

Disabling Crisis:
Mental Health Experiences of Visually and Hearing-Impaired People in Shanghai

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Abstract

This paper stems from over a year of fieldwork in Shanghai with visual and hearing disability communities in multiple sites: from official events or grassroots organizations to more personal and intimate encounters, we shared everyday activities as diverse as walking, eating, talking, or texting. It questions to whom mental health is a crisis. The paper proposes a carnal politics of disability as an alternative to the social model to understand how the experience of people with disabilities can contribute to rethinking the conceptualization of mental health crisis and its material implications.

Keywords: sensory disability, mental health, crisis, carnal politics of disability

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Our understanding of the experience of disability often focuses on visible, physical features of the bodily impairment. However, emotional and psychological states often do not receive sufficient attention from a political and relational perspective. This paper considers the integral nature of experience as a whole process within mental, bodily, relational, and environmental spaces.

The research this paper is based on consisted of more than a year of ethnographic fieldwork with communities of visually and hearing-impaired people in Shanghai. Some interactions occurred in official settings that government bureaus or grassroots hosted. Other more intimate and personal encounters also took place during the fieldwork, including sharing a meal or coffee, taking a walk together around parks in the city, or accompanying a participant to the hospital. We also participated in conferences and events organized by the deaf community, including weekly community meetings in an old park in the city suburbs. We also attended blind choir rehearsals. Additionally, we shared daily mobile phone interaction with primary informants, and communication via text messages provided us with a smooth bridge to share experiences and ideas, especially with deaf participants.

Fieldwork corresponded to a sensory ethnography within the theoretical frame of critical phenomenology. The sensorial aspect of fieldwork lies in two essential focus points. First, I emphasized the research participants' experience of the environment through their

particular embodiment of sensory impairments. Second, I paid attention to my own experience within the research participants' worlds as an emplaced ethnographic experience, committed to involving myself with all my senses while engaging participants.

In that sense, the relationships we created during the ethnographic encounter happened within a process of critical sensory analysis. It is an analysis in which I posed knowledge-making as a dynamic process that arose directly from the indissoluble relations between minds, bodies, and the environment. I followed Pink (2015), who argued that all ethnographies are sensory, just as embodied, gendered, and reflexive. Consequently, I asked how I, as the ethnographer, learned through experience and how research participants learn and know about themselves and the environment in which they dwell. How do they make sense of their world?

Our fieldwork stances and the experiences I shared with the research participants followed an analysis process in which I, as researcher, had to assume a not-knowing attitude (de la Cadena, 2021) toward the ethnographic encounter. The reflections and the interpretation I was able to reach required me to acknowledge my own presence in the ethnographic work. This epistemological positioning responded to our differences in sensory embodiment and our paths of perception.

I followed the pathways through which they lived and made sense of their experiences. Borrowing a concept from Strathern (2001), the research encounter offered a displacement (not a replacement) of categories. Instead of distancing myself from the divergence of the ethnographic encounter for fear of disturbing the habitual knowledge of biomedical or academic

categories, I understood the importance of producing knowledge and participating in spaces for not-knowing. Working with the research participants allowed me to better describe our ethnographic encounter with categories that got displaced but not erased. The descriptions in this paper are only a practice of interpretation that calls for others to develop better (distinct) descriptions than mine.

Research participants talked about their emotions or suffering, turning to bodily expressions but refused to explore it in discourse openly. They built associations of meaning that seemed unarticulated. Mine was a not-knowing experience of the routes I had to take to access the landscapes where I could understand those associations. I must emphasize that I was the bearer of lack. It was my predicament to not-know, not see things as such, and not understand what was in front of my eyes. Not-knowing attitudes let me escape the epistemological righteousness of assuming I knew better than the research participants. “As ethnographic practice, “not knowing” meets the feminist assumption that knowledges come with the world they make” (de la Cadena, 2021, p. 252). Not-knowing opened my chances to see all statements as a fresh possibility (Savransky, 2016) or events yet to emerge in the form of articulated knowledge (Strathern, 2001). I had to learn to work with the openings of what the research participants’ notions (events, practices, expressions, silences, complaints) might not contain while also being part of something that made sense to them.

The main research question I sought to answer was how sensory impairment becomes a disability of the everyday. The paper focused on drawing attention to the conflict that emerges

when individuals experience themselves (or when others perceive them) as having physical and mental disabilities or weaknesses.

Blind and deaf research participants negotiate disability identities in a conflict where physical impairment usually debunks psychological states. In other words, visually and hearing-impaired people in Shanghai dwelled in a system where there was strong pressure to behave and act “as disabled people do.” Psychological concerns added a burden to the social constrictions a disability may already place on the individual. Moreover, within blind or deaf disability communities, there may not be adequate access to treatment for psychological distress or a deeper understanding of the disability experience of the community members.

I argue that framing global and local mental health within crisis discourses provokes an intersectional marginalization of people with other disabilities. The crisis discourse overlooks the carnal politics of disability and how people with impairments manage their everyday lives. This discourse also pathologizes any emotional or psychological expression caused by social suffering or structural violence, which makes physically impaired people look for ways to avoid the additional stigmatization and material costs psychological pathologies provoke. The purpose of this paper is not only to bring forward the disability experiences of blind and deaf people in Shanghai but also to analyze the deeper reasons for blind and deaf persons having such experiences.

In this paper, I draw upon examples from Yu, a member of the deaf community, and Mrs. Shi, a member of the blind community. They were the primary informants due to the time

we shared, the rapport and trust we built, and the relevance of their experiences as members of a “we” community (Mattingly, 2019a). Yu and Mrs. Shi represented their communities for two main reasons. First, our encounters offered a different epistemological approach to understanding disability in a context where disability discourses are created and enacted from a male perspective (Kohrman, 2005). Being both women and members of established disability communities, they had to constantly manage their right to belong and to bring their disability embodiment as women, mothers, female bodies, and citizens. Second, I intended to show how visually and hearing-impaired people managed their psychological states. In that sense, Yu and Mrs. Shi’s willingness to share accounts of the psychological dimension of their lifeworlds opened a window to see common scapes in which disabled people live every day. It is important to note that this does not come as saying that Yu and Mrs. Shi’s psychological crises, such as fear, anger, or anxiety, were attributed to their hearing or visual impairments. The central argument is that their embodied difference sharpens limitations in how they express and experience psychological distress. Moreover, I ask how their physical impairments may impact their defining and exerting an appropriation of their whole experience. In sum, the paper intends to connect moments of their everyday life to broader political contexts to understand the concept of crisis as political construction. In that sense, bringing the body-psyche of people with sensory impairments to discussion of mental health crisis, I ask whose bodies can entail what crisis.

It is essential to acknowledge that, due to methodological and material reasons, some research participants received more attention than others in the account of the stories and the

analysis shared within this research. Methodologically speaking, my focus on the research participants' perceptions only allowed me to connect with a few of them with the depth such observations required. Materially speaking, while getting to know dozens of blind and deaf members of disability communities in Shanghai during fieldwork, I did not however have the time and the resources to work in teams or engage for extended hours with multiple research participants.

Positionality and rapport

Those who live in the margins are bound to bump into each other. To explain how I got to know the blind and deaf research participants with whom I worked during my fieldwork, the first answer that comes to mind is that somehow we belonged together. The people with whom I related, the issues that interested me, the research problem, and the learning process were directly related to my experience of the urban space in Shanghai. They also related to the circumstances in which I had to embrace that urban space as mine, where I had to dwell, work, and research with others. I say that we belonged together because I found in them a sense of “becoming to belong” that helped me understand my very own dislocation in that city of 25 million people. Although I do not identify as disabled, I did feel connected for two main reasons. First, when I started my PhD and looked for fieldwork resources and collaborators, I was diagnosed with cancer. My personal encounter with illness, the Chinese medical system, and the psychological and physical implications of the process that the diagnosis triggered, together put me in a privileged position to question medical concepts and practices on disease, healing, and the whole pathological discourse was this.

It also allowed me to experiment with the idea of disability identity. I wondered why I was not disabled. If the surgeries and the chemotherapy permanently cut off parts of my body, why did this not mean I was disabled? What was required for me or others to see me as disabled? Of course, this idea came from a concept of disability derived from lack, the lack that produces difference, the difference that disables. I contrasted my deficiency experience with the deficiency that made blind and deaf people disabled. Theirs was a sensory impairment which supposedly transformed them into disabled persons. Why did not the lack in my body make me disabled? Or did it? This self-reflective stance allowed me to better understand theoretical approaches to disability from medical, social, and other critical discourses.

Beyond these theoretical attempts, the mere experience of disease (physical, social, subjective, psychological, economic, and political) offered me a first-hand understanding of how bodily conditions are intrinsic to our being in the world. How we move, relate, and build our lives with and within the world depends on our bodies' dispositions, as well as the conditions those dispositions encounter.

The second reason that put me close to the research participants is the pervasive effects of the SARS-CoV-2 pandemic on everyone. At the time of fieldwork, we were all under the menace of lockdowns and isolation. We managed to meet many times but had to surrender to the control measures on many occasions. Blind and deaf research participants got closer to me when we could not meet. Their reactions and ways of coping with restrictive states of isolation showed me something about their everyday that I would not have seen otherwise. They almost

did not need to cope with anything new at all. It seemed in some sense being isolated was a familiar state, even if they used to go out to run some errands or to walk in the park, and, now, could not. Isolation did not seem to represent a breakdown in their lives. They told me they barely felt the effects of isolation in such restrictive conditions. Therefore, crisis was not in their landscapes. Thus, my encounter with disease and the universal effects of the pandemic on our socialization processes made our rapport intimate, visceral, and emotional.

Literature review

I built analysis from the stories, events, accounts, and insights I experienced during fieldwork. To shape them into arguments, I worked closely with the theoretical and ethnographic accounts on critical phenomenology and the ethical turn in anthropology (Desjarlais, 1994, 1997, 2003; Kleinman, 2012; Mattingly, 2019b, 2019a, 2022, 2022; Mattingly & Throop, 2018; and Zigon & Throop, 2014, 2022). Moreover, I put into dialogue works on the anthropology of disability and disability studies (Burch & Kafer, 2010; Dauncey, 2020; Deshen, 1992; Friedner, 2015, 2018; Friedner & Kusters, 2020; Friedner & Zoanni, 2018; Hammer, 2015, 2019; Kafer, 2013; Kohrman, 2005; Nakamura, 2013a, 2013b; Shakespeare, 2008, 2014; and Weiss, 2008).

Critical phenomenology pays close attention to bodily sensorial subjectivity. Different sensory dispositions produce different modalities of experience. Anthropological approaches have argued that difference relates not only to subjective experience. Intersubjectivity and intercorporeality always inform essential experiences of the physical environment and social

encounters. We are all sharing, experiencing, and making sense of the world together. However, all experiences are not the same. Phenomenologists have warned about the immanence of fundamental asymmetries and instabilities in experience (Desjarlais & Throop, 2011; Jackson, 1996, 2011). Subjectivity is always intersubjective; personhood and identity are social products (Biehl et al., 2007; DeIVecchio Good et al., 2008; Desjarlais, 2003). Thus, they have set up limits to purely subjectivistic approaches to experience. At the same time, critical phenomenology has proposed that the conditions of embodiment determine the relations with others in a dynamic interactive interpretation called intercorporeality that occurs in and with our bodies (Marrato, 2020).

Theoretical disability models follow Cartesian thinking about impairment-disability, body-psyche, individual-culture, and medical-social dichotomies. These modes have produced a disassociation between a body with impairments and its capacity to act. For instance, the theoretical stand of the social model of disability disregards the carnal relation between impairment and disability (Kafer, 2013; Paterson, 2001; Paterson & Hughes, 1999; Shakespeare, 2014). The physicality of impairment cannot be disentangled from the relational and contextual implications of disability (Kafer, 2013; Shakespeare, 2014). Both impairment and disability are the product of relational and contextual constructions under which intercorporeal experiences take place.

Namely, the medical/individual model of disability frames atypical bodies and minds as deviant, pathological, and defective and defines these characteristics in medical terms.

According to this model, the adequate approach to disability is treating the condition. In contrast, the person's experience somewhat gets overlooked. Moreover, the medical model does not 'treat' the social processes and policies that constrict disabled people's lives (Kafer, 2013).

Parallel to the biomedical framework of disability as a problem that needs a solution on the body of the disabled person, the social model of disability offers a human-rights-based theoretical stand that shifts attention from the individual to the social. Shakespeare refers to the origins of the social model and explains that "it is the society which disables physically impaired people. Disability is imposed on top of our impairments by how we are unnecessarily isolated and excluded from full participation in society (2014, p. 12)." The social model is materialist because it focuses on the material circumstances that produce disablement as a social product.

However, many authors are critical of the social model's separation between impairment and disability. "The materialist account of disability makes a distinction between impairment and disability; claims that disability can disappear through social change; and downplays the role of impairment in the lives of disabled people" (Shakespeare, 2014, p. 42). The gap between impairment and disability fails to acknowledge that both impairment and disability are social; the mere process of defining what constitutes impairment makes clear that impairment does not exist apart from social meanings and understandings (Kafer, 2013).

Although the social model of disability offers essential elements to question and transform structural violence and lack of support systems, it has produced a separation of the

body (embodied subject) from politics (Paterson, 2001). When the body becomes a mere recipient of social forces (Paterson & Hughes, 1999), impairment and illness appear as mere biological facts. To bridge this gap, I argue that it is necessary to bring back the unit body-psyche to discussions on disability (Goodley, 2009) to acknowledge that the intercorporeal construction of disability produces identities, limitations, and possibilities in which bodies with impairments simultaneously act and are acted upon. Disability does not happen only on the body or outside of it; it is a whole experience that emerges from the interaction between the bodily, the relational, and the environmental.

Conceptually, there are differences between impairment, disability, and predicament. Impairment refers to the embodied difference, the bodily condition that makes a body different-able. Disability refers to the social and political exclusions and barriers that emerge because of the physical and mentally impaired people's bodily differences. Predicaments arise when disabled people interact with the environment and others. It corresponds to the excess or the absence that shapes relationships with bodily impaired people. Thus, the predicament happens not only to the disabled person but also to the environment and the other persons interacting with them.

Acknowledging the distinction between impairment and disability follows the social model of disability. However, this paper assumes a critical stand before such a distinction. It is essential to make impairment political and visible as an immanent element of the relationships with disabled persons. Though disability is a socio-political construction, the predicaments that

impairment causes exist ingrained in the bodily conditions of the disabled person. Moreover, the whole experience of disability cannot be explained within the impairment/disability dichotomy because both concepts result from social and environmental conditions (Kafer, 2013; Shakespeare, 2014).

Experiences of discomfort or pain, for example, are intrinsic to the conditioning that impairment exerts on the body and the social spaces where those experiences emerge. Therefore, the paper follows a carnal politics of disability, one that does not overlook the physical implications of having an impaired body and the effects that it has on social relationships (Cunningham-Burley & Backett-Milburn, 2001; Paterson, 2001; Paterson & Hughes, 1999). This stance does not mean blaming physical impairment as the cause of the predicament but recognizing that it is an immanent determinant in the construction of disability and that people with impairments may always be at a vulnerable disadvantage.

This paper draws examples from engagements with visually and hearing disability communities in Shanghai. The analysis followed a critical phenomenological approach that provided instruments to analyze and interpret the experience of people whose bodies have impairments within a political-economic, material, and cultural context. Phenomenological studies in anthropology have put forward critical tools to question and trace the paths through which oppression, discrimination, creativity, and endurance become embodied in everyday life (Biehl, 2005; Desjarlais, 1997; Jackson, 1996, 2013; Mattingly, 1998, 2013; Paterson & Hughes, 1999; Ram & Houston, 2015). These studies have contributed to debunking the idea

that a phenomenological analysis is apolitical. On the contrary, Jackson emphasizes that a creative anthropological engagement with critical phenomenology and the ethics of difference helps us enrich our knowledge of “how people encounter, suffer, imagine, and negotiate their particular circumstances” (Ram & Houston, 2015, p. 293).

Thus, critical phenomenology offers a mode of inquiry to disable the concept of crisis that political discourses endow on mental health. A crisis calls for action, so it has political appeal. Etymologically, from the Greek *krisis*, crisis refers to a turning point or a moment of pronouncement. It changes perception; it alters the weight of and needs for living. Crisis falls out of the everyday (Giordano, 2020; Mattingly, 2022; Zigon & Throop, 2022). A crisis is when the ground called ordinary life breaks so that it no longer functions as a background but becomes the landscape (Weiss, 2008).

However, what happens when a crisis becomes ordinary, when there is no binary between ordinary times and times of crisis? What happens when only certain bodies fall within the action for what a crisis calls? What happens to the crisis of bodies without voice or power to make their ordinary crises visible? Sara Ahmed (2014) remarks how essential it is to put the “who” back into the politics of study. She reminds us repeatedly that when somebody is speaking, not everybody is speaking. Who is speaking?

Visually and hearing-impaired people in Shanghai do not possess the space or the power to speak about the crises they endure and resist daily. The global discourses on public health and the mental health crisis overlook the bodily differences of sensory-impaired people

and displace them from the political attention that mental health receives. It means that the discourse on mental health crises possesses an ableist bias that does not question the possibility of different ways to experience mental health by having different bodily conditions.

By disabling crisis, this paper makes a political statement on the need to think of crisis from other bodily perspectives. The call is for a concept of crisis that is not always available, affecting everyone similarly. Instead, we should work to understand that a rigid approach to the crisis in public health can lead to the disablement of people with physical differences who live in constant crises out of political attention. Moreover, it is essential to make the concept of crisis undertake a disabling perspective, so disabled people can participate in the definition of the policies that concern them.

In the following sections, I elaborate analysis of two moments in the lives of Yu and Mrs. Shi to better understand how visually and hearing-impaired people in Shanghai manage to live in states of constant crisis concerning their disability experience and their mental health.

On Yu: “I just want peace in my mind.”

Yu reached out to me whenever she felt distressed. She was a thirty-five-year-old Shanghainese deaf woman I met more than a year ago. Her words came suddenly, unarticulated, spilled in multiple text messages. She asked me to pray for her. She hoped for a lesser punishment.

Mao, a deaf woman and founder of an association for promoting Deaf culture, shared

Yu's mobile contact with me when I explained that I was interested in understanding mental health experiences from the perspective of people with diverse sensory experiences. Mao emphasized that Yu had to become one of my research participants. "She is what you are looking for," she said.

There is subtle complexity in how Mao determined "what I was looking for." How did Yu appear before others for Mao to see her as someone with a mental disability? The question provoked a reflection on the relationship between disabled psyches and bodies. How does someone in a disability community built around sensory impairment come to be perceived as mentally disabled by other community members? What does Yu's psyche look like for it to become disabling?

Yu and I shared a great deal since the day Mao introduced us. Most of our interactions happened over the phone via text messages. However, we also shared meals and walks around the city. For Yu, technologically mediated communication constituted a way to exist socially. She became deaf early in life and attended a school for children with hearing impairments. However, she was not fluent in sign language. She was more used to reading lips. Text messages opened up her world to communicate with virtually anyone. Technology helped her overcome ableist constrictions embedded within broader social encounters. In one of our multiple phone interactions, Yu wrote:

Are you there? I am in a bad mood. The *lingdao* [leader] is not good. Nothing has changed. He arranged a deal for my mom and me to go to hell. My mom did nothing

wrong. The biggest problem was that [my ex-husband] did something terrible, dragging my mother into hell by dragging her into the water. I have seen a lot, and I have counted. Is the country at ease? Then reassure the country that I have no life. I want to die with my mother and go to heaven, not hell. I wish my mother to go all the way to heaven and not to hell. I am not kidding. It is a fact. The *lingdao* is not good.

This message was representative of the tone and the topics around which Yu constructed her narrative. Sometimes she had better days, so she invited me to go out, eat something, and walk around. Yu felt happy to share her world. However, on the phone, she ruminated around these ideas that she experienced as facts. I argue that Mao thought Yu was “what I was looking for” precisely because she established connections between her experience and situations around and beyond her.

Yu saw the world as a messy meshwork. She experienced her life with an intimate connection to political conflicts. Yu deliberated about her divorce, making a clear association between the onset of the rupture with her ex-husband and some violent events involving England, the United States, and China. She was angry with the *lingdao* (political leader), whom she constantly substituted with *shangdi* (God).

According to her, her ex-husband’s misbehavior caused an imbalance in life, dragging her and her mother to suffering. She imagined futures in which her hell and prison appeared as immanent spaces. These spaces represented pervasive suffering and punishment. That she and her mother were in trouble because of the misconduct of her ex-husband made her angry. After

all, they were women, she said. “Why do I have to suffer only for being a woman? Why can men be free and I cannot? I want to have peace in my mind,” she said in another of our dialogues. Her words always transmitted angst and desperation.

Yu told me she had to turn to me to escape loneliness since no one else conversed with her about her feelings, fears, and anger. Through her ostensibly disparate dialogues, she helped me understand why Mao suggested she was “what I was looking for.” The deaf community did not welcome Yu’s worldview: She spoke poorly. She invoked the *lingdao* too many times. She was too angry, too heavy, too complicated. She did not make sense to others. She was too dangerous for the sake of harmony. She made trouble. However, Yu only yearned for peace. She was tired of the noise in her mind.

On Mrs. Shi: “How can I afford to live with a mental disability?”

Mrs. Shi went to the hospital to ask the doctor for sleeping pills to get some hours of rest. Usually, it was not easy to let herself relax. Especially when she had “nothing” to do, like when she went to sleep, doctors, her daughter, and others told her she was overthinking and should not ponder so many things simultaneously. They encouraged her to silence herself.

Mrs. Shi asked me how she could not “overthink.” She was a blind woman who lost her vision at 40. She was now of advanced age and lived by herself. She was not familiar with her neighbors. Her daughter and grandsons lived in another district, and her friends were not around.

Mrs. Shi needed to think ahead of everything for the next day: where she left her phone and where the clothes waited for her to put them on. Did she close the door? Did she turn off the oven? Did she put the pills in the same place so she could find them in the morning? Were the hospital documents all together in the same bag? Were those all the documents she needed? If missing a document, would Mrs. Shi waste all her time going to the hospital? Will it be easy to pick up the vegetables she bought online? Will the guard at the door allow her to get out of the gate, or will she have to walk around looking for another exit? Did she complete today's tasks? Did she send the message she had to? Did she take the sleeping pills? "How can I not think? They do not understand that I cannot see, that I must deal with all these things in my mind because I do not have my eyes to help me solve them," she told me.

It is not that visual impairment prevented Mrs. Shi from doing all she needed to do. However, she required different arrangements of time and space to move in her world. To participate in social encounters, firstly, she had to engage in mental wanderings that consumed her energy. Her eyes could not see, but the world did not stop because of it.

Talking about her everydayness, Mrs. Shi told me that adding a simple task meant increasing the number of details to which she had to pay attention. It could become grueling. "It is tiring enough to be a blind person; how can I dare talk about my distress or insomnia? How can I afford to live with a mental disability? I must adjust my mood; I must keep a good *xintai* [spirits, psychological state]."

Yu and Mrs. Shi's psychological crises were not a discreet outcome of their sensory

impairments. However, because of those impairments, their psychological states became either invisible or repellant to other members of their disability communities. Their experience, which included particular psychological states, happened within very limited scapes, representing a general phenomenon for disabled people in China.

It was not that being blind or deaf made Yu, or Mrs. Shi have these particular psychological states. While being blind and deaf, they had to deal with gendered, divorce-related, or social abandonment issues that provoked psychological distress and overlooked existential crises.

Bodies in (mental health) crisis

These vignettes show particular moments of Yu and Mrs. Shi's everydayness and my participation. For the sake of analysis, we could place these moments within the frame of a crisis to question how these situations help construct a concept of crisis that surpasses an always-already available definition. I argue that the embodiment of difference that sensory diversity conjures on Yu and Mrs. Shi allows an exploration of how crises emerge as products of political, relational, economic, and cultural constructions. Moreover, analyzing crisis through the category of disability helps turn our attention to how bodies and psyches experience a constant intersubjective and intercorporeal formation of identities.

Under the lens of a crisis, the hypothesis that stems from Yu and Mrs. Shi's experiences implies that the social environment in which their sensory-impaired bodies dwell determines how their (mental health) crises emerge and to what spaces and resources they can

expect to access. For instance, Mrs. Shi's need to think ahead of everything might show the effects of a systematic lack of social support that overloads the individual with the responsibility to "be independent." Emphasizing the importance of impairment concerning mental health does not intend to neglect the existence of social determinants that cause or worsen mental distress. On the contrary, it brings to analysis the relevance that bodily impairment exerts on how disability and mental health become intersectional elements of experience.

In September 2015, the United Nations (UN) included mental health in the Sustainable Development Goals (SDGs). This political escalation acknowledged the burden of disease of mental illness and its effects on economic development (Votruba et al., 2016). Some studies have placed mental illness as the first global burden of YLDs (years lost due to disability), pairing it with cardiovascular and circulatory diseases regarding DALYs (disability-adjusted life years). Such studies have advocated for governments to give mental health its political importance and mitigate mental illness's human, social, and economic costs (Vigo et al., 2016).

The UN discourse, which the World Health Organization (WHO) leads, capitalizes on the threat of economic stagnation. This discourse provides a solid floor to lobby for intervention resources for the global mental health crisis (Mackenzie & Kesner, 2016; Merali & Anisman, 2016; Ryan et al., 2018).

The vision of the SDGs imagines "a world with equitable and universal access to [...] health care and social protection, where physical, mental and social well-being is assured"

(Izutsu et al., 2015, p. 1052). Including mental health in the SDGs with specific goals and indicators is, without a doubt, a great leap forward to recognizing mental health as integral to what Butler called “a livable life” (2022). It is a life with the power to live in a world that fosters it.

To pose mental health within a crisis brings it back from its invisibility and moves economic and social resources toward it. However, it also produces “reductionist, economic, individualized and psychologized responses” (Mills, 2018, p. 843) to the intersections between mental health (conceived within the framework of a disability crisis) and other social issues, including disability writ large.

In China, the crisis discourse is also present. From an epidemiological perspective, the recognition rate of mental disorders is far below the global average, and the treatment rate for severe mental illnesses is 17 times lower than in high-income countries (Que et al., 2019). From a broader socio-political perspective, Jie Yang explains that “the mental health “crisis” was mainly brought about by dislocation and rapid change amidst China’s economic restructuring since the mid-1990s” (2018, p. 22).

The author argues that the government has responded to this crisis by engineering a kind of psychological therapy that works for the sake of governance. It is a psychology that makes happiness the ultimate moral aim and promotes *zheng nengliang* (positive energy) to ensure socio-political and economic objectives. The author elaborates on this engineering and says that it “is intended not only to regulate alienated and confused subjects but also to

“empower” them, making them contributors to political stability and market development” (2018, p. 22).

Mrs. Shi’s mood adjustment and keeping of a good *xintai* embody the politics of self-care and its material implications. It also speaks about the making of a good (blind) citizen. It is a blind person whose body and movements follow similar lines of behavior and aesthetics to other (disabled) people in a civilized embodiment (of disability) (Friedman, 2004). It points out another crucial political aspect of the everyday negotiation of being a disabled person. Namely, the “we” communities that emerge based on physically or sensory impaired bodies exert expectations and standards on the behavior and mindset of their members. Therefore, these groups provide spaces for disabled people to socialize but also produce anxieties. Mrs. Shi must make tremendous efforts so other blind fellows do not leave her behind. She often refers to her inability to be as good a blind person as her friends. Mrs. Shi is grateful for the community and the support she found in them. However, she is also aware of the distress that it causes her to “be at the same level” as the others. She is also cautious not to let them know she is this anxious about it.

The global focus on DALYs and the Chinese approach to psychology integrated into governance produce an intersectional marginalization of disabled people. First, for it to have political effects, mental health discourses rely on biomedical discourse and the reification of scientific language. The psyche and its somatic and psychological manifestations became a generalization equated to pathology, disorder, illness, burden, and disability so that it could play

some part in the distribution of economic and political resources. Second, the restrictive definition of the psyche as the site of mental disabilities produces a conflict of disability identities for people with physical or sensory disabilities. Since mental health became medicalized, pathologized, and individualized, having another disability label on top of a sensory disability increases the material burden for the individual: access to services, time management, time-sharing, medicines and treatments, economic resources, and social capital.

For instance, during a visit to the Shanghai Psychiatric Hospital, I asked the doctor to discuss statistics on disabled people seeking mental health services. The doctor told me that they did not keep track of patients with other than cognitive disabilities. She even showed me the admission system on her computer. The system did not provide options for assigning patients with physical or sensory disabilities. According to her, a mental illness is already a disability. Therefore, they must work with an either-or definition of health and bodily conditions. This material bureaucracy allows patients to fit within only one of the options, and options do not even exist.

When organizations and institutions strive to promote mental health as a crisis and a priority, they do so while imagining certain kinds of bodies that, once free of mental illnesses, can contribute to economic production. Thus, mental health issues disengage from bodily and social circumstances that disable people due to, for example, their sensory conditions. What are the bodies that matter for a mental health crisis to achieve recognition? If the bodies that matter are those where health manifests as productivity and functionality, where do bodies with

physical and sensory predicaments stand (sit, crawl, or roll)?

If disabled bodies correspond to broken gears of the social engine, what do we do for Yu and Mrs. Shi's everyday experience? Ableist systematic structures isolate them from spaces where their mental health can thrive. Global and local political arrangements often do not make it easy for sensory-impaired people to access, participate in, and determine the mental health care they imagine for themselves. For deaf and blind people in Shanghai, it is a luxury to talk about their mental distress and to expect mental health care.

During fieldwork, it was not easy to talk about mental health. Yu and Mrs. Shi had a strongly medicalized notion of mental states and emotions. Institutions like hospitals and disability groups have built their identities on biomedical concepts that pathologize emotional and psychological matters. For instance, Yu hated to talk about the time she went to the psychiatrist; she was a normal person, and they had no right to treat her as crazy, she said. When we went on walks with other blind fellows, Mrs. Shi did not dare to speak aloud about her exhaustion and her insomnia in front of them. They both refused the stigmatization that came from identifying themselves as having mental health concerns. Bodily, socially, and materially, they could not afford to "have" another disability.

Mental health became a burden concept so it could grasp political and economic capital. Thus, suffering and emotional distress entered the suspicious realm of the pathological, the abnormal, and the sick. Kleinman (2012), wondering about the difference between social suffering and mental health issues (or psychiatric conditions), asked what a difference this

difference makes.

Medical anthropology has pondered this very question of the limits between the normal and the abnormal. Following Kleinman's approach to difference, I argue that anthropology must focus on how different bodily and sensory conditions shape distinct ways to be-together-with others. This shaping focus corresponds to politicizing the carnal experiences of everyday life (Paterson & Hughes, 1999). This alter-politics will better inform definitions of crises and where (disabled) bodies appear within politically charged meanings of crisis. If suffering is immanent in life, we must explore not questions of normality but how ways different from ableism shape our suffering, emotions, and crises.

Associating the idea of crisis to a breakdown (Zigon & Throop, 2022), something out of the ordinary, one could say that blind and deaf people in Shanghai may experience no crisis regarding mental health concerns. However, one could say they live in constant crises that go unrecognized—Mattingly elaborated on conceptual approaches such as slow death, slow violence, or chronic crisis to speak about the paradox of a crisis that emerges and coexists with the ordinary (2022, p. 3). Yu and Mrs. Shi experienced chronic crises that conceptually and politically do not speak of them (Dyring & Wentzer, 2021).

What are the crises with which Yu lives constantly? Is it her inability to communicate her concerns? Or is it the unwillingness of others to understand her? How does a disability community improve or worsen its members' well-being? Does Mrs. Shi's insomnia fit within the concerns of mental health policies? Or is it her fault, her responsibility? What do these

women's crises look like for institutions or organizations to care about them?

Here I do not offer an answer to these questions. However, I argue that they motivate an analysis within what Ingold has called the education of attention. It is an analytical tool that centers on relationality and movement along a way of life (Ingold, 2000, p. 146). By paying attention to disability and its difference, we might learn that all we do is being-with and thinking-together-with others as part of a negotiation process to build our worlds.

To live every day as it comes

Yu and Mrs. Shi show an agentic feature of their experiences in the decisions, the choice of words, and the mechanisms they enact to continue living every day, letting every day come and go. Their silences, cries, efforts, and surrenders all built up to make ways to be in the world. However, there is also a pathic feature of their experiences, how the world acts on them. The disabled body is not an acultural passive recipient of external forces (the social, the environmental). A body-psyche experiences the world when interacting with other bodies and beings (Paterson, 2001; Paterson & Hughes, 1999). This enmeshment of agentic and pathic movements is critical to understanding how crises emerge and how some bodies live in constant predicaments that escape the political radar.

Such intersubjective enmeshment is evident in how research participants (did not) talk about mental well-being. They avoid expressing their emotions or do it only under certain circumstances where they will not expect social/community censure. Research participants conceal emotions, suffering, concerns, and bodily and *xin* (heart-mind) pains under other idioms

that shape the meaning-making of their body-psyche conditions.

For instance, they say *jiu shi nayang* (it is what it is) and *bu yao xiang tai duo* (you should not overthink). These idiomatic expressions populated our conversations and were prominent when well-being or emotional matters arose. These expressions function as a switch for energy and materialities to change direction to avoid going towards a deeper exploration of the *xin*.

Following Desjarlais (1997) and Guenther's (2022) invitation to build on critical phenomenology to knit other forms of analysis and approaches to experience, I reflect on the mundane moments that I lived with Yu and Mrs. Shi to attempt an analysis of their chronic crises. Some anthropologists have pointed out similar attitudes/strategies individuals enact to deal with crises. Their phenomenological attention focused on everydayness, significantly when it was tainted with shades of crisis and no-crisis disguised under chronicity and stillness. Desjarlais (1994) explains how mentally ill homeless people related to space and otherness while "struggling along" to survive in a world that, most of the time, seemed foreign to them.

Mattingly (2022) explains the endurance Black Americans need to "make a way out of no way" under racism, criminality, and poverty. Throop (2012) and McKearny (2021) explain how opacity in language and behavior offers an alternative path toward knowing and thinking together with others, primarily through the scapes of the mind.

Blind and deaf people in Shanghai built and dealt with mental health materialities in an opaque landscape (as opposed to a transparent one). In his afterword to *Phenomenology in*

Anthropology, Michael Jackson warned us that “there is always both continuity and discontinuity in the relationship between life as lived and life as we come to understand it” (Ram & Houston, 2015, p. 295). Ram and Houston (2015) referred to this discontinued opacity as the fundamental indeterminacy of experience. Yu and Mrs. Shi’s ways of expressing or being silent offered me a space in which I could understand them not by asking for knowledge but by knowing-with them (Mattingly, 2019b; Mattingly & Throop, 2018; Zigon & Throop, 2014).

The research participants’ “struggle along” strategy is to *guo rizi* (to live every day as it comes). “The *lingdao* should let my mother and I spend time in a quiet place and live peacefully. It is enough to live every day as it comes,” Yu once said. To *guo rizi* is an encompassing strategy of hope and action, a discontinuous process. It is to hope for a livable life and a time that is not eternal, so suffering or joy could pass (could happen). It leaves the door open to make ways out of no ways, to find peace in the middle of the noise, or to embrace dreaming when the mind is silent.

Disabling crisis

Are Yu and Mrs. Shi in crisis? What is their place in the attention politics has given to mental health’s economic and social burdens? I met Yu because the deaf community excluded her due to the apparent messiness in her head. Mrs. Shi suffered in silence the incommunicability her blindness produced on those around her. Yu and Mrs. Shi struggled to live a good life, to be a good blind person and an excellent deaf person whose biggest aim was to *guo rizi*.

Moreover, they did manage to *guo rizi*. However, it is precisely in pursuing such mundane acts that one can appreciate how responses to crises do not embrace everyone with the same effort. Because of their bodily impairments, some people struggle to make ways out of no ways and grasp some sense from the enduring task that being-in-the-world entails.

Some crises are disabling. They produce disability because of the reductions they yield on experience, the limited attention left for that which is not a crisis, and because they rely on concepts that ignore difference. Attention to experience allows for letting the unknown strike us, to become conspicuous of what individuals feel and how they come to feel and understand (Mattingly, 2019a). Letting this “unknown” immerse into the conceptualization of a crisis produces a more nuanced version of the concepts upon which we live and relate to each other.

Mental health institutions and organizations that pay attention to what blind and deaf people say about a crisis may have a better chance of designing transformative social policies. Policies impact and transform the lives of individuals who can only attempt to *guo rizi*. Disabling crises can introduce nuanced encroachments between creativity and struggle, ordinary and extraordinary conditions, and noise and silence.

A mental health crisis based on functional and productive bodies enables neglecting bodies that embody difference. It also overlooks the inalienable intercorporeality that must guide any quest for care and the imagination of a livable life. Paying attention to what Yu and Mrs. Shi feel and the social systems in which they feel it, one wonders: What crisis deserves a response? To enact a response, Mattingly, following Gadamer, explains that we must train our

gaze on “the things themselves,” which demands an openness for the other to tell us something (Mattingly, 2022).

Things themselves, like Yu and Mrs. Shi’s everydayness, tell us something about their psyche concerning their bodies, the social worlds, and the spaces of movement and thought in which they wander. In paying attention to crisis, this openness to the other beyond “us” is crucial to formulate responses of otherwise responses that will deliver and provoke transformation.

References

- Ahmed, S. (2014). *Willful subjects*. Duke University Press.
- Biehl, J. (2005). *Vita: Life in a zone of social abandonment*. University of California Press.
- Biehl, J., Good, B., & Kleinman, A. (2007). *Subjectivity: Ethnographic Investigations*.
University of California Press.
- Burch, S., & Kafer, A. (Eds.). (2010). *Deaf and Disability Studies: Interdisciplinary Perspectives*. Gallaudet University Press.
<http://ebookcentral.proquest.com/lib/ecnu/detail.action?docID=4860676>
- Butler, J. (2022). A livable life? An inhabitable world? Scheler on the tragic. *Puncta*, 5(2), 8–27.
- Cunningham-Burley, S., & Backett-Milburn, K. (2001). *Exploring the Body: Finding a Space for both the Carnal and the Political*. Palgrave Macmillan UK.
<https://doi.org/10.1057/9780230501966>
- Dauncey, S. (2020). *Disability in Contemporary China: Citizenship, Identity, and Culture*.
Cambridge University Press.
- de la Cadena, M. (2021). Not knowing: In the presence of... In *Experimenting with Ethnography: A Companion to Analysis*. Duke University Press.
- DelVecchio Good, M.-J., Hyde, S. T., Pinto, S., & Good, B. J. (Eds.). (2008). *Postcolonial Disorders*. University of California Press.
- Deshen, S. A. (1992). *Blind People: The Private and Public Life of Sightless Israelis*. State University of New York Press.

- Desjarlais, R. (1994). Struggling along: The possibilities for experience among the homeless mentally ill. *American Anthropologist*, 96(4), 886–901.
- Desjarlais, R. (1997). *Shelter Blues: Sanity and Selfhood among the Homeless*. University of Pennsylvania Press.
- Desjarlais, R. (2003). *Sensory Biographies: Lives and Deaths among Nepal's Yolmo Buddhists*. University of California Press.
- Desjarlais, R., & Throop, C. J. (2011). Phenomenological approaches in anthropology. *Annual Review of Anthropology*, 40(1), 87–102. <https://doi.org/10.1146/annurev-anthro-092010-153345>
- Dyring, R., & Wentzer, T. S. (2021). How life makes a conversation of us: Ontology, ethics, and responsive anthropology. In *Living with Concepts: Anthropology in the Grip of Reality* (pp. 50–72). Fordham University Press. <https://doi.org/10.1515/9780823294299-003>
- Friedman, S. L. (2004). Embodying civility: Civilizing processes and symbolic citizenship in southeastern. *The Journal of Asian Studies*, 63(3), 687–718.
- Friedner, M. (2015). *Valuing deaf worlds in urban India*. Rutgers University Press.
- Friedner, M. (2018). Beyond the social. *The Cambridge Journal of Anthropology*, 36(1). <https://doi.org/10.3167/cja.2018.360108>
- Friedner, M., & Kusters, A. (2020). Deaf anthropology. *Annual Review of Anthropology*, 49(1), 31–47. <https://doi.org/10.1146/annurev-anthro-010220-034545>
- Friedner, M., & Zoanni, T. (2018, December 17). Disability from the south: Toward a

lexicon. *Somatosphere*. <http://somatosphere.net/2018/disability-from-the-south-toward-a-lexicon.html/>

Giordano, C. (2020). Exceeding crisis. The psychic life of drawings. *Medical Anthropology Quarterly*, 34(1), Article 1. <https://doi.org/10.1111/maq.12547>

Goodley, D. (2009). Bringing the psyche back into disability studies: The case of the body with/out organs. *Journal of Literary & Cultural Disability Studies*, 3(3), 257–272. <https://doi.org/10.1353/jlc.0.0021>

Hammer, G. (2015). Ethnographies of blindness: The method of sensory knowledge: Methods for rethinking an ableist world. In *Disability and Qualitative Inquiry*. Routledge.

Hammer, G. (2019). *Blindness Through the Looking Glass: The Performance of Blindness, Gender, and the Sensory Body*. University of Michigan Press.

Ingold, T. (2000). *The Perception of the Environment: Essays on Livelihood, Dwelling and Skill*. Routledge. <https://doi.org/10.4324/9780203466025>

Izutsu, T., Tsutsumi, A., Minas, H., Thornicroft, G., Patel, V., & Ito, A. (2015). Mental health and well-being in the sustainable development goals. *The Lancet Psychiatry*, 2, 1052–1054. [https://doi.org/10.1016/S2215-0366\(15\)00457-5](https://doi.org/10.1016/S2215-0366(15)00457-5)

Jackson, M. (Ed.). (1996). *Things as they are: New directions in phenomenological anthropology*. Indiana University Press.

Jackson, M. (2011). *Life Within Limits: Well-being in a World of Want*. Duke University Press.

- Jackson, M. (2013). *Lifeworlds: Essays in existential anthropology*. The University of Chicago Press.
- Kafer, A. (2013). *Feminist, queer, crip*. Indiana University Press.
- Kleinman, A. (2012). Medical anthropology and mental health: Five questions for the next fifty years. In *Medical Anthropology at the Intersections: Histories, Activisms, and Futures* (pp. 178–196). Duke University Press.
<https://doi.org/10.1215/9780822395478>
- Kohrman, M. (2005). *Bodies of Difference: Experiences of Disability and Institutional Advocacy in the Making of Modern China*. University of California Press.
- Mackenzie, J., & Kesner, C. (2016). *Mental health funding and the SDGs: What now and who pays?* Overseas Development Institute. <http://www.sdgfund.org/mental-health-funding-and-sdgs-what-now-and-who-pays>
- Marrato, S. (2020). Intercorporeality. In *50 Concepts for a Critical Phenomenology*. Northwestern University Press.
- Mattingly, C. (1998). *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge University Press.
- Mattingly, C. (2013). Moral selves and moral scenes: Narrative experiments in everyday life. *Ethnos*, 78(3), 301–327. <https://doi.org/10.1080/00141844.2012.691523>
- Mattingly, C. (2019a). Critical phenomenology and mental health: Moral experience under extraordinary conditions. *Ethos*, 47(1), 115–125. <https://doi.org/10.1111/etho.12230>
- Mattingly, C. (2019b). Defrosting concepts, destabilizing doxa: Critical phenomenology and

- the perplexing particular. *Anthropological Theory*, 19(4), 415–439.
<https://doi.org/10.1177/1463499619828568>
- Mattingly, C. (2022). Crisis, alterity, and tradition: An anthropological contribution to critical phenomenology. *Puncta*, 5(2), 45–66.
- Mattingly, C., & Throop, C. J. (2018). The anthropology of ethics and morality. *Annual Review of Anthropology*, 47(1), 475–492. <https://doi.org/10.1146/annurev-anthro-102317-050129>
- McKearney, P. (2021). The limits of knowing other minds: Intellectual disability and the challenge of opacity. *Social Analysis*, 65(1), 1–22.
<https://doi.org/10.3167/sa.2021.650101>
- Merali, Z., & Anisman, H. (2016). Deconstructing the mental health crisis: 5 uneasy pieces. *Journal of Psychiatry & Neuroscience*, 41(4), Article 4.
<https://doi.org/10.1503/jpn.160101>
- Mills, C. (2018). From ‘invisible problem’ to global priority: The inclusion of mental health in the sustainable development goals. *Development and Change*, 49(3), 843–866.
<https://doi.org/10.1111/dech.12397>
- Nakamura, K. (2013a). *A Disability of the Soul: An Ethnography of Schizophrenia and Mental Illness in Contemporary Japan*. Cornell University Press.
- Nakamura, K. (2013b). Making sense of sensory ethnography: The sensual and the multisensory. *American Anthropologist*, 115(1), 132–135.
- Paterson, K. (2001). Disability studies and phenomenology: Finding a space for both the

carnal and the political. In *Exploring the Body*. Palgrave Macmillan.

<http://link.springer.com/10.1057/9780230501966>

Paterson, K., & Hughes, B. (1999). Disability studies and phenomenology: The carnal politics of everyday life. *Disability & Society*, 14(5), 597–610.

<https://doi.org/10.1080/09687599925966>

Pink, S. (Director). (2015, March 27). *What is Sensory Ethnography*.

https://www.youtube.com/watch?v=ON7hfORQUio&ab_channel=NCRMUK

Que, J., Lu, L., & Shi, L. (2019). Development and challenges of mental health in China.

General Psychiatry, 32(1), Article 1. <https://doi.org/10.1136/gpsych-2019-100053>

Ram, K., & Houston, C. (Eds.). (2015). *Phenomenology in anthropology: A sense of perspective*. Indiana University Press.

Ryan, G., Qureshi, O., Salaria, N., & Eaton, J. (2018). *Mental health and the 2030*

Sustainable Development Agenda: Global inaction on mental health is putting the brakes on development. London School of Hygiene & Tropical Medicine.

[https://globalmentalhealthcommission.org/wp-](https://globalmentalhealthcommission.org/wp-content/uploads/2018/10/UNGA_policy-brief_MHIN1.pdf.pdf)

[content/uploads/2018/10/UNGA_policy-brief_MHIN1.pdf.pdf](https://globalmentalhealthcommission.org/wp-content/uploads/2018/10/UNGA_policy-brief_MHIN1.pdf.pdf)

Savransky, M. (2016). *The Adventure of Relevance: An Ethics of Social Inquiry*. Palgrave

Macmillan UK. <https://doi.org/10.1057/978-1-137-57146-5>


Shakespeare, T. (2008). Disability: Suffering, social oppression, or complex predicament? In

The Contingent Nature of Life: Bioethics and Limits of Human Existence (Vol. 39).

Springer Netherlands. <https://doi.org/10.1007/978-1-4020-6764-8>

- Shakespeare, T. (2014). *Disability rights and wrongs revisited* (Second edition). Routledge, Taylor & Francis Group.
- Strathern, M. (2001). *The gender of the gift: Problems with women and problems with society in Melanesia* (3. paperback print). Univ. of California Press.
- Throop, C. J. (2012). On the Varieties of Empathic Experience: Tactility, Mental Opacity, and Pain in Yap. *Medical Anthropology Quarterly*, 26(3), 408–430.
<https://doi.org/10.1111/j.1548-1387.2012.01225.x>
- Vigo, D., Thornicroft, G., & Atun, R. (2016). Estimating the true global burden of mental illness. *The Lancet Psychiatry*, 3(2), 171–178. [https://doi.org/10.1016/S2215-0366\(15\)00505-2](https://doi.org/10.1016/S2215-0366(15)00505-2)
- Votruba, N., Thornicroft, G., & FundaMentalSDG Steering Group. (2016). Sustainable development goals and mental health: Learnings from the contribution of the FundaMentalSDG global initiative. *Global Mental Health*, 3.
<https://doi.org/10.1017/gmh.2016.20>
- Weiss, G. (2008). *Refiguring the ordinary*. Indiana University Press.
- Yang, J. (2018). *Mental Health in China: Change, Tradition, and Therapeutic Governance*. Polity Press.
https://www.researchgate.net/publication/321715166_Mental_Health_in_China_Change_Tradition_and_Therapeutic_Governance
- Zigon, J., & Throop, C. J. (2014). Moral Experience: Introduction. *Ethos*, 42(1), 1–15.
<https://doi.org/10.1111/etho.12035>

Zigon, J., & Throop, C. J. (2022). Introduction to the special issue. *Puncta*, 5(2), 1–7.

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