strategies beyond transcriptions to capture Kalika's complex communication repertoires during my data analysis process. Further elaboration on the strategies I employed is detailed below.

Planning for Experimentation. Deleuze and Guattari (1994) suggested that "to think is to experiment" (p. 111), emphasizing that thinking involves innovative and creative working with the world and encountering the unthought (Kuby & Rowsell, 2017). Thus, once I gained the holistic landscape of my data, I proceeded to the next stage of data analysis of my posthuman study, namely the planning for the experimentation. The planning process began with a reflection on my intersectionality and relationality with data as reflected in the wheel diagram in Figure 9.

To begin the reflection, I first drew a small circle on a piece of paper where I listed my identities, preferences, and hobbies. Then, I drew a bigger circle on the outer side of the first circle and listed my participants' intersectional identities, such as "individual with significant disabilities," "father," "female", "undergraduate student," "white American," and "Jewish." Following, I drew another bigger circle on the outer side and listed the theoretical factors guiding my thinking in this dissertation, namely posthuman, critical disability studies, and language and literacy education, and my wealth of data. Lastly, I reread my writings in the diagram, assigned different colors to each circle, and reflected on the important patterns in my intersectionality. This process helped me construct three conditions for data analysis methods that not only comply with the approved IRB proposal but also provide joy and are responsive to my intersectionality. The three conditions are:

Figure 9. My Wheel of Intersectionality

First, *the methods should mediate the informed theories and mode of thinking I opted for in this study, i.e., posthumanism and diagrammatical thinking*. As described earlier, diagrammatical thinking perceives humans and non-human elements as emerging assemblages. Diagrammatical thinkers seek to understand the inherent interconnection between humans and

non-human actors. They think with theories, experiment with the resources in hand, speculate things beyond the pre-determined categories, and are open to the multiplicity of interpretations. This condition requires me to have methods that can allow me to both sit with my data and think with the theories. The methods should ideally also provide an avenue for me to see data as assemblages and how these assemblages inform the intra-action between the human and non-human elements in my data and their dynamic entanglements.

Second, *the methods should allow me to engage with data in creative and innovative ways*. A consequence of engaging in posthuman research is the openness to experimental ways of doing research beyond the established methods (St. Pierre, 2019). The heavy reliance on standardized methods, Ulmer (2017) argued, leads to the misconception that knowledge is unchanging and specific 'correct' ways of thinking and doing research. Therefore, the methods I opted for should provide flexibility for me to explore new ways of data analysis beyond the "good old-fashioned qualitative inquiry" (Brinkmann, 2015, p. 620), such as coding.

Third, *the methods should be responsive to my interests and needs*. Having reflected on my intersectionality made me aware of what I like to do and what I do not like to do with the data. As a person with a vision disability (I have only one functioning eye), I found the prolonged and intense engagement with computer screen eye-hurting. It also makes me aware of my interest in doing work with colors and textures, which stems from my deep appreciation of visual arts after the temporary loss of my sight when I was in the fifth grade. Therefore, in this study, I wanted to have methods that can help me engage with data in multimodal ways; ones that not only facilitate data analysis but also spark joy to me. Together, these considerations led me to choose a combination of several methods of data analysis, namely coding, narrative

writing, and collage. Figure 10 and the following explanation describe the process for the data analysis in this dissertation.

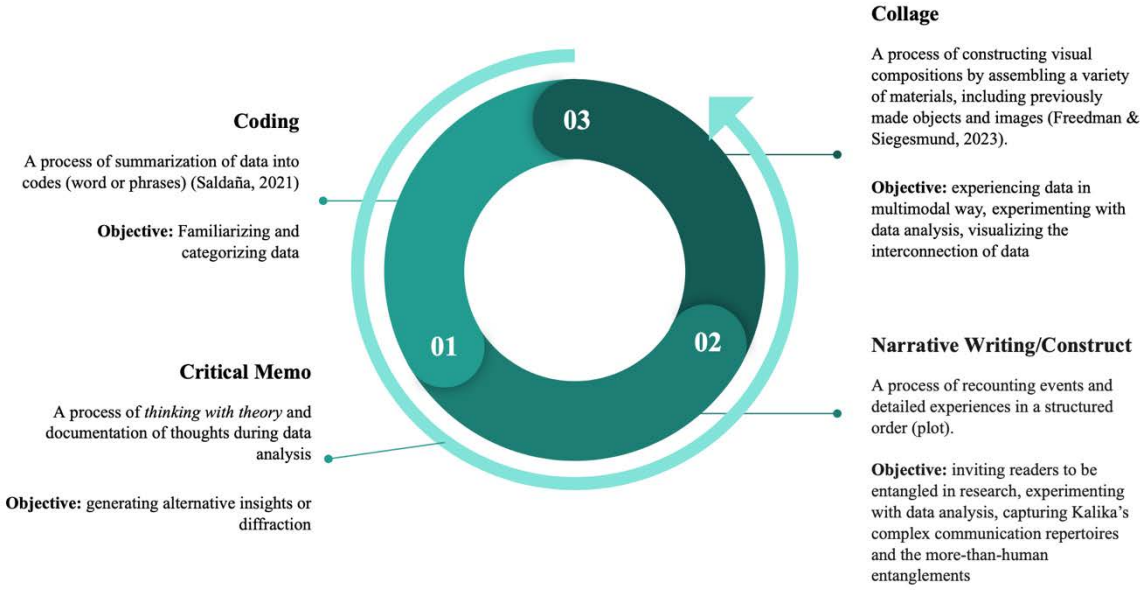

Figure 10. Data Analysis Process

Coding. Following data familiarization and transcription, the next stage of the data analysis process is coding the transcripts of interviews and focus group discussions. These transcripts are polished, meaning that the transcripts have been manually reviewed and checked by me to ensure the accuracy of words, information, and speakers with their corresponding audio files. After downloading them from Otter.ai., I decided to print, label, and arrange them based on the type of data sources (Interview or Focus Group Discussion) and names of the participants (Baba, Sofia, Sally, or Kalika). My decision to print the transcripts – instead of working on coding applications, such as NVivo or ATLAS.ti – was mainly guided by my third condition of data analysis methods, namely the preference to engage less with the computer screen and to engage more with creative work.

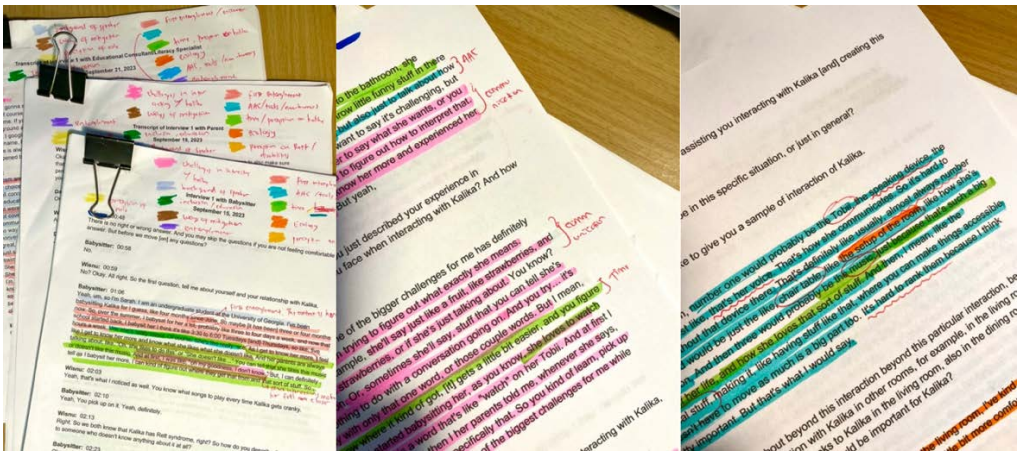

Figure 11. Color Coding and Wondering

The process of coding began with a quick reading of the transcripts where I circled all non-human elements mentioned in them. This process was done to help me gain a general idea of the transcripts and to identify the various kinds of non-human elements involved during Kalika's literacy activities with Sofia, Sally, and Baba. Following this process, I proceeded to descriptive coding, which is a coding technique that aims to capture key ideas in the data using a single word or phrase (Saldaña, 2021). Using different color markers (Figure 11), I reviewed each transcript and assigned labels to summarize ideas in the data. In total, there were 11 labels generated from this process, some of them include *ecology/environment* (orange), *roles of non-humans* (turquoise), *challenges* (pink), and *ways to mitigate challenges* (brown).

During this first cycle coding process, I also left a few notes on my wonders at the margin of the document. I define a wonder/wondering as a moment of contemplative reflection where the information I read on the transcripts connects with my thoughts in some ways and intrigues me to theorize, criticize, or question the situation. For example, I left a note on Baba's first interview transcript "Objects define/construct places" as I read his response to my question about the dining room and the objects within it, such as the table, Kalika's activity chair, and the Google home device. This wonder was relevant to Barad's (2006) conceptualization of the

entanglement between space, matter, and time, and the ways their intra-actions define their existence. On another occasion, such as in my field notes (see Appendix E and G), I wondered about the relationship of humans with animals as I saw Kalika's engagement with her cats. All these wonders supported me in developing narrative texts as an additional later of data analysis which I will explain in the next section.

Following the descriptive coding, I engaged in thematic coding to synthesize, "putting things together into new assemblages of meaning" (Saldaña, 2021, p. 5). In this stage, I arranged all relevant quotes from the transcripts based on the research questions of this study. This process was done on Word documents on my desktop for convenience in cutting and pasting segments of transcripts according to the categories. It involves another round of reading all transcripts, reviewing codes and wonders from the previous coding stage, and mapping the quotes to separate documents based on the research questions.

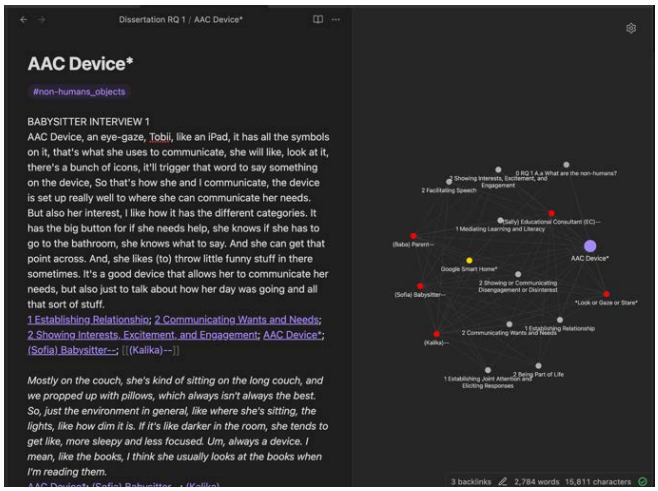

Figure 12. Screenshots of Obsidian on AAC Device Page

Lastly, I engaged in free coding or initial coding, which is a coding technique that allows researchers to "reflect deeply on the content and nuances of your data and to begin taking ownership of them" (Saldaña, 2021, p. 148). I experimented using a personal knowledge

management software called Obsidian which allows me to see connections between codes and data (Figure 12). Data on this software, according to their privacy webpage, are "saved locally on your device and is never sent to our servers" – they (the developer) "do not collect any personal data" nor "collect any telemetry data." Therefore, no other party except the user (me) has access to the data on this platform.

To code on Obsidian, I first ensured that all names of my participants were deidentified on the transcript using their pseudonyms (child, parent, babysitter, educational consultant). I then created a page on the platform followed by copying and pasting each segment of transcripts from the previous stage onto the page. After that, I reviewed the segment carefully and assigned codes to the segments based on the humans and non-humans mentioned in the segment and their roles in Kalika's literacy. These codes act as the linkages that connect the specific segment to other transcript segments with the same tags. This process was repeated until all segments from the previous stage were transported to Obsidian. Once all the segments were transported and coded, I could see graphs that visualize the network of data and their relationships.

As I engaged with the practices of coding, I experienced the feeling of distance not only from the nuance of my data but also from the theories that guide this study. As I explained earlier, posthuman studies require researchers to constantly engage or think with the data and the theories. Meanwhile, coding tends to take the researchers away from the texture, complexity, and context of the data (MacLure, 2013a). It also "ignores the entanglements of language and matter, words and things" (MacLure, 2013a, p. 171), which are central in posthuman research. Therefore, I feel the need to engage with additional practices of data analysis to bring me back to my data and explore their texture and complexity while thinking with theories or reading

diffractively. The following explains two additional layers of data analysis that help me mediate my thinking with data and theories.

Narrative Writing. Following the cycles of coding and identification of major themes, I decided to create three narratives from my observation experiences that later would be used as an opening and a context for the discussion on the thematic findings from the earlier analysis stage. Narrative is "the telling (or retelling) of a story in a specific time sequence" (Holley & Coylar, 2009, p. 681). Narrative analysis highlights the role of constructing a plot as a human strategy to know and understand the complexity of lived experiences. Plot, as Brooks (1984) argued, embodies "the principle of interconnectedness and intention" (p. 5) – it binds together the seemingly discrete aspects of life, characters, and series of events in human life. Narrative provides researchers with a framework to systematically organize, interpret, and communicate their experiences and understanding of events in a coherent and meaningful manner (Polkinghorne, 1995; Freeman, 2017). In this study, narratives are especially useful as a medium to not only express my experiences in doing the research but also to capture Kalika's complex communication repertoires as well the entanglement of humans and non-human elements, which transcripts and coding cannot effectively capture (MacLure, 2013a).

To create the narratives, I went back to the 'table of contents' of my data to identify photos, segments of videos, and notes that can support my narrative writing. Subsequently, I closely reviewed the selected data and organized it based on key themes identified during the coding process. This process was then followed by the development of the narratives and arrangement of visuals from the photos and screenshots of videos to provide richer narrative details. During the process of constructing the narratives, I engaged in some readings of research articles, guiding theories, and memos as a practice of diffractive reading. These three narratives

were growing narratives, meaning that I often revisited the narratives, made some edits, and added more details as I wrote the findings and discussions of this dissertation.

Collage. The last layer of thinking with data I engaged with was creating visual arts through collage. As I mentioned earlier, I would like to engage with data in multimodal ways beyond coding. This was done not only to provide joy and bring me closer to the data but also to experiment with data and data analysis, as Deleuze and Guattari (1994) advocated. This entanglement of data analysis and artmaking practices illustrates the conjoining of research and creation where "doing is thinking and philosophy is an experimental practice that co-exists with art and artmaking" (Flint, 2020).

Collage is a process of constructing visual compositions by assembling a variety of materials, including previously made objects and images (Freedman & Siegesmund, 2023). Collage provides an avenue for researchers to stimulate visual thinking and articulate ideas that cannot simply be expressed in words (Holbrook & Pourchier, 2014). In analyzing data through collage, I think with Bennett's (2011) notion of assemblages. Assemblages, Bennett (2011) argued, are "ad hoc groupings of diverse elements, of vibrant materials of all sorts" (p. 23); they are emerging open-ended confederations with agentic capacity that is derived from the agency of each member constituting it. For Bennett (2011), everything, including data, is a mosaic of diverse bodies that work together forming a new phenomenon that "is distinct from the sum of the vital force of each materiality considered alone" (p. 23).

My collage process began with reviewing the identified sources of data from the narrative writing stage and re-reading segments of transcripts from the last stage of coding, i.e., the free coding, on Obsidian. This includes rewatching selected videos and screenshotting some episodes that could be useful as parts of the collage materials. After that, I started categorizing the data

followed by juxtaposing and layering them one after another on a Microsoft powerpoint, so it formed a new composition of different media (i.e., pictures, words, writing, cuts out of magazines, etc.). This practice not only allowed me to engage with my data in a multimodal manner, but also helped me visualize their interconnection with each other.

Positionality

I wrote this study as a multilingual Southeast Asian individual with only one functioning eye. I was born and raised in a multicultural, multilingual, and multireligious family in a patriarchal, able-bodied society on the island of Java, Indonesia, where attributes such as whiteness, heterosexuality, and ability are perceived as social properties (see Boveda & Annamma, 2023). As a male Javanese Muslim from a middle-class family, I enjoyed the access and privileges associated with being a member of a dominant ethnic group and growing up on the most developed island in the nation. These privileges include attending good public and private schools, the opportunities to learn foreign languages such as English, French, and German, acquiring dominant local languages (i.e., Javanese and Sundanese) from my family and the communities, and earning my bachelor's degree in English Education from a prestigious private Roman catholic university on the island. My intersectional identities and privileges collectively played a role in my success in securing jobs abroad and receiving a Fulbright scholarship to study in the U.S. This eventually led to the path I am currently taking, i.e., pursuing a doctoral degree abroad, which by itself is a significant educational privilege that does not come easily for many Indonesians, including my own family.

Growing up in a country where hierarchy permeates every facet of life, I learned a disability as a defect, curse, weakness, shame, burden, pity, and bad karma that must be kept secret or hidden from public eyes. In my own family, I have multiple relatives with disabilities,

including those with mental illness and profound intellectual disability whom I have only seen a few times in my life. The last time I can recall seeing my niece Bunga (pseudonym), for example, was in 2005 during a family gathering at my house. As she grows older and requires extensive support from her family, Bunga never attends any family gatherings and celebrations anymore. No one in the family speaks up or talks about this, including me, for it is considered culturally impolite and insensitive to intervene in other family matters.

In my case, I had only known that humans are supposed to be able to see with their two eyes when my right eye was injured from contact with a sharp object when I was in 5th grade. For about a month, I was not able to see, read books, or attend school. I also experienced a temporary mobility issue following a hit-and-run on the school premises when I was in 7th grade. I remember the feeling of sadness, shame, and difference for being sick, having to use crutches in front of my friends, and not being able to access public spaces independently. I was battling with my own trauma of crossing the road and seeing my left foot railed by a car with no professional counselor support from the school. I practically lost most access to the school facilities, including the lab and library that were located on the second floor of the building. I spent most of my lunch break alone in class while other boys played soccer outside. Let alone going to the canteen, I could not even go to the restroom due to the lack of accessibility for people with mobility issues.

During those times, I experienced the paradox of being both seen and unseen by society. The crutches and eye-patch had somehow drawn people's attention over me and instigated pity on me. I realized how the temporary embodiment of the 'assistive' non-human elements on my body shifted people's perception of my being where I was no longer seen as 'Wisnu,' but as a 'sick Wisnu' who required assistance to walk. On the other hand, I felt unseen because the

experiences of overcoming the trauma and not being able to read, attend school, and even go to the restroom on my own suggested that my lived experience, my body with a disability, and my entanglement with the assistive tools were never imagined by the teachers and the school community. In other words, I existed beyond their consciousness when they devised instructional plans, designed for the classrooms, and established school policy.

As I work on this project, these experiences of being highly seen and completely invisible along with my intersectional identity guide my thinking. This is reflected not only in the choice of theories that inform this study but also in its orientation, locus of investigation, and selection of methods. As explained in *The Epistemological Shift Toward Entanglements* section in Chapter 1, the orientation of this study is on the entanglement of humans and non-human elements in the context of an individual with significant disability. It aims to turn the gaze toward how the humans and non-human elements interact, exert agencies, and form a mutual relationality. This is accomplished by steering away from perceived misconceptions of the hierarchical status between humans and non-human elements and thinking with the non-human elements that are entangled with humans in literacy.

My relationships with the participants in this study are complex. I am navigating the roles of being a researcher who has interacted with the family beyond the scope of this research, a person of color with an invisible disability, an individual who grew up in a society that upholds much respect for older people, an L2 speaker of English, and a student whose doctoral advisor happens to be the mother of the focal participant, among others. Throughout the process of conducting this study, I am mindful of the complicity of my intersectionality, power dynamics, and inherent biases that influence my research approach and design as well as my interpretation

of data. These aspects include understanding how my perceived identity influences the way I see myself and how my participants see me in the research.

Having to engage with Baba, for example, requires me to be mindful of how his status as a person who is older than me, the father of Kalika, the husband of my own advisor, and an assistant professor influence the way I perceive his roles as a participant in the study. Other challenges include fears of intruding on my participants' privacy and family time, concerns about whether my data collection activities burden the participants, especially Kalika, and occasional struggles in finding appropriate English words to express opinions and questions to the participants. Lastly, as I work with the only child of my Ph.D. advisor, I also need to be aware of our complex relationship as an advisor-advisee and parent-researcher.

I am mindful of the complexities that I had to navigate during this study. To preserve my desire to tell the story of Kalika's entanglement and to prevent my analysis from being overly influenced by these complexities, I practiced reflexivity throughout the research process. Reflexivity, Haynes (2017) explained, is a researcher's practice of critical thinking, questioning, and self-awareness on the ongoing and reciprocal influence between themselves and the research participants throughout the research process. In this study, my reflexivity is facilitated by creating visual and written memos, as illustrated in Figure 9, Appendix E, and Appendix G.

In this chapter, I have laid out the multiple ways I employed to approach, work with, and think with data. I have explained the methodological paradigm, the mode of thinking, and the methods of data collection and analysis used in this dissertation. I have also described the human participants involved in this study and the ways I intersect with this project. In the following section, we will explore the findings of my examination of Kalika's more-than-human literacy

entanglements. Specifically, we will unpack how humans and non-human actants are entangled during literacy activities at home in a significant disability context, who and what these humans are, what roles they play in the entanglements, and why their presences matter.

CHAPTER 4

THE VITALITIES AND ASSEMBLAGES OF HUMANS AND NON-HUMAN ELEMENTS IN KALIKA'S LITERACY

'' …our meaning-making and the learning we do is dependent on the material world around us. The material world acts upon our thinking just as much as our thinking acts upon it.''

(Lenz Taguchi, 2010, p. 49)

I open this chapter with a powerful quote from Lenz Taguchi on the significance of the non-human elements in our learning and meaning-making process. Lenz Taguchi's argument highlights the intra-active relationship between actants and the inseparability of non-human elements with the human processes of knowing, doing, and becoming. She called for the 'material turn' in research to challenge the longstanding ontological separateness between human and non-human actants that places humans at the core of knowledge production. Actants, as I described in Chapter 1, are both human and non-human elements possessing the efficacy to produce and alter a phenomenon (Latour, 2004). The term actant is adopted in this study to highlight the entity's distinctive capacities to "make a difference, produce effects, alter the course of events" (Bennett, 2011, p. viii). Their capacities, Latour (2004) continued, are not determined by preconceived notions of hierarchy between human and non-human elements, but are "deduced from its performance" (p. 237) in influencing and altering each other within a phenomenon. Thus, the use of the term 'actant' in this study aims to destabilize the taken-for-granted hierarchical relationship between humans and non-human elements that often places non-human elements subordinate to humans (see Braidotti, 2013; Nayar, 2014). The terms intra-

active relationship or intra-action, on the other hand, refer to the more-than-human interactions within a phenomenon where actants exist through their entangled intra-relating. Barad (2007) employed this term to contrast with 'interaction' which underscores the social interactions of people.

This dissertation responds to Lenz Taguchi's (2010) call to decenter humans, turn the gaze into the non-human elements, and delve into the entanglement between humans and non-human elements in language, literacy, and disability exploration. By taking a posthuman perspective in exploring the literacy entanglement of Kalika, a 7-year-old individual with significant disabilities, with other humans and non-human elements, I endeavor to revisit the established understanding of literacy engagement and communication. In short, this dissertation is part of a collective effort to cease and desist "the dictatorship of no alternatives" (Unger, 2005, p. 1) in our ethico-onto-epistemology of language and literacy. I pursued this goal through, among others, putting language and literacy scholarship in conversations with disability studies, employing different ways of thinking with and working with data, and adopting a posthuman lens, which is a relatively new perspective in language and literacy education, applied linguistics, and disability studies (see Goodley et al., 2014; Pennycook, 2018; Kuby et al., 2019).

As discussed in Chapter 2, posthuman studies highlight the vitality (Bennet, 2011) or agency (Barad, 2007) of humans and non-human elements in a phenomenon. It recognizes the roles of non-human elements in everyday social practices, meaning-making processes, and knowledge production (Barad, 2007). It challenges the taken-for-granted notion of humans as superior entities in the world. It is important to note that in posthuman studies, the roles of humans are not eliminated, but they are decentered and perceived to be part of an entanglement with non-human elements (Kuby, et al., 2019). Posthuman studies seek to understand the

bonding of humans and other types of beings, as well as how each actant exerts their vitalities in their interconnections.

This chapter presents the findings to answer my first research question, i.e., "How are humans and non-human actants entangled during literacy activities at home in a significant disability context?" Specifically, I unpack a) who and what the actants are part of Kalika's language and literacy activities and b) what roles these actants play in language and literacy activities for Kalika. I employed posthuman methodology and a diagrammatical mode of thinking as a methodological approach to answer the research questions. The methods I employed to examine data from my participants included coding, narrative constructions, and collage-making. These three different methods are employed to help me engage in different perspectives in analyzing data or diffraction (Barad, 2007) which posthuman scholars are encouraged to do in their research (Ulmer, 2017). The narrative constructions, especially, play crucial roles in mediating my "thinking with theory" (Jackson & Mazzei, 2011, p. 717) during the data analysis process. As Mazzei (2014) articulates, diffractive reading of scholarship and data "moves qualitative analysis away from habitual normative readings (e.g., coding) toward a diffractive reading that spreads thought and meaning in unpredictable and productive emergences" (p. 742).

As you begin reading the sections in this chapter, you will encounter narratives that I constructed during my data analysis. All narratives in this chapter, as well as the excerpts of observations, are interconnected with each other as they center on the same focal human participant, i.e., Kalika. Thus, it is important to read them carefully to gain a holistic view of the more-than-human entanglements in Kalika's literacy. These narratives are my invitations to you to be entangled with me and my dissertation – they retell my first-person point of view of

observing, interviewing, and discussing the roles of humans and non-human elements during Kalika's literacy sessions at her home. By laying them here, I endeavor to contextualize my discussions on Kalika's literacy entanglement and better display the types of actants in the entanglements, the intra-actions among the actants, and the roles of each actant during the literacy activities of my participants. They serve as a medium for me to present the observed entanglements of actants in a meaningful way, mobilize "a cultivated, patient, sensory attentiveness to nonhuman forces" (Bennet, 2011, p. xiv), and turn the gaze to the "matter as vibrant, vital, energetic, lively, quivering, vibratory, evanescent, and effluescent" (Bennet, 2011, p. 112).

Additionally, these narratives also serve as a demonstration of my engagement with theories and data during the course of this study. As (Jackson & Mazzei, 2011) suggested, a central aspect of posthuman research is the researcher's continuous engagement with theories to engender unexpected ripples of insights. I adopted narrative construction as a way to think with theories during my analysis and to invite my audience (you) to be entangled with me in my analysis journey. Specifically, I engaged in thinking with the conceptualizations of space, the vitality or agency of actants, and assemblages in critical posthumanism. Each of these conceptualizations will serve as a theoretical backdrop for my discussions of entanglements during Kalika's literacy activities with Sally, Baba, and Sofia, which will be further discussed in the next three sections.

This chapter is divided into three parts, namely *Part I: Thinking with Space and Its Intra-Acting Actants*, *Part II: Thinking with Actants in Complex Communication Repertoires*, and *Part III Thinking with the Assemblages of Humans and Non-Human Elements in Literacy*. As I mentioned earlier, each section/part begins with a distinct reconstructed narrative that I

developed from my diffractive readings of theories guiding this study, relevant research articles, and my research data (i.e., observation notes, interview and focus group discussion transcripts, and reflective memos. I initiate the discussions with an examination of the roles of space in Kalika's literacy and how space materializes and becomes matter in supporting Kalika's literacy engagement. Following this, the discussions transition to an exploration of the vitality of the human and non-human elements in Kalika's communication repertoires during her literacy activities. This section aims to unravel the entanglement of actants in facilitating Kalika's communication with Sally, Baba, and Sofia as she engages with them during storybook reading, spelling activities, and math homework, among others. Lastly, I delve into the assemblages of human and non-human actors that support Kalika's engagement in those activities.

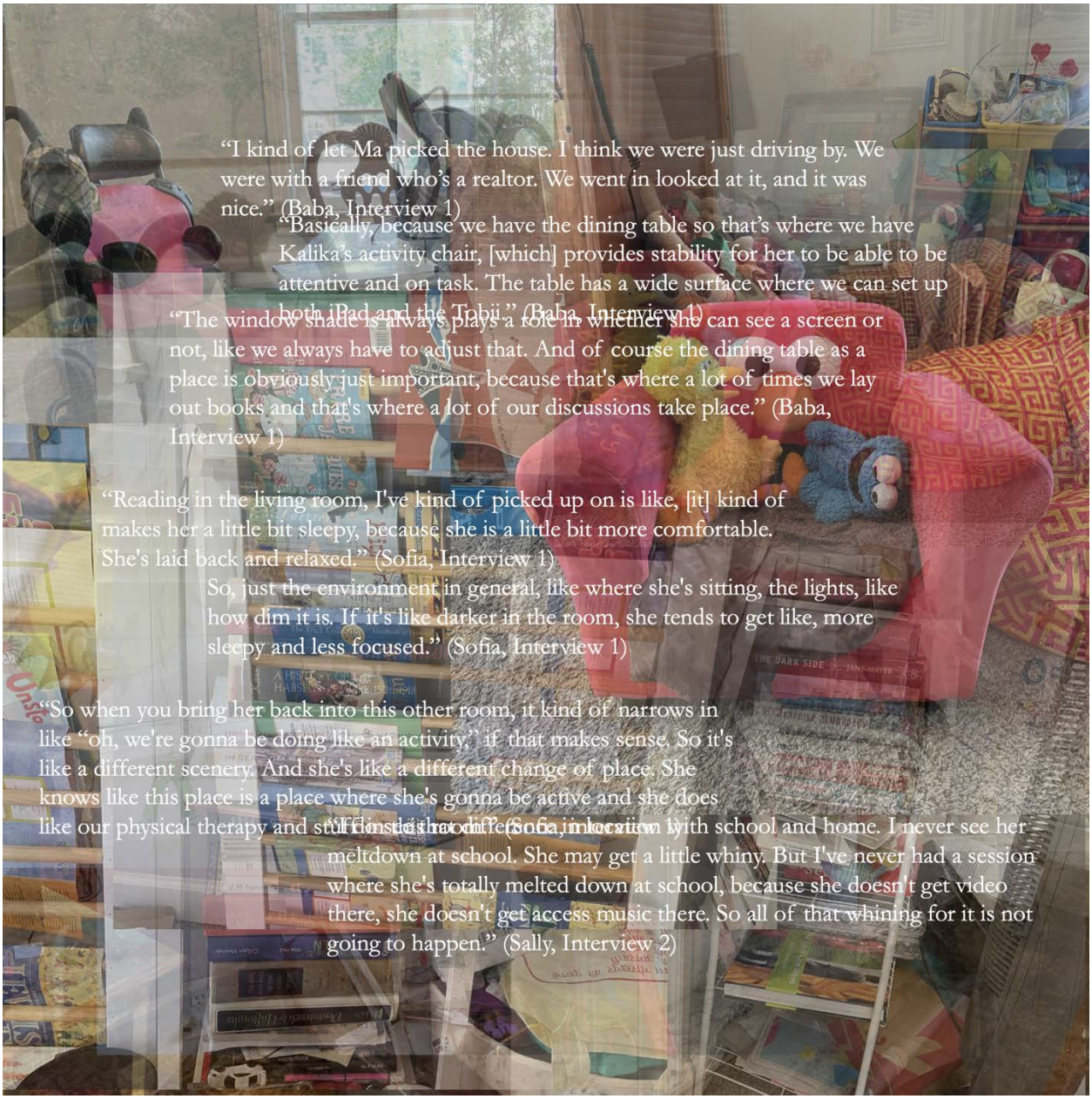

Illustration 1. Collage of Thinking with Space and Its Intra-Acting Actants

Part I: Thinking with Space and Its Intra-Acting Actants

The narrative below is a reconstructed narrative that retells my experiences of visiting Kalika's house for my last observation of Kalika's session with Sally on September 30. In crafting this narrative, I think with the posthuman conceptualization of space from Barad (2007) to provide more nuance to the narrative and continuously engage with theories as Jackson and Mazzei (2011) suggested. I also included data from the ones I gathered during the last observation as well as other data I collected from my earlier visits to the house. These include a visual memo on my observation on July 8 (see Appendix G), a written memo of Kalika's house location from my first visit on July 1, segments of transcripts from the first interview with Baba on September 19, and reflective memos during my data analysis, among others. The inclusion of data from various resources is intended to help me see the network of data I have for this specific theme, i.e., thinking with space and the intra-acting actants within it. An actant, as I described in Chapter 1, is either a human or non-human element that has the efficacy to produce and alter phenomena within an entanglement (Latour, 2004; Bennett, 2011). In the literacy context, such as during a story reading activity of a child with her mother before bed, some actants that are involved in their intra-action may include the book they are reading, the bed and pillows they lie their bodies on, the blanket covering their bodies, the reading lamps in their bedroom, as well as the child and her mother.

As you read this narrative, I invite you to tune in your attention to the space and the configurations of the non-human elements within it. If you are reading this dissertation in your workspace, you might begin by thinking about how you are related to the space, what makes

your workspace a ‘workspace’, what drew you to work and read this dissertation in the space, and how your body is orientated towards the space and other non-human elements within it, e.g., computer, laptop, chairs. etc. With the space I am going to share with you, which is Kalika’s house, I invite you to observe details in the narrative, including the pictures and the various non-human elements I mention in the narrative to help you see the various actants within a space have been continuously playing in the background as ‘humans’ do their activities. I specifically invite you to see how the space and the non-human elements within Kalika’s house intra-act with Kalika, Sally, Sofia, and Baba during their literacy activities.

Following this narrative, I provide a discussion of the narrative as a segue to the elaboration of the entanglement of space and Kalika’s literacy activities with her parents, her babysitter, and her literacy specialist.

Narrative 1

Space as An Actant: The Assemblages of Kalika’s Family House

September 30, 2023

“Thank you for driving me. I hope you have a great day,” I said to my Uber driver as I was about to close the rear door of the car. It was my last day coming to Kalika’s house to observe her session with Sally. As I got out of the car, I took a closer look at Kalika’s house for the very last time and began inspecting the elements that make up this house; starting from the pebbles on the driveway, the big tree that stood strong by the main road, the flowerpots and plants that decorate the house, the black metal handrails leading to the front door, and the brick façade of the house.

Constructed in the 1940s, Kalika’s house was a classic brick home situated in one of the county’s historic districts named after the institutional precursor of the college where Ma and Baba worked. It was strategically located between two nearby major hospitals, multiple restaurants, and a few elementary schools, including the school where Kalika attended.

My memory traveled back to the first day of my observation. On my notebook, I noted a few details about this house that were quite distinct to me:

“Frequently heard ambulance sirens.” (Field Note, July 8)

The sirens indicates that hospitals were in close proximity to the house. As I reflected on the profound disabling Rett syndrome symptoms that Kalika experience, I wondered if the decision to choose this house—out of the many houses in less busy and noisy areas in the city—was intentional and had something to do with the convenient access to the nearby hospitals. I questioned myself whether the nearby hospitals did have a specific entanglement with the family in a way that they provided ease to Baba and Ma in case something urgent happened to Kalika or if they needed to get medication for her. I extended my curiosity and asked Baba a question about why the family chose this house in our first interview. He responded that,

> "I kind of let Ma pick the house. I think we were just driving by. We were with a friend who's a realtor. We went in looked at it, and it was nice." (Baba, Interview 1)

Figure 13. Kalika's Wheelchair Parked in Front of The House

Before living in this house, the family resided in another house, approximately a 3-4-minute drive from their current location. I still remember the old house vividly, especially the living room where I made an attempt to read Kalika a book after a dinner we had with a few of my classmates a few years ago. At that time, Rett syndrome had not hit the family, nor did I know what entity or organization (Foucault, 1963/1994) it was—Kalika was still walking, running, holding toys with her hands, and babbling a few words from her mouth. It was interesting to think about how the old house, which I only visited one or two times in the past, had such power to evoke memories that had been idly sleeping at the back of my mind. Perhaps this was what Barad (2007) called 'agency' or 'vitality' in Bennett's (2011) 'Vibrant Matter' of the non-humans. Space does record memory and history; it is somehow 'alive' and plays a certain role within the complex web of entanglement that I have with the family since 2017.

While Baba's response to my question clarified that their decision to choose the house was not solely based on the house's proximity to the hospitals, he did acknowledge the convenience of having the hospitals nearby.

> "It just came in after. At one point Kalika was having recurring seizures. We had to get blood drawn several times a month, and we found that at the St. M [hospital], which is

still a 3-minute drive [from home]. There was a really good phlebotomist, so it was really convenient then having St. M [around]." (Interview 1)

The front yard of the new house featured an entrance way with small pebbles, a few square red concrete patio stones, and a big tree that stood right in front of the house for decades. The front facade of the house showcased red brick walls with three large windows painted in white and a black staircase leading to the entrance door. Notably, Kalika's wheelchair was often parked in front of the stairs, a fixture in the daily tableau of the house that served as a reference point for me and my Lyft/Uber drivers in locating Kalika's house from the main street during my initial visits (Figure 13).

Kalika's house spanned approximately 1,500 square feet, consisting of a living room, a modern kitchen, a dining room, three bedrooms, and a flex room that had been repurposed into Kalika's playroom. The architecture and design of this dwelling encapsulates a phenomenon where the past and the present temporalities intra-act, but are never eliminated. The existence of the classic 1940's red-brick design at the façade juxtaposes with its modern-design interior, especially the kitchen and remodeled bathrooms. Such temporal entanglement in the design of the house illustrates the house's iterative becoming across the time; the house carries within itself the sedimented history of its intra-actions within and as part of the world (Barad, 2007, p. 180).

Contrary to the notion of space as a fixed container, Barad argues that space is not just a collection of preexisting points in a set geometry, but a dynamic entity shaped by ongoing human-and-non-human interactions (Barad, 2007). What makes this building a 'home' is the interactions between each space, every piece of furniture within those spaces, and the humans inhabiting them, which together they form different spatial configurations for cooking, eating, sleeping, studying, and playing. These configurations stand in contrast to the spatial affordances found in other nearby buildings, such as schools, restaurants, hospitals, or even the Uber car that I was riding in today. Every element and their intra-actions within this space, including the tree, the bricks, the wheelchair parked in front of the entrance stair, the G-tube sets in the kitchen (Figure 14), and the oxygen tank resting on Kalika's bookshelves enact specific identities that distinguish this space from other buildings or dwellings on the street, forming a specific entanglement called "Kalika's family house."

One of the most crucial spaces in Kalika's family house was the dining room. Positioned adjacent to the kitchen and living room, the dining room boasted two large windows facing the street, a spacious wooden table at its center, Kalika's activity chair, and chairs on either side where Baba or Ma sit. The windows were equipped with window shades that Baba expressed, "always play a role in whether she can see a screen or not; we always have to adjust that" (Baba, Interview 1). Additionally, the family had a Google Home device placed on the window ledge. This virtual assistant technology was linked to Kalika's eye-tracking AAC device (Tobii), so she could request and play her favorite songs through her device.

Another significant room where Kalika often spent her afternoon was the playroom (Figure 15). Situated at the rear of the house, this space forms an L-shaped space with several big windows and doors that opened to the side and backyard. In this space, the family housed

various items, such as art and craft supplies, board games, a small wooden table, an Elmo-upholstered chair, and an array of children's' books in English, French, and Hindi. The walls were decorated with some decals of Kalika's favorites, such as the solar system, Elmo, BigBird, and Cookie Monster from Sesame Street. This was where Kalika and Sofia often spent their afternoon time together for book reading, play make ups and board games, doing homework, and watching Sesame Street from her iPad.

Figure 14. Kalika's G-Tube in the Kitchen

Figure 15. Kalika's Playroom

The last room that held importance to Kalika's literacy was the living room. It was a space where Kalika would sometimes sit with Ma as they waited for Sally's session, danced with Baba, and read storybooks with Sofia. The living room had two sofas and a coffee table where the family would lay out books and magazines. These included recipe books featuring world cuisines from Italy and countries in the African continent, Indian American community magazines, and children's books borrowed from the library. Among these children's books were 'Miracle Man: The Story of Jesus' by Hendrix (2016) and 'Muhammad' by Demi (2003), one of the few books the family borrowed from the city's library when they visited it with me

on July 8. Baba mentioned that he was introducing Kalika to world religions and the topic of refugees. This was done because Kalika came from a religious family with a history of being refugees and immigrants (Field Notes, July 8).

No one was in the living room as I entered the house today. I heard nothing but the gurgling water from the cat water fountain in the living room. Usually, I would hear the sound of a blending machine from the kitchen, indicating that either Ma or Baba was preparing food for Kalika's session with Sally. As I set up my recording tools at the kitchen, I observed that the dining room had been set up for Kalika's virtual session with Sally. On the table, there were Kalika's iPad that was mounted on a portable stand and her eye tracking AAC device (i.e., the big Tobii) that was propped up using a thick book on its back. I also saw Kalika's activity chair parked in its usual space (Figure 16).

Figure 16. Typical Set-Up of Kalika's Session with Sally

"Hi Wisnu," Ma greeted me from the back while carrying Kalika from the bedroom. After a brief exchange on how our days were, she then put Kalika on her activity chair, put on the harness on Kalika's body, covered Kalika's body with a *kapor* (blanket), and turned on Kalika's big Tobii (eye-tracking device) and the iPad on the table for Kalika's virtual session with Sally. Not long after, Sally logged in to the session and had a quick chat with Kalika about her session at school yesterday.

"Bad, bad," said Kalika through her big Tobii as Sally, Kalika, and Ma talked about how the session at the school went (Figure 17).

"No, not bad, it was really really good," Sally responded while pressing the words 'really' and 'good' on the Tobii to model Kalika where the words were located on the system. She then reminded Kalika that she spelled the words 'sad', 'and', and 'sand' at school yesterday.

Following this brief exchange, Sally explained the agenda of the day to Kalika. Kalika vocalized and began to express her discomfort. Ma responded to the signals by holding Kalika's right hand to help reduce her repetitive hand movement. As Sally noticed that Kalika whined and was about to cry, Sally said,

"So, here's what I want you to remember. I want you to remember how calm you kept your body at school. You kept it so calm and relaxed so that we could get so much work done."

After ensuring that Kalika was calm, Sally began the session by reviewing the lesson Kalika had at school. She wrote the word "as" on her device and projected it on Kalika's iPad so Kalika could see the writing. While writing, she elongated the 'a' sound so Kalika could hear the vocal sound in the word.

"A", said Kalika on her big Tobii.

"Uh uh, there is an 'a' there," Sally responded. She then wrote the word "an" for Kalika to see. Noticing that Kalika had hard time seeing the words on her iPad, Sally said,

Figure 17. Kalika Saying "Bad, bad" on Her Device

Figure 18. Ma Adjusting Kalika's Activity Chair

"I would have her face the iPad, so that she is looking straight at the letters." Ma then stood up and slightly changed Kalika's activity chair position so she could see straight to the iPad screen (Figure 18). Baba soon came from the bathroom and joined the session. He helped Ma adjust the position of the iPad and turned it 180 degrees so that the camera was facing a certain angle.

"There we go", said Sally. She then continued the lesson with the words "ban", "bad", "and", "sad", "sand", and "band" and elongated the sound 'a' in each word for Kalika to notice.

During the activity, Kalika had difficulties in maintaining her head up straight; she was observed looking down a few times when Sally explained the words to her. To help Kalika see Sally's instruction on the iPad, Ma and Baba occasionally held Kalika's head up. They were also observed holding Kalika's hands from each side to help reduce her repetitive hand movement.

The lesson progressed to the book reading activity, which required Kalika to look at the words and illustrations of a story on her big Tobii. After uploading the book onto Kalika's big Tobii, Sally reviewed each word in the book they read last time. Kalika looked at the words on her Tobii as Sally reviewed them.

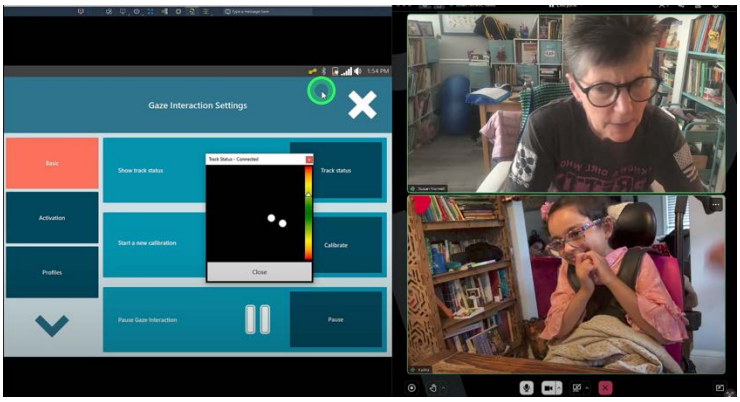

Figure 19. Sally Tracking Kalika's Eyes

"Oh, now we can put her in position to be in front of her device since we are reading. I forgot we need to move her back," said Sally to Baba. Earlier, she noticed that Kalika had been turning her head to the right to see the words on the screen of her Tobii.

Baba then adjusted Kalika's activity chair position so that it aligned straight in front of Kalika's big Tobii. After that, Sally navigated Kalika's Tobii from distance and opened an application to track Kalika's eyes position on the Tobii (Figure 19).

"She is a little close and the device needs to go to the right a little," Sally said. Baba raised from his chair and adjusted Kalika's big Tobii position based on Sally's direction. He moved the device a little to the right while observing the eye-tracker status on Kalika's Tobii.

"I would still move the device a little to the right," said Sally as she noticed that Kalika's eyes were still not in the ideal position. Baba followed by slightly moving the device to the right.

"There we go. Super. Super," said Sally before closing the application and continue the reading activity. To show her engagement during this activity, Kalika needed to fixate the presented words on her Tobii for a certain period (less than one second) until a pink border

appeared around the words (Figure 20). Fixation, as Mat Zain et al, (2011) expressed, indicates an individual's mental process of information; it requires the individual to look at a specific area of interest (e.g., words) for a certain period of time to show their attention. Thus, Kalika needed an ideal position so she could see the words easily and show her engagement.

Sally presented single words from the story on Kalika's Tobii for Kalika to fixate. As they came to the word "friends", Sally said:

"I think this (word) makes you very happy. These are all the kids in your class," Kalika looked at her Tobii while listening to Sally's description of the word. As a pink border had not appeared yet, Sally provided more time for Kalika to read the word by extending the conversation.

"Your friends make you really happy. That word starts with an 'f'", said Sally. Kalika turned her head to Sally and smiled at her. Soon after, Kalika looked at her Tobii and fixated the word "friend" until the pink border appeared.

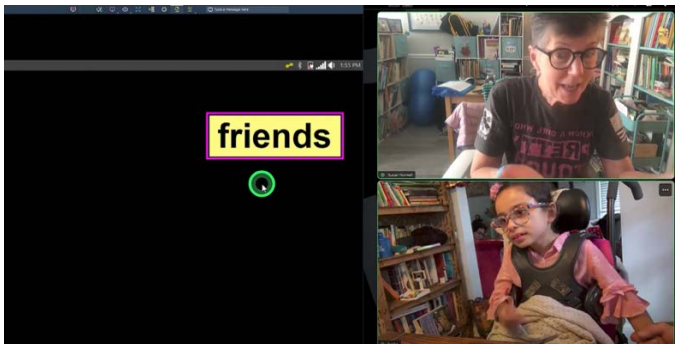

Figure 20. Pink Border Indicating Kalika's Successful Fixation on the Word "Friends"

Figure 21. Kalika Looking at the "Yes" Symbol in Response to Sally's Question

When they reached the middle of the book where Kalika had to identify if the word "bubbles" begin with the letter "b", Sally held up a communication board with the letters "a", "b", "c", and "d" as well as the "yes" and "no" symbols on it.

"Do I need a 'b' [to begin the word 'bubbles']? Yes or No?" asked Sally while pointing to the "yes" and "no" symbols on the board.

Kalika slowly raised her head, looking up at the ceiling, turned her head to the iPad where Sally was holding the board, and looked at the "yes" symbol on the board (Figure 21). To confirm her answer, Sally provided more time for Kalika to think and express her response for the second time. Kalika then looked up at the ceiling again, turned her head to the iPad, looked at the "yes" symbol on the board, and vocalized.

"Yes," said Sally and Baba. Kalika smiled as she heard Sally and Baba's response to her answer.

The narrative above captures curated moments where space is entangled with Kalika, Sally, Baba, and Ma in one of her Saturday afternoon literacy sessions. I began the narrative with a discussion of the house to provide an overview of the space or place where all of Kalika's literacy entanglement in this study occurs as well as a theoretical backdrop of how posthuman scholars conceive space. I specifically think with Barad's (2006) conceptualization of space to illustrate the ways in which space, which in this case is Kalika's house, is not simply a static and void non-living entity. I argued and elaborated how the house itself is not simply a 'thing', but it is an assemblage of human and non-human actants that continuously intra-act with each other. The specific tree, the bricks, the stairway, and the wheelchair are some of the actants that intra-act and form a specific entanglement called 'Kalika's house'. I also described the iterative becoming of the house throughout time in a way the classic design of the house façade somehow juxtaposes with the interior. Such juxtaposition, I contend, signifies the house as an entity that grows and changes alongside time and the humans inhabiting it.

Following the broader context of the space, I continued the narrative with the discussion of the three spaces where most of Kalika's literacy sessions with Sally and Sofia took place in this study, namely the dining room, the playroom, and the living room. In this part of the

narrative, I laid out key non-human elements that make up the spaces as a ‘dining room’, ‘playroom’, and ‘living room’ of Kalika’s house. For the dining room, for example, I specified the dining table, the windows, and the various non-human elements that are closely tied to Kalika’s literacy experiences, such as the activity chair, the iPad, and eye tracking AAC device (i.e., the big Tobii). This part of the narrative provides a ‘zoom-in’ perspective of the significant spaces where all Kalika’s literacy activities with Baba, Sally, and Sofia were conducted during the course of this study. I then continued the narrative by narrating events where the humans worked with the non-human elements within the dining room during Kalika’s literacy session with Sally. For example, I described how Ma, Baba, Sally, and Kalika intra-act with Kalika’s activity chair, eye-tracking AAC device (the big Tobii), and iPad by modifying their positions to different spaces on and around the dining table. I also described how Kalika engaged in literacy activities with Sally through her use of AAC device, gaze, body movements, and facial expressions (e.g., smiles).

In the following section, we dive deeper into how the spaces or rooms in the house and the materials within them play roles in shaping Kalika’s literacy experience and how Baba, Sally, Sofia, Ma, and Kalika intra-act and are entangled with the non-human elements in those spaces.

Space and Its Agency in Supporting Kalika’s Engagement in Literacy Activities

Space plays roles in shaping Kalika’s literacy experience with Sofia, Sally, and Baba. In this study, Kalika’s literacy activities took place in different parts of the house, namely the dining room, the playroom, and the living room. Specifically, two out of the eleven literacy sessions I observed occurred in the playroom, one took place in both the living room and the playroom, and seven sessions were held in the dining room, making it the most frequently utilized space for Kalika’s literacy sessions. Additionally, there is also one session conducted in

a city in the midwestern region of the country where Sally lived. However, this session only lasted for about 10 minutes of brief exchanges between Kalika and Sally; Kalika slept for the rest of the session due to fatigue from the long travel, time difference, and medication.

As Sofia, Sally, and Baba discussed the roles of the space in Kalika's literacy, they shared two main aspects that make the spaces or rooms in the house matter, namely 1) the significance of the spaces and the non-human elements within them; and 2) the vitality or agency of the spaces in influencing Kalika's behavior during literacy activities.

The Significance of Space and Intra-Acting Actants

Table and Seating Instruments in the Dining Room, Living Room, and Playroom

Spaces and the intra-acting actants (the humans and non-human elements) within them matter in shaping Kalika's literacy experience. When I asked Baba and Sofia to explain their considerations for choosing a specific room for Kalika to have literacy sessions with them, they described key non-human elements within the room that they perceived as crucial in ensuring Kalika's effective engagement during literacy activities with them. Baba, for example, specifically mentioned the dining table and the activity chair as crucial elements that underlay his decision to choose the dining room as a space for having Kalika's session with Sally. In responding to my question, *"from all the rooms in your house, why did you choose the dining room?",* he explained that:

> "Basically, because we have the dining table so that's where we have Kalika's activity chair, [which] provides stability for her to be able to be attentive and on task. The table has a wide surface where we can set up both iPad and the Tobii." (Baba, Interview 1)

In the text above, Baba particularly highlighted the dining table as a non-human element that offers spatial affordances for laying out other non-human elements that also play significant

roles in mediating Kalika's interaction with Sally, namely the iPad and AAC device. For Baba, the big Tobii serves as "a chalkboard" (Baba, Interview 1) for Sally's interaction with Kalika, "except that she (Kalika) is also writing on the chalkboard" (Baba, Interview 1). In Narrative 1 above, for example, the device serves as a means for Sally to present instructional materials for Kalika, such as a storybook where Kalika needs to look at the words and illustrations of the book during their reading activity. At the same time, the device also provides a medium for Kalika to show her engagement in the activity by fixating on the target words and illustrations as well as communicating her opinion about the book.

Meanwhile for the iPad, Baba perceived the role of the device as a medium "where the literacy really takes place" (Baba, Interview 1) and "where the learning happens" (Baba, Interview 1). He explained that the device mediated Kalika's interaction with Sally because their communication is mainly done "through partner-assisted scanning" (Baba, Interview 1). Partner-assisted scanning is a communication technique where a communication partner presents options or choices to an individual with complex communication repertoires, who then indicates their choice using signals such as eye movements, head movements, or finger movements (Bayldon et al., 2023). In Narrative 1 above, specifically, partner-assisted scanning occurred when Kalika responded to Sally's yes or no question on whether the word "bubbles" begins with the letter "b". During the interaction, Sally not only used a communication board for Kalika to signal her "yes" or "no" answer, but also continuously observed Kalika's gaze, gestures, and body language as part of her complex communication repertoire.

The importance of the dining table and its spatial aspects in accommodating other significant non-human elements in Kalika's literacy activity with Sally are also reflected in Baba's drawing of his entanglement with other humans and non-human elements (see Figure 22).

In responding to the prompt of drawing I gave to him, i.e., *"What does the entanglement between humans and non-humans during Kalika's literacy activities look like to you?"*, Baba drew all actants he considered important in the entanglement of Kalika's literacy activities in the dining room, namely the table, the iPad, the big Tobii/AAC device, the food for Kalika, Baba, Kalika in her activity chair, and the stuff under the table, such as the cords and chargers of Kalika's devices.

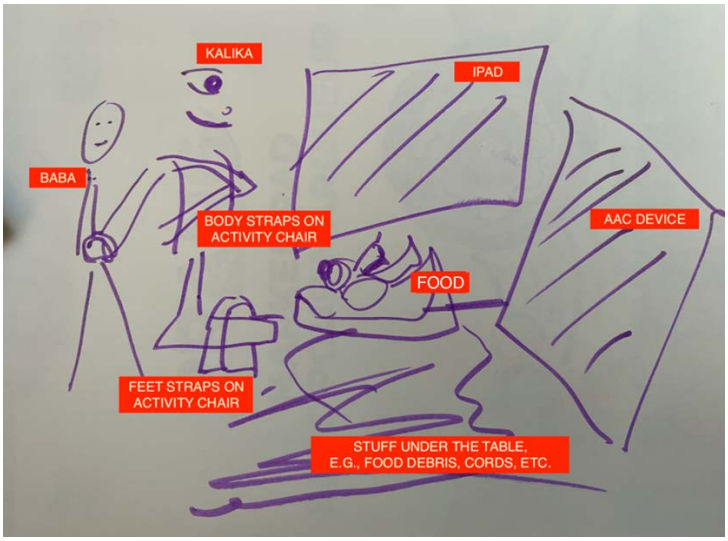

Figure 22. Baba's Drawing Illustrating His Entanglements

In the drawing, the table was set as the central space within the dining room where Kalika's literacy activities with Sally were organized. This table is a significant non-human element where Baba and Kalika are physically oriented throughout the session with Sally. It is also where Baba arranged all the things that matter to Kalika during her virtual literacy sessions with Sally, namely the iPad, the big Tobii, and the food. As Baba argued in our first interview, "the dining table as a place is obviously important because that's where a lot of times we lay out books and that's where a lot of our discussions take place" (Baba Interview 1). His drawing is reflective of the typical scene I observed during Kalika's session with Sally throughout the data collection process. Figure 16 in Narrative 1 above, for example, portrays Kalika's literacy

session with Sally where the table plays a significant role as a space where the entanglement of humans and non-human elements is established during Kalika's literacy activities with Sally. The table provides spatial affordances to connect not only Kalika and Baba with the crucial non-human elements but also with Sally, who resides in a different state.

Beyond being the space for Kalika's sessions with Sally and Sofia, the dining table also played a role as the heart of the family where literacy as a social practice took place on a daily basis. Around the dining table, Kalika engaged in various literacy activities with the adults. These activities encompassed reading newspapers with Baba and books with Sofia, playing board games, watching Sesame Street, having extended conversations with Ma and Baba after school, and video calling with her maternal grandparents in India (Field Note 4). These roles of the dining table align with numerous studies on home literacy that are centered around conversations in the dining room to support children's literacy and language development. Takei & Burdelski (2018), for instance, argued that conversations at the dining table facilitate the socialization of norms, identities, and politeness, which are beneficial for the children or novices as members of the larger culture. For bilingual families, mealtime conversation offers a crucial time for parents to reinforce the home language and culture of their children (Quay, 2008), fostering both L1 and L2 development and connecting the children to their family's cultural roots. These dining table conversations illustrate the intricate nature of literacy as a cultural and social practice that is entwined with materiality and space (see Rogoff, 2003).

As for the second non-human element that underlay Baba's decision in choosing the dining room for Kalika's literacy session with Sally, namely the activity chair, Baba argued that the chair was a "mechanism of support to calm parts of her body" (Baba, Interview 1), such as her upper body, hands, and feet. As explained in Chapter 1, among the many symptoms of Rett

syndrome are repetitive hand movements and difficulties in maintaining an upright sitting position or muscle weakness (Kaufmann et al., 2017; Stallworth et al., 2019). Some features on Kalika's activity chair, such as the feet strap and the upper body harness, are designed to help minimize the intensity of the movements and maintain her body posture. Therefore, by sitting on her activity chair, Baba believed that Kalika could be "alert and focused [rather] than being distracted by too many of her movements" (Baba Interview 1) during her session with Sally. Baba's perception of the role of the activity chair in helping Kalika calm her body resonated with his daughter's opinion. When asked if she liked sitting on her activity chair during her literacy sessions with Sally, Kalika moved her body toward the "yes" symbol (Kalika, Interview 1) and further described the chair as a "comfortable" space to sit on (Kalika, Interview 2) (Figure, 23).

Figure 23. Kalika Expressing Her Opinion about Her Activity Chair

Further, Baba also mentioned that the activity chair plays a role in supporting Kalika's body to access the iPad and her big Tobii on the dining table. In Narrative 1 above, for example, Baba and Ma intra-acted with the activity chair by moving it to a slightly different space around the table to ensure that Kalika could see Sally on the iPad and engage in the reading activity on her big Tobii at a particular angle. It supported Kalika to engage with Sally through her iPad and the big Tobii, so she could fixate on the illustrations of the book and the target words that Sally

presented, such as “me,” “make”, “happy”, and “friends”, as well as to look at Sally for partner-assisted scanning.

Figure 24. Sofia’s Drawing Illustrating Her Entanglements

Similar to Baba, Sofia also emphasized the significance of the non-human elements in the rooms when she had literacy activities with Kalika, such as “the chair and table” (Sofia, Interview 1). In her drawing (Figure 24), Sofia specifically included elements that she perceived to be entangled with herself and Kalika during their literacy sessions. Among the various human and non-human elements depicted, she highlighted the table and the activity chair as pivotal actants with which she and Kalika intra-acted. Moreover, Sofia drew the activity chair and the table in close proximity to Kalika’s AAC device, along with black lines connecting these elements. Through her drawings of objects and connecting lines, as well as their proximity, Sofia not only conveyed her perception of the importance of these elements in Kalika’s literacy activities but also demonstrated the interconnectedness among the activity chair, the table, and the Tobii device during Kalika’s literacy activities with her.

In discussing more about the role of the chair or seating instruments during Kalika’s literacy sessions with her, Sofia underscored the importance of the design of the seating

instruments in influencing Kalika's engagement and alertness. For instance, she argued that sitting on the couch in the living room could "make her a little bit sleepy" (Sofia, Interview 1). Sofia believed that the design of the long couch, which allowed her to be fully "laid back and relaxed" (Sofia, Interview 1), along with the ambiance and the design of the room could make her less alert to the task at hand. Importantly, the couch also made it difficult for Kalika to maintain her posture to access her AAC device and the book she read with Sofia. This was particularly observed in Observation 5 on August 1 where Kalika had difficulties maintaining her upright sitting position to see the book Sofia was reading and access her AAC device on the living room table (see Excerpt 2).

Excerpt 2

"Oops, you okay? You good?": Intra-Actions in The Living Room

Sofia and Kalika were sitting on the long red velvety couch in the room in the living room while reading 'Miracle Man: The Story of Jesus' by Hendrix (2016), one of the books that Baba picked up from the county's library. Laying her back on the cushions, Kalika was listening to Sofia reading the story.

"Finally one of the disciples said, 'We can never feed all these people. You should send them away so they could find something to eat'", Sofia reading part of the book.

Suddenly, Kalika raised her back and moved her body forward as if she was about to fall.

"Oops, you okay? You good?", asked Sofia. She then held Kalika's left hand while checking if Kalika needed help. "You are not comfy?", Sofia probed further. She then lifted Kalika's up and fixed Kalika's seating position on the couch. "Is that better?", she asked Kalika before continuing the reading.

"The man saw a girl with a small basket of bread," Sofia continued reading.

Kalika raised her back and moved her body forward again.

"Oops. You need help there?", asked Sofia while checking Kalika's seating position.

As they continued reading, similar events occurred a few times until they finished reading and decided to move to the playroom.

Figure 25. Sofia's Intra-Action with Kalika and Cushions

Note for Figure 25: Sofia Noticing Kalika's Difficulties in Sitting (left); Sofia Helping Kalika to Sit (middle); and Sofia Adjusting Her Seating Position so Kalika Could See the Book (right)

Figure 26. Kalika's Engagement with Sofia in The Living Room

Note for Figure 26: Kalika Looking at Sofia; Kalika Looking at The Book; Kalika Gestured Forward toward the Book

Unlike Kalika's engagement in Narrative 1 where she engaged with Sally through gestures, gazes, vocalizations, and an AAC device, Kalika's interaction with Sofia in the living room in Narrative 1 primarily involved her gaze and upper body movements towards the book (Figure 26). This was caused by the difference in height between the tea table and the sofa where Kalika was sitting, which prevented her from accessing her AAC device during the reading. Additionally, the design of the sofa that did not support her posture also made Kalika it difficult for Kalika to gaze toward the device and the book that Sofia read.

Throughout the reading, Kalika was seen continuously moving her body and vocalizing her discomfort with the seating and reading position. Sofia noticed these expressions of

discomfort, so she had to stop reading a few times, fix Kalika's eyeglasses that were dislocated due to her frequent body movement, and help Kalika with the seating position so she could have visual access to the book they were reading. To help mitigate these challenges further, Sofia propped up Kalika on her back with cushions, changed her seating position so Kalika could see and read the book with her, as well brought the book closer to Kalika (see Figure 25).

Room Brightness

Another significant non-human element that Sofia and Baba intra-act during their literacy sessions with Kalika is room brightness. As discussed earlier, in addition to the type of instruments where Kalika was sitting on during her literacy sessions, Sofia argued the amount of light in the room could also influence Kalika's engagement in the literacy activities. In dimmer settings, such as the living room, Sofia expressed that Kalika tended to "get more sleepy and less focused" (Sofia, Interview 1). This was particularly observed in Observation 5 on August 1. As Sofia read a book on 'Jesus and His Miracles' to Kalika, Kalika was seen laying her back on the cushions of the couch, occasionally closing her eyes, and yawning while listening to Sofia.

For Baba, room brightness affects Kalika's access to her AAC device. Baba argued that the abundance of light in the space created glares on the screen of Kalika's AAC device, which prevented her from viewing the pagesets on the device. Pagesets are linked communication pages on AAC device systems consisting of words, phrases, and symbols for a variety of communication purposes. The symbols and words on these pagesets are the elements that Kalika needs to fixate on her AAC device if she wants to speak to her communication partner. Consequently, Baba expressed that "the window shade always plays a role in whether she can see a screen or not, like we always have to adjust that" (Baba, Interview 1).

The importance of regulating the amount of light in the room was evident in all Kalika's sessions with Sally. To start, both Baba and Ma always ensured that the lights in the dining room were turned on before beginning Kalika's afternoon sessions with Sally. This can be seen from all video observations of Kalika's session with Sally where the lights in the dining room were turned on throughout the session. Second, Baba occasionally adjusted the window blinds in the dining room by opening and closing them depending on the amount of brightness of the room. For example, at the beginning of the session of Observation 6 on August 5 (see Excerpt 3), one of the window shades in the dining room was wide open. Ma, who was helping Baba brace one of Kalika's feet noticed that there were glares on Kalika's AAC device that made it difficult for Kalika to see the pagesets on her AAC device. She then asked Baba to adjust the window shades behind him to reduce the glares. Furthermore, it is important to also note that during Kalika's sessions with Sally, Baba always positioned himself by the window. This positioning not only enabled him to communicate with Kalika through partner-assisted scanning but also allowed him to regulate the room's brightness by adjusting his body position.

Excerpt 3

"There is a bit of glare": Room Brightness and Engagement

It was August 5, the day was partly sunny with a temperature of 77°F (25°C). Kalika was crying as she began the lesson with Sally. Ma and Baba were busy preparing Kalika to get ready for Sally session; beginning from harnessing her body to the activity chair, giving her a *kapor* (blanket) inside her mouth, adjusting her activity chair so Kalika could have a better view of Sally on the iPad, putting on Kalika's shoes, and bracing her feet to the activity chair.

"Maybe ((inaudible)) the window? Glare," said Ma as she finished bracing Kalika's right feet.

Baba, who was in the middle of bracing Kalika's left foot, then looked at Kalika's big Tobii to check if Kalika could see her AAC device's screen.

"Oh, okay," he said.

"There is a bit of glare," Ma repeated so Sally could also hear their conversation.

Baba then quickly finished bracing Kalika's foot, turned his body around, and reached the cord of the window shade behind him to minimize glares on Kalika's AAC device's screen (Figure 27).

Figure 27. Baba Adjusting the Window Blinds

The importance of regulating the brightness of the room was also observed during Kalika's session with Sofia in the playroom. Figure 28 depicts two literacy sessions with Sofia: the left figure was from Observation 8 on August 18 while the right figure was from Observation 10 on August 24. Similar to what Baba and Ma did before Kalika's session with Sally, Sofia always began the sessions by working with the non-human materials in the space to support Kalika's engagement with her. This includes turning on the lights in the playroom, setting the little table to place Kalika's AAC device, arranging the Sesame Street-themed upholster chair for Kalika to sit on, and adjusting the window shades to control the brightness.

Figure 28. Window Shades Configuration during Kalika's Session with Sofia in the Playroom

In Observation 8, Kalika was sitting with her back to the window (Figure 28 left). As she was enjoying one of her favorite Sesame Street episodes on healthy foods, the window blinds were kept closed throughout the session to ensure that Kalika could view her AAC device screen and iPad screen without any glares. Meanwhile, in Observation 10 (Figure 28 right), Kalika was sitting with the windows and Sofia on her left side. The window shades were seen half open as the light from the sun would not create glares on her AAC device screen.

Baba's and Sofia's strategies in regulating the room brightness underscore the important role of lights in ensuring Kalika's access to her devices. During Kalika's session with Sally, specifically, Kalika's access to her big Tobii is crucial as it not only serves as a tool that facilitates Kalika's ocular (eye-gaze) and verbal engagements during the literacy activities but also as a medium for Sally to project her teaching materials for Kalika. In Narrative 1, for example, Sally projected a digital storybook onto Kalika's big Tobii and asked her to fixate on the illustrations and words in the story, such as "friends", "make", and "happy". Having glares on her AAC device screen during this activity would make it hard for Kalika to accomplish this task as the glares prevent her from viewing the screen clearly.

Further, Baba's and Sofia's actions of working with the lights and window shades during Kalika's literacy sessions in the dining room and the playroom also illuminate an important aspect regarding the entanglement between space, actants (which in this case is brightness), and communication accessibility. Ensuring communication accessibility for individuals with complex communication repertoires, such as Kalika, goes beyond simply providing an AAC device or communication tool. It involves working with a network of intra-acting elements within the same space to ensure that individuals can access and effectively communicate through the device. In this case, this encompasses working with the window shades and lights to maintain

the appropriate brightness of the room to avoid glares on the screens that could impede Kalika's access to the pagesets.

The Arrangements of Actants in The Space to Support Engagement and Communication

In addition to the space and its intra-acting actants, the arrangements of humans and non-human elements within a space also matter in ensuring Kalika's effective engagement during literacy activities. Narrative 1 illustrates some events where Kalika, Ma, Baba, and Sally intra-acted with the non-humans in the dining room, specifically around the dining table, to achieve certain positioning and angles. Ma, for example, moved Kalika who was sitting on her activity chair slightly to the left so that Kalika could see straight to Sally on the iPad. Baba was also noted turning the iPad around, so its camera was on a specific side of the dining table. They both were also seen holding Kalika's head, so she faced a certain angle toward the iPad and her big Tobii. Meanwhile, Sally worked with an eye-tracker embedded in Kalika's big Tobii to see where Kalika was positioned and asked Baba to adjust Kalika's and her device's positions based on the tracker. Lastly, they also made use of a thick book to prop Kalika's big Tobii and mounted her iPad with a stand, so the devices held still and were directed to Kalika at specific angles.

These scenes are not exclusive to Observation 11 from which I constructed Narrative 1. In all observations I conducted on Kalika's sessions with Sally and Sofia for this study, there were always moments where the humans had to intra-act with the non-human elements and their specific arrangements within a space. During my observation of Kalika's sessions with Sofia in the playroom on August 15 (Observation 8), for example, Sofia adjusted the angle of Kalika's AAC device (TD Pilot) by altering the position of the mounting plate on the back of Kalika's AAC device while saying, "Maybe this is too low." She did this action after not hearing Kalika's response to her question (see Excerpt 4). Meanwhile, in another observation on August 24

(Observation 10), Sofia used a thick storybook to prop Kalika's AAC device so that it aligned well with Kalika's eyes.

Excerpt 4

"Maybe this is too low": Device Angle and Communication Access

Kalika and Sofia were in the playroom doing the make-up play. Kalika's favorite songs 'Mammy Blue' was playing in the background as Sofia put a blue lipstick on Kalika's lips.

"Okay, look at yourself in the mirror. How do you look?", said Sofia.

Kalika looked at the mirror and smiled.

"Do you look pretty? You look so pretty," added Sofia.

Kalika then looked at her AAC device for a few seconds, yet it was not saying any words for her.

Noticing that the AAC device did not trigger words for Kalika, Sofia adjusted the mount plate on the back of Kalika's AAC device.

"Maybe this is too low," said Sofia.

She then took a quick look at the position of the device once more and readjusted the mount plate to better align the device with Kalika's eyes (Figure 29).

"Pretty," said Kalika after Sofia adjusted her AAC device position.

Figure 29. Sofia Adjusting The Angle of AAC Device

Baba and Sally expressed that there were specific angles and positionings of humans and non-human elements that they believed would provide a more effective teaching and learning environment for Sally and Kalika. For the position of the iPad on the dining table, for example, Baba noted that it "has to obviously right next to the Tobii" (Baba, Interview 1). He argued that placing the device next to Kalika's big Tobii would make it easier for Kalika to "turn her attention from one to the other, talk to Sally, then communicate with Sally using her eyes" (Baba, Interview 1).

Further, he explained that the camera of the iPad also had to be on a certain side of the big Tobii. He noted that "usually when we have it set up, the camera of the iPad is facing the outer edge of the table. That way we had to flip it" (Baba, Interview 1). Baba expressed that this specific alignment of the camera position of the iPad was purposefully made to facilitate communication through partner-assisted scanning between Sally and Kalika. As Baba argued, the camera angle "allows Sally a better sense of whether Kalika's saying yes or no" (Baba, Interview 1) in response to her questions, such as answering whether the word "bubble" began with the letter "b" in Narrative 1.

The significance of these specific arrangements of the non-human elements during Kalika's literacy activities is also depicted in Baba's drawing. Figure 22 visualizes not only how Baba perceives his entanglement with other humans and non-human elements during Kalika's session with Sally but also depicts the positions of Kalika, her activity chair, Baba, the table, the iPad, and the big Tobii on and around the dining table in the dining room. The fact that his drawing mirrors the arrangements of the actants during my observations of Kalika's sessions with Sally (see Figure 16) suggests that there is a consistency in the position of every actant on and around the table. It also shows how the positions of these actants play a crucial role in

Kalika's literacy. Therefore, for Baba, ensuring Kalika's effective engagement during literacy activities does not only involve interacting with the non-human elements per se but also working with their positions and angles in the space.

Figure 30. Sally and Baba on the Left Side of Kalika

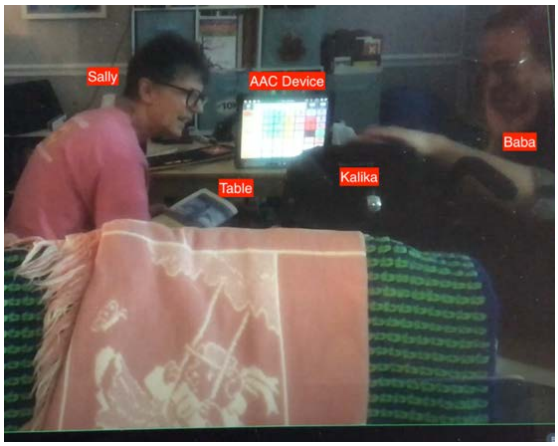

Figure 31. Sally Sitting on the Left Side of Kalika

Baba's statement on the importance of the arrangement of actants resonates with Sally's remarks on the communication characteristics of individuals with Rett syndrome. She articulated that, "there's a natural tendency for the girls (individuals with Rett syndrome) to look at you in agreement. It's the first 'yes' they ever give you is to look in agreement" (Sally, Interview 1). Harnessing the individuals' "natural tendency" of looking at their communication partner to say "yes" and express agreement, Sally believed that there should be consistency in where their

communication partner and the devices are positioned in the space during literacy activities as most of the communication is done through partner-assisted scanning. Sally argued that such consistency would help individuals with complex communication repertoires communicate their responses to yes or no questions quickly without using their eye-tracking AAC device. Therefore, for Sally, "positioning of where you are in space is really important" (Sally, Interview 1).

During her literacy sessions with Kalika and other individuals with Rett syndrome she worked with, Sally specifically designated the left side of the individuals as the space where she assigned the meanings of "yes" or "agree", while assigning the right side to signify "no" or "disagree". Therefore, during her virtual weekend sessions with Kalika, she requested Baba to place the iPad on the left side of Kalika so Kalika could respond to her yes or no questions simply by looking at her or looking away at other sides of the room (Figure 30). She expressed that, "I always want the face-to-face [view with Kalika]. It can be on a computer, can be on an iPad, and I want it (computer/iPad) on the left side [of Kalika]" (Sally, Interview 1).

When they met in person for the first time in Sally's house (Observation 4), Sally was also observed sitting on the left side of Kalika to ensure consistency of the connection between the left space and the meanings she had built with Kalika so far (Figure 31). This consistency is further demonstrated in the placement of the yes and no symbols on her communication board. Figure 21 in Narrative 1 illustrates the ways in which she purposefully placed the yes symbol on the left side and the no symbol on the right side of the board. For Sally, this strategy helped Kalika and other individuals with Rett syndrome to communicate effectively by harnessing their strongest communication modality, i.e., eye gaze (see Wandin et al., 2023).

The established connection between space and meanings, Sally further argued, could become a reliable communication strategy for Kalika and her interlocutor when the AAC device or the communication board is nonexistent due to some reasons, such as being outdoors or the device being broken. She expressed that in such situations, communication with Kalika could always be carried out because by being "on the 'yes' side, she's going to look to me for yes, and look away for no. I travel with it. They travel with it" (Sally, Interview 1). It is a practical communication strategy that could be implemented anywhere without necessarily having AAC tools in hand, because the individuals had developed a "motor plan" (Sally, Interview 1) or skill to associate the space with certain meanings.

In Narrative 1, for example, the success of Kalika's and Sally's communication through partner-assisted scanning was partly facilitated by the established mutual understanding between Kalika, Sally, and Baba on the interconnection between space, meaning, and the materialities on the communication board (e.g., the symbols). As Sally showed her communication board with the yes and no symbols on each side, she directed Kalika's attention to the symbols by pointing to them one after another using her index finger and asked Kalika to respond to her question using her gaze or body movements.

Kalika understood Sally's prompt and multimodally responded to Sally's question on whether the word "bubble" began with the letter "b" by slowly moving her head upward, turning her head to the left, and looking at the left side of the communication board to say "yes" to Sally. She responded to Sally's question twice, each by using the same pattern of head movement and gaze. Her responses to the questions were acknowledged by both Sally and Baba as they both said "yes" in agreement with Kalika's response. The entanglement of space with humans and non-human elements in this case is so specific and powerful that a slight alteration in the

alignment and composition of the entanglement could impact the entire interaction between Kalika and Sally during their literacy activities.

Space and Its Vitality in Influencing Kalika's Engagement

Baba, Sally, and Sofia argued that intra-acting with the spaces/rooms in the house and their non-human elements also helps establish expectations of behavior and influences Kalika's engagement during literacy activities. Both Sofia and Baba argued that Kalika understood that specific spaces required particular behaviors from her. The playroom, for example, Sofia believed that Kalika recognized it as "a place where she's going to be active" (Sofia, Interview 1) and would participate in the activities. This was influenced by the intra-action between the room and the non-human elements within it, such as books, board games, chairs, tables, and decals of planets and Sesame Street characters on the walls, which together form an ecological assemblage that supported their interactions in the literacy activities. For Sofia, the assemblage that is constructed by the intra-acting non-human elements (e.g., the books, the table) in the playroom has significant roles in supporting Kalika's engagement during literacy activities with her. In relation to these non-human elements and their intra-action in supporting Kalika's engagement, she further argued that "there's not necessarily one thing that you can account to her success... Everything's important, everything plays a different role" (Sofia, Interview 2). Sofia's statement indicates that there is not only one independent material that matters in Kalika's literacy – they, in fact, become matter as they are entangled with each other.

Sofia also argued that another factor influencing Kalika's understanding of the playroom as a space for her to be "active" (Sofia, Interview 1) was the routine activities carried out in the room. Sofia and Baba noted that Kalika typically spent most of her physical therapy sessions with her therapists and her literacy sessions with Sofia in this room. These established routines

along with the non-human elements in the playroom made Kalika aware that the room was a space where she would be involved in activities requiring her participation (Sofia, Interview 1).

The roles of the space and the intra-acting human and non-human elements in influencing Kalika's engagement were also noted by Sally. Having been teaching Kalika both in school and at home, Sally expressed that there was a difference in Kalika's engagement in both spaces. In school, Sally noted that while Kalika might get a little whiny during her literacy sessions, Sally had "never had a session where she's (Kalika) totally melted down" (Sally, Interview 2). She further stated that "the hardest place to work with Kalika was [she was] at home" (Sally, Interview 2). At school, Sally continued, "she (Kalika) can be so much calmer" (Sally, Interview 2). It is important to note that in most of the sessions with Sally, Kalika cried at some points during the session, typically either at the beginning or in the middle of the session.

The difference in Kalika's engagement in school and at home was also highlighted in Narrative 1 above: as Kalika whined and began to cry before they began the session with Ma at home, Sally asked Kalika to "remember how calm you kept your body at school. You kept it so calm and relaxed so that we could get so much work done." By asking Kalika to remember her behaviors in school, Sally not only underscores the difference between Kalika's behaviors in school and at home but also sets the school as a space of referent or spatial orientation for Kalika to recall what kinds of behaviors she expects from Kalika during the session with her, i.e., to be calm and relax.

Sally believed that part of the difference in Kalika's literacy engagement in school and at home was influenced by her access to certain non-human elements in the spaces. In school, specifically, Sally mentioned that Kalika "doesn't get a video (Sesame Street programs on iPad) there, she doesn't get access to music there. So, all of that whining for them is not going to

happen" (Sally, Interview 2). Meanwhile, at home, Kalika had more access to her iPad and other devices where she could watch her favorite Sesame Street programs and listen to music.

For Sally, these two elements that she could get at home from her parents could potentially become "an addiction" (Sally, Interview 1) that might impact her engagement. She emphasized that while she acknowledged the benefits of using songs and videos to facilitate Kalika's learning to read – she did sing songs and occasionally incorporate videos in her instruction for Kalika, such as in Observation 1 and Observation 6 (see also Narrative 3 in the next section) – she opposed their use as a means to calm her down and soothe her cries. She argued that relying on music and on-demand videos to regulate Kalika's emotions and motivate her to learn would make her dependent on them; they would lead Kalika to think that "the only way I could soothe myself is if I have music or a video" (Sally, Interview 1) instead of self-soothing through practices like controlled breathing and emotional control.

In this section, I have explored the entanglement of Kalika's literacy with space. By examining the intra-action of Sofia, Sally, Baba, and Kalika with non-human elements in the dining room, playroom, and living room of the house, I have demonstrated the roles of the non-human elements in Kalika's literacy, the ways spatial aspects matter, and how the humans work with the spaces and the non-human elements within them to support Kalika's engagement in literacy activities. In the subsequent section, we delve into the entanglement of human and non-human elements in Kalika's complex communication repertoires.

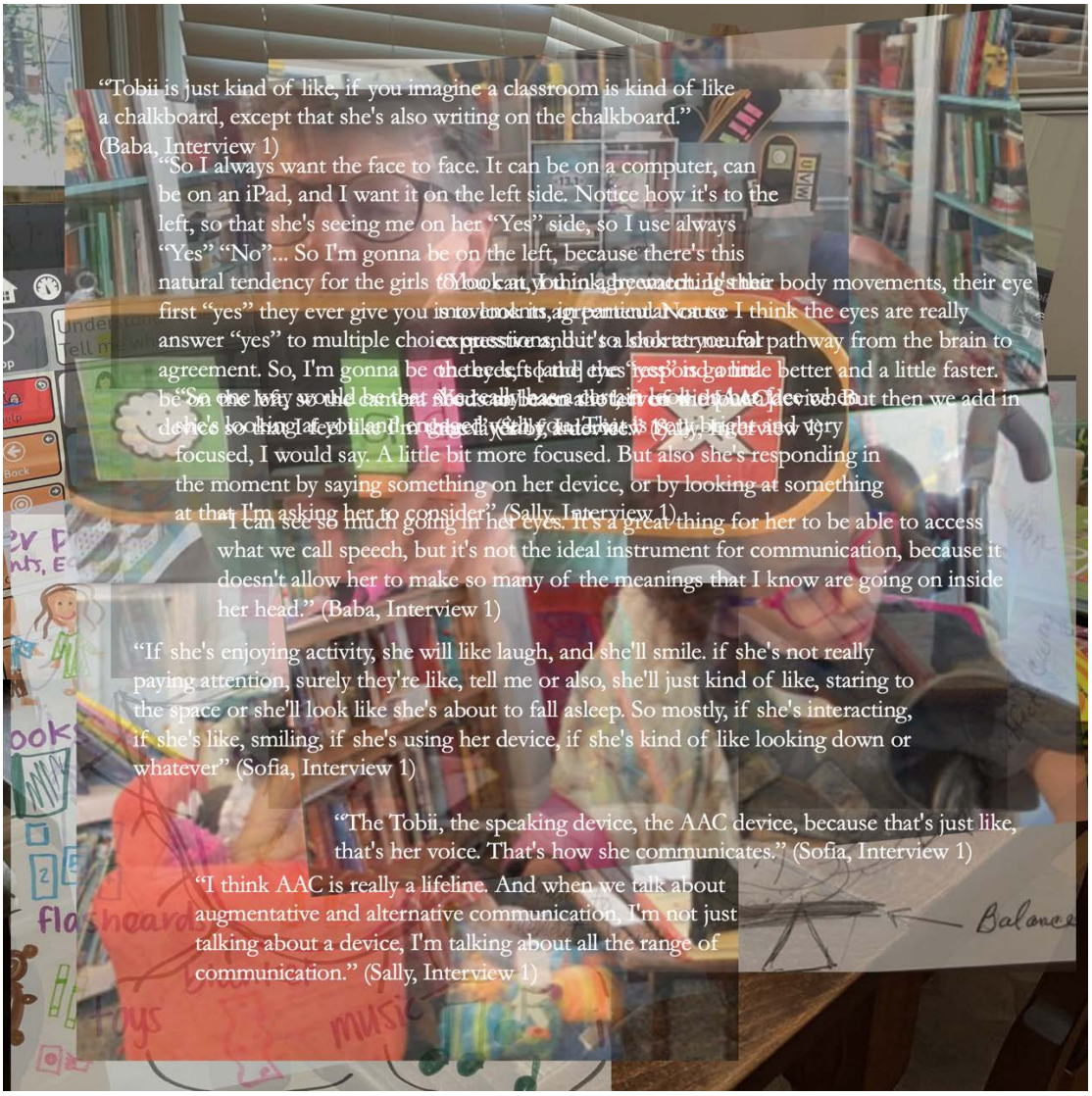

Illustration 2. Collage of Thinking with Actants in Complex Communication Repertoires

Part II: Thinking with Actants in Complex Communication Repertoires

The narrative below is curated from my experience of observing Kalika on August 24, 2023. In this narrative, I invite you to think with the vitality of actants in complex communication repertoires. Vitality, as Bennett (2011) conceptualized, is "the capacity of things—edibles, commodities, storms, metals—not only to impede or block the will and designs of humans but also to act as quasi agents or forces with trajectories, propensities, or tendencies of their own" (p. viii).

As you read this narrative, I invite you to ponder how communication, especially in the contemporary digital age, is entangled with non-human materials. For example, when you give a comment on your friend's status and pictures on a social media platform, what roles do the phone or the computer you are using, the internet it is connected to, the algorithm of the social media platform that leads you to see the status, and the pictures play in the interaction? Or when you teach your students a specific concept using a powerpoint and a projector in a classroom, is it simply a human-to-human interaction or a more-than-human interaction? What will you do when, out of a sudden, the electricity in your classroom goes off and you lose access to the projected powerpoint? How does the absence of electricity, the powerpoint, the projector, and the lights alter your interactions with the students? The fact that their absences influence how you engage with your students demonstrates their vitality in the interactions and the entanglement you have built with the non-human elements.

In the following narrative, I will discuss how humans and non-human elements are entangled in this research and in Kalika's complex communication repertoires. I specifically

invite you to observe how a piece of paper containing math questions, flashcards, make-up products, and an eye-tracking AAC device are entangled with Kalika and Sofia as they were discussing math homework from school.

Narrative 2

"Three! You pointed right at it. It is three!": The Vitality of Non-Human Elements

August 24, 2023

It was a sunny Thursday afternoon in Ἀθῆναι, the city where Kalika and her family lived. The city bears one of the world's oldest city names, which is named after the Greek goddess of wisdom. This was the space where I spent the last seven years pursuing both my master's and doctoral degrees; the space where I spent most of my time in the country where people often call "the land of the free"; and the space where my entanglement with Kalika and her family occurred.

The time was 3:50 PM when I arrived in Kalika's house. Upon entering the house, I found the lights in the living room, dining room, and kitchen off, with no one in sight.

"Hello," I said while peeking into the kitchen to see if Ma or Baba was there.

The house was quiet. I saw Gin, one of the family's cats, was sleeping on her tree tower by the window of the living room. Tap, the other family's cat, was nowhere to be found.

"Tap must be with other humans in the house," I said to myself.

Cats exhibit distinct attachment styles towards humans (Pongrácz & Szapu, 2018). Similar to dogs, Vitale et al. (2019) argued, cats display profound social adaptability with humans. They suggested that the more cats intra-act socially with humans, the more they develop connections and entanglements with humans. This was true in my case with Gin and Tap who had been accompanying me since Day 1 of data collection in this house. Gin, especially, had been following me wherever I sat observing Kalika's inter-action with other humans and non-human elements in this study (Figure 32).

Almost all visual data I collected during my observations in Kalika's house feature Gin and Tap. I also noted some instances where Kalika interacted with the cats through her gaze during her session with Sally and Sofia. At one point during Observation 2 on July 8, for example, Kalika looked at Tap who was walking around the dining room while Sally was briefing her the agenda of the session. In other observations, such as Observation 6 on August 5 and Observation 11 on September 30, Sally and Kalika read a book on her big Tobii about things that make the characters happy. During this reading activity, Kalika was not only asked to read strings of words on each page of the book the book but also look at its illustrations

before moving on to another page. Among the things that Kalika had to fixate on during the reading activity were the word “cats” and the illustration of a little girl carrying a ginger and black cat on her chest (Figure 33).

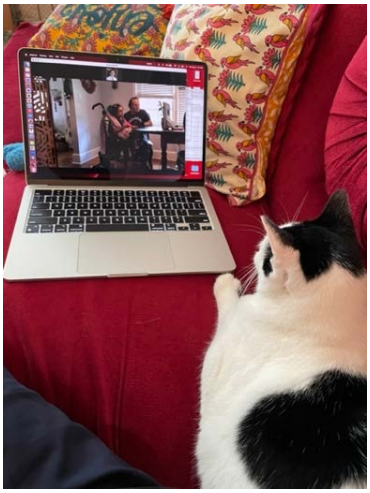

Figure 32. Gin with Me Observing Kalika and Baba from the Living Room

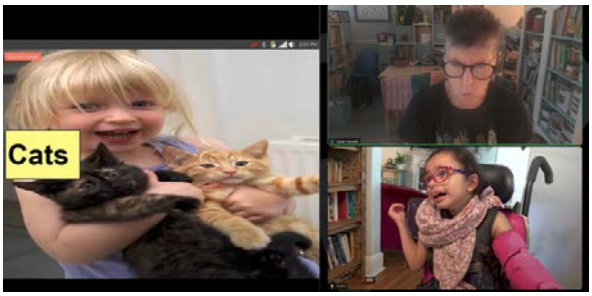

Figure 33. Kalika Reading about Things That Make Children Happy with Sally

It was interesting to think how Gin and Tap, non-human participants that were not part of my IRB, involved and exerted their vitality in this study. Vitality, as Bennett (2011) argued, is “the capacity of things—edibles, commodities, storms, metals—not only to impede or block the will and designs of humans but also to act as quasi agents or forces with trajectories, propensities, or tendencies of their own” (p. viii). Their presence was not only a source of comfort for me, reminiscent of Inul and Otto, my late cats in Indonesia, but was also part of the material-discursive apparatuses (Barad, 2007) that continually intrigued me to think about their entanglement in my research. On my Observation 11 field note, for example, I noted my curiosity on how Kalika built relationship with her cats and the ways in which she developed a mental correlation between the cats she was seeing in the book that Sally presented with Gin and Tap.

Soon after I put my bag on the sofa in the living room, I heard Ma, Sofia, and Kalika talking in the playroom. I then approached the room while carrying my researcher’s notebook, a camera tripod, a wireless microphone, and a mini-iPad that I used to record my observations.

As I made an entrance to the playroom, I saw Tap was lying down on the floor while Ma, Sofia, and Kalika were engaged in a discussion on what to do in the next hour. After a brief greeting with everyone in the room, I set up my recording devices and hide myself behind a wall to observe them unobtrusively.

"Maybe like 10 or 15 minutes of this," said Ma to Sofia while showing a math worksheet from school that Kalika had to work on. A Punjabi hip-hop song was playing subtly from Kalika's phone as the three of them engaged in the conversation about the agenda of today's session.

Figure 34. Kalika's Playroom and the Elmo's Upholstered Chair

Kalika was sitting in a red upholstered chair with Elmo's face on it, surrounded by three soft toys of Sesame Street characters: Abby and Bigbird on her right side and Cookie Monster on her left side (Figure 34). In front of her was a small table with her TD Pilot AAC device that was propped up on it. Later in my interview with Sofia, I showed her a short clip of this observation and asked why she put soft toys around Kalika's body. Her response was that she used them to "…prop her up in while she is in the chair, since she doesn't have a lot of control over her movement, she'll fall over. So, I put those over so she can be like propped up and alert" (Sofia, Interview 1).

Before Ma left the room to work, Ma modelled some strategies for Sofia to work with Kalika in answering math questions in the worksheet: she slowly read one question on the worksheet to Kalika, held up two flashcards of possible answers to the question for Kalika to choose, asked Kalika to either look or touch one flashcard that she thought was the answer to the question, provided ample time for Kalika to express her answer, and repeated the question if necessary. Once Ma left the room, Sofia and Kalika began working on the math problem in the worksheet.

Figure 35. Kalika Looking at the Flashcards Held up By Sofia

Figure 36. Kalika Looking at the Flashcards on the Table

"Okay, so here are your options. This one is 'four,' and this one is 'three,'" Sofia said while holding up two flashcards and showed them to Kalika: One flashcard with '3' in her left hand and another with '4' in her right hand (Figure 35).

Kalika, who was looking at the bag of soft toy under the table, straightened up her upper body and looked at the flashcards before Sofia put them on the table in front of Kalika. She then gazed to her AAC device and said,

"Gross."

"Gross? Don't say math is gross. It's fun," Sofia answered while giggling. She then proceeded to read a question that Kalika had to answer while holding up the worksheet for Kalika to see.

"Okay look, so here's the question. Five plus what number equals eight?", said Sofia.

Kalika looked at Sofia as Sofia read the question to her. When Sofia finished reading, Kalika turned her head to the table and looked at the two flashcards that Sofia put earlier (Figure 36). Soon after, she looked at the window on her left side followed by a brief look to the right.

"Five plus what number equals eight?" Sofia repeated the question while grabbing the flashcards on the table and held them up for Kalika to see. She then provided a few seconds for Kalika to process and answer the question.

"Either three or four," Sofia said to Kalika as she held the flashcards up.

Kalika looked at Sofia and the flashcards, her hands were clapping as she looked at the options and her body slowly leaned forward.

"Here, let's put this right here," Sofia said as she grabbed a ziplock bag of soft toys onto Kalika's feet. She noticed that Kalika might need some weight on her feet to help her focus better. This bag acts as 'straps' for Kalika's feet to reduce uncontrollable movements that might distract her attention (Sofia, Interview 1). Immediately after Sofia put the bag on Kalika's feet, Kalika raised her body to its initial position and gazed at the flashcards on Sofia's hand. Here, again, I witnessed how a non-human element, a simple as a ziplock bag of soft toys, expressed their vitality in supporting Kalika's focus during a literacy activity. Kalika's entanglement with the non-human elements did resonate with Bennett (2011) argument on the more-than-human entanglement:

> "Humanity and nonhumanity have always performed an intricate dance with each other. There was never a time when human agency was anything other than an interfolding network of humanity and nonhumanity; today this mingling has become harder to ignore" (Bennett, 2011, p. 31).

Figure 37. Kalika Looking at Flashcards with a Weighted Ziplock Bag on Her Feet

"So, five plus what number equals eight," Sofia repeated the question while presenting the worksheet on the table. She then held up the flashcards again for Kalika to choose.

Kalika looked the flashcards that Sofia held up then looked away to the window on her left (Figure 37).

Figure 38. Kalika Saying "Gross! Gross!" and Grinning

"If you don't wanna look, I can do it where you touch it. Do you wanna do that?" offered Sofia as she thought Kalika might prefer another modality to answer the question.

"Alright, you touch which one," prompted Sofia while repeating the question for Kalika.

Kalika looked at Sofia's face as Sofia read the question again to her. She briefly touched the flashcard "3" using her left hand yet Sofia did not see it. Kalika then looked at her Tobii and said,

"Gross, gross." She grinned after saying it (Figure 38).

"You can't say it's 'gross'," Sofia said as she giggled upon hearing Kalika's opinion and reaction on the activity.

It was the second time Kalika expressed "gross" during the activity, which indicated her desire to do something other than math homework. Before that, Kalika suggested some activities to Sofia, such as asking, "what time?"—a cue familiar to the family and Sofia which signified her interest in watching her favorite show, Sesame Street — and proposing Sofia and Kalika to "dance to music."

Figure 39. Kalika Touching the Flashcard and Looking at Sofia

"Let's just try this one, you touch which one you think it is," Sofia persuaded.

Kalika looked away to the right briefly, she then leaned her body forward, broke her uncontrollable repetitive hand movement, and touched the '3' flashcard with her left hand (Figure 39).

"Three! You pointed right at it. It is three! That was so good! Good job!" Exclaimed Sofia, excited to see that Kalika touched the right option.

Kalika looked at Sofia and smiled to her as Sofia complemented her great work.

Figure 40. Kalika Looking at the Make-up Products as Sofia Counting Them

Following this activity, they did another math problem. Kalika again answered the question by touching a flashcard, yet it was not the flashcard with the correct answer to the question. Then, Sofia explained the answer to the math problem to Kalika. She grabbed some make-up products that they used for their make-up play and presented them one by one on the little table in front of Kalika.

"One, two, make up products. And then I have one, two, three, four, five [make up product]," Sofia said to Kalika. After that, Sofia repeated the counting from one to seven while pointing at the make-up products on the table.

Kalika looked at the make-up products as Sofia counted them for her (Figure 40).

"I am sorry," said Kalika on her AAC device.

"No that's okay. You are learning, that's what happens when you learn. Don't apologize [for the mistake you made]", Sofia said.

After this activity, Kalika and Sofia were engaged in other activities as directed by Ma earlier. One of the activities they did was a storybook reading of a book entitled 'A Cat's Guide to the Night Sky' by Stuart Atkinson. Tap was present as they read the book about a cat and the star constellation. She was sitting on the window ledge quietly, gazing at the backyard of the house.

The narrative above captures moments where the non-human elements are entangled with Sofia and Kalika as they interact to finish math homework from school. I began the narrative with my reflection on the presence and involvement of Tap and Gin in my research as well as the entanglement that I have built with the cats over the course of data collection. As I reflect, I specifically think with Bennett's (2011) argument on the vitality of non-human elements and the roles of the family's cats in providing comfort for me, as well as serving as a discursive object for Kalika as she talked about the animal with Sally and Sofia during their literacy activities.

I then continued the narrative with a discussion of events where Kalika and Sofia intra-act with flashcards, a worksheet, an eye-tracking AAC device propped up on a book, make-up products, and a bag of soft toys during their literacy session. I highlighted the ways in which Kalika communicated and engaged in the activity by gazing, touching, and approximating her body to the non-human elements. I also described how Kalika expressed her opinion on the activity she was doing with Sofia and negotiated alternative activities through her AAC device. By directing her eyes toward the symbols and words on the AAC pagesets, she articulated her preferences for watching Sesame Street and dancing to a song instead of doing the homework.

In the following section, I am inviting you to explore Kalika's complex communication repertoires and their entanglement with actants that are involved during their literacy activities at home. The section will specifically discuss how Kalika communicates through her eye gaze, body movement, gesture, and eye-tracking AAC device during her literacy activities with Sofia, Sally, and Baba as well as the roles of the non-human elements in mediating their dyadic and multiparty interactions. In short, Kalika's communication is not only multimodal, but also multiactant.

The Entanglement of Complex Communication Repertoires with Actants

Narrative 2 portrays the entanglements of Kalika's complex communication repertoires with other human and non-human elements during a literacy activity with Sofia. Repertoires, as Kusters et al., 2017 argued, are "all the 'means of speaking' that users of a language know, know how to use, and use with specific reasoning in mind while engaged in a communicative encounter" (p. 222). In the narrative, Kalika orchestrated her complex repertoires of communication through her gazes, hand movements, and body movements that she directed toward Sofia and arrays of the non-human elements that were present within the space (i.e. the playroom). For instance, as Kalika looked at Sofia and the flashcards that Sofia held up for her, Kalika communicated her engagement to her communication partner by purposefully directing her gaze toward the human and the non-human elements one after another. Similarly, when Kalika turned her head and looked away from Sofia and the flashcards as well as saying things through her AAC device, such as "gross", Sofia responded to these cues of disinterest in the activity by persuading Kalika to answer just one question, providing more time for Kalika to think, repeating the question to Kalika, and offering an alternative way to answer the question – from looking at the flashcards to touching them. Such complex communication exchange between Kalika and Sofia illustrated the ways in which human bodies intra-act with humans and non-human elements in complex communication repertoires.

Baba, Sally, and Sofia argued that Kalika's body is her primary communication system. Kalika's eye gaze, specifically, was highlighted by Baba, Sofia, and Sally as one of Kalika's prominent communication modalities during her literacy session. For example, during her partner-assisted scanning communication with Sally (see Narrative 1 and earlier discussion on space), Kalika's gaze is an instrumental communication modality that helps Sally understand

Kalika's response to her yes or no question. Similarly, Kalika's eye fixation on the words and illustrations of the book during her reading activity on her big Tobii also played a crucial role for Sally in determining whether Kalika processed the presented texts.

Baba expressed that there is "so much going in her eyes" (Baba, Interview 1). The crucial role of Kalika's eyes in her communication was, in fact, one of the primary reasons that made him spend "a lot of time, just making, holding eye contact with Kalika" (Baba, Interview 1). For Baba, Kalika's eyes were "actually expressing something" (Baba, Interview 2); they provided a window for him to know if she engaged in the activity or if "she needs something" (Baba, Interview 1) during the session. For example, her prolonged eye gaze toward her cup or food on the dining table suggested her interest in drinking or eating. Meanwhile, Kalika's sustained eye contact with him could indicate her "needs to use the bathroom" (Baba, Interview 1). At one point during a reading session with Sally on Observation 9 on August 19 (see Excerpt 5), for example, Kalika took a long pause between reading and made a prolonged eye gaze toward the side where Baba sat. Baba responded to this complex communication repertoire by asking if she needed to go to the bathroom, which Kalika confirmed by making extended eye contact with him. Sally also validated Kalika's complex communication repertoire by saying to Baba that Kalika made "a very direct look" toward him, indicating that Kalika indeed responded "yes" to his question and needed assistance.

Excerpt 5

"That look was a very direct look, Dad": The Eyes That Communicate

Kalika was reading a book on her eye-tracking AAC device with Sally. She was fixating on an illustration of a girl on a swing followed by some strings of words from the book, namely "swings" and "make me", one after another. However, as she reached the next word to fixate, which was the word "happy", she took a long pause by looking down to the table and taking a deep breath.

"H-a-p-p-y. H-a-p-p-y. Spells?", Sally sang each letter of the word that Kalika had to fixate as she waited for Kalika's response.

Kalika looked at her big Tobii then slowly moved her head down toward the side where Baba sit.

"Do you need to use the bathroom, Kalika?" asked Baba.

Kalika quickly raised her head and made a long eye contact (about 3-4 seconds) with Baba (Figure 41).

"Ooh," Sally said.

"Yeah? Okay," Baba said while giggling.

"That look was a very direct look, Dad," said Sally.

Baba then stood up and unbraced Kalika's feet straps and upper body harness on her activity chair before carrying her to the bathroom.

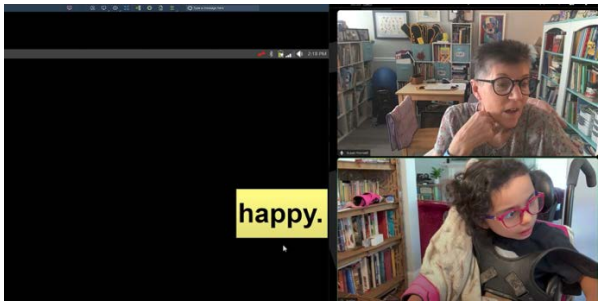

Figure 41. Kalika Making a Long Eye Contact with Baba

Baba's opinion on the significant role of Kalika's eyes in her complex communication repertoires is also evident in his drawing. In illustrating Kalika (see Figure 22), Baba drew Kalika's "trademark smile" (Baba, Interview 2) and wide eyes in front of "two massive screens [of iPad and her big Tobii]" (Baba, Interview 2). He described Kalika's wide eyes as elements that were "really important" (Baba, Interview 2) to access books and other literacy materials that Sally presented to her, express her mind, and "make the Tobii work" (Baba, Interview 2). For

Baba, Kalika's eye-tracking AAC device was a "second level" (Baba, Focus Group Discussion) communication that comes in after Kalika's complex communication repertoires. He argued that,

> "It's a great thing for her to be able to access what we call speech [through AAC device], but it's (AAC device) not the ideal instrument for communication, because it doesn't allow her to make so many of the meanings that I know are going on inside her head." (Baba, Interview 1)

Baba further emphasized that while Kalika's big Tobii's helpful, the device was "imperfect" (Baba, Interview 1). He argued that there were "a lot of important things going on with Kalika that just happened through eyes and other modalities" (Baba, Interview 1).

Similar to Baba, Sofia and Sally also expressed that Kalika's eye gaze communicates messages that are not necessarily expressed through her AAC device. During her literacy session with Kalika, Sofia noted that one of the signals that Kalika often used to express her disinterest in doing the activity was "staring into the space" (Sofia, Interview 1) and looking away from her. On the other hand, she argued that Kalika would "look and make eye contact" (Sofia, Interview 1) with her, smiled, and said something on her device when she was engaged in and liked the activity. In Narrative 2 above, for example, Kalika demonstrated her engagement by looking at Sofia when Sofia read the math problem, looking at the flashcards of answer options to the problem, and touching the flashcard that represented her answer to the problem. At the same time, Kalika also expressed her preference for doing another activity by occasionally looking away from the flashcards and making a comment on the activity (i.e., "gross") as well as proposing other activities (i.e., watching Sesame Street) through her eye-tracking AAC device.

Sally also highlighted that Kalika's eyes were "really expressive" (Sally, Interview 1) and provided more practical and quicker responses than her device. She argued that "you can learn a

lot [about what Kalika communicates], even without a device" (Sally, Interview 1). For instance, Kalika's "bright and very focused" (Sally, Interview 1) gaze towards Sally on the iPad or her eye fixation on a specific target area on the big Tobii's screen suggests Kalika's interest and engagement in the activities.

In Kalika's reading sessions with Sally, especially, Kalika's eye fixation on designated words and illustrations of the book serves as a fundamental indicator of her engagement in the activities. Figure 42 illustrates an instance of Kalika's eye fixation during a spelling activity involving the word "cats" with Sally. In the left picture, Kalika is observed looking at Sally on the iPad, with no fixation on the word "cats" on her big Tobii. Meanwhile, the right picture shows Kalika facing the big Tobii, fixating on the word "cats," as highlighted by the pink border around the word. In this activity, Kalika's eye fixation on the target words is a crucial literacy behavior that provides Sally with insights not only into Kalika's engagement in the activity but also her attention on the target word that Sally presented.

The importance of Kalika's ocular engagement during literacy activities is also reflected in the way Sally designed her instructional materials. The use of black colors as a background and the yellow border on the communication board, for example (see Figure 43), is "for a reason" (Sally, Interview 1). She argued that the use of different colors on the communication board would help "the vision [of Kalika] to be pulled in" (Sally, Interview 1) because they "snug in the visual field" (Sally, Interview 1). For instance, Sally considered the use of a light green background for the vowels and a pink background for the consonants "really important" (Sally, Interview 1), because they help Kalika visually discern the vowels and the consonants in a word.

Further, as explained in the previous section on *Actants and Their Arrangements in a Space,* Kalika's eye gaze is instrumental in Kalika's dyadic communication with Sally, which is

mainly done through partner-assisted scanning. To recall what Sally expressed regarding the importance of Kalika's eye contact with her: "there is a natural tendency for the girls to look at you in agreement" (Sally, Interview 1). This was one of the primary reasons why Sally insisted on being on Kalika's left side during their literacy sessions. By consistently being on the left side, Sally could harness the "natural tendency" (Sally, Interview 1) of Kalika to look at her to express an agreement or provide a "yes" response to her yes or no questions without using Kalika's eye-tracking AAC device.

Figure 42. Spelling Activity with Sally with Pink Border Indicating Kalika's Eye Fixation

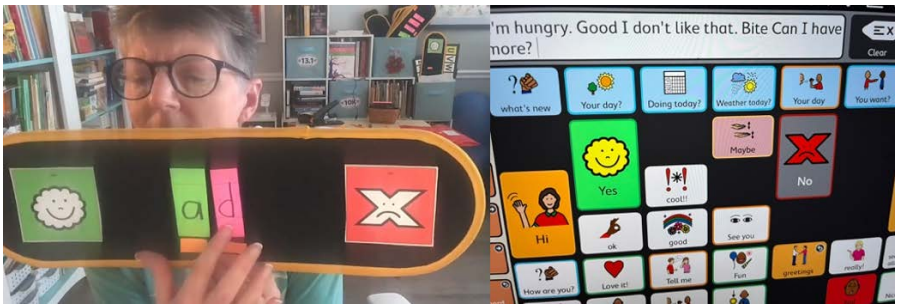

Figure 43. Sally's Yes/No Communication Board & Kalika's Yes/No Pageset on AAC Device

For Sally, Kalika's eye gaze, gestures, body movements, and facial expression are primary communication modalities that she "travel[s] with" (Sally, Interview 1) wherever she goes. Similar to Baba, while Sally acknowledged the usefulness of her AAC device, she considered the tool as an "add in" (Sally, Interview 1) modality that helped Kalika communicate through speech. Together, these complex communication repertoires of the human body and the

materiality of the AAC device form an assemblage that acts as a "lifeline" (Sally, Interview 1) for Kalika to communicate things in her mind to her interlocutors.

While Kalika's eye gaze, eye contact, and eye fixation have been underscored as key complex communication repertoires, it is important to note that Kalika's communication during her literacy sessions with Sofia, Sally, and Baba is multimodal and entangled with other humans and non-human elements. In other words, while Kalika's ocular engagement during her literacy activities has been highlighted as her crucial complex communication repertoire by Sofia, Sally, and Baba, this communication modality works in concert with other repertoires of communication (e.g., body movements, facial expressions, touches) and the actants (e.g., Sofia, flashcards) around her.

For example, following Sofia's reading of a math problem in Narrative 2, i.e., *"Okay look, so here's the question. Five plus what number equals eight?"*, Kalika was observed not only looking at Sofia to express her attention to Sofia during their dyadic interaction but also moving her head down and looking at the flashcards of answer options on the little table in front of her (Figure 44 and Figure 45). This multimodal engagement did not happen once. When Sofia repeated the question and the options of answers to Kalika, i.e., "*Five plus what number equals eight? Either three or four*," Kalika looked at Sofia once more followed by moving her head and looking at the flashcards that Sofia held up for her.

Kalika's multimodal complex communication repertoires and their entanglement with actants were also observed when she expressed her opinion regarding the activity. As Sofia re-read the question for the third time, Kalika moved her head from Sofia on her left side to her eye-tracking AAC device in front of her. She then fixated on one of the cells in a pageset on the screen of her eye-tracking AAC device to say "gross". She grinned as she said the word through

her AAC device while Sofia giggled after hearing the speech and said, "*you can't say it's gross*" (Figure 38). Moreover, when Sofia presented an alternative method for answering the question and instructed Kalika to touch one flashcard she believed was the answer, Kalika looked at the answer options once more followed by leaning her upper body forward and using her left hand to touch the flashcard on her left.

Figure 44. Kalika Intra-acting with Sofia and the Flashcards

Figure 45. Kalika Looking at and Touching the Flashcard

The interactions above illustrate how Kalika engages in a literacy session with Sofia beyond using her ocular complex communication repertoires. By moving her head toward Sofia and the flashcards, expressing an opinion on the activity and grinning at her own speech, leaning her upper body forward toward the flashcards, and touching one of the flashcards she regarded as the answer to the question, Kalika demonstrated the multimodality of her engagement in literacy activities more than just making an eye gaze, eye contact, and fixation on the actants around her, namely Sofia, the flashcards, and AAC device.

Baba, Sally, and Sofia also noted other instances of Kalika's multimodal complex communication repertoires during their literacy sessions. For example, when Kalika disengaged in the activity, Kalika would often whine, howl, scream, and cry (Sofia, Interview 1; Baba, Interview 1; Sally, Interview 1), "stare off into space" (Sofia, Interview 1), "look like she is about to fall asleep" (Sofia, Interview 1), and "look away" (Sofia, Interview 1) from the communication partner and the book she was reading. Meanwhile, when she preferred to stop and do another activity, Kalika would often shake her legs and make eye contact (Baba, Interview 1) and say things on her AAC device, such as "Can we do something else?" or asking time to signal her preference to watch her favorite show, i.e., Sesame Street (Sofia, Interview1).

Baba, Sally, and Sofia agreed that there was not one specific communication modality that Kalika would always depend on to communicate. Sally, specifically, highlighted the "elasticity" (Sally, Focus Group Discussion) or flexibility of Kalika's communication repertoires based on the situations. During our focus group discussion, Sally shared her observation of Kalika's ability to orchestrate her multimodal communication repertoires during their literacy activities.

> "I can't put the Tobii above the smiles in the interaction, but I also can't put it below that, because it (the Tobii) really gives you sometimes to this really precise [message]. She nails you I mean, she just kind of get you with what she says. And I think that she knows so well how to do that. (Sally, Focus Group Discussion)

Sally's statement above highlights Kalika's effective communication strategies in getting the message across to her using various communication repertoires. In her observation, Sally did acknowledge the usefulness of Kalika's speech through her big Tobii, because it gave her a "really precise [message]" (Sally, Focus Group Discussion). For example, when she said, "'I

don't want to do this.' There's no doubt in your mind that they don't want to do it right now" (Sally, Interview 1).

Similarly, Sofia shared the same opinion regarding the important role of Kalika's AAC device as "her voice" (Sofia, Interview 1) and likened the act of taking away Kalika's device from her with "put[ting] hands over their mouth" (Sofia, Interview 1) to silence her. For Sofia, Kalika's AAC device was a crucial non-human element that must be present when she had a literacy session with Kalika. Sofia expressed that the device was "the first thing I carry" (Sofia, Interview 1) when she and Kalika had to move to a different room for doing the literacy activities, such as from the living room to the playroom in Observation 5 on August 1.

Their perspectives regarding the usefulness of Kalika's eye-tracking AAC device are in line with Kalika's viewpoint on the device. When asked whether she liked her device, Kalika moved her body and gazed toward the "yes" symbols I presented in front of her (Kalika, Interview 1) (see Figure 46, left side). Additionally, during our second interview, she expressed that the device was "fantastic" when I inquired about her opinion on her AAC device (Kalika, Interview 2) (see Figure 46, right side).

Despite the usefulness of the AAC device in mediating their dyadic interactions with Kalika, Sally, Baba, and Sofia said that the device was just one of many modalities that Kalika employed to communicate with them. Sally likened Kalika's effective use of complex communication repertoires with an entanglement of different communication modalities: "when you look at the entanglement, some things are entangled kind of loosely and some are entangled a little bit more tightly" (Sally, Focus Group Discussion). For Sally, Baba, and Sofia, Kalika's orchestration of complex communication repertoires relies on the situation and the needs of communication. For example, during the reading session with Sally in the dining room, Kalika

might gaze at her cup in front of her to "signal if she's thirsty" (Baba, Interview 1) instead of saying "thirsty" on her device, which would require her to navigate different pagesets to find the word "thirsty" on her AAC device system. Another example is when Kalika smiled instead of looking at Sally to express her agreement or "yes" response to Sally's yes or no question. As Sally described, "the whole thing [Kalika's body movement, eye gaze, cup, AAC device, communication board, interlocutor] kind of just [working] together" – all elements play roles in mediating and enriching Kalika's complex communication repertoires.

Figure 46. Kalika Responding "Yes" and "Fantastic" to My Interview Questions

An important aspect of Kalika's multimodal communication repertoires is their entanglement with the non-human elements around her. In Narrative 2, for example, the flashcards play at least three vital roles in supporting Kalika's communication and interaction with Sally.

First, the flashcards provide a joint-attention avenue for Kalika and Sofia to be materially entangled in the literacy activity. Joint attention, as Bakeman and Adamson (1984) argued, is one's ability to coordinate attention toward a social partner and a shared object of interest (see also Perra & Gatis, 2012). By holding up the flashcards in front of Kalika and saying "*okay, here are your options*", Sofia directed Kalika's attention toward the flashcards and defined a specific behavior for Kalika to engage — to *look at* the flashcards. Kalika, who was looking at the bag of soft toys under the little table in front of her, responded to Sofia's prompt by sitting up straight

and looking at the flashcards in front of her. Kalika's ability to follow the directions showcases both her understanding of the prompt as well as her ability to regulate attention between different objects of interests, i.e., the bag of soft toys and the flashcards.

Second, the flashcards provide Sofia with an instructional tool to reinforce Kalika's mastery of numbers. By presenting the flashcards one by one, prompting Kalika to observe them, and emphasizing their differences by saying, *"This one is 'four,' and this one is 'three,'"* Sofia helped Kalika associate each card and its corresponding number based on its auditory representation, i.e., "four" and "three". The repetition of these actions by Sofia, combined with the consistent placement of the flashcards (i.e., "3" on the left and "4" on the right hand of Sofia), further helped Kalika differentiate between the flashcards representing "three" and "four".

Lastly, the flashcards serve as aided AAC materials that render Kalika's body movement, which in this case is her hand gestures, meaningful and representative of her answer to Sofia's math problem. As Sofia presented the two flashcards in front of Kalika and assigned meanings to them by saying "three" and "four", Kalika's hand gestures toward the flashcards held specific meanings associated with the flashcards. When Kalika touched the flashcard "three" using her left hand, for example, her hand gesture was communicative due to its contact or intra-action (Barad, 2007) with the non-human material (the flashcard "3"). The significance of this gesture as a communication modality is further affirmed by Sofia's exclamation following Kalika's touch to the flashcard, i.e., *"Three! You pointed right at it."* Sofia's exclamation signifies that the intra-action of Kalika's hand with the flashcard is meaningful and communicative to Sofia.

A similar principle of the entanglement between Kalika's complex communication repertories with actants also applies in Kalika's use of eye gaze toward her cup to "signal if she's

thirsty" (Baba, Interview 1) to Baba and her eye gaze toward the symbols and letters on Sally's yes/no communication board to Sally. Excerpt 6 describes the entanglement of Kalika's eye gaze with the non-human elements on Sally's communication board during their spelling activity in Observation 2 on July 8.

During the spelling activity in Except 5 Kalika multimodally responded to Sally's yes or no question by moving her head and looking away from Sally on the iPad. Through these complex communication repertoires, Kalika communicated her disagreement or "no" response to Sally's question on whether the letter 'd' came right after the letter 'a' in the word 'an'. In this case, Kalika's head movement and eye gaze are communicative not because they hold meanings by themselves, but because they are entangled with the actants, namely the communication board (and all the non-human elements on it, such as the symbols), the space, and Sally as her interlocutor.

Excerpt 6

"It's such an obvious 'no'": Communicative Body Movements

Kalika and Sally were doing a spelling activity of the word "an". Using her yes or no communication board, Sally asked Kalika to determine whether the letter 'd' came after the letter 'a' in the word "an". On the communication board, Sally had a yes symbol with the green color on the left and the no symbol with the red color on the right side of the board. Between these yes and no symbols, Sally put two letters: 'a' and 'd' – the letter 'a' was written on a light green color paper while the letter 'd' was on a pink color paper. She also put a strip of orange paper below each letter to help Kalika identify the numbers of letters needed to make the word "an".

"Does this say 'an'?", asked Sally to Kalika while pointing to the letters 'a' and 'd' on the communication board. Sally elongated the sound 'n' as she said the word "an" so Kalika noticed that she needed the letter 'n' instead of 'd' to make the target word.

Kalika quickly moved her head to the right and looked away from the iPad to signal a "no" response to Sally's question (Figure 47).

"Oh, you don't want the letter either, huh? You looked at it off and fast," Sally said.

Kalika moved her head up and looked at the iPad where Sally presented the communication board.

"So take a look at it (the letter) again. That (the previous response) might have been a [head] drop. So, let's make sure," prompted Sally. She wanted to make sure if Kalika's previous head movement and gaze to the right was indeed her answer to the question, not a head drop that individuals with Rett syndrome often experience.

Kalika then moved her head to the right and looked away from Sally.

"'No.' Thank you," Sally thanked Kalika for confirming her previous answer. "That helped me Kalika, because you looked at it and then you looked away, so it's such an obvious 'no'" Sally continued.

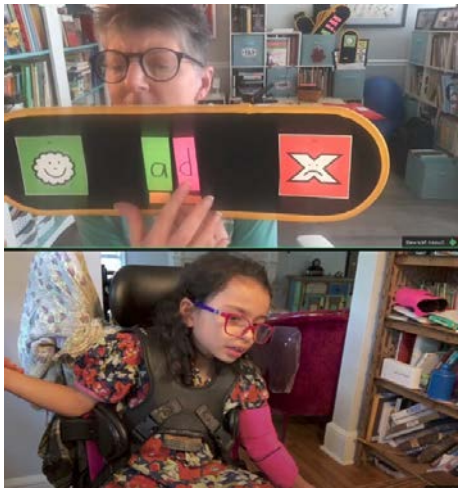

Figure 47. Kalika Saying "No" to Sally by Moving Her Head and Looking to The Right

As I explained in the previous section on *Actants and Their Arrangements in a Space,* earlier in the program, Sally assigned meanings to the left and the right side of Kalika to help Kalika communicate her "yes" or "no" statement by looking or moving her body toward the sides. Sally's strategy to designate meanings to the space – namely the left side for a "yes" response and the right side for a "no" response – is reflected in the way she consistently positioned herself relative to Kalika and the "yes" symbol on the communication board, both of which are located on Kalika's left side. As a consequence, Kalika's eye gaze and body

movement toward the left or right sides hold specific meanings of "yes" or "no" when they are done following Sally's yes or no question.

In Except 5, for example, following her question whether the letter 'd' came after the letter 'a' in the word 'an', Sally registered Kalika's head movement and eye gaze toward the right side as a "no" response from Kalika. In other words, Kalika's head movement and eye gaze acquire meanings for Sally due to their intra-action with the non-human elements, i.e., the space on the right side of Kalika as well as the "no" symbol on the communication board. The communicative aspect of Kalika's head movement and eye gaze and the mutual understanding between Kalika and Sally in this regard is further reflected as Sally asked Kalika to repeat her response to confirm her answer. By moving her head and gazing to the right for the second time, Kalika reaffirmed her "no" response to Sally's question *"Does this say 'an'?"*. Kalika's response was further acknowledged by Sally as she thanked Kalika for Sally for confirming her previous answer and said, *"it's such an obvious 'no'"*.

In this section, I have explored the entanglement of complex communication repertoires with humans and not-human elements during Kalika's literacy activities with Baba, Sally, and Sofia. I have elucidated how the non-human elements, such as the flashcard, the communication board, the make-products, and the eye-tracking AAC device intra-act with Kalika's eye gaze, fixation, body movement, and gesture to demonstrate her literacy engagement. In the following section, we will illuminate more non-human elements and their roles in the more-than-human literacy entanglement of Kalika with Baba, Sally, and Ma.

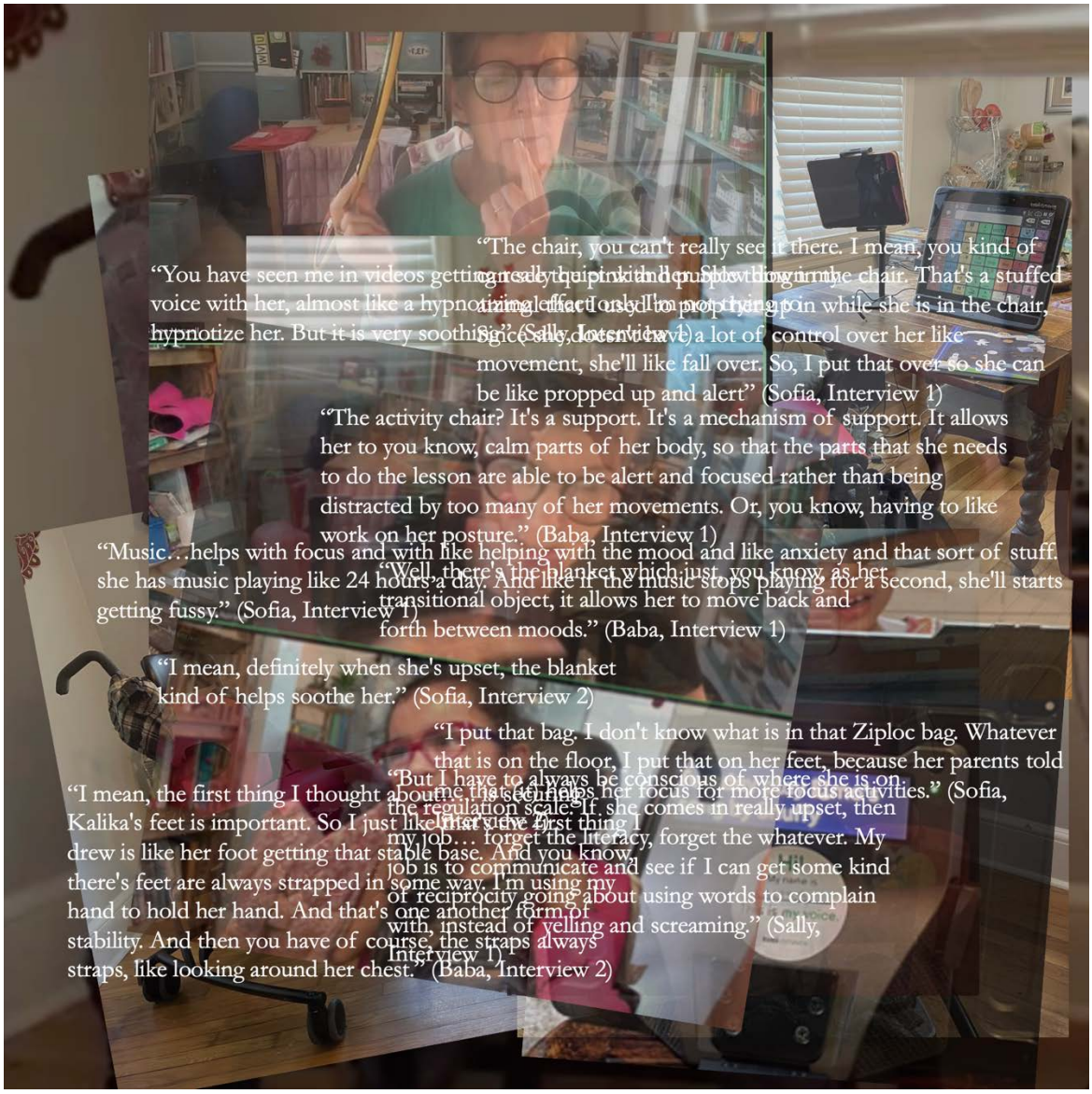

Illustration 3. Collage of Thinking with Assemblages of Humans and Non-Human Elements

Part III: Thinking with the Assemblages of Humans and Non-Human Elements in Literacy

Have you ever wondered what happens after a tree is cut down in a forest? Researchers argue that as soon as a tree is cut down, its neighboring trees, regardless of their species, form alliances and send nutrients to the stump of the injured tree through their root tips via the underground fungal network or mycelium (see Wohlleben, 2016). This invisible intra-action within the assemblages of different trees can allow the stump of the tree to live for decades or even centuries. How do you think this kind of supportive intra-action would look like in literacy? What kind of more-than-human assemblages or alliances are formed to develop the literacy of a child with significant disabilities?

In this section, we explore the assemblages of humans and non-human elements that are intra-acting during Kalika's literacy activities. Assemblages, as Bennett (2011) conceptualized, are the "ad hoc groupings of diverse elements, of vibrant materials of all sorts" (p. 23). They are "living, throbbing confederations" (Bennett, 2011, p. 23) of humans and non-human elements whose vitality is unique – it is not the same as the sum of the vitality of each actant considered alone (Bennett, 2011). Just like the assemblages of diverse trees providing much-needed nourishment to the injured tree, each actant is vital and their groupings play multiple roles during Kalika's literacy activities with Sally, Sofia, and Baba. Narrative 3 provides an illustration of how these assemblages are formed, what constitutes the assemblages, and what roles they play within Kalika's literacy entanglement at home. As you read this narrative, I invite you to observe how the humans work with each other and with the non-human elements, how they play their roles, and how their assemblages support Kalika to engage in literacy activities. Following this

narrative, we will discuss key points in the narrative and discuss the more-than-human assemblages in Kalika's literacy.

Narrative 3

"Why don't you give Kalika her brace?": More-Than-Human Assemblages

August 5, 2023

It was a sunny Saturday in Ἀθῆναι, with the temperature outside reaching 88 degrees Fahrenheit and a humidity level of 70%. Seated on a red sofa with Ma in the family living room, Kalika was enjoying her lunch from her feeding tube before her next session with Sally, while Baba was in the shower. Gin and Tap, the family cats, kept us company—Tap rested by my feet on the floor, while Gin perched on her cat tree by the window. After exchanging a few conversations about my research with Ma, I went to the kitchen and set up my recording gear to observe today's session. Meanwhile Ma carried Kalika in her arms to the dining room.

"Hi, Sally," Ma greeted Sally on the iPad. She then placed Kalika in her activity chair that was parked in the family dining room.

Kalika began to fuss as she sat in her activity chair, showing her displeasure in beginning the session that afternoon.

"Look at you in your cute little summer dress!" exclaimed Sally over the iPad, excited to see Kalika again after the summer break.

Kalika looked at Sally on the iPad and continued crying.

Figure 48. Ma and Baba Putting Kalika's Shoes and Fastening the Feet Strap

Ma proceeded by adjusting Kalika's eyeglasses and fastening the chest harness on the activity chair around Kalika's body. Baba then joined them and helped Ma set up the big Tobii and put it on charging. After that, they put Kalika's shoes on and secure her feet with straps on the activity chair (Figure 48). Kalika was still crying as Ma and Baba worked with this assemblage of the non-human elements that support Kalika's posture and feet. Assemblages,

as Bennett (2011) argued, are the "ad hoc groupings of diverse elements, of vibrant materials of all sorts" (p. 23). In this particular moment, the harness, the feet straps, and other elements in the activity chair is an assemblage that supports Kalika's body as she is sitting in the chair. Each element in the activity chair "has a certain vital force, but there is also an effectivity proper to the grouping as such: an agency of the assemblage" (Bennett, 2011, p. 23).

Figure 49. Baba Holding Kalika's Left Hand and Fixing Her Kapor

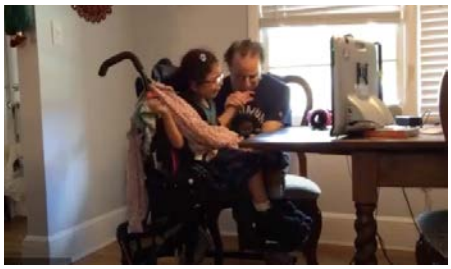

Figure 50. Baba Kissing Kalika's Hand to Sooth Her Cries

Baba then moved the activity chair closer to the dining table and adjusted the window shades to reduce sun glare on Kalika's eye-tracking AAC device. As the lesson began, Ma left the room to work in her office located next to the dining room. Baba was observed holding Kalika's left arm and fixing her kapor (a muslin cloth) that had been placed by Ma around Kalika's shoulder earlier (Figure 49).

"I know I can tell, it's just downright terrible for you. It is," said Sally to Kalika as Kalika did not stop crying after 15 minutes into the lesson. She pressed the word "terrible" on Kalika's device to model for her where the word was located and how it sounded.

Kalika continued crying. She then looked at Sally on the iPad.

"Kalika," Baba called his only child's name. He then looked at Kalika, kissed her hand, and moved his head closer to Kalika to soothe her cries (Figure 50).

"I am trying really hard because I can, because I am so smart. I can calm my body [and] I can relax because I am pretty awesome. I have had a hard time before, and I have been able to calm my body. Then I felt really proud about it," said Sally, modeling for Kalika on how to talk to herself and calm her body. As she spoke, she pressed some words on Kalika's device, namely "try", "calm", "relaxed", "awesome", and "proud", while modulating her voice to be low (Figure 51).

Figure 51. Sally Modeling for Kalika How to Calm Her Body

Kalika and Sally then continued the session by reading a book on the big Tobii. Kalika was still crying. Not long after, Ma returned to the dining room as she heard Kalika's prolonged cries. She then put Kalika's kapor inside her mouth and stroke her hair. Following this action, Kalika stopped crying for a while and continued crying when the kapor dropped out of her mouth.

"Baba, why don't you put her brace on?" asked Ma to Baba. "It's much easier for Kalika to focus when she has her brace on," she continued.

"No, that's okay," Baba declined softly while gesturing to Ma that he was holding Kalika's hand to help mitigate the repetitive hand movements.

"We'll put your brace on," said Sally agreeing to Ma's idea while navigating her desktop computer to put the digital book onto Kalika's big Tobii.

Baba then grabbed the pink arm brace from the table, secured it around Kalika's left arm, and continued holding her hand. Ma lifted Kalika's head, adjusted the brace on her body, and placed the kapor in Kalika's mouth for her to chew before leaving the room to resume her work.

Figure 52. Kalika Smiling as She Saw the Illustration with Her Arm Braced

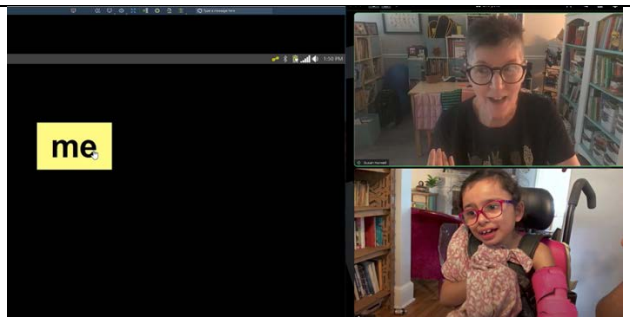

Figure 53. Sally Stopped Crying as Sally Sang the Letters

"Yeah, that kind of help, doesn't it? It gets your body calm down", said Sally after noticing Kalika's pink arm brace on wrapped around Kalika's left arm.

As Sally successfully uploaded the book on Kalika's big Tobii system, she prompted Kalika to look at her big Tobii to fixate on illustrations of the book that they would read.

Kalika stopped crying for a moment and smiled as she saw the book illustrations (Figure 52). She then began to fuss again.

"em, ee, em, ee, em ee says me me me," Sally sang the letters of the word 'me' that Kalika had to fixate on her big Tobii.

Kalika stopped crying and fixated on the word 'me' on her Tobii (Figure 53).

"There you go, you got it," Sally said. She then sang another song for the next word Kalika had to fixate, i.e., the word 'make: "em, ei, kay, ee make make make me happy please, make make make me happy please."

Kalika looked at her Tobii, looked at Sally on the iPad, and smiled briefly to her.

Narrative 3 lays out instances where the humans collaborate with the assemblages of non-human elements to support Kalika's body and soothe her cries during Kalika's session with Sally. These instances are not exclusive to my Observation 6 on August 5, 2023, from which I created this narrative. Almost all afternoon sessions with Sally involved Kalika crying for the first quarter to half of the sessions.

The more-than-human assemblages in this narrative unfold as Ma positions Kalika on her adaptable activity chair in the dining room followed by putting on the harness on Kalika's chest

and the straps around Kalika's feet with Baba's help. As the session progressed, Baba, Ma, and Sally intra-acted with Kalika and other actants to support Kalika's engagement in the reading activities. Ma, for example, prompted Baba to put on Kalika's arm brace. She specifically expressed that "it's much easier for Kalika to focus when she has her brace on," to which Sally agreed. Baba then followed by bracing Kalika's left arm and holding her arm. Further, Baba and Ma were observed working with Kalika's kapor: they attached it to Kalika's activity chair, put it inside Kalika's mouth, and covered it around her neck as Kalika did not stop crying. Baba was also seen looking at Kalika in the eyes, approaching his body to hers, calling her name, and kissing her arm to calm Kalika. On the other hand, Sally worked with Kalika and modeled for her how to calm her body. She accomplished this by lowering her voice and pressing some words on Kalika's AAC device to accompany her speech. She also made up some songs from the letters of the words that Kalika had to fixate on her AAC device and sang them a few times to attract Kalika's attention and pique her interest in doing the activities. The intra-actions of actants within these more-than-human assemblages supported Kalika in calming her body, soothing her cries, and engaging in the activities, as shown by her successful fixation on the target words and illustrations on her big Tobii.

Each actant involved in this narrative, namely the feet straps and harness of Kalika's activity chair, the pink arm brace, kapor, AAC device, Baba, Ma, and Sally, is vital – they play significant roles by themselves, yet when they are entangled with each other, they form a distinct vitality that is not necessarily the same as the sum of the vitality of each of them considered alone (Bennett, 2011). In the following two sections, we will unravel the kinds of assemblages that emerged during Kalika's literacy activities at home and what roles they play in supporting Kalika's literacy engagement.

More-Than-Human Assemblages in Kalika's Literacy Entanglement

The Assemblage of Kalika, Baba, Sofia, Sally, Arm Brace, Activity Chair, Soft Toys, and Weighted Ziplock Bag

Narrative 3 portrays the assemblages of humans and non-human elements that support Kalika during her literacy activities by alleviating several Rett syndrome symptoms. Baba, Sofia, and Sally argued that these symptoms, namely repetitive hand movements and muscle weakness, contribute to Kalika's ability to "focus" (Baba, Interview 1) and be "alert" (Sofia, Interview 1) during her literacy activities. Baba, especially, highlighted the significant role of the activity chair and its non-human elements as a "mechanism of support" (Baba, Interview 1) that mitigates the symptoms. He argued that each non-human element in the activity chair, such as the chest harness, the lateral support, and the foot straps (see Figure 54), helped Kalika to "calm parts of her body" (Baba, Interview 1) so she could "be alert and focused rather than being distracted by too many of her movements or having to work on her posture" (Baba, Interview 1). In other words, for Baba, mitigating these symptoms during Kalika's literacy activities is crucial to ensure her engagement with Sally.

The significance of working with the non-human elements to support Kalika's seating posture and mitigate her repetitive movements is observed in all observations I had conducted in Kalika's house. Narrative 3, for example, depicts a typical view of each beginning of Kalika's session with Sally where Baba or Ma intra-act with the foot straps, the chest harness, and the lateral support on Kalika's activity chair right before the session starts, and as soon as Kalika sits on the chair. The same intra-action is also seen in Kalika's sessions with Sofia that occurred in the dining room where the activity chair is mainly parked, i.e., Observation 3 on July 19 and Observation 7 on August 8. This phenomenon shows the entanglement of the humans with non-

human elements as well as the humans' mutual understanding of the roles of the non-human elements in supporting Kalika during her literacy activities. The armbrace and its function to mitigate the repetitive hand movements, for example, was highlighted by Ma, Sally, and Baba in Narrative 3 as an element that made it "much easier for Kalika to focus" on the activities. Their understanding of the importance of alleviating the movements aligns with the studies from Fabio et al. (2011) who argued that minimizing repetitive movements led to an improvement in the accurate selection of symbols and enhanced attention to choice-making tasks among the individuals with Rett syndrome. Similarly, Stasolla et al. (2014) also found that a decrease in repetitive hand movements in Rett syndrome is correlated with better communication.

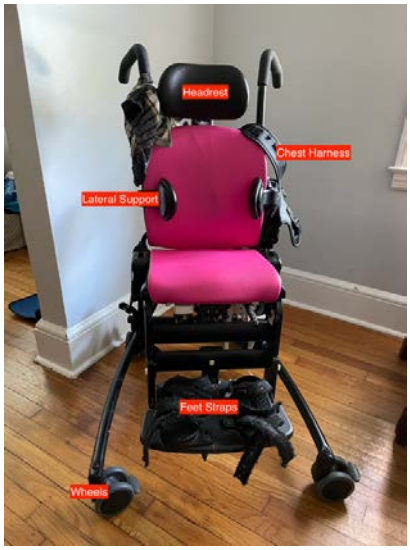

Figure 54. Kalika's Activity Chair and Its Elements

The crucial roles of these non-human elements and the importance of supporting her posture and as well as reducing the movements are also reflected in Baba's drawings of his entanglement with other humans and non-human elements during Kalika's literacy activities (see Figure 22). In responding to my question *"what objects did you draw first?"*, Baba expressed that "the first thing I drew is her feet" (Baba, Interview 2) that were "always strapped in some ways" (Baba, Interview 2). These straps along with the chest harness were in fact among the

most noticeable non-human elements that Baba included in his drawing and were part of his portrayal of Kalika. Further, when drawing Kalika, he conveyed that he "was thinking about her posture" (Baba, Interview 2) and how Kalika "curves and hunches forward" (Baba, Interview 2) due to her muscle weakness. His statement highlights Kalika's muscle weakness as a particular symptom that hinders her ability to maintain an upright sitting position for extended periods. This ability is crucial for Kalika to be able to access her big Tobii and the iPad on the dining table. To speak through her big Tobii, especially required Kalika to maintain a certain head angle and seating position, as we discussed in the earlier sections. Therefore, the chest harness helped Kalika "hold her shoulder blades so she could straighten up" her body and engage in the activities (Baba, Interview 2).

The significance of supporting Kalika's body and working with the non-human elements is also reflected in Baba's perception of his role during Kalika's literacy activities with Sally. He expressed that he saw his role as "kind of the same as [the role of] the activity chair" (Baba, Interview 1) during the session. He stated that, in the entanglement of humans and non-human elements in Kalika's literacy, he was also "an object" or a "primary thing that supports her body" (Baba, Interview 1). He further explained that a lot of time he would be "holding her arms and giving her support… and was doing the same kind of work" (Baba, Interview 1) as the non-human elements involved during her literacy activities with Sally, such as the activity chair and the arm brace. For example, in Narrative 3, Baba was observed continuously holding Kalika's arms throughout the session to alleviate Kalika's repetitive hand movements which he believed would help Kalika's engagement in the activities (Baba, Interview 1). When Ma suggested he wrap Kalika's arm with the arm brace instead of holding her hands, he initially refused the idea until Sally expressed her agreement with Ma's suggestions. His preference to 'brace' Kalika's

arms with his own hands was also observed in Observation 11 on September 30 where he declined Ma's suggestion to use an arm brace to mitigate Kalika's repetitive hand movements. His preference and persistence in holding Kalika's arms during her session with Sally demonstrate his understanding of the importance of alleviating the movements to help Kalika engage in the activities. Additionally, it shows his perception of the similar roles between his grip over Kalika's arms and the arm brace.

The importance of reducing repetitive hand movements to support Kalika's focus and engagement in literacy activities is also seen in other Kalika's sessions with Sally and Sofia. During Observation 2 on July 8, for example, Kalika's arms were both braced and held as they were moving intensely during Kalika's session with Sally (see Excerpt 7). Kalika, who was doing a comprehension check of a book they read last week with Sally, cried during the activity. Her left arm was continuously held by Baba since the start of the session while her right was moving repetitively. She took a longer time to respond to Sally's questions and had been making mistakes in her answers. Noticing that the intense arm movement might distract Kalika's engagement, Sally asked Baba to brace Kalika's right arm and expressed that the movements were "interfering" with her engagement. She also told Kalika that bracing the arm "helps us think a little better". Sally's initiative to ask Baba to brace Kalika's arm and her statement on how it helps the thinking process resonate with Baba's argument on the importance of mitigating Kalika's repetitive hand movements to help Kalika focus during the activity. After the bracing, while Kalika was still crying, the intense hand movements were reduced significantly, and she was able to provide Sally with a correct answer to the question.

The same case was also observed in Narrative 3. When Baba wrapped Kalika's arm with the arm brace and held her arm, Kalika's cries soothed for a while. Sally then expressed "Yeah,

that kind of help, doesn't it? It gets your body calm down" after seeing Kalika stop crying. Following these actions, Kalika was able to engage in the activity by looking at the book illustration on her big Tobii and smiling.

Excerpt 7

"There's just a lot of interfering movements": The Practice of Bracing

Kalika was crying while doing a comprehension check with Sally on the book they read last week about baking a cake. Sitting on her activity chair, Kalika left arm was held by Baba. She had made a few mistakes for the same questions that Sally asked.

"Does it mostly take place in the kitchen?" Sally repeated the question. She held up her yes or no communication board for Kalika to facilitate Kalika's complex communication repertoires.

Kalika looked at the iPad briefly while crying. She then moved her head down while crying. Her right arm was moving up and down intensely to her face.

"Yeah, what do you think?", Sally asked while waiting for Kalika's answer and observing Kalika's behaviors.

Kalika continued crying. She moved her head toward the kitchen and then moving it down again. Her right arm moved uncontrollably to different directions, including over her head (Figure 55).

"So, Baba, do you think it would help her if we brace her other arm?", asked Sally. She noticed that Kalika' right arm movement was getting more intense as Kalika cried.

"I'll try. Yes, sure," said Baba. He then stood up and grabbed Kalika's arm brace on the shelf nearby.

"There's just a lot of movements that's interfering with a lot of things," said Sally to Baba while he was wrapping Kalika's right arm with the arm brace.

Kalika continued crying.

"Hey Kalika, we are just gonna try to brace your other arm and see if that helps you to calm your body, because there's just a lot of movement going on. Sometimes that (bracing the arm) helps us think a little better," said Sally to Kalika.

Kalika was still crying. However, the repetitive movements on her right hand were reduced significantly after the application of the brace. Not long after, Kalika looked up and gazed at the "yes" symbol on Sally's yes or no board.

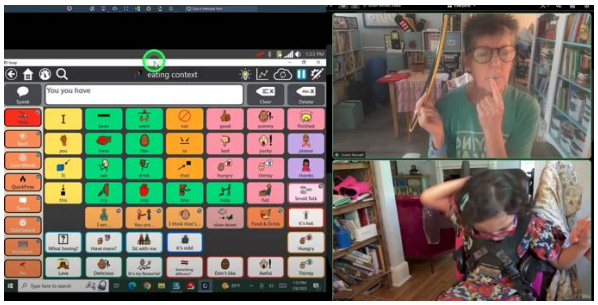

Figure 55. Kalika's Left Arm Being Held by Baba While Her Right Arm Moving Over Head

Baba's and Sally's statements demonstrate their mutual understanding of the significant roles of the non-human elements and their entanglement with Kalika in alleviating her repetitive hand movements. Further, Baba's perception of his role as "an object", a "primary thing", and "kind of the same as [the role of] the activity chair" illustrates his way of thinking with the non-human elements. The association of his role with the non-human elements shows his posthuman thinking as well as his understanding of the inherent entanglement of actants (humans and non-human elements) in Kalika's literacy experience. By holding Kalika's hand, Baba provided a biological form of support that functions similarly to the straps on Kalika's activity chair and the pink arm brace that Ma recommended for Baba to use around Kalika's arm during her session with Sally.

A similar understanding of the importance of collaborating with the non-human elements to support Kalika's body was also observed in Kalika's sessions with Sofia in the dining room, the playroom, and the living room where Kalika would sit on three different seating instruments, namely the activity chair, the Elmo-upholstered chair, and the sofa respectively. Sitting in the living room, for example, necessitated Sofia and Kalika to work with the cushions on the sofa to

help Kalika with her sitting posture during their storybook reading activities in the living room. By using the cushions, Sofia creatively made temporary torso supports whose functions reflect an element of Kalika's activity chair, namely the lateral supports (see *Table and Seating Instruments in the Rooms* in the earlier section for further discussion on this). Meanwhile, sitting on the upholstered chair in the playroom necessitated Kalika and Sofia to work with the soft toys to support Kalika's posture.

Figure 56. Soft Toys and a Ziplock Bag of Toys as Postural Support

Figure 56 and Narrative 2 (see earlier section, *Thinking with Actants in Complex Communication Repertoires*) illustrate the intra-action of Kalika and Sofia with some soft toys around Kalika's body and a ziplock back of stuffed animals on Kalika's feet during their math homework session in the playroom room. When prompted to explain why she employed the non-human elements and their roles in supporting Kalika's engagement during literacy activities with her, Sofia conveyed that the setup of the soft toys around Kalika's body was meant to support Kalika's body because she did not "have a lot of control over her movement. She'll like fall over" (Sofia, Interview 1). Sofia argued that working with the soft toys around Kalika's body would help "prop [Kalika] up and [made her] alert" (Sofia, Interview 1) during the activities. Meanwhile, the use of the ziplock bag and its placement on Kalika's feet would "help her focus" (Sofia, Interview 1) during the activities. Sofia's perception of the importance of supporting

Kalika's body and working with the non-human elements resonates with Baba's highlight on the role of the activity chair during Kalika's session with Sally. In Sofia's context, the functions of the soft toys around Kalika's body and the weighted ziplock bag on the feet resemble the functions of the lateral support and the foot straps on Kalika's activity chair (see Figure 54).

The Assemblage of Baba, Sally, Sofia, Kapor, Music/Songs, and AAC Device

In addition to mitigating repetitive movements and supporting sitting postures for Kalika to be able to focus and engage during literacy activities, the assemblages of human and non-human elements help Kalika with making her body calm and giving her comfort. As seen in Narrative 3 and Excerpt 7, Kalika cried in most of the session with Sally and Sofia. Specifically, 7 of the 11 observations I conducted involved Kalika's moments of crying for various reasons, including wanting to watch Sesame Street or feeling tired. During her sessions with Sally, for example, Kalika usually cried at the beginning and toward the end of the sessions. This resonates with what I discussed in the section *Space and Its Vitality in Influencing Kalika's Engagement* where Sally compared Kalika's literacy engagement at school versus at home. Sally expressed that at home, Kalika could get "whiny" (Sally, Interview 2) and "totally melted down" (Sally, Interview 2) in comparison to being at school. As explored earlier, Baba, Sally, and Sofia identified Kalika's "whining" (Sofia, Interview 1), "howling" (Baba, Interview 1), "screaming" (Sofia, Interview 1), and crying as some complex communication repertoires that Kalika orchestrated to express her disengagement or disinterest in doing the literacy activities with them. During Kalika's meltdown moments, Baba, Sally, Sofia, and Ma work with each other and with the non-human elements to calm her body and soothe her cries, so that Kalika can engage in literacy activities with them.

Among the many non-human elements that always intra-act with Kalika, Baba, Sally, Sofia, and Ma during Kalika's meltdown moments is her kapor. Kalika's kapor is a muslin cloth that is always entangled with her wherever she is. During the family's visit to the city's library on July 8, for example, Kalika was wrapped in her kapor as she and Baba sat on a long sofa before exploring the aisles of books to select which ones they would read the following weeks. The importance of the kapor for Kalika was highlighted by Baba, Sofia, and Sally during our interviews and is reflected in the drawings they made. Baba expressed that having Kalika's kapor around during Kalika's session was "important" (Baba, Interview 1), because Kalika "need[ed] them to comfort herself through chewing" (Baba, Interview 1). He further argued that the kapor was a "transitional object that allows her to move back and forth between moods" (Baba, Interview 1) – an argument that Sally agreed with (Sally, Interview 2). A transitional object or a comfort object is an item used to provide a psychological sense of security and comfort for children (Arthern & Madill, 2002). It is a "defense against anxiety and must appear to the child to have its own *vitality* such as giving warmth or having texture" (Arthern & Madill, 2002, p. 369, emphasis added to highlight the vitality of the non-human element). Children, regardless of their abilities and cultural background, grow some kind of attachment to non-human elements to develop a sense of self and ease their anxiety of separation from their first external object, i.e., their mothers (Litt, 1983; Custodero et al., 2016). In Kalika's case, the non-human object that Baba and Sofia believed would provide comfort was her kapor.

Being Kalika's transitional object, the kapor was present in all observations I made during Kalika's sessions with Sally, Baba, and Sofia across different spaces, namely the dining room, the living room, the playroom, and Sally's house. During Kalika's session with Sofia in the playroom, for example, the kapor was usually laid on Kalika's lap as they were reading a

storybook, playing a board game, or watching Sesame Street (Figure 57). Sofia expressed that having a kapor around during her session with Kalika was useful. She argued that when Kalika "was upset, the blanket (the kapor) kind of helped soothe her" (Sofia, Interview 2).

Figure 57. Kapor during Kalika's Session with Sofia

During Kalika's sessions with Sally, Baba or Ma usually tucked the kapor in the activity chair to cover the upper part of Kalika's body as soon as the session started. In Narrative 3, for example, Kalika's kapor was placed around the handles of the activity chair by Ma so it could cover Kalika's shoulder and arms during her session with Sally. The placement of this kapor before the session started indicated the importance of this object as a non-human element that accompanied Kalika during her literacy activities. When Kalika began to fuss and cry, both Baba and Ma intra-acted with the kapor by covering Kalika's upper body with it and putting it inside Kalika's mouth so she could chew it. Kalika was seen to be calmer and stopped her cries for a while until the kapor fell out of her mouth. The collaboration among Baba, Ma, and the kapor to help Kalika calm her body was appreciated by Sally. She found such more-than-human intra-action "really important" (Sally, Interview 2) in supporting Kalika's engagement in her literacy activities. The intra-action of Kalika, Baba, Ma, and kapor in Narrative 3 highlights the vitality of the more-than-human assemblage in helping Kalika calm her body during her literacy routines. The kapor, especially, served as a comfort-inducing non-human element for Kalika; it

calmed her body, helped soothe her cries (Sofia, Interview 2), and influenced her moods (Baba, Interview 1).

Figure 58. Kalika Saying "Yes" to My Question and Mentioning Her Favorite Songs

In addition to the kapor, music or songs were highlighted as a crucial non-human element that accompanied Kalika during her literacy activities at home. Sofia, for example, argued that music was "an important part of her (Kalika) life" (Sofia, Interview 1). She expressed that Kalika had "music playing like 24 hours a day. If the music stopped playing for a second, she'll start getting fussy" (Sofia, Interview 1). Sofia believed that music helped Kalika "with the mood and anxiety" (Sofia, Interview 1) that she might have during their literacy activities. Similarly, Baba highlighted music as a non-human element that "we use to appease Kalika during the day" (Baba, Interview 1). He argued that some music, such as Cuban music, could "really really get her happy" (Baba, Interview 1) and was useful to get her excited about the activities. His argument on the importance of music and its role to "appease" (Baba, Interview 1) Kalika or calm her body resonated with Sofia's understanding of Kalika's repertoires of music. She expressed that Kalika had

> "one that's for calming to help her go to sleep, and it's slower music. She does have one that's a little bit more upbeat, where it kind of helps her like wake up and have more energy. And that definitely helps like set her mood." (Sofia, Interview 1).

For example, during Observation 8 on August 15 (see Excerpt 8), Kalika was whining during her make-up play activity with Sofia even though her favorite song, 'Mamy Blue' was playing in the background. Sofia, who had no idea why Kalika was whining, asked her why she was whining. She tried to console Kalika's cries by holding Kalika's left hand and playing Kalika's favorite songs on Kalika's phone. Only after the song 'Oh, Marie' by Louis Prima, which Kalika requested herself through her AAC device, played in the background Kalika stopped whining and continued to engage in the activity. The important role of music while engaging in literacy activities was also expressed by Kalika. When asked whether she liked listening to music during story-reading activities, she gazed at the "yes" symbol I presented in front of her (Kalika, Interview 1) and mentioned some of her favorite songs, such as 'Mamy Blue', 'Sunanda Sharma', and 'Umm Rit Maan' (Kalika, Interview 2) (Figure 58).

Excerpt 8

"Play 'The Wildest' by Louis Prima": Music and Mood

Kalika was fussing as she was doing a makeup play with Sofia in the playroom. Tap, the black and white cat, joined their activity. She was sitting behind Kalika's eye tracking AAC device and the make-up accessories. Kalika's one of favorite songs, i.e., 'Mamy Blue', played in the background.

"You look so pretty. Don't cry. Hey," Sofia said to Kalika while holding Kalika's left arm to calm her repetitive hand movements.

Kalika stopped fussing, smiled, and laughed as she made an eye contact with Sofia.

"Why are you laughing? Make up your mind. Are you gonna be sad or are you happy or are you just going to tease me?" Sofia asked to Kalika while giggling.

Not long after, Kalika's favorite song ended. Another song played and Kalika whinnied.

"Okay, I know you don't like this song. I am sorry," said Sofia. She then replayed 'Mamy Blue'.

Kalika looked at Sofia, smiled, and stopped crying. A few seconds later she said, “Play Elmo song by Snuffy” through her AAC device (Figure 59).

“Okay, let’s see. It looks like I don’t have that song downloaded. I am sorry. Is there a different song you want me to play?” asked Sofia to Kalika.

Kalika then gazed to her Tobii and said, “Play ‘The Wildest’ by Louis Prima.”

“Okay, I will. Hold on,” Sofia responded. Soon after, the song ‘Oh, Marie’ by Louis Prima played. “Is this better? This is getting you hyped up now,” said Sally.

Kalika looked at Sofia and smiled. She then continued doing the make-up play with Sofia with no whining at all.

Figure 59. Kalika Requesting Songs and Smiled to Sofia

As for Sally, while she opposed the use of music to soothe Kalika “because it then becomes an addiction” (Sally, Interview 1 - see *Space and Its Vitality in Influencing Kalika’s Engagement* for discussion of this), she did mention that she occasionally sang and “made up a goofy song” (Sally, Interview 1) to help Kalika learn the topics they discussed in the session. In Narrative 3, for example, Sally sang made-up songs from the letters of the words that Kalika had to fixate on her big Tobii, i.e., the letters ‘me’ and ‘make’. By spelling each letter in tune, Sally tried to gain Kalika’s attention and teach the letters to Kalika. The effectiveness of the songs as a medium of instruction was observed as Kalika stopped crying and fixated on the words following Sally’s made-up spelling songs.

In addition to the kapor and music, the humans were also observed intra-acting with Kalika to comfort her body and soothe her cries. As described in Narrative 3, Baba, Ma, and Sally used various strategies to comfort Kalika, such as employing body contact, eye contact, and verbal encouragement to Kalika. Baba, for example, provided verbal and tactile comfort to Kalika by calling her name, moving his body closer, stroking her head, and kissing her hand to calm Kalika's cries (Figure 48 and Figure 49). Similarly, Ma also intra-acted with Kalika physically by approaching Kalika from her office to the dining room, stroking her hair, and putting her kapor inside her mouth. Meanwhile, Sally used verbal modeling through Kalika's AAC to help Kalika soothe her cry and calm her body. By first and foremost saying "*I know I can tell, it's just downright terrible for you. It is.*" to Kalika, Sally acknowledged Kalika's feelings and validated her cries as part of her complex communication repertoires to express her disengagement and disinterest in doing the activities with Sally. Kalika responded to Sally's validation of her feelings by looking at Sally on the iPad while crying, which signified Kalika's understanding of Sally's acknowledgment and validation of her feelings and complex communication repertoires.

Additionally, by "slow[ing] down" (Sally, Interview 1) her voice and saying *"I am trying really hard because I can, because I am so smart. I can calm my body [and] I can relax because I am pretty awesome. I have had a hard time before, and I have been able to calm my body. Then I felt really proud about it,"* while pressing the words, such as "try", "calm", "relaxed", "awesome", and "proud", on Kalika's big Tobii, Sally provided a "soothing… almost like a hypnotizing effect" (Sally, Interview 1) for Kalika to calm her body. Importantly, Sally modeled for Kalika how to access words on her eye-tracking AAC device to express her feelings to others. The collaboration between Ma, Baba, and Sally as well as their intra-action with the non-

human elements (the kapor and AAC device) in Narrative 3 illustrate a lively more-than-human assemblage that supports Kalika by providing comfort, time to process her feelings, and validation of the feelings.

In further discussing her strategy, Sally argued that an important aspect of teaching literacy to Kalika and other students with profound disabilities was emotional reciprocity. She conveyed that,

> "I think we loan kids our egos while we're working with them. We loan them our strength, we loan them our confidence, we loan them our structure, we loan them our regulation. (Sally, Interview 2)

Sally further explained that when she was faced with circumstances where her students were "totally dysregulated" (Sally, Interview 2), i.e., whining, screaming, crying as reflected in Narrative 3, she had to "come under them. We're like, 'Oh, yeah, I know, this is hard.' You know, we don't get ratcheted up with them" (Sally, Interview 2). In other words, for Sally, the best intra-action with the meltdown or "dysregulated" moments of a student like Kalika is through acknowledgment and validation of their feeling as well as dialogues with them about their feelings.

Baba, Sally, and Sofia expressed that their roles during Kalika's literacy activities were to support Kalika and to work with her when she was disengaged in activities. In responding to my question *"what is your role in Kalika's literacy entanglement*?", Sofia expressed that she played a "middleman between her and what she wants" (Sofia, Interview 2). She argued that Kalika was "her own person, and she is capable of producing her own thoughts and having her own ideas" (Sofia, Interview 2). However, Sofia continued, Kalika "just needs someone to get there" (Sofia, Interview 2), especially when she was "wanting certain things and not wanting certain things"

(Sofia, Interview 2). From her response, Sofia highlighted the gap between what Kalika wanted and what she could get by herself. She perceived Kalika as someone who needed a material actant (human and non-human element) that could bridge her to what she desired. Thus, Sofia saw herself as a supportive material or a "middleman" between Kalika and the world around her.

Correspondingly, Baba, also expressed that "most of my work is sort of custodial, like keeping the place ideal for their (Kalika and Sally) business" (Baba, Interview 1). This included giving Kalika food and drink, going to the bathroom, assisting with technology and devices from Kalika's end, and "help(ing) with Kalika's mood" (Baba, Interview 1). Specifically, Baba described that

> "my primary role, obviously is knowing how to get through to Kalika and how to figure out whether we can talk her out of what [made her] her funk, or whether this is just a place where there are no options, and she just needs rest." (Baba, Interview 1)

From his statements above, Baba perceived his role as a custodial provider that helped ensure an ideal environment for the interactions between Kalika and Sally during their literacy activities. He explained that he endeavored "not to be as obtrusive as possible, because I know Sally really privileges the conversations between her and Kalika, so I do not wanna insert myself in there" (Baba, Interview 1). This echoes his choice of a metaphor for his role being "kind of the same as the activity chair" (Baba, Interview 1) which he considered to be a "mechanism of support" (Baba, Interview 1) that was significant and obtrusively supporting Kalika to engage with Sally during their "business" (Baba, Interview 1). In other words, in the literacy entanglement of Kalika and Sally, Baba saw himself as "an object" (Baba, Interview 1) or a material that played behind-the-scenes roles that supported Kalika's interaction with Sally.

An important aspect of his role that Baba highlighted was to work with Kalika's "mood", especially when she was in a "funk", i.e., the state of being unhappy, sad, or depressed. His statement resonates with his argument on the role of kapor as a transitional object for her to "move back and forth between moods" (Baba, Interview 1). Both of these statements highlight Kalika's range of moods during her literacy activities with Sally. This is reflected in Narrative 3 and Excerpt 7 where we can see moments of Kalika crying, smiling, and laughing during a session with Sally and Sofia that show her rich communication repertoires in expressing her engagement/interest and disengagement/interest in the activities. When Kalika cried or was in a "funk", Baba saw himself as someone who needed to "talk her out" (Baba, Interview 1) and figure out what she needed, so Kalika and Sally could have an "ideal place" (Baba, Interview 1) to work with.

Regarding Baba's roles, Sally argued that Baba was "an integral part of this weaving of everything together" (Sally, Interview 2) or Kalika's literacy entanglement. She expressed that there were "things that he does, I can't do" (Sally, Interview 2), such as giving her the "blanket to kind of chew or help[ing] her arm stay still" (Sally, Interview 2). He considered Baba's presence and what he did during her sessions with Kalika "really important" (Sally, Interview 2), especially when Kalika was "starting to fall apart" (Sally, Focus Group Discussion).

In a similar vein, Sally likened her work with Kalika to "being a juggler" (Sally, Interview, 2) who engaged in a delicate "dance on the head of a pin" (Sally, Interview 1). This is particularly reflected in the drawing that she made to illustrate her entanglement with Kalika (Figure 60). At the bottom of the humans and non-human elements she included in her drawing, such as Baba, iPad, big Tobii, activity chair, and yes or no board, she drew a board on a pointy surface and wrote "balance" to support her perception of being a juggler who was "holding up

everything while they were working, holding up different plates" (Sally, Interview 2). Losing the balance, she further explained, "everything is gonna fall over… it's all gonna collapse" (Sally, Interview 2).

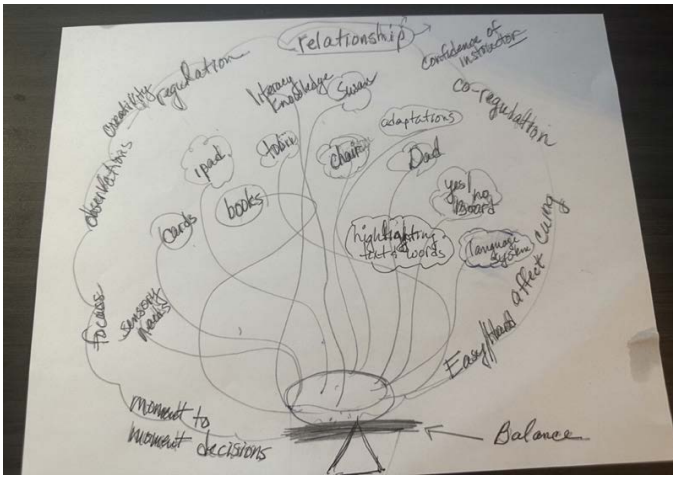

Figure 60. Sally's Drawing Illustrating Her Entanglement with Kalika

Beyond providing instructions for Kalika, she expressed that there were "moment-to-moment decisions" (Sally, Interview 2; Figure 60) that she had to make as she worked with Kalika whom she considered to be "a regulation kid" (Sally, Interview 1). Therefore, for Sally, among the most significant roles she played during her literacy session was to work with Kalika's "affects" (Sally, Interview 2) or "funk" or "moods" in Baba's and Sofia's terms. She expressed that,

> "I have to always be conscious of where she is on the regulation scale. If she comes in really upset, then my job [is], forget the literacy, forget the whatever. My job is to communicate and see if I can get some kind of reciprocity going about using words to complain with, instead of yelling and screaming." (Sally, Interview 1)

She further highlighted that "usually, in every session, you can find a period of time where she's really with me, even though it might be short" (Sally, Interview 2). Her statements indicate a range of moments when Kalika was 'with her' and 'not with her' during their literacy

activities. When Kalika was ‘not with her’ or having her “meltdown” (Sally, Interview 1), or “dysregulated” (Sally, Interview 2), or “fall apart” (Sally, FGD) moments, Sally argued that her role or “job is to communicate” with Kalika to gain “some kind of reciprocity” (Sally, Interview 1) with her. Her approach to dialogue with Kalika was reflected in Narrative 3 where she delayed her reading activity with Kalika to talk to her slowly, validate her feelings, and model for her how to express her feelings through her AAC device “instead of yelling and screaming” (Sally, Interview 1). These moments of pausing, Sally argued, “let her have a chance to breathe before she goes to the next” (Sally, Interview 2) activity. In further explaining her strategy, Sally expressed that her relationship with Kalika includes a profound emotional entanglement where Kalika could “pick up on”, “borrow”, or “loan” (Sally, Interview 1) strength, confidence, regulation, calmness, and assurance (Sally, Interview 1 & 2) from her.

In this section, I have presented and explained the assemblages of human and non-human elements and the inherent more-than-human entanglement in Kalika’s literacy. Specifically, I have elucidated the ways in which the intra-actions among Baba, Sally, Sofia, Ma, kapor, music/songs, AAC device, arm brace, activity chair, soft toys, and weighted ziplock bag form coalitions that support Kalika’s engagement during her literacy activities. Such phenomena highlight not only a dynamic intra-action between the actants, where their mutual interdependencies shape and influence Kalika’s literacy experience but also the vitality of each actant in being entangled with each other and co-creating a supportive literacy environment for Kalika. They show the entanglement between materiality and literacy engagement in a significant disability context.

CHAPTER 5

DISCUSSION, IMPLICATIONS, FUTURE RESEARCH CONSIDERATIONS, AND CONCLUSION

> "Humanity and nonhumanity have always performed an intricate dance with each other. There was never a time when human agency was anything other than an interfolding network of humanity and nonhumanity; today this mingling has become harder to ignore." (Bennett, 2010, p. 31)

This case study aims to explore the more-than-human literacy entanglements of Kalika, a seven-year-old individual with Rett syndrome, with Baba (her parent), Sally (her literacy specialist/teacher), Sofia (her babysitter), and non-human elements at home. By employing the posthuman lens, I analyzed data from 25-hour video-recorded observations, 7-hour video-recorded interviews, and 1-hour focus group discussion to answer two interrelated research questions, namely: "How is a child with Rett syndrome entangled with other human and non-human interactants during literacy activities at home?" and "What are the larger implications of these entanglements for inclusive language and literacy education practices?" The explorations of this study also include the examinations of who and what kinds of actants are part of the child's language and literacy activities and what roles these intra-actants play in navigating language and literacy activities for the child.

To analyze the data, I adopted a diagrammatical mode of thinking (Freeman, 2017) using three layers of analysis methods, namely coding, narrative writing, and collage-making. The coding was done through descriptive coding, thematic coding, and free coding (Saldaña, 2021).

MacLure (2013a) argued coding in research tends to take the researchers away from the complexity and context of the data (MacLure, 2013a). It also "ignores the entanglements of language and matter, words and things" (MacLure, 2013a, p. 171). Therefore, I employed narrative writing and collage-making as additional layers of analysis and a medium for me to re-engage with my data, explore their textures, and mediate my thinking with theories, which is a central aspect of posthuman research (Jackson & Mazzei, 2011). Collectively, my approach to engaging with the data in this research facilitates what Maclure (2013b) called "the wonder of data" (p. 228), which is a relational "cognitive passion" (p. 228), a desire of a researcher to connect with the non-human elements (the data) in/as an assemblage.

In the previous chapter, which is primarily aimed to answer the first research question, I discussed how humans and non-human elements intra-acted and were entangled during Kalika's literacy activities with Sofia, Baba, and Sally at home. I explained how actants (humans and non-human elements) exerted their vitality (Bennett, 2011) or agency (Barad, 2007) and formed more-than-human assemblages during story reading, math homework, and learning to read (spelling) sessions. I divided my explorations into three parts, namely *Part I: Thinking with Space and Its Intra-Acting Actants*, *Part II: Thinking with Actants in Complex Communication Repertoires*, and *Part III: Thinking with the Assemblages of Humans and Non-Human Elements in Literacy*.

In Part I, I explored how space, actants, and the positioning of actants in space materialize or come to matter (Naraian, 2021) in Kalika's literacy activities. They play roles in providing accessibility for Kalika to engage with some crucial non-human elements in her literacy journey (i.e., eye-tracking AAC device, iPad, books), communicating expectations and conditioning behaviors, influencing focus/alertness, and facilitating partner-assisted-scanning

and communication between Kalika and her interlocutors, among others. In Part II, I examined how humans and non-human elements are entangled in complex communication repertoires, especially in facilitating Kalika's expressions of interest, disinterest, wants, needs, preferences, and responses to questions posed by Sofia, Sally, and Baba. In this section, I argued how Kalika's communication is not only multimodal but also multiactant due to its entanglement with humans and non-human elements. Lastly, in Part III, I discussed how humans and non-human elements form relational networks or assemblages (Bennett, 2011) to calm and comfort Kalika's body and mitigate some Rett syndrome symptoms, namely repetitive hand movement and muscle weakness, so she can better focus during her engagement with Sofia, Sally, and Baba.

This last chapter of my dissertation aims to revisit the findings of my exploration, discuss how they are situated within previously published research and theory on posthumanism and literacy, as well as answer the second research question. In the following sections, I lay out two key points from my findings and analysis of Kalika's literacy entanglements with other humans and non-human elements. I then present the implications of these takeaways for inclusive language and literacy education practices. I conclude the chapter with discussions on the limitations of this study, future research directions, and overall conclusions of the study.

More-Than-Human Literacy Entanglements

My exploration of Kalika's literacy entanglement sheds light on the inseparability of humans and non-human elements in literacy. The dynamic intra-actions between humans (Kalika, Sofia, Baba, Sally) and non-human elements (e.g., table, seating instruments, room brightness, flashcards, books, handout, eye-tracking AAC device, symbols on communication board, colors, arm brace, activity chair, soft toys, and weighted ziplock bag) in this study demonstrate that literacy is more-than-human entanglements. It is an entangled, distributed, and

multiactant phenomenon that goes beyond individual thought/internal processes and exclusive human-to-human interactions. This understanding of literacy as a more-than-human entanglement process challenges us to value and account for the significant roles of non-human elements and their intrinsic connection with literacy. In the following sections, I laid out two key points gained from my exploration of Kalika's literacy entanglement and its relationality with posthuman thinking, namely *Literacy as a Collaborative Endeavor* and *Literacy as an Emergent More-Than-Human Phenomenon*.

Literacy as a Collaborative Endeavor

The turn toward the entanglement or "performative" turn (Barad, 2007, p. 135) in this study shifts the focus of literacy exploration into the vitality of human and non-human actants and the interconnectedness between them. This shift in perspective, Hultman and Taguchi (2010) argued, challenges the "*anthropocentric gaze*, a gaze that puts humans above other matter in reality, that is, a kind of human supremacy or humanocentrism" (p. 526, emphasis in original). From the exploration of Kalika's literacy entanglement with other humans and non-human elements in the previous chapter, we have seen the collaborations across bodies of actants during Kalika's literacy activities, and the ways the intra-action between actants shapes Kalika's literacy experiences. Actants, as I explain in Chapter 1, are either humans or nonhuman elements possessing agency or vitality to alter phenomena (Latour, 2004). In this study, the term actants may include, among others: Kalika, Sally, Sofia, Baba, Ma, a dining table, an eye-tracking AAC device, soft toys, flashcards, an arm brace, and other possible humans and non-human elements involved in Kalika's literacy activities at home.

The entanglements among actants during Kalika's literacy activities are porous, meaning that they are open to various bodies of actants beyond humans. Within such entanglements, all

actants involved in literacy are significant and performative (Barad, 2007); each of them has causal gravity to influence one another during literacy activities and is "equally at play and work as constitutive factors in children's learning and becomings" (Hultman & Taguchi, 2010, p. 527). Therefore, a slight change in their composition will affect their intra-actions in the entanglement.

As an example, in Kalika's literacy, this could be observed from the way Baba, Sally, and Kalika consistently positioned themselves around the dining table, arranged the big Tobii and the iPad on it, and maintained the angles of the devices in every meeting. Baba and Sally expressed that a slight alteration in this entanglement composition, such as the change in the angle of the iPad's camera and the big Tobii, would influence Kalika's ways of engagement with Sally during the activities. Among the primary reasons why those non-human elements were arranged in such a configuration on the dining table was because of the strategy of communication between Kalika and Sally which was mainly done through partner-assisted scanning. Another example could be seen from Kalika's assemblage with her kapor that always accompanied her during her literacy activities with Baba, Sally, and Sofia. As Baba argued, the muslin cloth was an important transitional object that helped Kalika calm her body during her literacy activities with Sally. Therefore, its presence during Kalika's sessions with Sally was significant to "allow her to move back and forth between moods" (Baba, Interview 1), which was an argument that Sally and Sofia agreed with.

The nature of Kalika's literacy as a porous and collaborative endeavor can be observed in all her literacy sessions with Sally, Baba, and Sofia. For example, in the second part of Chapter 4 (i.e., *Thinking with Actants in Complex Communication Repertoires*), I explained the intra-actions among Kalika, Sofia, Sally, Baba, eye-tracking AAC device, flashcards, communication board, cup, space, colors, and iPad. Their collaboration serves specific missions: to develop

Kalika's literacy skills through reading, spelling, and counting activities as well as to ensure Kalika's effective multimodal engagement and communication during her literacy activities. In Narrative 2, specifically, we see how Sofia intra-acted with the non-human elements, such as the flashcards, the eye-tracking AAC device, the little table, and the soft toys to facilitate Kalika's engagement during their math homework session. By presenting the flashcards in front of Kalika, prompting Kalika to observe the cards clearly and touch one she believed was the answer to the question, arranging some soft toys around Kalika's seating position to support her body posture, loading Kalika's feet with a bag full of soft toys to support her focus, placing Kalika's eye-tracking AAC device at the right angle so she could also engage in the activity verbally, and moderating the amount of light in the room to avoid glares on her AAC device, Sofia ensured a supportive ecology for Kalika to engage in literacy activities with her.

At the same time, we can also see how Kalika responded to this arrangement and intra-acted with the non-human elements around her. By smiling and establishing eye contact with Sofia, looking at and moving her body toward the flashcards, saying "gross" through her AAC device, and following Sofia's prompt to observe the flashcards and touch only one flashcard that represented her answer, Kalika's intra-action with other actants showed us how a purposeful arrangement of humans and non-human elements in a specific space could facilitate effective literacy engagement for a child with significant disabilities. Additionally, it also shows the entanglement between Kalika's complex communication repertoires with humans and non-human elements, which is often rendered invisible in anthropocentric literacy investigation (see Hultman & Taguchi, 2010).

The more-than-human intra-actions in Kalika's literacy demonstrate how diverse actants collaborate and form an assemblage during her literacy activities with Sofia. An assemblage, as

we have discussed earlier in the previous chapter, is an open-ended system of diverse actants that interrelates and collaborates to form a new lifeworld (Bennett, 2010). Within such a collapsing of humans and non-humans, each participating actant involved in the entanglement is "agentive and intra-active" (Barad, 2007, p. 170). They play their own significant roles in shaping Kalika's engagement and complex communication repertoires during literacy activities.

The role of the flashcards during Kalika's math homework session with Sofia in Narrative 2, for example, can not necessarily be substituted with other non-human elements, including her eye-tracking AAC device, as they would alter the ways Kalika intra-acts with the non-human element to express her engagement and response to the math question posed by Sofia. In Narrative 2, the flashcards presented by Sofia in front of Kalika provided affordances for Kalika to engage with them through specific ways, namely her gaze, body movement, and touch. I argue that the same intra-action could not necessarily be replicated if Sofia chose another non-human element for Kalika to intra-act or if Sofia decided not to collaborate with the non-human elements at all. For example, only presenting Kalika with her eye-tracking AAC device in front of her would limit her engagement specifically through her eye gaze and the speech Kalika produced through the device. The case would also be different if Sofia collaborated with Sally's yes-or-no communication board which would afford Kalika to engage with it primarily through her body movements and eye gaze. As it is a yes-or-no communication board, the question for Sofia would also be different: instead of asking *"Five plus what number equals eight"* as in Narrative 2, she would say *"Is five plus three equals eight? Yes or no?"* In other words, the non-human element in this example, namely the flashcards, plays roles in Kalika's literacy and her interaction with Sofia. They influence what kinds of activities that Sofia can do with Kalika (e.g., asking "what" questions instead of "yes/no questions") and provide unique affordances for

Kalika to engage in specific manners. The interrelatedness between actants in this phenomenon resonates with Barad's (2006) argument on the very nature of entanglement, i.e., the *inseparability* of intra-acting actants whereby the manipulation of one actant affects the state of the actant(s) in the other end of the entanglement.

From this example, we observe how non-human materials matter and are entangled with literacy, and how important it is to think with the materials in literacy instructions, especially in the context of significant disabilities for creating a more inclusive literacy environment. This turn toward the entanglement stands in contrast with the existing human-centric paradigm in literacy. From the humanist standpoint, literacy "focuses on developing one's ability to articulate decisions through increasing an individual's agency (I-subject") (Wargo, 2018, p. 504). This anthropocentric perspective regards literacy as a cognitive activity exclusive to the human body and perceives agency or vitality to reside exclusively in the human. It views humans as "the only possible constructors of language and discourse" (Hultman & Taguchi, 2010, p. 526), the epicenter and origin of all-knowing, and the most determinant elements for success in language and literacy instructions. It privileges independence, i.e., what one can do independently with their own body, and separation of mind from the world in the process of being and becoming literacy (Toohey et al., 2020). In contrast, posthuman literacy endeavors to shift such orientation of "I-subject" toward a collective "We-subject" (Wargo, 2018). It views literacy as an ongoing, porous, collaborative, and relational phenomenon involving more than just human bodies (see Kuby & Rowsell, 2017).

The "withness" (Micciche, 2014, p. 495) in Kalika's literacy with other humans and non-human elements in this study renders her process of knowing, doing, and becoming literacy codependent with other humans and non-human elements that coexist in the world. Specifically,

we observe how arrays of actants, from Baba, Sofia, Sally, and Ma to flashcards, books, soft toys, and her eye-tracking AAC device collaborate to create a supportive literacy ecology that embraces and values Kalika's complex communication repertoires, engagement, and disabilities. Their intra-actions demonstrate literacy as a co-creative endeavor with the world and to be part of the world. Literacy, thus, is a collaborative more-than-human endeavor, a conduit where humans and non-humans are enmeshed, entangled, and exerting agencies; it is an open-ended system of network beyond humans, porous of diverse modalities and representations of actants.

Literacy as an Emergent More-Than-Human Phenomenon

The interconnectedness of diverse actants in Kalika's literacy challenges us to expand our understanding of what it means to being, doing, and becoming literacy. On the surface, one might perceive Kalika's smiles, gazes, body movements, or touch toward other humans and the non-human elements during literacy activities as something other than literacy engagement. Multiple studies on the literacy of individuals with significant disabilities found that such dismissal of multimodal literacy engagements is common among students with complex communication repertoires (see Flewitt et al., 2014; Bhattacharya & Pradana, 2022). Bhattacharya and Pradana (2022) argued this dismissal is predominantly caused by the limited conception of what it means to engage in literacy, which fundamentally disorders the populations' diverse ways of engagement with literacy texts (e.g., books and pictures).

Further, many would also regard the collaborations between Kalika's parents with the non-human elements, such as the intra-actions between Baba with the angle of the iPad and the eye-tracking AAC device or Ma with Kalika's kapor and the positioning of Kalika's activity chair, as non-literacy endeavors not worth exploring in literacy studies. However, as we zoom into how these human and non-human actants intra-act with each other and form a network of

assemblages during Kalika's literacy activities, it becomes evident that their intra-actions are emergent, unexpected, and ever-changing; they represent a phenomenon known as pedagogical border crossing (Giroux, 1992).

Pedagogical border crossing refers to the practice of education that crosses boundaries or moves beyond the traditional conceptions and boundaries in teaching and learning (Giroux, 1992). In literacy studies, pedagogical border crossing includes the examination of space, movements, sounds, and play in various literacy activities (see Van Viegen, 2020; Braund, 2023). It emphasizes the importance of embracing diversity, promoting inclusivity, and fostering cultural awareness and understanding in educational contexts. In this paradigm, conceptions of teaching and learning are interrogated. This involves the reexamination of what literacy means, which has historically been defined in "monolithic terms, from the center, within a linear logic that erases uncertainty" (Giroux, 1992, p. 244), including its limited understanding that historically privileges human-to-human interactions and obscures the crucial roles of non-humans in enacting and shaping literacy experiences (Kuby et al., 2019).

For example, in anthropocentric literacy investigations, the roles of the dining table, the positioning of non-human elements on and around the dining table, Sally's placement of yes or no symbols and her choice of colors on the communication board, as well as Sofia's use of soft toys around Kalika's body might be deemed peripheral or even disregarded completely, as the researcher tends to tune their gaze (Foucault, 1980) toward the humans' experiences during literacy events. This includes how the humans interact with each other, how they manipulate – as opposed to work with – the non-human elements to benefit humans, and how their interactions advance Kalika's reading and writing skills. Further, Kalika's entanglements with other humans and non-human elements during her literacy sessions would also be perceived as limitations,

atypical, or "misfit" (Garland-Thompson, 2011, p. 594). This is due to the tendency of anthropocentrism to champion individualism and autonomy as opposed to interdependency and collaboration – it conceived humans as a "sovereign, coherent, and autonomous" (Nayar, 2014, p. 2) entity in the world. Such explorations place humans at the center of their investigations and disconnect the process of knowing from being (Taguchi, 2010). In this perspective, learning is conceived as an isolated human-to-human process that endeavors to advance humanity and renders the roles of the non-human elements invisible. It reinforces the binaries of culture-nature, fundamentally ignores the inherent interconnectedness of humans with non-human elements in the world, and separates knowing, doing, and becoming literacy. It is this separation or agential cut (Barad, 2007) that continuously overtones the hierarchy and disconnection of humans and the non-human elements in our literacy education and research.

I argue that the ongoing omission of withness between humans and non-human elements in literacy leads to its monolithic conception as a universal practice and the disordering/disabling of diverse ways of literacy engagement of individuals with significant disabilities. By enacting the perimeters or boundaries of literacy and literacy engagement, anthropocentric literacy creates specific agential cuts and a standard universal form of literacy that privileges and legitimizes certain forms of literacy and ways of literacy engagement, while undermining other forms and ways of engagement that fall outside the boundaries. A boundary, Hańderek (2021) posited, "simultaneously unites and divides what lies beyond it, thus creating a liminal space, a space of what lies between, and a space of ritual passage, change, and entrance into the sphere of the other" (p. 17). It possesses significant political and cultural effects that designate a certain phenomenon as marked and unmarked (Hańderek, 2021).

In Kalika's literacy context, the boundaries and universalism in anthropocentrism mark Kalika's more-than-human literacy entanglement and literacy engagement. They work as an insidious system of discrimination designed to rationalize the practices of marginalization and othering, rendering Kalika's literacy entanglement and engagement illegitimate, atypical, and secondary forms of literacy. This includes devaluing her complex communication repertoires and their interconnectedness with the non-human elements. For example, Kalika's gaze and body movements toward the left side of the room to express "yes" during her literacy sessions with Sally may be perceived as non-communicative or non-intentional behaviors, because anthropocentrism conceives language as a phenomenon limited to verbal systems that favors order and homogeneity (Canagarajah, 2018). Such a limiting paradigm of language and communication establishes a hierarchy between verbal and non-verbal communication, ignores the multimodality of communication, and denies the interconnectedness between language and the world (see Kendon, 2000; Pennycook, 2018).

The exploration of Kalika's literacy entanglement in this study demonstrates that literacy is a collective emergent hybrid phenomenon of multiactants. It cuts across bodies and involves more-than-human entities that continuously intra-act with each other. Kalika's entanglements with other humans and non-human elements challenge the longstanding anthropocentric concepts of literacy. They confront the preconceived, unquestioned boundaries of literacy and literacy engagement as merely human-to-human social interactions, inviting us to explore literacy as unbounded dynamic more-than-human relational endeavors.

Implications for Inclusive Language and Literacy Education

Building on the understanding of interconnectedness across diverse bodies in Kalika's literacy sessions with Sally, Baba, and Sofia, I propose three suggestions for language and

literacy teachers, teacher educators, and researchers to create a more inclusive and responsive language and literacy education:

1. *To turn the gaze into the entanglement of humans and non-human elements in language and literacy*. Kalika's literacy entanglements bring together people, materials, and space in literacy and enable us to see how these actants intra-act in providing inclusive language and literacy instructions. They enlarge the cuts (Barad, 2007) to be more inclusive toward diverse representations of actants in literacy and how their intra-actions support and shape one's literacy. This includes an invitation for us to value the relationality between students and non-human elements in their environment as well as to think and work with material elements beyond texts (e.g., books) to create a more responsive literacy environment for all students regardless of their abilities.

   From the intra-actions between Kalika, Sally, Baba, Sofia, Ma and the non-human elements during her literacy sessions in the dining room, playroom, and living room, we observe how the relationality between humans and non-human elements creates possibilities for an inclusive literacy space that appreciates Kalika's bodily representations and abilities; these actants collaborate with each other to embrace and value Kalika's complex communication repertoires and her diverse ways of engagement in literacy activities. For example, by thinking and working with the space, as well as Kalika's disabilities and symptoms of Rett syndrome, Kalika, Sally, and Baba establish an effective communication repertoire through eye gaze, body movements, and gestures to express agreement and disagreement over a yes/no question (i.e., left side for "yes" and right side for "no") during their literacy sessions (see Chapter 4 section *Thinking with Actants in Complex Communication Repertories*). This is especially seen in the ways they

place the non-human elements on the dining table, where they sit around it, and which side they (Sally) put the yes or no symbols on the communication board and the eye-tracking AAC device. Similarly, by collaborating with Kalika's preserved ocular communication modality and the benefits of color contrasts in drawing people's attention, Sally helps channel Kalika's attention on the morphology of words and areas of interest that Kalika has to observe on her eye-tracking AAC device and communication board.

The more-than-human interconnectedness in this study demonstrates language and literacy education as collaborative processes – as opposed to individual human endeavors and masteries – of different kinds of actants that continuously engage with one another. It challenges us to reconceptualize inclusivity in language and literacy instructions beyond the humanist sense that privileges individualism and autonomy, portrays disability as a burden/disease to eradicate/cure to be able to integrate into society, and perceives accessibility as a privilege that one must ask. In many of our classrooms, inclusivity is a price too high; students with disabilities and their families are constantly pushed to *earn* their humanness by proving their children's abilities to be independent in many ways, including their ability to think, perform, and self-regulate, because the mainstream classrooms require human bodies that are autonomous.

Further, their relationality invites us to observe, think, and work with diverse actants, value their agency and roles in influencing and shaping one another, explore their interconnections, and examine how their relational activities can create newness in language and literacy instructions. In the contemporary era, embracing the vitality of non-human elements, such as digital technology, assistive technology, nature, and animals, and intra-acting with them in the classrooms are inevitable. Students nowadays are

becoming more entangled with non-human elements than ever. Shifting our gaze to the vitality of actants and their entanglements provides ways for us to ponder alternatives of learning environment that values the crossovers of students with other life forms (e.g., technology, assistive devices, ecology), reimagine new personhood of students, especially those with disabilities as a dynamic, messy, and complex assemblage of humans and non-human elements (Deleuze & Guattari, 1987), and speculate the futures of language and literacy classrooms that are inclusive to all bodily representations and abilities.

2. *To interrogate and go beyond the assumed perimeters of language and literacy.* The interconnectedness of Kalika with other humans and the non-human elements in this study opens up what Deleuze and Guattari called haeccities. St. Pierre (2017) described haeccities as becomings or the potentialities to become otherwise, an infinite series of possibilities, formation, and transformation. In this context, Kalika's more than-human entanglement offers segues to create haeccities in language and literacy education, ways for us to travel the field beyond its anthropocentric perimeters that conceive them as sets of isolated fixtures and properties apart from the world (see Canagarajah, 2018; Toohey et al., 2020). They help create diffractions or plurality in our ethico-onto-epistemological orientations (Barad, 2007) of language and literacy. Ethico-onto-epistemology, as Barad (2007) argued, is the unity of ethics, ontology, and epistemology which historically have been conceived as separate entities in humanism.

    An example of haeccities from Kalika's literacy exploration is her complex communication repertoires and their entanglements with the non-human elements. As what Baba, Sally, and Sofia described during our interviews, among Kalika's most

frequently orchestrated complex communication repertories to express her engagement during literacy activities is her ocular communication (i.e., her eye contact with interlocutors, eye gaze towards a page of a book being read, as well as eye-fixation on the eye-tracking AAC device). Both Baba and Sally even specifically conceived her communication via the eye-tracking AAC device as a secondary level of communication that comes in after her ocular communication, gestures, and body movements.

During Kalika's sessions with Sally and Baba, the importance of Kalika's eyes to engage in literacy activities and access literacy texts is reflected in the use of different colors to discern vowels and consonants on the communication board as well as their consistent placement of the iPad and eye-tracking AAC communication and their seating positions. Similarly, during Kalika's session with Sofia, the importance of Kalika's eyes to engage with and access literacy texts was also seen in Narrative 2 where Sofia explicitly asked Kalika to look at her and the flashcards, held the flashcards up for Kalika to see, paused and gave Kalika ample time to observe the flashcards, and put flashcards in front of Kalika so she could review the cards anytime she needed.

The fact that many instructions and activities during Kalika's literacy sessions are geared towards her visual engagement prompts us to interrogate what communication and literacy engagement mean in the context of significant disabilities. For a long time, language has historically been perceived as a "self-defining and closed structure" (Canagarajah, 2018, p. 32) of verbal resources. Within this paradigm, also known as structuralism (see Ames, 1973; Canagarajah, 2018), the exploration of linguistic elements is privileged over other forms of communication thereby creating a dualism and a longstanding hierarchy between the verbal and non-verbal forms of communication. This

is particularly seen in the many second language teaching methods and strategies that primarily focus on developing students' mastery of linguistic resources, such as grammar, affixation, etc. as *the* way to acquire new languages (Toohey & Smythe, 2022). As a result, other modalities of communication and variations of languages, including visual communication, gestures, gaze, facial expression, body movement, sign language, and the various "disabled ways of languaging" (Henner & Robinson, 2023, p. 16) are depicted as secondary, defective, or even illegitimate forms of communication.

Kalika's more-than-human entanglements in this study demonstrate that language and literacy are multimodal and multiactant; the verbal resource during Kalika's literacy sessions is an intra-acting element that works with non-human elements to achieve certain communicative and literacy goals (see Canagarajah, 2018; Pennycook, 2018). In this context, the success of communication and engagement between Kalika, Baba, Sally, and Sofia during their literacy sessions are achieved by the intra-activity or entanglement among Kalika's complex communication repertoires, verbal language by Baba, Sally, and Sofia, and the non-human elements involved during their interactions. These include the space, the cup and its placement on the dining table, the colors and pictures on the communication board, and the eye-tracking AAC device that are primarily designed to harness and facilitate Kalika's complex communication repertoires and engagement through eye gaze, eye contact, and eye fixation.

While the arguments on the multimodality of communication and literacy engagement have been explored in applied linguistics and literacy, many studies still conceal the significant roles of non-human elements in the interactions. As a result, communication and engagement in literacy activities have been predominantly explored

in the humanistic logic. They conceive language and literacy as isolated and independent entities that define humans versus non-human elements. Naraian (2021) posited that the dominance of anthropocentrism in our ethico-onto-epistemology highlights the idea of "self" as an independent, white, male, middle-class position. Such orientation, she argued, "runs the risk of erasing the ways of knowing and being" (Naraian, 2021, p. 15) of individuals with disabilities.

For language and literacy teachers, especially those who serve students with complex communication repertoires and L2 learners in their classrooms, it is important for us to transform our notions of language and literacy beyond the humanistic logic, and to interrogate what counts as language, literacy, and competencies in those areas. For a long time, our teaching approach has been oriented toward uniformity and perfection, which is informed by the false imagery of the 'human' body that is inherently a 'he' body – "he is white, European, handsome, and able-bodied" (Braidotti, 2013, p. 24). Among the many residuals or byproducts of the perpetuation of false humane imagery are deeply ingrained misconceptions of the 'standard' looks and behaviors associated with being 'human.' In this case, variations in ways of languaging and doing literacies are perceived as aberrant, non-standard, inferior, and in need of 'cure'. These misconceptions lead to the justification of the practices of fixing or curing our students' 'flaws' in language and literacy in our classrooms. By adopting the posthuman perspective, we are challenged to think and work with the haeccities in our classrooms, embracing, acknowledging, and valuing variations and infinite students' possibilities of being, doing, and becoming otherwise.

3. *To embrace the messiness in language and literacy education*. The entanglement of humans and non-human elements in this study demonstrates that the teaching of language and literacy can be messy. In posthumanism, the term messy signifies becoming, instability, complexity, and entanglement of actants in a phenomenon, including in teaching (see Barad, 2007; Braidotti, 2013). Sally's perception of her role as a "juggler" during her literacy sessions with Kalika illustrates the messiness of language and literacy teaching in the context of students with significant disabilities. During her juggling, Sally highlighted the significance of thinking with and collaborating with other humans and non-human elements. Chapter 4 section *Thinking with the Assemblages of Humans and Non-human Elements* lays out the entanglements that Kalika, Sally, Baba, and Ma built with the non-human elements during Kalika's 'meltdown' moments or crip time.

   Crip time, as Samuels (2017) put it, is a "broken time" (n.p.) – "it forces us [individuals with disabilities] to take breaks, even when we don't want to, even when we want to keep going, to move ahead" (n.p.). As we discussed in the previous chapter, Kalika's crip time can be instigated by various factors; these include mood changes, fatigue, medication side effects, changes in sleeping patterns, or symptoms of Rett syndrome (e.g., repetitive hand movements). During Kalika's literacy activities with Sally, the crip time often manifested in Kalika's screams and cries for wanting to stop and do alternative activities or prolonged responses as she navigated some symptoms of Rett syndrome, such as repetitive hand movements that may affect her focus. Such crip time required Sally to adjust her agenda or lesson plans to be responsive to Kalika's ongoing needs.

Among the many strategies that Sally employed to work with Kalika's crip time was pausing. By providing sufficient time for Kalika to process her crip time, acknowledging her feelings and difficulties she experiences, valuing her complex communication repertoires (e.g., cries, screams), and expressing compassion through verbal messages, Sally demonstrated her understanding and skills in collaborating with Kalika's crip time during their literacy sessions. In many anthropocentric classrooms, such crip time or 'meltdown' moments are often considered misbehaviors, laziness, and regression or a threat to the linear trajectories of language and literacy progressions. Sally, however, opted to pause, establish dialogues with Kalika, and show her how to work with her eye-tracking AAC device to express her feelings instead of reprimanding Kalika for these moments of crip time. Sally turned these crip times into teachable moments to help Kalika regulate herself and develop proficiency in using her eye-tracking AAC device for communication. By pressing useful vocabulary on the eye-tracking AAC device, such as "calm" and "relaxed", Sally modeled to Kalika how to calm her body and express herself through her device.

Sally's pausing strategy during Kalika's crip time showed the multiple possibilities that teachers could come up with to value and work with the students' entanglement with non-human materials. The key is to exercise empathy and be open to uncertainties that we might encounter during the lessons.

Future Research Considerations

This qualitative case study explores the more-than-human literacy entanglements of an individual with significant disabilities in the home context. Using posthumanism as a theoretical lens, it aims to investigate how a child with Rett syndrome is entangled with her parent, literacy

teacher, babysitter, and non-human elements during literacy activities, such as storybook reading time, math homework sessions, and spelling activities, among others. Building on the results of the entanglement investigations, the study offers some implications for inclusive language and literacy education.

While this study offers detailed explorations of literacy entanglements, the context of this study is specific to the literacy activities of a child with Rett syndrome at home. Future research could benefit from expanding the study into larger contexts and involving more participants in the study. For example, expanding the scope into a school context would allow researchers to work with more diverse students regardless of their abilities, race, language, and socioeconomic background. It would offer more opportunities for researchers to examine the intra-actions and entanglements of students with their peers, teachers, paraprofessionals, therapists, parents, and unexpected non-human elements that are part of their processes of being, doing, and becoming literacies and languaging. Students in Schulte (2019), for instance, think and work with the unexpected death of bird as a narrative site about the life and death of a non-human living organism. Similarly, students in Kuby et al. (2015) collaborate with space, time, and materials to interrogate the idea of 'writing.'

Other contexts worth exploring are the more-than-human entanglements of individuals with disabilities in therapy and medical settings. Many individuals with disabilities, especially those with significant disabilities, and their families engage in various therapy activities throughout their lives (Orlin et al., 2014). Kalika, for example, attended multiple therapies since her diagnosis of Rett syndrome. These include speech therapy, physical therapy, and occupational therapy which involve collaborations with different humans and non-human elements in various settings. Some of the therapies invite individuals to engage with nature and

animals. For example, hippotherapy facilitates individuals to work with horses in outdoor settings to help them with emotional regulation, stress reduction, and physical, social, and sensory functions (Koca et al., 2015). Expanding the study into these contexts would enable researchers to explore the messiness of intra-actions and entanglements of the individuals with other humans and non-human elements.

Future research would also benefit from exploring the entanglements of students with their intersectional identities beyond disabilities. This may include the examinations of students' intra-actions with their racial, linguistic, educational, and socioeconomic backgrounds. The explorations on how students think and work with their intersectionality, especially in terms of how their multiple identities privilege and marginalize them in their access to quality education and instructions, including the availability of responsive literacy texts and second language learning opportunities, would offer more critical posthuman literacy explorations.

Another aspect worth exploring is challenging the binary of human and non-human elements during literacy activities. This dissertation illuminates the interconnectedness and interdependency of human and non-human elements, which is a locus of interest in posthuman investigation (Deleuze and Guattari, 1987; Barad, 2007; Bennett, 2010). This was done by unraveling the agency of non-human elements that have been rendered invisible in anthropocentrism and demonstrating how they come together with humans to form assemblages in a literacy context. As a result, the binary of human and non-human elements (e.g., machines) is still maintained in the discussions. Future research can problematize the binarism of human and non-human elements to better capture the blurring boundaries of actants.

Next, the examination of the power dynamics between actants in literacy activities can further expand the understanding of posthuman literacy and its intersection with disability. This

includes taking a neurodiversity perspective to investigate the autonomy of students with significant disabilities as they intra-act with other humans and non-human elements. For example, future research may question: how does a student's use of an arm brace support their literacy engagement yet simultaneously limit their ability to move freely during these activities? And how does the practice of bracing 'normalize' or 'rehabilitate' their unique ways of engagement in literacy activities? Taking Foucault's (1980) perspective on power and disciplinary mechanisms in relation to the entanglements of students with other humans and non-human elements, such as arm braces, body harnesses, and other therapeutic practices, can be a good starting point to uncover the nuanced ways in which power operates in more-than-human literacy entanglements in significant disability contexts.

The exploration of the roles of language and affect in influencing students' engagement is also an important investigation in posthuman literacy. As Deleuze and Guattari (1987) argued, "…the only assemblages are machinic assemblages of desire and collective assemblages of enunciation" (p. 22). They described desire or agency (Barad, 2007) and enunciation as an assemblage that cannot be separated from the speaker, interlocutor, context, and their implications for certain actions (Stratford, 2002). In Kalika's context, for example, we can examine how her literacy engagement is shaped by where and when the interactions take place, how the interactions are mediated, how social roles and hierarchy play into the interactions, what actants involved in the interactions, and what roles language play in the interactions. This includes investigating how Kalika's literacy engagement is affected by the relationships she has with Sally, Sofia, and Baba, how diction, pace, and tone of speech affect Kalika's engagement in the activities (see Narrative 3), and how the setting and time of instructions play roles in shaping Kalika's literacy experience, among other factors.

Lastly, as Barad (2007) highlights the ethico-onto-epistemological shift in research, future researchers may benefit from extensively exploring how they are entangled in their own research as part of the "agencies of observation" (Barad, 2007, p. 114) and as an apparatus of research. In this dissertation, for example, a future investigation could examine the influence of my presence as a researcher during Kalika's literacy sessions with Sally, Baba, and Sofia. Specifically, how do my presence, the camera, and the wireless microphone alter Kalika's engagement in literacy activities? Additionally, how does my perspective as a researcher influence the way I interpret the literacy phenomena I observe? Engaging in the practices of reflexivity through critical memoing, as I did in this dissertation, can be a useful strategy to investigate the entanglement of researchers in their own research.

Conclusion

This study engaged in posthuman thinking of literacy entanglements of a 7-year-old child with Rett syndrome named Kalika during various literacy activities at home. Using data gathered from in-situ observations, interviews, and focus group discussions with the child, her parent (Baba), her literacy teacher/specialist (Sally), and her babysitter (Sofia), the study endeavored to answer two research questions, namely: "How is a child with Rett syndrome entangled with other human and non-human interactants during literacy activities at home?" and "What are the larger implications of these entanglements for inclusive language and literacy education practices?" Included in this exploration are the examinations of who and what kinds of actants are part of the child's language and literacy activities and what roles these actants play in navigating language and literacy activities for the child.

In analyzing data and writing up the study, I think and work with the conceptualizations of space, vitality, and assemblage from posthuman scholars, such as Barad (2007), Bennett

(2010), and Braidotti (2013). The study found that, in addition to being entangled with Baba, Sally, and Sofia, the child is entangled with various non-human elements during her literacy activities at home. Space and the intra-acting human and non-human actants within it, such as the dining table, the upholstered chair, and room brightness, were highlighted by participants as some of the non-human elements that play roles in Kalika's literacy experiences. Specifically, they mediate literacy instructions to occur by providing affordances to organize literacy activities and lay out important literacy objects for Kalika, such as the iPad, eye-tracking AAC device, activity chair, and books. Angle and positional configurations of humans and non-human elements within a space were also argued by the participants to facilitate effective communication, which was mainly done through partner-assisted scanning, during literacy activities. Space and the intra-acting actants within it were noted to have roles in communicating expectations and conditioning Kalika's behaviors during the activities. Lastly, some elements in the space, such as the amount of light, influence Kalika's alertness and accessibility to communicate through her eye-tracking AAC device.

The study also examines the entanglement of Kalika's complex communication repertoires with humans and non-human actants. The study found that there are relational activities between Kalika's eye-gaze, body movement, touch, and gesture with the humans (Baba, Sally, and Sofia) and non-human elements (flashcards, books, the eye-tracking AAC device, the communication board, and space). Their linkages mediate Kalika's complex communication repertoires, facilitating Baba, Sally, and Sofia to understand her expressions of interest, wants, needs, engagement, and disengagement beyond verbal communication through the eye-tracking AAC device.

Other non-human elements were also found to be significant parts of Kalika's assemblages during her literacy activities with Baba, Sally, and Sofia. The arm brace, activity chair, soft toys, and weighted bag are among the non-human elements that help Kalika focus during the activities by mitigating her repetitive hand movements and muscle weakness. Additionally, kapor (a muslin cloth) and selected music/songs also help Kalika calm her body and give her comfort.

From my exploration of Kalika's literacy entanglement, I argued that literacy is a porous and collaborative endeavor. It is not an individual endeavor as it has been historically conceptualized in anthropocentric literacy. I also argued that literacy is an emergent more-than-human phenomenon. It is inherently messy and collaborative; it never works in isolation and has always been entangled with non-human elements.

Drawing on the results and discussions of my exploration, I propose three suggestions for teachers and researchers in language and literacy education, namely: First, to turn the gaze into the entanglement of humans and non-human elements in language and literacy. Second, to interrogate and go beyond the assumed perimeters of language and literacy. And lastly, to embrace the messiness in language and literacy education.

REFERENCES

Adams, C., & Thompson, T. L. (2016). *Researching a posthuman world: Interviews with digital objects*. London: Palgrave Macmillan UK.

Ahmed, S. (2006). *Queer phenomenology*. Duke University Press.

Alford, W. P. (2021). The discordant singer: How Peter Singer's Treatment of Global Poverty and Disability Is Inconsistent and Why It Matters. *American Journal of Law and Equality*, *1*, 194-220.

Alper, M., Ellcessor, E., Ellis, K., & Goggin, G. (2015). Reimagining the good life with disability: Communication, new technology, and humane connections. In H. Wang (Ed.), *Communication and the "Good Life"* (pp. 197–212). New York, NY: Peter Lang.

Alqatarneh, N., Dunford, C., & Kramer-Roy, D. (2022). An Examination of the Impact of Culture on Early Intervention Programmes—An Islamic Arabic Perspective from Jordan. *International Journal of Early Childhood*, *54*(3), 401-419.

Al-Zoubi, S. M., & Al-Zoubi, S. M. (2022). The portrayal of persons with disabilities in Arabic drama: A literature review. *Research in Developmental Disabilities*, *125*, 104221.

Amankwah-Amoah, J., Khan, Z., Wood, G., & Knight, G. (2021). COVID-19 and digitalization: The great acceleration. *Journal of Business Research*, *136*, 602-611.

Ames, S. S. (1973). Structuralism, language, and literature. *The Journal of Aesthetics and Art Criticism*, *32*(1), 89-94.

Amir, R. E., Van den Veyver, I. B., Wan, M., Tran, C. Q., Francke, U., & Zoghbi, H. Y. (1999). Rett syndrome is caused by mutations in X-linked MECP2, encoding methyl-CpG-binding protein 2. *Nature genetics*, *23*(2), 185-188.

Annamma, S. A., Connor, D., & Ferri, B. (2013). Dis/ability critical race studies (DisCrit): Theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education*, *16*(1), 1-31.

Bakeman, R., & Adamson, L. B. (1984). Coordinating attention to people and objects in mother-infant and peer-infant interaction. *Child development*, 1278-1289.

Baker, A. M., Sonn, C. C., & Meyer, K. (2020). Voices of displacement: A methodology of sound portraits exploring identity and belonging. Qualitative Research, 20(6), 892–909. https://doi.org/10.1177/1468794120909765

Balmer, A. (2021). Painting with data: Alternative aesthetics of qualitative research. *The Sociological Review*, *69*(6), 1143-1161.

Bappenas. (2021). Tinjauan Peningkatan Akses dan Taraf Hidup Penyandang Disabilitas Indonesia.

Barad, K. (2003). Posthumanist performativity: Toward an understanding of how matter comes to matter. *Signs: Journal of women in culture and society*, *28*(3), 801-831.

Barad, K. (2007). *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. Duke university Press.

Barbareschi, G., Carew, M. T., Johnson, E. A., Kopi, N., & Holloway, C. (2021). "When they see a wheelchair, they've not even seen me"—Factors shaping the experience of disability stigma and discrimination in Kenya. *International Journal of Environmental Research and Public Health*, *18*(8), 4272.

Barnes, C. (2018). Theories of disability and the origins of the oppression of disabled people in western society. In *Disability and society* (pp. 43-60). Routledge.

Bégout, B. (2007). Husserl and the phenomenology of attention. *Rediscovering phenomenology: Phenomenological essays on mathematical beings, physical reality, perception and consciousness*, 13-32.

Beneke, M. R., & Cheatham, G. A. (2020). Teacher candidates talking (but not talking) about dis/ability and race in preschool. *Journal of Literacy Research*, *52*(3), 245-268.

Benjamin-Thomas, T. E., Rudman, D. L., McGrath, C., Cameron, D., Abraham, V. J., Gunaseelan, J., & Vinothkumar, S. P. (2022). Situating occupational injustices experienced by children with disabilities in rural India within sociocultural, economic, and systemic conditions. *Journal of Occupational Science*, *29*(1), 97-114.

Bennett, J. (2005). The agency of assemblages and the North American blackout. *Public Culture* 17(3): 445–65

Bennett, J. (2010). *Vibrant matter: A political ecology of things*. Duke University Press.

Beukelman, D. R. & Light, J. C. (2020). *Augmentative & alternative communication: Supporting children and adults with complex communication needs* (5th ed.). Brookes Publishing.

Bhattacharya, K. (2017). *Fundamentals of qualitative research: A practical guide*. Routledge.

Bhattacharya, U., & Pradana, W. A. (2022). Exploring literacy engagement in a significant disability context. *Journal of Early Childhood Literacy*, 14687984221100129.

Binger, C., & Light, J. (2006). Demographics of Preschoolers Who Require AAC. *Language, Speech & Hearing Services in Schools*, *37*(3), 200–208. https://doi.org/10.1044/0161-1461(2006/022)

Bodén, L. (2013). Seeing red? The agency of computer software in the production and management of students' school absences. *International Journal of Qualitative Studies in Education*, *26*(9), 1117-1131.

Bono, J. J., Dean, T., & Ziarek, E. P. (2008). *A time for the humanities : futurity and the limits of autonomy* (1st ed.). Fordham University Press.

Botha, S., & Harvey, C. (2022). Disabling discourses: contemporary cinematic representations of acquired physical disability. *Disability & Society*, 1-23.

Boxall, K., & Ralph, S. (2011). Research ethics committees and the benefits of involving people with profound and multiple learning disabilities in research. *British Journal of Learning Disabilities*, *39*(3), 173-180.

Braidotti, R. (2013). *The posthuman*. Cambridge: Polity Press.

Braidotti, R. (2019). A theoretical framework for the critical posthumanities. *Theory, culture & society*, *36*(6), 31-61.

Braund, M. (2023). Crossing Borders. Studies with Student Teachers Using Physical Role-plays in South Africa. In *Learning Science Through Drama: Exploring international perspectives* (pp. 89-101). Cham: Springer International Publishing.

Bravo-Ruiz, M. I., & Flynn, L. (2022). Immigrant Latino Parents' Experiences and Participation in the Special Education Process. *Journal of Family Diversity in Education*, *5*(1), 1-21.

Brinkmann, S. (2015). GOFQI and the phoenix of qualitative inquiry. *Qualitative Inquiry*, *21*, 620-622.

Brooks, P. (1984). *Reading for the plot: Design and intention in narrative*. New York, NY: Alfred A. Knopf.

Bunning, K., Gona, J. K., Newton, C. R., & Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PloS one*, *12*(8), e0182214.

Bucholtz, M., & Hall, K. (2016). Embodied sociolinguistics. Sociolinguistics: theoretical debates, 1(1), 173-200.

Calculator, S. N. (2013). Use and Acceptance of AAC Systems by Children with Angelman Syndrome. *Journal of Applied Research in Intellectual Disabilities*, *26*(6), 557–567.

Campbell, F. (2000). Eugenics in a different key? New technologies and the "conundrum" of "disability". *A Race for a Place: Eugenics, Darwinism, and Social Thought and Practice in Australia*, 307-318.

Canagarajah, S. (2018). Translingual practice as spatial repertoires: Expanding the paradigm beyond structuralist orientations. *Applied linguistics*, *39*(1), 31-54.

Capewell, C., Ralph, S., & Bonnett, L. (2015). The continuing violence towards disabled people. *Journal of Research in Special Educational Needs*, *15*(3), 211-221.

Cholewa, B., Hull, M. F., Babcock, C. R., & Smith, A. D. (2018). Predictors and academic outcomes associated with in-school suspension. *School Psychology Quarterly*, *33*(2), 191.

Christle, C. A., Jolivette, K., & Nelson, C. M. (2007). School characteristics related to high school dropout rates. *Remedial and Special education*, *28*(6), 325-339.

Clare, E. (2017). *Brilliant imperfection*. Duke University Press.

Clarke, H., McConachie, K., Price, P., & Wood, M. (2001). Views of young people using augmentative and alternative communication systems. *International journal of language & communication disorders*, *36*(1), 107-115.

Clarkson, T., LeBlanc, J., DeGregorio, G., Vogel-Farley, V., Barnes, K., Kaufmann, W. E., & Nelson, C. A. (2017). Adapting the Mullen scales of early learning for a standardized measure of development in children with Rett syndrome. *Intellectual and Developmental Disabilities, 55*(6), 419-431.

Coffey A., Atkinson P. (1996). *Making sense of qualitative data: Complementary research strategies*. Sage.

Coleridge, P. (2000). Disability and culture. *Asia Pac. Disabil. Rehabil. J. Sel. Read. Community-Based Rehabil. Ser*, *2*, 22-41.

Conn, R., & Bhugra, D. (2012). The portrayal of autism in Hollywood films. *International Journal of Culture and Mental Health*, *5*(1), 54-62.

Connor D. J., Ferri, B. A. & Annamma, S. A. (2016). *DisCrit: Disability studies and critical race theory in education*. Teachers College Press.

Coole, D. & Frost, S. (Eds.). (2010). *New Materialisms: Ontology, Agency, and Politics*. Duke University Press.

Copes, H., Tchoula, W., Brookman, F., & Ragland, J. (2018). Photo-elicitation interviews with vulnerable populations: Practical and ethical considerations. *Deviant Behavior*, *39*(4), 475-494.

Dada, S., Flores, C., Bastable, K., & Schlosser, R. W. (2021). The effects of augmentative and alternative communication interventions on the receptive language skills of children with developmental disabilities: A scoping review. *International Journal of Speech-Language Pathology*, *23*(3), 247-257.

Daniels, H., Thompson, I., & Tawell, A. (2019). Practices of exclusion in cultures of inclusive schooling in the United Kingdom.

Davies T., (1997), *Humanism*, London: Routledge.

Davis, P. (2007). Storytelling as a democratic approach to data collection: Interviewing children about reading. *Educational Research*, *49*(2), 169-184.

Deleuze, G., & Guattari, F. (1983). *Anti-Oedipus: capitalism and schizophrenia*. University of Minnesota Press.

Deleuze, G., & Guattari, F. (1987). *A thousand plateaus: Capitalism and schizophrenia.* University of Minnesota Press.

Deleuze, G., & Guattari, F. (1994). *What is philosophy?*. Columbia University Press.

Demeter, K. (2000). Assessing the developmental level in Rett syndrome: an alternative approach? *European Child & Adolescent Psychiatry*, *9*(3), 227. https://doi.org/10.1007/s007870070047

Djukic, A., McDermott, M. V., Mavrommatis, K., & Martins, C. L. (2012). Rett syndrome: Basic features of visual processing—A pilot study of eye-tracking. *Pediatric neurology*, *47*(1), 25-29.

Di Rocco, E. (2016). Sublime and Tragic Fall: When Tiresias Met Athena. *thersites. Journal for Transcultural Presences & Diachronic Identities from Antiquity to Date*, *3*.

Diffrient, D. S. (2017). Always, blind, and silenced: disability discourses in contemporary South Korean cinema. *Journal of Literary & Cultural Disability Studies*, *11*(3), 249-269.

Doak, L. (2021). Rethinking family (dis)engagement with augmentative & alternative communication. *Journal of Research in Special Educational Needs*, *21*(3), 198–210.

Downs, J., Stahlhut, M., Wong, K., Syhler, B., Bisgaard, A.-M., Jacoby, P., & Leonard, H. (2016). Validating the Rett Syndrome Gross Motor Scale. *PLoS ONE*, *11*(1), 1–11. https://doi.org/10.1371/journal.pone.0147555.

Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual Disability Research*, *54*(8), 736-748.

Erevelles, N. (2000). Educating unruly bodies: Critical pedagogy, disability studies, and the politics of schooling. *Educational theory*, *50*(1), 25-47.

Erevelles, N. (2011). "Coming out crip" in inclusive education. *Teachers College Record*, *113*(10), 2155-2185.

Etherington, K. (2007). Ethical research in reflexive relationships. *Qualitative Inquiry, 13*(5), 599- 616.

Fabio, R. A., Giannatiempo, S., Oliva, P., & Murdaca, A. M. (2011). The increase of attention in Rett syndrome: a pre-test/post-test research design. *Journal of Developmental and Physical Disabilities, 23*, 99-111.

Fabio, R. A., Antonietti, A., Castelli, I., & Marchetti, A. (2009). Attention and communication in Rett syndrome. *Research in Autism Spectrum Disorders*, *3*(2), 329-335.

Freeman, M. (2017). *Modes of thinking for qualitative data analysis*. Taylor & Francis.

Fahn, C. W. (2020). Marketing the prosthesis: Supercrip and superhuman narratives in contemporary cultural representations. *Philosophies*, *5*(3), 11.

Fahy, J. K. (2014). Language and executive functions: Self-talk for self-regulation. *Perspectives on language learning and education*, *21*(2), 61-71.

Feldman, M. A., Battin, S. M., Shaw, O. A., & Luckasson, R. (2013). Inclusion of children with disabilities in mainstream child development research. *Disability & Society*, *28*(7), 997-1011.

Felton, D. (2012a). Monstrosity or disability? Ancient accounts of accelerated ageing. *Folklore*, *123*(3), 355-361.

Felton, D. (2012b). Rejecting and embracing the monstrous in ancient Greece and Rome. *The Ashgate research companion to monsters and the monstrous*, 103-131.

Ferguson, S.T. (2013). Using visual methods in social science research. In M. Walter (Ed.), *Social research methods* (pp. 1-10). South Melbourne, AU: Oxford University Press.

Ferri, B. A., & Connor, D. J. (2014). Talking (and not talking) about race, social class and dis/ability: Working margin to margin. *Race Ethnicity and Education*, *17*(4), 471-493.

Flanagan, R. M., & Symonds, J. E. (2021). Self-talk in middle childhood: A mechanism for motivational resilience during learning. *Psychology in the Schools*, *58*(6), 1007-1025.

Flewitt, R., Kucirkova, N., & Messer, D. (2014). Touching the virtual, touching the real: iPads and enabling literacy for students experiencing disability. *The Australian Journal of Language and Literacy*, *37*(2), 107-116.

Flint, M. (2020). Fingerprints and pulp: Nomadic ethics in research practice. *Art/Research International: A Transdisciplinary Journal*, *5*(1), 1-15.

Flint, M. A. (2022). More-than-human methodologies in qualitative research: Listening to the Leafblower. *Qualitative Research*, *22*(4), 521-541.

Fish, W. W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure: Alternative Education for Children and Youth*, *53*(1), 8-14.

Foley, A., & Ferri, B. A. (2012). Technology for people, not disabilities: Ensuring access and inclusion. *Journal of Research in Special Educational Needs*, *12*(4), 192-200.

Fortuna, K., Baor, L., Israel, S., Abadi, A., & Knafo, A. (2014). Attachment to inanimate objects and early childcare: A twin study. *Frontiers in psychology*, *5*, 486.

Foucault, M. (1966/2005). *The order of things*. Routledge.

Foucault, M. (1963/1994). *The birth of the clinic. An archeology of medical perception.* Vintage.

Foucault, M. (1980). The eye of power. In M. Foucault & C. Gordon. *Power/knowledge: Selected interviews and other writings 1972-1977* (1st American ed.). Pantheon Books.

Fox, N. J., & Alldred, P. (2023). Applied research, diffractive methodology, and the research-assemblage: challenges and opportunities. *Sociological Research Online*, *28*(1), 93-109.

Freedman, K., & Siegesmund, R. (2023). *Visual methods of inquiry: Images as research*. Taylor & Francis.

Freeman, M. (2017). *Modes of thinking for qualitative data analysis*. Taylor & Francis.

Garland-Thomson, R. (2002). The politics of staring: Visual rhetorics of disability in popular photography. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson. *Disability studies: Enabling the humanities*. Modern Language Association of America.

Garland-Thomson, R. (2011). Misfits: A feminist materialist disability concept. *Hypatia*, *26*(3), 591-609.

Gee, J. (Ed.). (2000). *The New Literacy Studies: From "socially situated" to the work of the social*. London: Routledge.

Gibson, B. E., Carnevale, F. A., & King, G. (2012). "This is my way": reimagining disability, in/dependence and interconnectedness of persons and assistive technologies. *Disability and rehabilitation*, *34*(22), 1894-1899.

Giroux, H. A. (1992). *Border crossings: Cultural workers and the politics of education*. Routledge.

Giroux, T. H. (1983). *Theory and Resistance in Education: A Pedagogy for the Opposition*. New York: Berginband Garvey Publishers.

Goodley, D., Lawthom, R., & Runswick Cole, K. (2014). Posthuman disability studies. *Subjectivity*, *7*, 342-361.

Guattari, F. (2013). Schizoanalytic cartographies (trans. by Andrew Goffey). London: Bloomsbury Academic.

Hackett, A., & Somerville, M. (2017). Posthuman literacies: Young children moving in time, place and more-than-human worlds. *Journal of Early Childhood Literacy*, *17*(3), 374-391.

Hallemans A, Van de Walle P, Wyers L, Verheyen K, Schoonjans A-S, Desloovere K, Ceulemans B, Clinical usefulness and challenges of instrumented motion analysis in patients with intellectual disabilities, *Gait and amp; Posture* (2019), https://doi.org/10.1016/j.gaitpost.2019.04.016

Hańderek, J. (2021). The Boundaries of Humanity. *ACADEMIA-The magazine of the Polish Academy of Sciences*, 16-19.

Handoyo, R., Ali, A., Scior, K., & Hassiotis, A. (2021). Attitudes of key professionals towards people with intellectual disabilities and their inclusion in society: A qualitative study in an Indonesian context. *Transcultural Psychiatry*, *58*(3), 379-391.

Haraway, D. (1992). The promises of monsters: A regenerative politics for inappropriate/d others. In *Cultural studies* (pp. 295-337). Routledge.

Harden, J., Scott, S., Backett-Milburn, K., & Jackson, S. (2000). Can't talk, won't talk?: methodological issues in researching children. *Sociological research online*, *5*(2), 104-115.

Harwood, D., & Collier, D. R. (2017). The matter of the stick: Storying/(re) storying children's literacies in the forest. *Journal of Early Childhood Literacy*, *17*(3), 336-352.

Haynes, K. (2017). Reflexivity in qualitative research. *Qualitative organizational research: Core methods and current challenges*, *26*, 72-89.

Heath, S. B. (1982). What No Bedtime Story Means: Narrative Skills at Home and School. *Language in Society, 11*(1), 49-76.

Henner, J., & Robinson, O. (2023). Unsettling languages, unruly bodyminds: A crip linguistics manifesto. *Journal of Critical Study of Communication & Disability*, *1*(1), 7-37.

Herini, E. S., Sunartini H, Mangunatmadja, I, Purboyo, & Pusponegoro, H. D. (2005). The Epilepsies of Rett Syndrome in Indonesia. *Paediatrica Indonesiana*, (5), 203. https://doi.org/10.14238/pi45.5.2005.203-6

Holbrook, T., & Pourchier, N. M. (2014). Collage as analysis: Remixing in the crisis of doubt. *Qualitative inquiry*, *20*(6), 754-763.

Holley, K. A., & Colyar, J. (2009). Rethinking texts: Narrative and the construction of qualitative research. *Educational researcher*, *38*(9), 680-686.

Holmqvist, K., Nyström, M., Andersson, R., Dewhurst, R., Jarodzka, H., & Van de Weijer, J. (2011). *Eye tracking: A comprehensive guide to methods and measures*. OUP Oxford.

Horodecki, R., Horodecki, P., Horodecki, M., & Horodecki, K. (2009). Quantum entanglement. *Reviews of modern physics*, *81*(2), 865.

Hultman, K., & Lenz Taguchi, H. (2010). Challenging anthropocentric analysis of visual data: A relational materialist methodological approach to educational research. *International journal of qualitative studies in education*, *23*(5), 525-542.

Human Rights Watch. (2020). *Living in Chains: Shackling of People with Psychosocial Disability Worldwide.* Accessed from: https://www.hrw.org/report/2020/10/06/living-chains/shackling-people-psychosocial-disabilities-worldwide#_ftn54

Hunter, K. The Rett Syndrome handbook (2nd.). Clinton, MD. IRSA Publishing.

Hwang, S. K., & Charnley, H. (2010). Making the familiar strange and making the strange familiar: Understanding Korean children's experiences of living with an autistic sibling. *Disability & Society*, *25*(5), 579-592.

Iriki, A., Tanaka, M., & Iwamura, Y. (1996). Coding of modified body schema during tool use by macaque postcentral neurones. *Neuroreport*, *7*(14), 2325-2330.

Ismail, H., Khoo, S., Idrus, M. M., Cheong, J. P. G., & Razman, R. (2022). Newspaper Coverage of Paralympic Athletes: A Multimodal Discourse Analysis. *SAGE Open*, *12*(2), 21582440221102434.

Jackson, A. Y., & Mazzei, L. (2011). *Thinking with theory in qualitative research: Viewing data across multiple perspectives*. Routledge.

Jöns, H. (2006). Dynamic hybrids and the geographies of technoscience: Discussing conceptual resources beyond the human/non-human binary. *Social & Cultural Geography*, *7*(4), 559-580.

Karaca, K. G., Brito, D. V. C., & Oliveira, A. M. M. (n.d.). MeCP2: A Critical Regulator of Chromatin in Neurodevelopment and Adult Brain Function. *International journal of molecular sciences*, *20*(18). https://doi.org/10.3390/ijms20184577

Kasiyati, W. (2008). Jenis dan Bentuk Pengobatan Pada Relief Candi Borobudur. *Borobudur, 2*(1), 25-29.

Kaufmann, W., Percy, A., & Clarke, A. (2017). *Rett Syndrome*. London: Mac Keith Press.

Kemdikbud. (2021). Statistik Sekolah Luar Biasa 2020/2021.

Kendon, A. (2004). *Gesture: Visible action as utterance*. Cambridge University Press.

Koca, T. T., & Ataseven, H. (2015). What is hippotherapy? The indications and effectiveness of hippotherapy. *Northern clinics of Istanbul*, *2*(3), 247.

Kritikos, E. P. (2003). Speech-Language Pathologists' Beliefs About Language Assessment of Bilingual/Bicultural Individuals. *American Journal of Speech-Language Pathology*, *12*(1), 73. https://doi.org/10.1044/1058-0360(2003/054)

Kuby, C. R., & Rowsell, J. (2017). Early literacy and the posthuman: Pedagogies and methodologies. *Journal of early childhood literacy*, *17*(3), 285-296.

Kuby, C. R., Spector, K., & Thiel, J. J. (2019). *Posthumanism and Literacy Education: Knowing/Becoming/Doing Literacies*. Routledge

Kusters, A., Spotti, M., Swanwick, R., & Tapio, E. (2017). Beyond languages, beyond modalities: Transforming the study of semiotic repertoires. *International Journal of multilingualism*, *14*(3), 219-232.

Kvale, S., & Brinkmann, S. (2009). *InterViews: Learning the craft of qualitative research interviewing* (2nd ed.). Thousand Oaks, CA: Sage.

Ladson-Billings, G. (2006). From the achievement gap to the education debt: Understanding achievement in US schools. *Educational researcher*, *35*(7), 3-12.

Lapenta F. (2011). Some theoretical and methodological views on photo-elicitation. In Margolis E., Pauwels L. (Eds.). *The Sage handbook of visual research methods* (p. 201). Sage.

Latour, B. (2004). *Politics of nature: How to bring the sciences into democracy*. Harvard University Press.

Latour, B. (2005). *Reassembling the social: An introduction to actor-network-theory.* Oxford, UK: Oxford University Press.

Larios, R., & Zetlin, A. (2022). Bilingual and monolingual parents' counterstories of the Individualized Education Program (IEP) meeting. *Urban Education*, *57*(7), 1207-1229.

Leander, K., & Boldt, G. (2013). Rereading "A pedagogy of multiliteracies" bodies, texts, and emergence. *Journal of Literacy Research*, *45*(1), 22-46.

Leung-Gagné, M., McCombs, J., Scott, C., & Losen, D. J. (2022). *Pushed Out: Trends and Disparities in Out-of-School Suspension*. Learning Policy Institute. https://learningpolicyinstitute.org/sites/default/files/2022-09/CRDC_School_Suspension_REPORT.pdf

Lessy, Z., Kailani, N., & Jahidin, A. (2021). Barriers to employment as experienced by disabled university graduates in Yogyakarta, Indonesia. *Asian Social Work and Policy Review*, *15*(2), 133-144.

Linneberg, M. S., & Korsgaard, S. (2019). Coding qualitative data: A synthesis guiding the novice. *Qualitative research journal*, *19*(3), 259-270.

Lipenga, K. J., & Ngwira, E. (2018). 'Black on the inside': albino subjectivity in the African novel. *Disability and the global south*, *5*(2), 1472-1487.

Loraux, N. (1995/2014). *The Experiences of Tiresias*. Princeton University Press.

MacLure, M. (2013a). Classification or wonder? Coding as an analytic practice in qualitative research. *Deleuze and research methodologies*, 164-183.

MacLure, M. (2013b). The wonder of data. *Cultural Studies? Critical Methodologies*, *13*(4), 228-232.

MacRae, C. (2020). Tactful hands and vibrant mattering in the sand tray. *Journal of Early Childhood Literacy*, *20*(1), 90-110.

Margolis, H., & Shapiro, A. (1987). Countering negative images of disability in classical literature. *The English Journal*, *76*(3), 18-22.

Maravita, A., & Iriki, A. (2004). Tools for the body (schema). *Trends in cognitive sciences*, *8*(2), 79-86.

Martin-Denham, S. (2021). *Alternative approaches to school exclusion: Perspectives of headteachers in England*. University of Sunderland

Marshall, C., & Rossman, G.B. (2016). *Designing qualitative research* (6th ed.). Sage.

Marschik, P. B., Sigafoos, J., Kaufmann, W. E., Wolin, T., Talisa, V. B., Bartl-Pokorny, K. D., … Einspieler, C. (2012). Peculiarities in the gestural repertoire: An early marker for Rett syndrome? *Research in Developmental Disabilities*, *33*(6), 1715–1721. https://doi.org/10.1016/j.ridd.2012.05.014.

Mazzei, L. A. (2014). Beyond an easy sense: A diffractive analysis. *Qualitative Inquiry, 20*(6), 742–746.

McCall, F., Marková, I., Murphy, J., Moodie, E., & Collins, S. (1997). Perspectives on AAC systems by the users and by their communication partners. *International Journal of Language & Communication Disorders*, *32*(S3), 235-256.

McCord, M. S., & Soto, G. (2004). Perceptions of AAC: An Ethnographic Investigation of Mexican-American Families. *AAC: Augmentative & Alternative Communication*, *20*(4), 209–227. https://doi.org/10.1080/07434610400005648

McCoy, K. (2012). Toward a methodology of encounters: Opening to complexity in qualitative research. *Qualitative Inquiry*, *18*(9), 762–72.

McNaughton, D., & Light, J. (2013). The iPad and Mobile Technology Revolution: Benefits and Challenges for Individuals who require Augmentative and Alternative Communication. *Augmentative and Alternative Communication*, *29*(2), 107–116.

McRuer, R. (2018). *Crip times: Disability, globalization, and resistance* (Vol. 1). NYU Press.

Mendoza, M., Blake, J. J., Marchbanks III, M. P., & Ragan, K. (2020). Race, gender, and disability and the risk for juvenile justice contact. *The Journal of Special Education*, *53*(4), 226-235.

Merleau-Ponty, M. (2012). *Phenomenology of perception*. Routledge.

Mero-Jaffe, I. (2011). 'Is that what I said?'Interview transcript approval by participants: an aspect of ethics in qualitative research. *International journal of qualitative methods*, *10*(3), 231-247.

Metzler, I. (2016). *Fools and idiots? : intellectual disability in the Middle Ages*. Manchester University Press.

Micciche, L. R. (2014). Writing material. *College English*, *76*(6), 488-505.

Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: a mixed methods study. *Journal of Intellectual Disability Research*, *53*(6), 559-570.

Mishra, S. Abhiramis. (2021). Exploring the Concept of Disability as a Karmic Outcome in Greek & Hindu Mythologies: A Comparative Analysis. *Turkish Online Journal of Qualitative Inquiry*, *12*(9).

Mitchell, W. J. (2004). *Me++: The cyborg self and the networked city*. MIT press.

Moorcroft, A., Scarinci, N., & Meyer, C. (2021). "I've had a love-hate, I mean mostly hate relationship with these PODD books": parent perceptions of how they and their child

contributed to AAC rejection and abandonment. *Disability and rehabilitation: assistive technology*, *16*(1), 72-82.

Mulvihill, T. M., & Swaminathan, R. (2019). *Arts-based educational research and qualitative inquiry: Walking the path*. Routledge.

Murphy, R. F. (2001). *The body silent*. WW Norton & Company.

Murphy, R. (2022). How children make sense of their permanent exclusion: a thematic analysis from semi-structured interviews. *Emotional and Behavioural Difficulties*, *27*(1), 43-57.

Napitupulu, E. L. (2023, 3 Desember). *Pendidikan Inklusif untuk Anak Difabel Belum Optimal* [Inclusive Education for Children with Disabilities is Not Yet Optimal]. Accessed from https://www.kompas.id/baca/humaniora/2023/12/03/pendidikan-inklusif-untuk-anak-disabilitas-terus-dikembangkan

Naraian, S. (2021). What Can "inclusion" Mean in the post-human Era?. *Journal of disability studies in education*, *1*(1-2), 14-34.

Nayar, P. K. (2014). *Posthumanism.* Polity Press.

National Center for Educational Statistics (NCES). (2022). *School Directory Information.* https://nces.ed.gov/ccd/schoolsearch/school_detail.asp?ID=130117000454

Nelson, C. A. (2000). White marble, Black bodies and the fear of the invisible Negro: Signifying Blackness in mid-nineteenth-century neoclassical sculpture. *RACAR: Revue d'art canadienne*, *27*(1), 87-101.

New London Group. (1996). A pedagogy of multiliteracies: Designing social futures. *Harvard Educational Review, 66*(1), 60-92.

Nordstrom, S. N. (2015). A data assemblage. *International Review of Qualitative Research*, *8*(2), 166-193.

Nov-Klaiman, T., Raz, A. E., & Hashiloni-Dolev, Y. (2022). A test of faith? Attitudes of ultraorthodox Jewish parents of children with down syndrome toward prenatal testing. *Disability & Society*, 1-21.

Olaiya, K. (2013). Commodifying the "Sacred," Beatifying the "Abnormal": Nollywood and the Representation of Disability. *The Global South*, *7*(1), 137-156.

O'Neill, T., & Wilkinson, K. M. (2020). Preliminary investigation of the perspectives of parents of children with cerebral palsy on the supports, challenges, and realities of integrating augmentative and alternative communication into everyday life. *American journal of speech-language pathology*, *29*(1), 238-254.

Orlin, M. N., Cicirello, N. A., O'Donnell, A. E., & Doty, A. K. (2014). The continuum of care for individuals with lifelong disabilities: role of the physical therapist. *Physical Therapy*, *94*(7), 1043-1053.

Pacini-Ketchabaw, V., Taylor, A., & Blaise, M. (2016). Decentring the human in multispecies ethnographies. In C. Taylor & C. Hughes (Eds.), *Posthuman research practices in education* (pp. 149–167). London: Palgrave MacMillan.

Papadimitriou, C. (2008). Becoming en-wheeled: the situated accomplishment of re-embodiment as a wheelchair user after spinal cord injury. *Disability & society*, *23*(7), 691-704.

Pennycook, A. (2018). Applied linguistics as epistemic assemblage. *AILA review*, *31*(1), 113-134.

Pepper, C., & Wildy, H. (2009). Using narratives as a research strategy. *Qualitative Research Journal*, *9*(2), 18-26.

Perra, O., & Gattis, M. (2012). Attention engagement in early infancy. *Infant behavior and development*, *35*(4), 635-644.

Phelps, A. T. (2019). Prevalence and Demographics of Augmentative and Alternative Communication (AAC) Users Birth-21: A Survey of Speech-Language Pathologists Serving Learners with Complex Communication Needs (CCN).

Phillips, J. (2006). Agencement/assemblage. Theory, Culture & Society, 23(2-3), 108-109.

Pickering, L. (2020). Applications of Applied Linguistics to Augmentative and Alternative Communication Device Users in the Workplace. *The Cambridge Introduction to Applied Linguistics*, 187.

Polkinghorne D. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education*, 8, 12–28.

Puar, J. K. (2017). *The right to maim: Debility, capacity, disability*. Duke University Press.

Quay, S. (2008). Dinner conversations with a trilingual two-year-old: Language socialization in a multilingual context. *First language*, *28*(1), 5-33.

Riany, Y. E., Cuskelly, M., & Meredith, P. (2016). Cultural beliefs about autism in Indonesia. *International Journal of Disability, Development and Education*, *63*(6), 623-640.

Robinson, G. C., & Norton, P. C. (2019). A decade of disproportionality: A state-level analysis of African American students enrolled in the primary disability category of speech or language impairment. *Language, Speech, and Hearing Services in Schools*, *50*(2), 267-282.

Rose, G. (2016). *Visual methodologies : an introduction to researching with visual materials* (4th edition.). SAGE Publications Ltd.

Rose, S. A., Wass, S., Jankowski, J. J., Feldman, J. F., & Djukic, A. (2019). Attentional shifting and disengagement in Rett syndrome. *Neuropsychology*, *33*(3), 335.

Rossetti, Z., Burke, M. M., Hughes, O., Schraml-Block, K., Rivera, J. I., Rios, K., ... & Lee, J. D. (2021). Parent perceptions of the advocacy expectation in special education. *Exceptional Children*, *87*(4), 438-457.

Roulston, K. (2010). *Reflective interviewing: A guide to theory and practice*. Sage Publications.

Saini, M., & Kapoor, A. K. (2020). Perception, attitude, and behavior toward persons with disabilities in India. *Indian J Phys Med Rehabil*, *31*(2), 425-445.

Saldaña, J. (2021). The coding manual for qualitative researchers. *The coding manual for qualitative researchers*, 1-440.

Samuels, E. (2017). Six ways of looking at crip time. *Disability studies quarterly*, *37*(3).

Schulte, A. R. (2021). *Dancing with daddy* (Z. Chen (Ed.); First edition.). Two Lions.

Schulte, C., M. (2019). The untimely death of a bird. In C. R. Kuby, K. Spector, & J. J. Thiel, (Eds.). *Posthumanism and Literacy Education: Knowing/Becoming/Doing Literacies*. Routledge.

Schwartzman, J. S., Velloso, R. D. L., D'Antino, M. E. F., & Santos, S. (2015). The eye-tracking of social stimuli in patients with Rett syndrome and autism spectrum disorders: a pilot study. *Arquivos de neuro-psiquiatria*, *73*, 402-407.

Segrest, M. (2020). *Administrations of Lunacy: Racism and the Haunting of American Psychiatry at the Milledgeville Asylum*. The New Press.

Siebers, T. (2010). *Disability theory*. University of Michigan Press.

Sigafoos, J., O'Reilly, M., Seely-York, S., & Edrisinha, C. (2004). Teaching students with developmental disabilities to locate their AAC device. *Research in Developmental Disabilities*, *25*(4), 371-383.

Skiba, R. J., Poloni-Staudinger, L., Simmons, A. B., Renae Feggins-Azziz, L., & Chung, C. G. (2005). Unproven links: Can poverty explain ethnic disproportionality in special education?. *The Journal of Special Education*, *39*(3), 130-144.

Snow, C. E., & Beals, D. E. (2006). Mealtime talk that supports literacy development. *New directions for child and adolescent development*, *2006*(111), 51-66.

Stallworth, J. L., Dy, M. E., Buchanan, C. B., Chen, C.-F., Scott, A. E., Glaze, D. G., … Kaufmann, W. E. (n.d.). Hand stereotypies Lessons from the Rett Syndrome Natural History Study. *NEUROLOGY*, *92*(22), E2594–E2603. https://doi.org/10.1212/WNL.0000000000007560

Stasolla, F., De Pace, C., Damiani, R., Di Leone, A., Albano, V., & Perilli, V. (2014). Comparing PECS and VOCA to promote communication opportunities and to reduce stereotyped behaviors by three girls with Rett syndrome. *Research in Autism Spectrum Disorders*, *8*(10), 1269-1278.

St. Pierre, E. A. (2017). Haecceity: Laying out a plane for post qualitative inquiry. *Qualitative Inquiry*, *23*(9), 686-698.

St. Pierre, E. A. (2019). Post qualitative inquiry in an ontology of immanence. *Qualitative inquiry*, *25*(1), 3-16.

Stratford, H. (2002). Collective Assemblages, Embodiment and Enunciations. *Advances in Art, Urban Futures*, *2*, 107-17.

Street, B. (1997). The implications of the ‘new literacy studies’ for literacy education. *English in education*, *31*(3), 45-59.

Street, B. (2001). *Literacy and Development: Ethnographic Perspectives*. London: Routledge.

Street, B. V. (2017). New literacy studies in educational contexts. In J. Phil, S. van der Kooij, & T. C. Carlsten (Eds.). *Teacher and librarian partnerships in literacy education in the 21st century* (pp. 23-32). Brill.

Stone-MacDonald, A. (2012). Cultural beliefs about disability in practice: experiences at a special school in Tanzania. *International Journal of Disability, Development and Education*, *59*(4), 393-407.

Suharto, S., Kuipers, P., & Dorsett, P. (2016). Disability terminology and the emergence of 'diffability'in Indonesia. *Disability & society*, *31*(5), 693-712.

Sunardi, Yusuf, M., Gunarhadi, Priyono, & Yeager, J. L. (2011). The implementation of inclusive education for students with special needs in Indonesia. *Excellence in Higher Education, 2*(1), 1-10.

Sunarto, S. (2012). Panakawan Wayang Kulit Purwa: Asal-usul dan Konsep Perwujudannya. *Panggung, 22*(3), 298400.

Sullivan, A. L., & Bal, A. (2013). Disproportionality in special education: Effects of individual and school variables on disability risk. *Exceptional Children*, *79*(4), 475-494.

Tager-Flusberg, H., & Kasari, C. (2013). Minimally verbal school-aged children with autism spectrum disorder: The neglected end of the spectrum. *Autism research*, *6*(6), 468-478.

Taguchi, H. L. (2010). *Going beyond the theory/practice divide in early childhood education: Introducing an intra-active pedagogy*. Routledge.

Takei, N., & Burdelski, M. (2018). Shifting of "expert" and "novice" roles between/within two languages: Language socialization, identity, and epistemics in family dinnertime conversations. *Multilingua*, *37*(1), 83-117.

Tankard, A. (2022). Disruption and Disability Futures in Captain America: The First Avenger and Captain America: The Winter Soldier. *Journal of Literary & Cultural Disability Studies*, *16*(1), 41-57.

Taylor, S., & Balandin, S. (2020). The ethics of inclusion in AAC research of participants with complex communication needs.

Titchkosky, T. (2011). *The question of access : disability, space, meaning*. University of Toronto Press.

Thomas, J., & Rayner, C. (2021). A Preliminary Study of Students With Disabilities in 'Flexi'Education Settings. *Australasian Journal of Special and Inclusive Education*, *45*(1), 76-89.

Toohey, K., & Smythe, S. (2022). A different difference in teacher education: Posthuman and decolonizing perspectives. *Language and Education*, *36*(2), 122-136.

Toohey, K., Smythe, S., Dagenais, D., & Forte, M. (Eds.). (2020). *Transforming language and literacy education: New materialism, posthumanism, and ontoethics*. Routledge.

Tucker, A. C. (2013). *Interpreting and Treating Autism in Javanese Indonesia* (Doctoral dissertation, UCLA).

Ulmer, J. B. (2016). Diffraction as a method of critical policy analysis. *Educational Philosophy and Theory*, *48*(13), 1381-1394.

Ulmer, J. B. (2017). Posthumanism as research methodology: Inquiry in the Anthropocene. *International Journal of Qualitative Studies in Education*, *30*(9), 832-848.

UNICEF. (2021). *Embracing Diversity and Inclusion for All: Landscape Analysis on Children with Disabilities in Indonesia*. Accessed from

https://www.unicef.org/indonesia/media/19746/file/Landscape%20analysis%20on%20children%20with%20disabilities%20in%20Indonesia.pdf

Unger, R. M. (2005). *What should the left propose?*. Verso.

U.S. Department of Education. (2019). *42nd Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act, 2020*. https://sites.ed.gov/idea/files/42nd-arc-for-idea.pdf

U.S. Department of Education. 2021. An overview of exclusionary discipline practices in public schools for the 2017-18 school year. Accessed from https://www2.ed.gov/about/offices/list/ocr/docs/crdc-exclusionary-school-discipline.pdf

Van Brakel, W. H., Sihombing, B., Djarir, H., Beise, K., Kusumawardhani, L., Yulihane, R., ... & Wilder-Smith, A. (2012). Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination. *Global health action*, *5*(1), 18394.

Vannini, P. (2015). Non-representational ethnography: New ways of animating lifeworlds. *Cultural Geographies*, *22*(2), 317-327.

Van Viegen, S. (2020). Becoming Posthuman: Bodies, Affect, and Earth in the School Garden. In *Transforming Language and Literacy Education* (pp. 54-71). Routledge.

Verma, R. (2021). Sacrifice, revenge, villainy: the problematic depiction of women with disabilities in mythology. https://eshe.in/2021/03/04/women-with-disability-in-mythology/

Vygotsky, L. S. (1987/1934). The collected works of L. S. Vygotsky, Thinking and speech (Vol. 1). Plenum.

Wandin, H., Lindberg, P., & Sonnander, K. (2023). Aided language modelling, responsive communication and eye-gaze technology as communication intervention for adults with Rett syndrome: three experimental single case studies. *Disability and Rehabilitation: Assistive Technology*, *18*(7), 1011-1025.

Wargo, J. M. (2018). Writing with wearables? Young children's intra-active authoring and the sounds of emplaced invention. *Journal of Literacy Research*, *50*(4), 502-523.

Whitebrook, M. (2001). *Identity, narrative and politics*. London: Routledge.

Widayanti, C. G., & Fletcher, J. (2022). 'Everybody knows': students labelled as having learning disabilities in the Indonesian education setting. *Education 3-13*, 1-13.

Wohlleben, P. (2016). *The hidden life of trees: What they feel, how they communicate—Discoveries from a secret world* (Vol. 1). Greystone Books.

Wolfe, C. (2003). *Animal Rites: American Culture, the Discourse of Species, and Posthumanist Theory*. University of Chicago Press.

Worah, S. (2011). A Survey of Augmentative and Alternative Communication (AAC) Services in Connecticut. *Connecticut State Education Resource Center.* Preuzeto sa: https://ctserc.org/documents/resources/Augmentative-and-Altenative-Communication-survey-2011.pdf.

Yin, R. K. (2018). *Case study research and applications* (Vol. 6). Thousand Oaks, CA: Sage.

Yu, B., Epstein, L., & Tisi, V. (2021). A DisCrit-informed critique of the difference vs. disorder approach in Speech-Language Pathology. In R. Horton (Ed.). *Critical perspectives on social justice in Speech Language Pathology*. IGI Global.

Zeitlin, V. M., & Curcic, S. (2014). Parental voices on individualized education programs: 'Oh, IEP meeting tomorrow? Rum tonight!'. *Disability & Society*, *29*(3), 373-387.

APPENDIX A

DATA SOURCES

Table 1
Data Sources of the Study

Data Source	Date	Setting	Participants	Length
Observation 1	07/01/2023	Virtual at Home	Kalika, Baba, Sally	2 Hours
Observation 2	07/08/2023	Home and library	Kalika, Baba, Sally	5 Hours
Observation 3	07/19/2023	Home	Kalika, Sofia	2 Hours
Observation 4	07/28/2023	Virtual in Chicago	Kalika, Baba, Sally	1 Hour
Observation 5	08/01/2023	Home	Kalika, Sofia	1.5 Hours
Observation 6	08/05/2023	Home	Kalika, Baba, Sally	3 Hours
Observation 7	08/08/2023	Home	Kalika, Sofia	2 Hours
Observation 8	08/15/2023	Home	Kalika, Sofia	1.5 Hours
Observation 9	08/19/2023	Home	Kalika, Baba, Sally	2 Hours
Observation 10	08/24/2023	Home	Kalika, Sofia	2 Hours
Observation 11	09/30/2023	Home	Kalika, Baba, Sally	2 Hours
Individual Interview 1	09/15/2023	Virtual	Sofia	1 Hour
Individual Interview 2	09/19/2023	Virtual	Baba	1 Hour
Individual Interview 3	09/21/2023	Virtual	Sally	1.5 Hours
Individual Interview 4	09/29/2023	Campus	Sofia	1 Hour
Individual Interview 5	10/04/2023	Virtual	Sally	1 Hour
Individual Interview 6	10/05/2023	Campus	Baba	1 Hour
Focus Group Discussion	10/18/2023	Virtual	Sofia, Sally, Baba	1 Hour
Individual Interview 7	11/07/2023	Home	Kalika	30 Minutes
Individual Interview 8	11/16/2023	Home	Kalika	30 Minutes

APPENDIX B

INTERVIEW PROTOCOLS WITH SOFIA, BABA, AND SALLY

Interview 1 with Sofia

Thank you for volunteering to be my participant for this research. In the next 45-60 minutes, I will be asking you some questions and play a short clip of your interaction with Kalika. I am especially interested in understanding your own perception about Kalika, her disabilities, and the objects involved during your interaction with Kalika, such as AAC, books, wheelchairs, chairs, etc. There is no right or wrong answer and you may skip the questions if you are not feeling comfortable to answer. Any questions before we start?

1. Tell me about yourself and your relationship with Kalika?
2. So, we both know that Kalika has Rett Syndrome. How do you describe Rett syndrome to someone who does not know anything about it?
3. Tell me about your experience in engaging with/interacting with Kalika?
4. What challenges do you face when engaging with/interacting with Kalika? How do you mitigate these challenges?
5. Now, I am going to play a short clip of you with Kalika. Please tell me if you need me to replay the video again before you answer the question. I am going to ask you questions, and your answers are not limited to the clip that you just saw. The clip was just to let you know my point of view when I was observing you. So feel free to recall any memories you have with Kalika.
    a. Tell me how do you interact or communicate with Kalika? What strategies do you do?
    b. How do you know if Kalika is engaging with you?
    c. How do you know if Kalika is NOT engaging with you? What do you do next?
6. Now, I am going to play the same short clip. This time, I want you to pay attention to anything besides Kalika and yourself. In other words, I want you to pay attention to the "objects"/"non-humans" that help your interactions with Kalika. Please tell me if you need me to review the video again before you answer the question.
    a. What objects do you see?
    b. Tell me about the objects. What are their roles in your interaction with Kalika?
    c. If you can rank the objects based on their importance in your interaction with Kalika, how do you rank them?
    d. Besides the objects in the clip, what objects do you think also hold importance to your interaction with Kalika?
    e. What challenges do you experience with AAC?
    f. If you remember, Kalika took time when she is responding to your answer. Tell me about this wait time.

Interview 1 with Baba

Thank you for volunteering to be my participant for this research. In the next 45-60 minutes, I will be asking you some questions and play a short clip of your interaction with Kalika. I am especially interested in understanding your own perception about Kalika, her disabilities, and the objects involved during your interaction with Kalika, such as AAC, books, wheelchairs, chairs, etc. There is no right or wrong answer and you may skip the questions if you are not feeling comfortable to answer. Any questions before we start?

1. Tell me about yourself. And since you have a language and literacy background, I am interested to know your perspective on language and literacy.

2. As a father of Kalika, how do you describe her?
3. So, we both know that Kalika has Rett Syndrome. How do you describe Rett syndrome to someone who does not know anything about it?
4. As I mentioned earlier, the primary focus of my research is exploring the entanglement of Kalika with her humans and non-humans interactants during literacy activities. These entanglements do not happen in isolation. From my observations, time and space have important roles in the entanglements. In relation to time and space, I am interested to know the story about your house. Tell me what considerations you take when you chose this house?
5. Next, I am going to play a clip that I took during Kalika's literacy session with Susan. Then, I will ask you questions, and your answers are not limited to the clip that you will see. The clip is only used to help contextualize my questions.
    a. Tell me about the setting. Where is it and why did you select that room in your house for Kalika's literacy session with Susan? What considerations did you take?
    b. Walk me to through the way you set up the environment/setting for Kalika's literacy session with Susan? What considerations did you take?
    c. If you could describe your role during Kalika's session (besides being a father), what would it be? Tell me more about it.
    d. How do you know if Kalika is engaging in the session?
    e. How do you know if Kalika is NOT engaging in the session? And considering your roles in the interaction, what would do you do next?
    f. In your roles as a parent or facilitator during Kalika's session with Susan, what challenges do you experience? How do you negotiate these challenges?
6. Next, I am going to play the same clip. But this time, I want you to pay attention to the non-humans, especially their roles in during Kalika's literacy session.
    a. What non-humans/objects did you see, feel, or hear?
    b. Tell me about the non-humans. What are their roles in Kalika's literacy goals?
    c. If you can rank the objects based on their importance in Kalika's language and literacy goals, how do you rank them?
    d. In your opinion, besides the objects in the clip, what objects do you think also hold importance to Kalika's language and literacy goals?
    e. What challenges does Kalika experience in speaking through AAC?
    f. What challenges do you experience when communicating with Kalika in general? How do you negotiate these challenges?
    g. Now I am going to ask about time. If you notice, Kalika took time when she is responding to your questions or prompts. Tell me your opinion about this wait time.

Interview 1 with Sally

Thank you for volunteering to be my participant for this research. In the next 45-60 minutes, I will be asking you some questions and play a short clip of your interaction with Kalika. I am especially interested in understanding your own perception about Kalika, her disabilities, and the objects involved during your interaction with Kalika, such as AAC, books, wheelchairs, chairs, etc. There is no right or wrong answer and you may skip the questions if you are not feeling comfortable to answer. Any questions before we start?

1. First of all, I am interested to know more about your story. Tell me about yourself and Rett syndrome?
2. As someone who has worked with many individuals with Rett syndrome, how do you describe Rett syndrome to someone who does not know anything about it?
3. Now, after all these years working with people who rely on AAC for communication, what is AAC to you? What is it for Kalika and people like Kalika?
4. How about your relationship with Kalika. How do you know each other and become entangled eventually?

5. Now tell me about your setting when you are teaching Kalika:
    a. Where are you? From my observation of all videos you shared, you seem to be in the same setting and place. So, tell me about the room?
    b. Why did you choose that particular room as your "teaching" or "working" space?
    c. Walk me through the way you set up the environment/setting when you are teaching Kalika. What non-humans/objects that must be present when you have a session with Kalika?
    d. What are the roles of the non-humans that you just mentioned when you are working with Kalika?
    e. If you could rank the objects based on their importance in helping you teach or work with Kalika, how do you rank them?
    f. What challenges do you experience when using/interacting with these objects?
6. In your opinion, what/who must be present when you have a session with Kalika? Your answers can include both humans and non-humans.
7. What are the roles of the objects (human and non-humans) that you just mentioned when you are working with Kalika?
8. If you could rank the objects (humans and non-humans) based on their importance in helping you teach or work with Kalika; and helping Kalika learn literacy with you, how do you rank them?
9. In your opinion, besides the objects in the photo, what objects (humans and non-humans) do you think also hold importance to Kalika's language and literacy goals?
10. What challenges do you experience when navigating Kalika's AAC device?
11. In your opinion, what challenges does Kalika experience when she is speaking through her AAC device?
12. Next, I am going to play a clip from the video you shared with me. Then, I will ask you questions, and your answers are not limited to the clip that you will see.
    a. Tell me how do you interact or communicate with Kalika? What strategies do you do?
    b. How do you know if Kalika is engaging with you?
    c. How do you know if Kalika is NOT engaging with you? What do you do next?
    d. In your role as Kalika's teacher, what challenges do you experience?
    e. How do you negotiate or mitigate these challenges?
    f. Now I am going to ask about time. If you notice, Kalika took time when she is responding to your questions or prompts. Tell me your opinion about this wait time.

Interview 2 with Sofia, Baba, and Sally

Activity 1
This activity will require you to read segments of interview transcripts between Wisnu and other participants in this study. Please read the transcripts carefully and focus your attention on the non-human subjects discussed in the interview. Start by reading the interview transcript between you and Wisnu.

1. If you are the **Babysitter**, start by reading the **Pink** transcript first. Afterward, you may read other transcripts in any order you prefer.
2. If you are the **Parent**, start by reading the **Blue** transcript first. Afterward, you may read other transcripts in any order you prefer.
3. If you are the **Educational Consultant (EC)**, start by reading the **Yellow** transcript first. Afterward, you may read other transcripts in any order you prefer.

When you are reading the transcripts, please **underline** important points you **agree or resonate** with your experience as the babysitter/parent/EC. You may ask Wisnu if you are not sure about the interview contexts or if you experience confusion while reading the transcripts.
After reading the transcripts, you will have a short discussion with Wisnu.

1. Tell me what you underline in the transcripts. How do they resonate with your experience?
2. What new objects did you underline/circle?
3. What new insights did you gain about other human participants after reading the transcript?
4. What new insights did you gain about non-human participants after reading the transcript?

Activity 2

This activity will require you to draw an illustration of the entanglement between the humans and non-humans during Kalika's literacy activities at home. Here's the prompt:

"What does the entanglement between humans and non-humans during Kalika's literacy activities look like to you?"

Unleash your imagination. You may use the stationaries that Wisnu provides to draw the entanglement. After you finish your drawing, you will have a short discussion with Wisnu.

1. Tell me about your drawing. How is it an entanglement?
2. What objects did you draw first?
3. What objects did you draw the last?
4. What new objects did you draw? These are the ones that are not included in your transcripts. Why did you include them in there?
5. Other questions of clarification from Interview 1

APPENDIX C

INTERVIEW PROTOCOLS WITH KALIKA

Interview Protocols with Kalika

Wisnu will read a children's book entitled *Dancing with Daddy* by Anitra Schulte and Ziyue Chen to Kalika.. During the reading, Wisnu will need to be accompanied by a parent or babysitter to provide some contexts/clarifications on her responses in case he needs it. While reading the book, Wisnu will ask some questions related to the book and his research. Below are some potential questions and activities that Wisnu will do with Kalika:

Activity: Reading and pointing to illustration. Wisnu will ask "Which dress do you think Elsie will choose? Pink or Red?"; and "How about you, do you like Pink or Red?" To elicit a response from Kalika, Wisnu will use Pink and Red flashcards that he makes.

Activity: Reading and pointing to illustration. Wisnu will also say, "Look, Elsie also speaks through Tobii. This is her Tobii. She said, "Special." Wisnu will ask, "Do you like speaking with your Tobii? Is it special to you?" Wisnu will use Yes and No flashcards that he makes.

Activity: Reading. Wisnu will also say, "Look, Elsie uses G-Tube to eat, just like you." And then he will say "I like eating, especially when I am reading. Do you like eating when you read a book?" Wisnu will use Yes and No flashcards that he makes.

Activity: Reading and pointing to illustration. Wisnu will also ask, "Do you like reading with Baba?"; Wisnu will use Yes and No flashcards that he makes. "How about reading with Sarah and Ms. Susan. Do you like reading with Sarah or Susan?" Wisnu will use Sarah and Susan flashcards that he makes.

Activity: Reading and pointing to illustration. Wisnu will say, "This is her Ma."

Activity: Reading and pointing to illustration. Wisnu will also say, "Look, this is just like you and Baba. I have seen you dancing in the living room with Baba."

Activity: Reading and pointing to illustration. Wisnu will also say, "Look, Elsie has the same color of wheelchair like yours. It's pink! (Wisnu will use the pink flashcard that he makes). She also has straps on her body – just like when you are reading with Ms. Susan. Baba put straps on your body, and also your feet. Do you like reading in your wheelchair?" Wisnu will use Yes and No flashcards that he makes.

Activity: Reading and pointing to illustration. Wisnu will also say, "She loved listening to the music. She loved it. Do you like listening to music?" Wisnu will use Yes and No flashcards that he makes.

Activity: Reading and pointing to illustration. Wisnu will say, "Then Elsie reached for her Tobii. She said 'dance'. Look, she is touching 'dance' on her Tobii. Her Tobii also has pictures just like yours."

Activity: Reading and pointing to illustration. Wisnu will ask, "So, do you like to dance with Baba?" Wisnu will use Yes and No flashcards that he makes.

APPENDIX D

FOCUS GROUP DISCUSSION PROTOCOLS

Focus Group Discussion Protocols

First of all, thank you so much for attending this focus group discussion. This is gonna be our last meeting for data collection. Of course, I will still meet Kalika for some informal data collection at home – but yeah, I have been enjoying my time listening to and learning from you these past months.

Okay, so, in this group discussion, my goal is to have a collective understanding of certain aspects that become my focus of research. Therefore, in the next 60 minutes, please feel free to respond to and interact with one another throughout this group discussion. You may agree or disagree with one another – that's fine as long as it is courteous. Feel free to also:

a. Keep your speakers off mute – this will allow for more "realistic" and spontaneous interaction. We are on zoom we sometimes forget to unmute ourselves before speaking.
b. Everybody needs to say something.
c. Be respectful of others' opinions.
d. There is no judgement
e. There is no right and wrong answers

As part of an entanglement, I am aware some of you do not know each other. You have seen the transcripts and probably heard the names, but I bet this is the first time for you all to see each other (as a group) and talk about Kalika and her language and literacy. So why don't we shortly introduce each other, our background, and our role in Kalika's entanglement (I would say). Anybody wants to begin?

Now, my first question will be, very general, it's a warm up question, but I wanted to know our collective understanding on entanglement:

1. As a team, considering each other's role (including the non-humans if you want), what do you mean by entanglement? And how do you think our entanglement can support Kalika reach her best potential in language and literacy?
   Follow-up Questions:
   a. You mentioned _____. Could you talk more about that?
   b. You mentioned _____. Could you describe an example of that?
   c. You described _____. Could you explain what that was like for you?

2. As a team, what do you think we need to work on more to support Kalika reach her best potential in language and literacy? You may share your challenges and why you think they are important for Kalika.
   Follow-up Questions:
   a. You mentioned _____. Could you talk more about that?
   b. You mentioned _____. Could you describe an example of that?
   c. You described _____. Could you explain what that was like for you?

3. As a team, how do you think each of us can support Kalika to reach her best potential in language and literacy? What do we need from each other? You may give suggestions to each other on things that we should focus to work on.
   Follow-up Questions:
   a. You mentioned _____. Could you talk more about that?
   b. You mentioned _____. Could you describe an example of that?
   c. You described _____. Could you explain what that was like for you?

4. Now my last question will be very general: but, what do you think inclusive education mean? How is it related to entanglement?
   Follow-up Questions:
   a. You mentioned _____. Could you talk more about that?
   b. You mentioned _____. Could you describe an example of that?
   c. You described _____. Could you explain what that was like for you?

APPENDIX E

SAMPLE OF FIELD NOTES

Date : July 8, 2023
Time : 1:30-5:00 PM
Method : Observation/Interview/Elicitation
Location : House & Library

Noticing	Comments/Wonders	Non-Humans
Kalika looked at a cat who was drinking water from the fountain (1:41 PM).	The same event happened last week. She was aware of the cats' whereabouts. I wonder: • What is Kalika's relationship with the cats? How is she entangled? • What do scholars say about the relationship of animals and individuals with disabilities?	Cats
There was music playing at the background. Cuban Music by Benny Moore. Kalika listens to music from different languages, e.g., English, Bengali, French. From the parent's story, Sally did not really like to play music for Kalika during her study.	Music and learning. I wonder: • What kinds of music Kalika likes to listen to? • What does the parent's think about music? How does music help Kalika's learn? • What does Sally think about music and Rett syndrome?	Music
Sally suggested Dad put Kalika her bracing arm (one arm only) (1:54 PM). From the conversation at the library, the parent said that it helped Kalika focus on the lesson by reducing movements. In fact, from my observation, the parent administered bracing not only for Kalika's arm, but also her feet during the session with EC.	Movement and focus. Seeing her bodies being restricted reminded me about Foucault's discipline and punish, i.e., the way school disciplines "unruly" bodies to help students embody the qualities of ideal students. I wonder: • What does the research say about Rett syndrome movement and learning? What is the use of the brace for learning focus? What are the side effects?	Arm brace, Foot brace
Kalika was crying. Sally asked if I was (the researcher) around, because Kalika might be distracted by the camera.	This instance really made me think about my entanglement with Kalika. I wonder: • How am I entangled with Kalika? How is my presence as a researcher (with camera, laptop, notebook) influence Kalika's learning and interaction with others?	Camera

"I'll wait for you." Sally always said this if Kalika was crying and needed time to think.	Sally said this sentence many times last week and this week. Interesting to see how she really appreciate time for Kalika to process the information. I wonder: • What does EC know about wait time in Rett syndrome?	Time

APPENDIX F

TABLE OF CONTENTS OF DATA (SIMPLIFIED)

Table 2
Table of Contents of Data

Data Source	Setting	Participants	Data	Blurbs
Observation 1 07/01/2023	Virtual at Home (Dining Room)	Kalika, Baba, Sally	Videos Field notes	Kalika was crying at the beginning of the lesson – it was her first week after being rushed to the hospital – she began enjoying the lesson as the lesson progressed. Kalika was reading "Now We Bake" with Sally. Kalika read each sentence despite crying. Baba said "Okay, Google, stop!" at the beginning. Baba was holding Kalika's hand in most part of the lesson. Baba fed Kalika through Gtube. Sally kept saying "I will wait for you", providing Kalika time to calm her body. Sally used Yes/No spelling board. Sally asked Baba to help lift Kalika's head so she could see her eyes and where she was looking. Sally played an ABC song on YouTube for Kalika; Kalika did not seem happy.
Observation 2 07/08/2023	Home and library (Dining Room)	Kalika, Baba, Sally	Videos Photos Field notes	Kalika cried at the beginning. Kalika looked at the black and white cat coming to her. Kalika did comprehension questions on the book they read last week. Kalika doing spelling of *an, and, band*. Baba gave Kalika her blanket as soon as the lesson started. Baba fed Kalika and she stopped crying. Baba looked at Kalika and asked, "would like a sip?" Baba reminded Kalika to pay attention to Sally by calling her name. Baba braced her arm. Sally said, "we will do the lesson slow". She used Yes/No spelling board Photos: activity chair, set up of the table, map to Kalika's house, Kalika in the library with Ma and Baba.

Observation 3 07/19/2023	Home (Dining room)	Kalika, Sofia	Videos Photos Field notes	Kalika was crying. Sofia was feeding Kalika through mouth. Later, Baba gave food to Kalika through GTube. Kalika's arm was braced. Sofia asked if she wanted to read books, Kalika refused (she vocalized). Baba said, "Okay, Google stop" and played a song for Kalika trough his phone - Kalika calmed afterwards. Sofia and Kalika then read books, i.e., "Bird Count"; "One fish two fish". Kalika said though her AAC that she wanted to go to the bathroom. She also said words, such as "I don't understand", "How was your day?" to Sofia. Ma offered Sofia some board games to play with Kalika. They played, "candy land" – kind of *ular tangga* in Indonesian. After that, they watched sesame street. Kalika looked very excited as she watched the show. Photos: Cats, Kalika's GTube, Candy Land board game
Observation 4 07/28/2023	Virtual in Sally's House	Kalika, Baba, Sally	Video Field notes	There was a tech issue at the beginning of the lesson, i.e., pairing Kalika's small Tobii device to Sally's desktop, so I could see Kalika's AAC page. Sally showed some books to Kalika. They discussed what non-fiction book was. She used yes/no board to elicit Kalika's responses. Kalika was tired, she slept after a few minutes the lesson began. Baba and Sally ended up talking to each other.
Observation 5 08/01/2023	Home (Living Room and Playroom)	Kalika, Sofia	Videos Photos Field notes	Kalika was in the living room, reading a book with Sofia. Earlier, Sofia prepared some cushions and soft toys to support Kalika's body so she could sit straight. They read "the miracle man", one of the books that Baba picked up at the library. Surrounding Kalika were her soft toys. There were many instances where Sofia worked with the non-humans to support Kalika, such as cushions, blanket, glasses. Kalika looked at the book as Sofia read; she also occasionally

				looked at Sofia. Other books they were reading include “Girl on a motorcycle”. After reading, they moved to the playroom and played make up with dolls. Kalika requested change of music through AAC. Following the make-up play, they played a board game. She also asked, “are you having fun?” to Sofia. Photos: Living room, all stuff in the playroom, cats following me.
Observation 6 08/05/2023	Home (Dining Room)	Kalika, Baba, Sally	Videos Photos Field notes	Black and white cat was present as Kalika cried at the beginning of the lesson. Sally noticed the eye-tracker was not in the right angle. Baba helped adjusted the angle – he used a book to prop the device. Ma came after hearing Kalika’s unconsoleable cry, she suggested Baba to brace Kalika’s arm. She also tucked Kalika’s blanket to Kalika’s body harness. Baba held Kalika’s hand. Kalika was crying half of the lesson. She read a book “What makes me happy?” with Sally. The book featured animals, e.g., dogs, cats. Sally sang a spelling song (based on the letters in the book) to entertain Kalika. The songs include, “if you are happy clap your hand.” Sally added word “curious” on Kalika’s device. There was a tech error – the book page did not load properly. Sally read a printed book with Kalika about a polar bear. Kalika enjoying the book. Sally praised Kalika as she calmed her body. Photos: Cat accompanying research
Observation 7 08/08/2023	Home (Dining room)	Kalika, Sofia	Videos	Sofia fed Kalika though mouth. They read a book “Stacey Abrams”. Kalika was cranky during reading; she wanted to watch her favorite shows. Music seemed to affect her mood; she smiled and calmed a moment as a Hindi/Bengali song played in the background. Ma came and gave food through GTube. She said, “Let’s stop [the reading]”. Ma said Kalika must finish reading the book then watch.

				The cries got louder, Ma gave up and let her watch the show. Kalika smiled and stopped crying as the show played.
Observation 8 08/15/2023	Home (Play room)	Kalika, Sofia	Videos Photos Field notes	Kalika played make up with Sofia using the soft toys, but it did not last long. She was crying loudly; she wanted to watch the show. She stopped crying as the show played. Ma said, "the moment she saw iPad, it's game over"; iPad reminds her of her favorite shows. After watching, they continued playing make-up. Music was playing in the backgorund. She requested a song, such as "Mamy Blue." Photos: Camera hiding behind blanket, Cats, Cat food dispenser, Kalika's soft toy, Kalika dancing with Baba, Kalika requesting song by Snuffy, Kalika's AAC page, Elmo bag, Kalika watching Elmo.
Observation 9 08/19/2023	Home (Dining Room)	Kalika, Baba, Sally	Videos Photo Field notes	Baba braced Kalika's arm as soon as the lesson started. He fed Kalika via GTube. Kalika started the lesson without crying, then she cried in the middle. Sally and Kalika discussed some words they discussed last time using the yes/no board. They then re-read the same book, "what makes me happy?". There was a tech glitch – the windows OS bar blocking the last row of Kalika's AAC pageset. Bathroom break – Baba noticed that Kalika's needed to go to the bathroom. Photo: Camera hiding behind the wall at the kitchen
Observation 10 08/24/2023	Home (Playroom)	Kalika, Sofia	Videos Photos Field notes	Kalika was doing Math homework with Sofia. Kalika answered questions using touch on the correct flashcards. She also engaged by saying words through AAC, including saying her preference for watching her favorite shows. Sofia used a bag of soft toys as an alternative of feet straps. Sofia used make up objects to explain math

				addition to Kalika. After doing math, they played a toy to practice spelling, played board games. The AAC froze a few times during the game. Ginger cat jumped to the table as they played. They read a book about cat and planets. After that, Kalika had a snack. Sofia arranged a few soft toys on Kalika's chair to support her posture. Photos: Kalika's AAC pagesets, Kalika's AAC froze, cat at the window ledge, book about cat, Kalika's wheelchair
Observation 11 09/30/2023	Home (Dining Room)	Kalika, Baba, Sally	Videos	The lesson began with spelling session. The words were *as, an, ban, and, bad.* Sally asked Ma to adjust Kalika's activity chair so it faced her properly. Ma noticed that Kalika was on her quick fires personal needs pageset. She paused the lesson and asked if Kalika needs something. Kalika said she was uncomfortable. She said thirsty. Sally and Kalika read the same book as last time. She asked Baba to re-adjust Kalika's seating as she needed to see her AAC device. They were doing a spelling lesson. This time, Sally used a handout and whiteboard where she wrote letters for Kalika on it. Kalika was generally calm during the lesson.
Individual Interview 1 09/15/2023	Virtual	Sofia	Video Field notes	First interview with Sofia
Individual Interview 2 09/19/2023	Virtual	Baba	Video Field notes	First interview with Baba
Individual Interview 3 09/21/2023	Virtual	Sally	Video Field notes	First interview with Sally
Individual Interview 4 09/29/2023	Campus	Sofia	Videos Photos Field notes	Second interview with Sofia Photos: Set up of interview room; Sofia's drawing.
Individual Interview 5 10/04/2023	Virtual	Sally	Video Field notes	Second interview with Sally
Individual Interview 6	Campus	Baba	Videos Photo	Second interview with Baba Photo: Baba's drawing

10/05/2023			Field notes	
Focus Group Discussion 10/18/2023	Virtual	Sofia, Sally, Baba	Video Field notes	Discussion on their entanglement, what they need from each other, and how they plan to move forward.
Individual Interview 7 11/07/2023	Home	Kalika	Videos Field notes	Interview while story reading with Kalika Picture: Kalika's AAC pageset
Individual Interview 8 11/16/2023	Home	Kalika	Videos Picture Field notes	Interview while story reading with Kalika Picture: Kalika's AAC pageset

APPENDIX G

SAMPLE OF VISUAL NOTE AND MEMO

Visual Memo on July 8 Observation and Data Analysis of Thinking with Space