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Editorial

Editorial: Special Issue on China and Disability

Dr. Luanjiao Hu[1]

Dr. Fengming Cui[2]

[1] Lurie Institute for Disability Policy, Brandeis University

[2] Harvard Law School Project on Disability, Harvard University

The publication of this special issue of *Review of Disability Studies: An International Journal* on China and Disability comes at a time when this field is facing three realities in relation to China. First, there has been change and advancement not only in disability rights awareness raising, but also in disability policy and practice on the ground. Second, it is increasingly important to explore how these developments influence the lives of people with disabilities and society. Third, there is a need to promote idea exchange, understanding, and engagement between China and other parts of the world on disability studies and its implications. With these views in mind, we offer the articles included in this issue to our readers.

Disability continues to be a strongly stigmatized trait and identity in Chinese society. It has been dominantly treated as a medical issue to be fixed to become so-called "normal" or an individual tragedy to be pitied. Changes have taken place to address attitudinal issues. However, a dilemma between disability rights advocates' fight against the negative clinical connotation of the Chinese term of disability and slow popular acceptance of requested change persists. Non-disabled people in Chinese language are referred to as "健全人" or "正

常/普通人”, which literally translates to “healthy and wholesome people” or “regular/normal people”, while disabled people are commonly referred to as “残疾人,” meaning “disabled and diseased people.” Such views and language use, engrained in system construction and service delivery, have created barriers to people with disabilities in multifaced realms, including education, employment, healthcare, housing, epidemic and emergency responses, legal justice, right to parenthood, etc. Disabled people with additional marginalized identities (e.g., women, sexual minorities, rural residents) experience multiple discrimination in their lives. For more than a decade, those in the disability community and their allies have been addressing this problem through pursuing a shift to a social and human rights model of disabilities.

Meanwhile, there has been a more dynamic process of disability law and policy development at home in China in the past 15 years or so since the United Nations Convention on the Rights of Persons with Disabilities went into force in China in September 2008. The most recent example is the Law on the Construction of a Barrier-Free Environment, effective September 1, 2023. A daunting task of persons with disabilities and their representative organizations and their allies is to make concerted efforts to contribute to the effective implementation of such laws for valued outcomes and equal participation of persons with disabilities.

Social and cultural changes for disability inclusion take a winding and prolonged journey. It is even more challenging for the general public to understand that segregation and exclusion affect the whole society with long-lasting consequences. As disability rights movement participants, observers, and scholars with disabilities born and reared in China, the guest editors are deeply aware of the lived experiences and concerns of persons with disabilities and their families. We are keen to join such efforts, and, through this platform and opportunity, promote a fuller understanding of the complexities of disability issues in China and expand the thinking and potential actions of readers regarding roles they may play in times of change.

This issue is one small piece in the larger collective efforts to advance disability rights and justice globally. Utilizing different research methodologies, the articles in this special issue delve into multiple topics of disability issues in China, from inclusive education, community living, disability embodied experience, to disability history and more. We hope this collection will shed light on multiple issues concerning disability and people affected by disability in China, and moreover spark meaningful conversations about disability rights within and beyond China. Brief overviews of the articles in this special issue follow.

Xu et al. uses a participatory action research approach to examine barriers faced by Chinese people with disabilities and seniors during the COVID-19 pandemic, especially their participation in and access to healthcare, employment, and community living. Twenty-two members with lived experiences actively participated in the process of a priority mapping focus group and presented their action results at a town hall meeting. Another article by Xiong et al. adopts an intersectional focus on disability and gender and provides a timely examination of the media representation of Chinese women with disabilities during the COVID-19 pandemic.

From a legal perspective, Huang's article examines the key elements of "community" that empower persons with disabilities to live and participate and be included in community. Huang provides a critical evaluation of the "community residence/placement" of persons with disabilities in China and points out the distance from actual personal independence, autonomy, and community inclusiveness. Jin, a lawyer with blindness in China, critically analyzes multiple layers of discrimination people with disabilities experience in China and proposes a series of legislative recommendations for lawmakers and policymakers. Based on insightful observations, Jin also advocates for the urgency to empower people with disabilities so they may safeguard their own rights.

Cai et al. uses a case study method to examine the experience of college students with visual impairments in China, especially the barriers they face in higher education. The article offers a much-needed synthesis of the trajectory of higher education for people with visual impairments, filling an important gap in the disability studies and disability history in China. It unravels the systematic barriers that students with visual impairments face in college, from independent living, academics engagement and pursuit, to full inclusion in extracurricular life and activities. An article by McCabe et al. also examines inclusive education issues, especially the gap between policy and practice. Their study analyzes how eleven Chinese parents experienced inclusive education opportunities for their children with autism spectrum disorder (ASD) and other developmental disabilities.

Shi et al.'s article examines the past, present, and future of the hukou system and its impact on Chinese migrant workers' social mobility especially those with disabilities in the labor market. Hukou system in China is not only a household registration system and a means of evaluating migratory patterns, but also a signifier of social status and identity, as well as a determinant of access to employment opportunities and social mobility. Based on evidence from qualitative interviews, the article suggests that the system confers additional disadvantages on disabled people.

Two articles in this issue provide important accounts of China's disability history. Analyzing official disability magazines, Di argues that China's disability mass organization in the 1980s curated deliberate space for persons with disabilities to publicly express grievances, among which labor and employment were central concerns. This history shows that intensified bureaucratization marginalized persons with disabilities within the very institution that was meant to serve them. Based on historical literature and archive on Chinese Deaf Community, Wan’s article provides an original historical review of the emergence of deaf education in late-imperial and Republican China and its role in the later formation of a cross-class deaf community in the 1930s during the war crisis.

Two other articles in this issue explore caregivers/parents’ experiences and perspectives. Wu’s article describes a mix-method study examining how caregivers of children with disabilities from two different regions in mainland China experience rehabilitation services. The study reveals noticeable differences between two regions regarding participants’ perceptions of rehabilitation and the impact of regional, cultural, and social economic factors. It organizes the findings of caregivers’ experiences in five themes: being different, feeling vulnerable, being resilient, valuing kindness and support, and accepting disability. Article by Hui et al. analyzes qualitative interviews of sixteen parents of children with autism. Using Bourdieu’s Social Capital framework, the authors provide insights into how “guanxi” works in parents’ efforts in getting their children with autism into regular schools in China. Findings of the study suggest that a parent’s use of social capital surpasses explicit national policies as an effective strategy for garnering adequate services for their children.

Quesada’s piece follows a critical phenomenological approach to analyze and interpret the experience of people with visual and hearing disabilities based on over a year of ethnographic fieldwork in Shanghai. Through close examination and analysis of two individual cases, the article proposes a carnal politics of disability as an alternative to the social model to understand how disabled people’s experience could contribute to rethinking the conceptualization of mental health crisis and more.

We want to conclude by expressing our warm appreciation and deep gratitude to Mengxi Cai, currently seven and half years old, who contributes her painting to us for the cover of this special issue. She is the daughter of Cong Cai and Jia Xiao, both with visual impairments and widely recognized disability rights leaders and advocates in China and beyond. Her painting's colorful and dancing figures with disabilities, the subjects of their own rights, forming the Chinese character of disability “残”, make a present, organic and genuine statement of disability in her eyes based on her lived experience with visually impaired parents. It is a future worth striving for.

A Participatory Action Research Project with People with Disabilities and Seniors in China During the COVID-19 Pandemic

Yue Xu[1], Luanjiao Hu[2], Chengqing Shen[3], and Jiani Guo[4]
[1]Department of Health Sciences Education, University of Illinois College of Medicine Rockford
[2]The Lurie Institute for Disability Policy, Brandeis University
[3]Executive Director, Minority Voice, Self-Advocate
[4]Media Manager, Minority Voice, Self-Advocate

Author Note

Yue Xu, PhD, MSW**,** is a clinical assistant professor at the Department of Health Sciences Education, University of Illinois College of Medicine Rockford.

Luanjiao Hu, PhD, is a postdoctoral research associate at The Lurie Institute for Disability Policy, Brandeis University.

Chengqing Shen, BS**,** is executive director at Minority Voice and a self-advocate.

Jiani Guo is media manager at Minority Voice and a self-advocate.

Abstract

We used a participatory action research approach to examine the barriers faced by people with disabilities and seniors during the COVID-19 pandemic. Twenty-two members with lived experiences actively participated in the process of a priority mapping focus group and presented their action results at a town hall meeting.

Keywords: China, people with disabilities, participatory action research

A Participatory Action Research Project with People with Disabilities and Seniors in China During the COVID-19 Pandemic

The COVID-19 pandemic has directly influenced billions of people's lives around the globe. A few major aspects of life, such as healthcare, employment, and community living, have changed due to the lockdowns and the social and economic consequences of the pandemic. People with disabilities are more severely impacted during natural disasters and public health emergencies such as the COVID-19 pandemic (Tate et al., 2015; Jonkman et al., 2009). The COVID-19 Disability Rights Monitor's project was conducted in over 100 countries to evaluate the impacts of the COVID-19 pandemic on disability rights (Brennan, 2020). The main findings revealed appalling denial of access to medication and essential healthcare and the lack of measures to protect vulnerable subgroups among people with disabilities, such as children with disabilities (Brennan, 2020). However, the Disability Rights Monitor project did not collect data in mainland China. Our study fills the gap in examining the impact of the COVID-19 pandemic on people with disabilities in their participation in and access to healthcare, employment, and community living in China.

The COVID-19 pandemic started in China's Wuhan province. Since the inception of the outbreak, China's COVID-19 policies have evolved with a strong focus on containment and strict measures to control the spread of the virus. On January 23rd 2020, the Chinese government issued a city-wide lockdown on Wuhan, suspending all public transportation and closing all public spaces. Within the same month, a few major cities of Hubei province surrounding Wuhan was also locked down. The lockdown in Wuhan continued until April 2020. Later a few major cities like Shanghai, Chengdu, and Beijing experienced strict lockdowns as the virus continued to mutate and spread in China. Schools, businesses, and public transportation systems were heavily impacted during these lockdowns. As a result, many aspects of people's life including, community living, access to healthcare, childcare and education, and employment, were heavily impacted. The pandemic disproportionally impacted people with disabilities. To investigate the different aspects of impact, such as health, community living, and economic consequences, the research team convened a meeting with Minority Voice's leadership, a disabled people's organization specializing in online peer community building, to determine which aspects to include in the research project. Three major areas of life were identified as most impacted by the pandemic: healthcare; community living; and employment,

Disaster Preparedness for People with Disabilities

China is located in one of the most disaster-prone regions of the world: the Asia Pacific Region (United Nations Office for the Coordination of Humanitarian Affairs, 2017). Although most countries in the region have established disaster response systems, people with disabilities are among the most vulnerable populations during major disasters such as the 2004 Indian Ocean Earthquake and Tsunami and the 2008 Wenchuan Earthquake in China (International Society of Red Cross and Red Crescent Society, 2007; Phoenix TV, 2013). As a response, non-governmental organizations, including disabled people's organizations, took the initiative to advocate for the inclusion of people with disabilities in disaster preparedness. For example, after the 2004 Indian Ocean Earthquake and Tsunami, Handicap International (renamed as Humanity and Inclusion), an NGO, advocated for the inclusion of people with disabilities in the reconstruction process, developed capacity-building projects such as community-based rehabilitation training for social workers with the participation of local disabled people's organizations (Handicap International, 2005). However, Priestly and Hemingway's (2006) case study on post-disaster reconstruction for people with disabilities argued that the engagement of disabled people's organizations was not prioritized in the reconstruction process.

The lack of including and prioritizing people with disabilities voices in emergency response and preparedness is also reflected in the COVID-19 pandemic more than a decade later. There are similarities in how the pandemic and natural disasters like tsunamis and earthquakes impact people with disabilities. However, one cannot overlook the differences, such as the lengths of the pandemic, how the COVID-19 virus impacted the health of people with disabilities and their access to care, and the significant economic impact on their economic stability. Therefore, in the current study, we highlight the experiences of people with disabilities during the first six months of the COVID-19 pandemic in China with an emphasis on healthcare, community living, and employment.

Healthcare and Emergency Preparedness

Access to healthcare is critical for both people with disabilities and senior citizens, even at times without disastrous events such as COVID-19. Recent studies have shown that senior citizens and others with disabilities make low use of healthcare services in China (Guo et al., 2016; Zhang et al., 2017). The under-utilization of healthcare services among these two groups can be attributed to the lack of features promoting access, such as height-adjustable examination tables, scales with handrails for people with physical disabilities, a lack of sign-language interpreters for those who are deaf or hard of hearing, to name but a few. Although we did not find any studies on the 'reasonable accommodation' of people with disabilities and senior citizens during disasters and pandemics, given the low utilization of healthcare in general, one could argue that these two groups are exceptionally vulnerable during pandemics like the COVID-19 when it comes to accessing healthcare. An in-depth needs assessment may uncover more first-hand experiences with the healthcare system by people with disabilities and senior citizens. Moreover, their first-hand experiences will further guide future practices to serve them better during emergencies and be able to reach them to prevent tragedies and unnecessary mortality.

Community Living and Emergency Preparedness

Community living involves individuals' day-to-day activities in the neighborhood they live in. The COVID-19 pandemic has shown how important community leaders and frontline social workers are in preventing the spread of the coronavirus. How many people with disabilities live in the community, institutions, or nursing homes in China is unknown. However, what is known is that community-based organizations and practitioners tend to be ill-equipped to serve people with disabilities. In their reflections on an online disability volunteer network that is combating COVID-19 in China, Xu and Han pointed out the critical nature of the efforts of community leaders and social workers to communicate with people with disabilities, despite not being well-trained in supporting them (Xu & Han, 2021). Current literature on emergency preparedness often lists neighbors as a critical element in any emergency plan. In a survey of disaster preparedness among people with mobility impairments, Rooney and White (2007) found that neighbors, friends, and family often form spontaneous networks that assist people with mobility impairments in the US. However, such spontaneous local community responses during an emergency may be difficult to carry out in many communities in China due to the lack of buildings accessible to people with disabilities. For example, if a person who uses a wheelchair lives in a condo on the fifth floor without an elevator, even when family and friends are available to assist with evacuation during an emergency, it probably would take too long to evacuate safely.

Community living for senior citizens is equally important. Many senior citizens rely on their communities for day-to-day social activities. For example, a survey of 1992 senior university students revealed that, during COVID-19, the lack of senior university activities in their community affected their ability to participate in the latter and that they would prefer in-person learning to remote learning (Wan, 2020). Such an impact on community participation for people with disabilities and senior citizens could lead to negative mental health outcomes. For example, during the lockdown in Hubei province, social workers provided mental health support to people with disabilities through online social media platforms (Liu, 2020). However, such virtual support in mental health may not be viable for senior citizens who lack internet literacy and accessibility (Chen, 2020). Therefore, it is important to look back and evaluate how stakeholders, policymakers, and community workers can improve their assistance in community participation during a public health emergency like the COVID-19 pandemic in the future.

Employment and Emergency Preparedness

Employment is another important sector in the lives of people with disabilities. More than nine million people with disabilities are employed in China (People's Daily人民日报, 2018). However, little is known about whether sufficient accommodation and emergency planning are geared toward employees with disabilities in China. The COVID-19 pandemic has drastically impacted the global economy, especially in increasing unemployment due to business closures (International Labor Organization, 2020). To the best of our knowledge, there is no nationwide relief fund in China to buffer the economic impact of the lockdown. Although the exact number of people with disabilities who lost jobs is unknown, we do know that they tend to be employed in the service sector (Shi & Wang, 2013). A significant number of people with disabilities held jobs like giving massages and providing online or traditional customer services by telephone. Since the service sector has been impacted severely by

COVID-19 (Kochhar & Barroso, 2020), there is reason to believe that the pandemic has disproportionately affected the employment of many people with disabilities. With an in-depth needs assessment and a better understanding of the experiences of those with disabilities with employment or unemployment during COVID-19, we can help frame future emergency preparedness policies related to employment for this marginalized population.

Research Questions

Our literature review revealed a lack of documented first-person experience dealing with an emergency from the perspectives of people with disabilities and senior citizens and how these experiences inform policy and practice. The present study, therefore, attempts to contribute to the literature on emergency management for vulnerable populations by adopting a participatory action research (PAR) approach and conducting a needs assessment to inform policy and practice. Accordingly, we ask the following research questions:

1. How did people with disabilities (PWD) and senior citizens access information at the beginning of the COVID-19 pandemic?
2. What were PWDs' and senior citizens' experiences of preventative and protective measures during the pandemic?
3. How did the pandemic affect PWDs' and senior citizens' activities concerning their day-to-day lives, employment, and access to healthcare?
4. What were some of the urgent unmet needs of PWDs and senior citizens during the pandemic?
5. How should these experiences, set out in the four questions above, guide future policy and practice in emergency preparedness for PWD and senior citizens?

Methods

Participatory Action Research

Participatory Action Research (PAR) is a community-based practical research method challenging traditional research approaches that exclude marginalized populations from participating in research projects. PAR assumes that people from marginalized groups can fully engage in the research process themselves, thus centering their voices and priorities (Nelson et al., 1998; Baum et al., 2006). The fact that people from under-represented groups participate and lead research efforts under the PAR paradigm aligns well with the international disability rights slogan, "Nothing About Us Without Us" (Charlton, 1998). Furthermore, this research method effectively answers our research questions since authentic lived experiences should be integrated into an in-depth needs assessment to further inform policy and practice on emergency preparedness for PWDs and senior citizens.

Project Context and Procedures

This article presents the initial findings and key action items that emerged from a PAR project undertaken by a researcher from the University (university name omitted for peer review) and Minority Voice, a grassroots disabled person's organization (DPO) in China. Minority Voice is one of the largest online disability communities, serving a thousand members with disabilities. In February 2020, as the COVID-19 pandemic spread through China, leaders of Minority Voice participated in an online volunteer network supporting those with disabilities who were in need. Seeking a better understanding of the needs and priorities of people with disabilities and senior citizens, the leadership of Minority Voice met with the researcher to discuss a research partnership.

Data were collected through three main methods: 1) a focus group with action team members reflecting on their experiences during the lockdown caused by the pandemic and identifying issues and concerns related to their experiences; 2) designing a questionnaire based on the priorities mapped out in the focus group to collect quantitative data; and 3) the reflections of volunteers and the research team while providing support to the action team members.

Participants

PAR Team Members

Minority Voice identified 22 participatory action team members. For seniors, we used age 55 as the cut-off point for senior citizens since 54 is the average age for retirement in China (BBC, 2015). Half of the PAR members were seniors, while the other half consisted of younger individuals with disabilities (between 18 and 54 years old). Among PAR members who are seniors, only two do not live with any disability.

Action team members were recruited from Minority Voice's online community, and the snowball sampling method was used for senior citizens. The selection criteria included: 1) lived experiences with a disability or being a senior citizen; 2) demonstrated leadership in the community or willingness to connect with others in the disability and senior community; and 3) a commitment to complete the research project as an active research member. Table 1 describes the characteristics of the action team's members.

Table 1. PAR Team Member Characteristics

Demographic Characteristics	N (%)
Gender	
Male	12 (54.5)

Female	10 (45.5)
Age	
18-29	8 (36.4)
30-54	4 (18.2)
55-70	10 (45.5)
Disability Type	
Senior without disability	2 (4.5)
Physical Disability	14 (63.6)
Deaf or Hearing Impairment	3 (13.6)
Visual Impairment	2 (9.1)
Autism Spectrum Disorder/ ADHD	1 (4.5)

Questionnaire Participants

There were 223 questionnaire participants. The majority of the questionnaire participants identified as women (55.2%). Among questionnaire participants, over one-third (36.3%) were employed, about a quarter (23.8%) retired, and close to a quarter were looking for jobs (22.4%). There were also a small number of students (7.6%) and people who were not actively seeking work (9.9%). Most (70.4%) of the questionnaire participants were people with disabilities under 55. Approximately one-fifth (21.8%) were senior citizens (55 and above) without disabilities. There were also a few seniors with disabilities (8.5%).

Data Collection and Analysis Methods

Priority Mapping Focus Group

After recruiting PAR team members, we set up a priority mapping focus group online via video conferencing to provide a forum for stakeholders to engage in a dialogue, develop collective testimonies, and brainstorm ways to make changes (Kamberelis and Dimitriadis, 2005). All PAR members participated in this meeting to discuss their experiences during COVID-19 and its impact on the three aspects of their life: healthcare, community living, and employment. The focus-group questions were developed based on input from Minority Voice's leaders, who are themselves, people with disabilities who had volunteered for the disability volunteer network during the lockdown.

Our priority-mapping exercise draws its methodological guidelines from Mitton et al.'s work (2003) on priority-setting frameworks. After an in-depth discussion of each topic, volunteers summarized the key points mentioned on that one topic and let all the members vote for the three priorities using the following criteria: 1) I believe this is a critical issue for future pandemics and emergency preparedness for people with disabilities in China; 2) I believe changes can be made through concrete actions regarding this issue; and 3) changes in this issue may result in a significant positive impact in my life moving forward to be better prepared. After all the participants had selected their top three issues within each topic area, the focus-group facilitator then announced the three that won the most votes.

The audio recording of the priority-mapping focus group was transcribed, de-identified, and coded independently by two coders using content analysis (Bengtsson et al., 2016). The two coders then met to discuss commonalities and differences with each other's coding. Any disagreements were discussed to reach a consensus. Key themes were identified through the analysis process.

Questionnaire

We developed a questionnaire based on the results of the focus group discussion to examine if the findings from the focus group see wider trends outside our PAR group. We identified issues specific to people with disabilities and senior citizens during the lockdown under the three main topics. Once we developed the questionnaire's initial draft, we sent a copy to PAR members for comments and editing. The final version of the questionnaire was launched on September 23rd 2020 on LingXi360.com, a Chinese questionnaire management platform. We concluded this phase of data collection on October 3rd 2020. Appendix A shows a copy of the questionnaire translated into English.

Questionnaire data were extracted to calculate descriptive statistics for multiple-choice questions, i.e., the number and percentage of people who selected each option.

Town Hall Meeting

After the priority-mapping focus group, PAR team members divided themselves into three groups for the three topics: healthcare, employment, and community living. The top three issues voted under each topic during the focus group were then provided as a starting point for each sub-group to embark on their activities. Each group used different ways to brainstorm decisions regarding the materials, information, and testimonies it chose to include in its presentation for the town hall meeting. Stakeholders such as researchers, non-profit organizations, media, and public audiences were invited to the meeting, in which forty-one people participated. A recording of the meeting can be accessed on Minority Voice's public blog to amplify the reach and impact of the PAR team's actions.

Reflections

After the conclusion of the PAR project, the research team, including Minority Voice's leaders and four volunteers who provided support to each subgroup, reflected on their experiences on how the PAR project affected themselves, and on critical incidents during the project. All research members and two of the four volunteers identified as people with disabilities. The research and support team's reflections provided insights on improving support to PAR team members from marginalized and low-resource communities. The reflections were analyzed using content analysis (Bengtsson et al., 2016).

Results

We present the results of the PAR project in two main sections: research results and action results. Research results include themes that came up during the priority-mapping focus group and from the questionnaire analysis. Here we only present the barriers identified by questionnaire participants to evaluate whether the priority mapping focus group findings are generalizable. We present a more comprehensive list of barriers identified by questionnaire participants in Appendix B. Action results involve actions taken through this process and the reflections of the volunteers and the research team.

Research Results

Healthcare Barriers

The COVID-19 pandemic disrupted previously existing services and care for people with disabilities, exposing the absence of a continuous and resilient service model in China's healthcare service system. Access to medication for chronic conditions such as hypertension, diabetes, and high cholesterol levels was identified as one of the most pressing issues. One PAR member, a senior with a physical disability, reported that her relatives from Wuhan, who had visited her in Guangdong province, could not travel back home. For three months, eleven people lived in her condo, many of them seniors, needing medications for their chronic conditions. Some of them ran out of medications before they were released from the quarantine. Another PAR member, also a senior with a disability, had to discontinue her cholesterol control medication for nearly half a month. When asked if discontinuing her medication had had any impact on her health, she said, "Yes. I felt dizzy". This also happened to seniors with urgent healthcare needs other than COVID-19. One PAR member with Parkinson's disease was unable to receive the surgical treatment prescribed by her doctor. She was supposed to go to the hospital for treatment right after the Chinese New Year. However, due to COVID-19 and the quarantine policy, she had to postpone her treatment, and her condition worsened.

Another common barrier faced by people with disabilities and seniors is receiving information on the pandemic. Technology played a significant role in the control of the COVID-19 pandemic. However, the digital divide between seniors and younger generations, as well as the lack of accessibility features in the case of some technologies, made it challenging for people with disabilities and seniors to access up-to-date information about the pandemic. One team member, a senior without a disability who lives in a senior community, stated that many seniors in her community did not know how to use WeChat, a messenger app. Consequently, "they are not getting information through this way at all". Receiving information at the beginning of the pandemic was critical in ensuring that everyone could take action to protect themselves. However, many people with disabilities did not receive information promptly due to the lack of consideration given to accessibility. One deaf PAR member who was in Wuhan during the lockdown stated that many deaf people there were not aware of the pandemic in the beginning because the TV news did not have sign-language interpreters. Another member with a hearing impairment pointed out that, although doctors usually wear a mask during appointments, this was difficult for people who read lips. It became even more challenging to communicate with doctors now that they are more covered up in all Personal Protective Equipment (PPE). Questionnaire results also reflected the barriers to accessing PPE timely (47% of participants reported this barrier). Other concerns brought up by questionnaire participants included deteriorating mental health due to the lockdown and the lack of accessible features on public transportation to make people using a wheelchair or other assistive technology feel safe during the pandemic.

Community Living Barriers

One of the community-living barriers identified by both members with disabilities and seniors was the lack of flexibility and accessibility awareness in the execution of community lockdowns. Before the lockdown, packages were delivered to people's doorsteps. However, to help contact tracing and management, many communities only allow delivery drivers to leave packages at the entrances to neighborhoods or in a designated facility. As a result, picking up packages became a challenge for many people with disabilities and seniors. One member, a senior without a disability, lives in a larger community from which she had to walk three miles to retrieve her packages from the neighborhood entrance. Similarly, 55% of the questionnaire participants also reported difficulty getting their packages due to the lockdown. Another challenge imposed by the lack of flexible quarantine management is that many communities closed their entrances apart from just one left for people to go in and out of their neighborhoods. Without disability accessibility awareness, many communities closed their wheelchair-accessible entrances. One PAR member, a wheelchair user, had to move back to his parents' home during the lockdown. However, as the community also closed the elevator exit to the parking lot, he had to be carried by his parents down the stairs from the second floor. Similarly, one deaf member lived in a community where people were only allowed to get groceries through an organized group effort to reduce the risk of leaving their homes. These grocery trips were announced through loudspeakers instead of by text messages or WeChat, and she could not hear any of those announcements.

Social isolation and the stress caused by isolation is another commonly identified barrier. For people with disabilities, disability community gatherings and activities were all canceled due to the lockdown. One member from Shanghai, a senior with a disability, reported that the disability community used to get together to sing and play music, but it was all canceled. Another senior with disabilities, who was single, said he felt isolated during the lockdown since he could not participate in the social clubs and volunteer activities as he usually would. Similarly, in the case of seniors without disabilities, one retired member stated that since all the community activities for seniors had been canceled, she could no longer see her friends. In addition, she had to provide childcare for her grandchildren, as her son, daughter-in-law and grandchild had all moved back in with her. The lack of social activities and the additional childcare burden made her feel socially isolated and stressed. Social isolation is also one of the top community living barriers identified by questionnaire participants (31%).

One critical barrier for people with severe disabilities is the discontinuation of personal assistant (PA) services. In China, the government pays organizations to provide a PA for people with disabilities. PAs are usually not family caregivers, and at each visit, there might be a new PA attending the same person. One of our members with severe disabilities lives alone and is heavily dependent on PA services. However, all PA services were shut down to enforce social distancing and prevent the virus from spreading. He did not have PA services for nearly a month.

Employment Barriers

The economic impact of the pandemic extends to unemployment and challenges with online job interviews. One issue commonly identified by working-age people with disabilities is the detrimental consequences the pandemic has on people in the service sector, which employs many people with disabilities. In China, people with a visual impairment or who are legally classed as blind tend to be employed in the massage industry. Special schools are dedicated to training blind massage therapists. According to a recent quantitative study of the needs of people with disabilities, close to 90% of those with visual impairments reported that their incomes had fallen during the lockdown (Li & Cai, 2020). The percentage of participants with other disabilities who reported a reduction in income ranges from 44% (hearing impairment) to 69% (intellectual disability). This disproportionate financial impact may be due to the cluster of employment in the massage industry. One blind member is a massage therapist, but he has had to stop working for a long time since the work he does is considered high-risk. Similarly, approximately half (50.1%) of the questionnaire participants also identified financial challenges and the lack of government relief funds as a barrier. Another member with a physical disability is a street vendor. Street vendors have been highly regulated in the past decade, but due to the economic downturn caused by the pandemic, China has started to allow people to sell merchandise on the streets without a license or other official approval. However, this has opened up competition for many people with disabilities. One of our members, who is a wheelchair user, was threatened by a non-disabled man competing with him for the spot he had selling toys in a park.

Another barrier to those seeking employment is the lack of accessibility awareness of employers moving work and job interviews online. One member with a hearing impairment works as an IT tester. Due to the pandemic, he had to work remotely. Meetings held remotely rely heavily on hearing. He was unable to communicate with his co-workers efficiently with these communication barriers in place. Another member with physical disabilities was seeking another job during the pandemic. Since all interviews were moved online, he could not visit the company's premises to check its accessibility features.

Action Results

Town Hall Meeting

After the PAR team had prioritized issues and selected which topic they would like to take action on, each subgroup formed a WeChat chat group to discuss how to do so. The employment and community living groups chose to do a PowerPoint presentation, and the healthcare group wrote a letter addressing policymakers and other stakeholders. Each group was assigned a volunteer to help conduct literature or policy searches based on the direction of the group's discussion. For example, the community living group discussed how seniors without access to IT would call grocery-store owners to deliver groceries instead of shopping through online platforms. Another group member suggested that resourceful people in the community, such as grocery store owners, should get together and offer more help during a crisis. The research team and volunteers then provided examples of community coalitions in the United States where social workers, police officers, school principals, researchers, and teenagers discuss issues related to teenage violence and plan actions together. The subgroup then brainstormed to identify important stakeholders to include in a coalition for the rights of people with disabilities and seniors in a community.

As each group gathered resources and put together its action item, the research team collected questionnaire data and shared the preliminary results based on each subgroup's topic area so that each team could draw data related to its topic. As they prepare for their final actions, the quantitative data provide references on perceptions of the identified issues by the larger community outside our action teams. Minority Voice leaders invited researchers from Hong Kong University, Zhejiang Normal University, and the Chinese University of Political Science and Law. Leaders of community-based organizations such as Lion's Club, Co-

Founder of One Plus One, a DPO, and Sprout Disability Association were also contacted/invited. We also invited one blind self-advocate who pushed for accommodation for China's college entrance exam and a journalist from a medical media group. Other stakeholders who could not attend the live town hall meeting included a people's representative, an associate professor of law from Wuhan University, and an assistant professor of business from the Central University of Finance and Economics. Stakeholders provided feedback and comments during the live town hall meeting. Those unable to attend the live meeting watched the recordings and provided comments.

The town hall meeting was held online via Zoom. Using technology was initially challenging for some PAR members. However, with practice (priority-mapping focus group and two other testing exercises), all the members could present their action items to stakeholders. The de-redacted recording was de-redacted to protect the privacy of PAR members. After the redaction, we publicized the recording on Minority Voice's media platforms. Table 2 showcases some of the proposed action items from each group.

Table 2. Proposed Ideas for Future Policy and Practice

Topic	**Summary of Proposed Ideas**
Healthcare	1. Community clinics can divert the pressure from hospitals for chronic condition management and prescriptions. Building accessible and community-oriented clinics can help maintain care when hospitals face challenges during a pandemic. Community clinics should maintain an emergency supply of medication and first aid to help buffer the effects of medication shortages. 2. Be aware of the access needs of people with disabilities. For example, provide extra PPE for those who need to sanitize their wheelchairs or other assistive technology.
Community Living	1. Allow reliable delivery services to enter communities to deliver packages for people with disabilities and seniors instead of retaining all packages at the community gate. 2. Train community workers on accessibility, disability rights, and knowledge of basic emergency responses to support vulnerable people with disabilities and seniors during evacuation.

	3. Build a dataset of people with disabilities, empty-net seniors, and their special access needs, and coordinate community resources to provide precision emergency support. 4. Enact a flexible policy to ensure independent living for people with disabilities, including allowing personal assistant services to continue with clear guidelines. 5. Build a community coalition around the issue of emergency responses for people with disabilities and seniors. Key stakeholders may include social workers, people with disabilities, seniors, grocery-store owners, senior food services, community workers, and homeowner's associations.
Employment and Financial Impact	1. Issue an emergency relief fund for people with disabilities. 2. Add information about employers' accessibility infrastructure to job-listing websites. 3. Offer stable stalls for street vendors with disabilities; expand philanthropy or disability service job opportunities for people with disabilities. 4. Ensure reasonable accommodation for both online and offline employment. 5. Mandate employers to plan and practice emergency evacuation for employers with disabilities.

Research Team and Volunteer Reflection on Critical Incidents

Research team members and volunteers reflected on the process of the project after the conclusion of the town hall meeting. They declared that they had been amazed at the level of participation and how resourceful the PAR members were in sharing insightful ideas. In addition, the PAR members' lived experiences provided a rich source for proposing action ideas among people with disabilities in low-resource countries.

The two groups with the most senior members were the community living group and the healthcare group. Compared to the employment group, these two had relatively less discussion in the first ten days. The two volunteers assigned to them had a hard time facilitating the discussions. Realizing that the group members may prefer a scheduled meeting instead of online messages, the research team set up a Zoom call for the community living subgroup and a scheduled online chatting time on WeChat for the healthcare group. As these modes of communication were preferred, these two groups made progress with the two volunteers and the research team's support.

Another key point of reflection was the issue of accessibility. Our PAR members had diverse disabilities and access needs. To ensure each event's accessibility, we provided captioning for the focus group and both captioning and sign-language interpreting for the town hall meeting. Although we set aside time for testing the technology, the captioning specialist could not connect to Zoom until half an hour after the focus group started. As a result, the first half an hour was messy, with the research team trying to type everyone's speech for the captioning. Similar issues happened during the test meeting on Zoom three days before the town hall meeting. Such technical issues are often unavoidable, but with practice and having learned lessons from these two incidents, we ensured the town hall meeting got off to a smooth start.

A few critical incidents happened as the subgroups worked on their action items. For example, one member of the community living group emphasized self-advocacy during the priority-mapping focus group. However, he proposed that people with disabilities and seniors should "perform" in a way that was "rude" or "difficult to deal with" at community centers and service organizations: he thought that people working in the community would prioritize meeting his needs if he were "difficult to deal with." The research team attempted to redirect his attention by asking, "In an ideal world if you did not have to 'perform' as if you were mean or rude to get support from community and service organizations, would you still do that?" We also invited him to reflect on how someone with severe physical or social communication disabilities could "perform" and whether this kind of "performance" would be feasible and sustainable for all people with disabilities and seniors. This member may have felt challenged or offended by these questions, as he chose not to attend the town hall meeting and left the WeChat group two days before it took place.

Discussion

In this project, we set out to examine the priorities and unmet needs of people with disabilities and seniors during the COVID-19 pandemic using a participatory action research method. Twenty-two PAR members who are PWDs or Seniors embarked on a journey of seeking solutions for better emergency pandemic service and policies for PWDs and seniors.

To answer our first research question, "How did people with disabilities (PWD) and senior citizens access information at the beginning of the COVID-19 pandemic?" PAR members reported barriers in accessing information and updates on COVID-19 due to the lack of sign-language interpreting, image descriptions of maps, and the digital divide that affects seniors who are not fluent in using smartphones. Such barriers are also being faced by people with disabilities and seniors from other countries as the pandemic continues to spread worldwide. For example, in the US, the White House did not provide sign-language interpreting and was later ordered by a federal judge to do so from October 1st, 2020, following a lawsuit filed by the National Association of the Deaf (Polantz & Kelly, 2020). In India, a group of volunteers provided live sign-language interpreting on Facebook for the deaf community (Arya, 2020). The digital divide between younger generations and seniors in South Korea existed before the pandemic, but the COVID-19 pandemic has heightened the issue due to the push for contact-free industries and social distancing (Lee, 2020). Our results highlight the importance of providing timely and accessible information to people with disabilities and seniors. Promising practices from other countries worldwide may provide solutions: Paraguay, Panama, and Mexico have all adopted systems to ensure that relevant information is provided in an accessible version (UNOHCHR, 2020).

Research question two asked about people with disabilities and seniors' experiences of preventative and protective measures. PAR members and questionnaire participants brought up the issue of delayed information resulting in a lack of preparedness. Another salient issue identified by wheelchair users is the challenges they face when using public transportation during the pandemic. The fear of catching the virus and the challenges of using public transportation further prevent them from accessing services and participating in their community. On the other hand, personal protective equipment such as masks has made it challenging for people with a hearing impairment who normally rely on lip-reading and social communication. Wheelchair users often need extra time to clean their equipment after returning home from outside. However, not being provided with extra alcohol, wipes, and other hand sanitizers during the PPE shortage resulted in their further social isolation.

Research question three asked, "How did the pandemic affect PWD and senior citizens' activities of daily living, employment, and healthcare access?" We presented the top concerns of the PAR members and the barriers the questionnaire participants most frequently selected. Perhaps the most significant barrier shared by people with disabilities and seniors in these three aspects is the lack of accessibility awareness in China's emergency response. Access not only applies to people with disabilities but also affects seniors' experiences. The lack of accessibility awareness in emergency responses is reflected in every aspect we discussed. One of the common barriers for the two population groups is the complete shutdown of government-paid personal assistant services during the lockdown. This blanket prohibition of PA services heavily impacted the quality of life for people with disabilities and seniors. Promising practices in other developing countries include PA exemptions from government restrictions in Argentina (UNOHCHR, 2020).

Research question four asked about urgent unmet needs for people with disabilities and seniors during the pandemic. In addition to the discontinuation of personal assistant services, perhaps the most alarming issue was the discontinuation of medication and the problem of urgent healthcare needs going unmet. Although other vulnerable populations may experience similar barriers when accessing healthcare during the lockdown, the impact on people with disabilities is more pronounced. As mentioned in the results section, one PAR member did not receive proper treatment for her Parkinson's disease, and her body was deteriorating. Urgent unmet healthcare needs were also identified by twenty (8.9%) questionnaire participants. Although this number does not seem significant, urgent unmet healthcare needs may have serious consequences for sufferers' health, activities of daily living, and quality of life. One death is too many in this case.

Our last research question asked how the experiences of barriers and unmet needs during the COVID-19 pandemic should guide future policies and practices. The lived experiences of our PAR members provide rich testimony of future policies and practices at different levels. Among the many proposed ideas in Table 6, we highlight a few critical steps in the implications section.

Key Policy Lessons

The results of this project highlight the importance of improving disability and accessibility awareness in emergency responses and taking into consideration the digital divide facing seniors.

First responders and community service providers should be familiar with accessible evacuation routes and understand how to support people with disabilities and seniors during an emergency. In addition, information should be accessible and in plain language so that people with disabilities and seniors can receive emergency information in a timely fashion.

Second, a strengthened vocational rehabilitation system should be created that expands employment channels for people with disabilities to avoid the overwhelming impact on people with disabilities and provide an individual relief fund for those who are employed in industries that may be affected the most by the economic consequences of a pandemic, natural disasters, and other social emergencies.

Third, prior emergency planning should take place at the individual, community, and social levels to ensure the rights of people with disabilities and seniors are met. There is a pressing need to develop emergency preparedness curriculums.

Limitations

Our study demonstrates the strengths of integrating the voices of people with disabilities and seniors into the research process. Each step in our research and actions was taken with the active participation of PAR members. Despite the strengths, a few limitations should be noted.

First, although PAR members actively participated throughout our research, we did not have sufficient time for them to develop all the research questions of the study. The topical areas were also pre-selected by the research team. For a more organic process, the research questions and topics to explore should all have been developed by PAR members. Second, given our use of technology, some PAR members may not have fully participated in the process. As we pointed out in our discussion, the digital divide facing people with disabilities and seniors may prevent certain members from fully engaging in the process. In line with this limitation, although we aimed to recruit a diverse group of PAR members, we were unable to recruit anyone older than seventy. This may be due to our recruitment procedures. All recruitment happened online through WeChat. The lack of older members further reflects the issue of the digital divide. Future studies should consider a mixed recruitment method over solely recruiting online. Thirdly, although some of the volunteers have lived experiences of disability, they are not trained in PAR research, nor were they trained in any particular topical area. All the members of the research team and volunteers are in their twenties or early thirties. Without a senior citizen in our core research and volunteer team, we may not have fully considered ways of facilitating the discussions and actions for the two groups with more senior members (healthcare and community living).

The questionnaire part of the study also has a few limitations. First, we did not collect data on the socio-economic status (SES) of the questionnaire participants. Without information on SES, we are unable to perform a statistical analysis controlling SES. Second, as we ranked the issues selected by participants, we did not have any way of ranking the urgency of each issue. Although some issues may not be as prevalent, they may have had detrimental effects on a small group of individuals. A survey designed for people to choose relevant issues and rank the severity of the issue to them would help clarify the level of urgency of the different issues.

Conclusion

During the lockdown, 22 people with disabilities and seniors' lived experiences provided critical insights for future policy and practice in protecting the rights of people with disabilities and seniors. Based on the results of the priority-mapping focus group involving the PAR members, we designed an online questionnaire targeting more people from these communities to amplify our PAR members' voices about these concerns. In addition, PAR members took the initiative to gather testimonies and promising practices worldwide to put together four action items on healthcare, community living, and employment. Their presentations were well-received at a town hall meeting with stakeholders, including researchers, disability-serving community-based organizations, and the media. This study's results underscore the urgent need to build a comprehensive emergency response system in which stakeholders, service providers, and policymakers are made aware of the special needs of people with disabilities and seniors.

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Appendix A

Questionnaire Designed Based on Focus Group Results

1. I belong to the following group:
    a. People with disabilities (under 55)
    b. Seniors (55 and above, without disabilities)
    c. Seniors (55 and above, with disabilities)
2. I am
    a. Employed
    b. Not employed but seeking for jobs
    c. Not interested in looking for a job
    d. Retired
3. During the lockdown, information about the pandemic is critical. Did you run into any of the following barriers accessing information?
    a. Due to the lack of a sign language interpreter, or the lack of image description for maps, I had trouble accessing information.
    b. I do not know how to use WeChat or other technologies. I had trouble accessing information online.
    c. Due to the delay in receiving information, I was unable to purchase PPE in time.
    d. Due to the lack of information, I did not take preventative measures at the beginning of the pandemic.
    e. Healthcare workers were all covered in PPE gear, I had barriers communicating with them (e.g. reading lips).
    f. Homeowner associations announced information about grocery shopping in a way I was not able to access (solely online through WeChat, or phone calls I cannot answer).

   g. I did not have trouble accessing information.

4. Regarding my disability (such as rare disease, epilepsy), mental illness (such as bipolar disorder, schizophrenia, major depression), or chronic conditions (such as hypertension, high cholesterol, or diabetes).
   a. I was unable to purchase medication for my condition or disability.
   b. I had to discontinue medication during the lockdown.
   c. Since I was unable to get medication refills, it took a toll on my health.
   d. Due to fear and anxiety, I felt very stressed out.
   e. During the lockdown, my mental illness became worse.
   f. I had urgent healthcare needs during the lockdown that did not receive timely treatment.
   g. No impact.
5. Regarding preventative and protective measures during the pandemic, what barriers did you experience?
   a. I had to sanitize my wheelchair or other assistive technology when returning home. It took lots of time, and I needed more alcohol than others.
   b. I was afraid to hold on to poles when using public transportation.
   c. My disability heavily relies on the sense of touch; the pandemic prevented me from touching anything.
   d. None.
6. Various social services stopped during the lockdown. What impacts did it have on your life?
   a. The discontinuation of personal assistant services heavily impacted my independent living in the community.
   b. The discontinuation of rehabilitation services heavily impacted my life.

   c. I do not need any social services. No impact.

7. During the lockdown, events, social activities were canceled or moved online. What barriers did you face?
   a. My social network suddenly narrowed since work or school moved online. I felt isolated and helpless.
   b. Due to the lockdown, I was unable to attend any senior university classes or senior interest clubs, which narrowed my social network.
   c. Many social activities and connections happened online, but as a senior, I am not familiar with how to use apps and technologies to stay connected.
   d. My mental illness became worse due to the unpredictability and cancellation of all social activities and events.
   e. The reduction of social activities took a toll on my physical health.
   f. No impact.
8. During the lockdown, many families chose to stay together. Some families had multiple generations under the same roof. Family dynamics have changed drastically.
   a. My child moved back home (or I moved back to my parents' house), and fear and anxiety led to increased family conflicts.
   b. My family members did not understand my access needs during the lockdown.
   c. Dealing with my family was taxing for me, and it took a toll on my mental health.
   d. No impact.
9. Challenges with grocery shopping and delivery
   a. Packages were not delivered to my doorstep. I faced barriers picking up packages.

   b. Homeowners' associations did not know how to communicate with me or provide reasonable accommodation. I felt isolated and did not receive any help from them.
   c. Due to the discontinuation of personal assistant services, no one could help me purchase food, water and other necessities.
   d. No impact.

10. My employment was heavily impacted due to the lockdown
    a. My industry was shut down for a long time. I did not have any income.
    b. My salary was cut during the lockdown.
    c. Chinese New Year is the time when I get most of my income for the year. The lockdown heavily influenced my income this year.
    d. Due to the economic setback, I lost my job.
    e. I recently graduated from college; I had a hard time getting a job due to the economic setback.
11. Did government relief or financial support help with your financial needs?
    a. Government did not issue financial support to individuals; I can barely make ends meet.
    b. Government did not issue financial support to our industry.
    c. Government relief fund helped me make ends meet.
    d. N/A
12. Issues regarding working remotely during the lockdown
    a. The remote working platform does not work well with my screen reader.
    b. Virtual meetings did not have a sign language interpreter or captioning. I was unable to participate actively.

c. I have a visual impairment, or light sensitivity: I cannot work on my computer or other screens for prolonged periods of time.

d. N/A

Appendix B

Top Healthcare Barriers During Lockdown

Unmet Need or Barrier During Lockdown	N (%)
Due to the delay in receiving information, I was unable to purchase PPE or be prepared at the beginning of the pandemic	105 (47.09%)
Due to fear and anxiety, my mental health was not well during the lockdown	59 (26.46%)
I was unable to secure myself on public transportation when using my wheelchair or other assistive technology, since it was not safe to hold on to any public surface	59 (26.46%)
Online community grocery shopping groups were not accessible. I was not able to receive their information on grocery shopping	57 (25.56%)
I was not able to buy my medication, or I had to stop taking my medication during the lockdown	33(14.8%)
During the pandemic, healthcare workers are all covered with PPE, so I could not communicate through lip-reading.	23(10.31%)
During the pandemic, government-financed personal assistant services were stopped, which had a significant impact on my life	23(10.31%)

Top Community Living Barriers

Unmet Need or Barrier During Lockdown	N (%)
Packages were not delivered to my doorstep due to lockdown; I had difficulty getting my packages due to my age or disability	128 (55.16%)
Work or school were moved online, and I felt isolated	70 (31.39%)
Social activities were cancelled, my health is being affected by social isolation	49 (21.94%)
During the lockdown, my family members did not understand my access needs	37 (16.59%)
I had to move back to my hometown; family conflict made my mental health worse	37 (16.59%)
During the lockdown, most social activities and connections happened online; as a senior who did not grow up with these apps, I am not tech-savvy	35 (15.7%)
Senior universities and senior hobby clubs were shut down during the lockdown, and I felt isolated	25 (11.21%)

Top Employment/Economic Impact

Unmet Need or Barrier During Lockdown	N (%)
We did not receive any financial relief fund from the government, and I could not make ends meet	73 (32.74%)
The government did not offer a relief fund for our industry; I could not make ends meet	38 (17.4%)

Working remotely was not a good option for me due to the lack of accommodation	33 (14.8%)
I did not have any income due to the lockdown	30 (13.43%)
Software platforms for working from home did not have features making them accessible to me	28 (12.56%)

Media Representation of Women with Disabilities Affected by COVID-19: Evidence from China

Ying Xiong and Xiuli Wang (corresponding author)

School of New Media, Peking University, Beijing, China

Author Note

Ying Xiong is a post-doctoral researcher at School of New Media, Peking University. Her research focuses on communication for social development, media culture, and health communication. She has published in journals such as *Journal of Disability Research*, *Chinese Women's Studies*, and *Global Journal of Media Studies*.

Xiuli Wang is an associate professor at School of New Media, Peking University. Her research focuses on public relations, health communication, and human-machine communication. She has published in various journals such as *Journalism and Mass Communication Quarterly*, *Computers in Human Behavior*, *American Journal of Media Psychology*, and *Chinese Journal of Communication*.

Abstract

Based on the content analysis of news samples from 23 Chinese media outlets, this study examines the media representation of women with disabilities affected by COVID-19. We found that women with disabilities are marginalized, stereotyped, and stigmatized under the combined influence of ableism, sexism, and the pandemic.

Keywords: women with disabilities, media representation, COVID-19

Media Representation of Women with Disabilities Affected by COVID-19: Evidence from China

Persons with disabilities (hereafter refers to as PWD) are among the most marginalized in any crisis-affected community. Coronavirus Disease 2019 (hereafter refers to as COVID-19) and related control measures have further compounded this situation, disproportionately impacting PWD both directly and indirectly (United Nations, 2020). As a marginalized group both in disability status and gender, women with disabilities (hereafter refers to as WWD) affected by COVID-19 are more vulnerable than men with disabilities (hereafter refers to as MWD) and non-disabled women in various aspects (Thomas et al., 2021). Meanwhile, WWD have shown powerful resilience when responding to the crisis (Le, 2020). However, it was hard to find more scientific data referring to WWD affected by COVID-19 worldwide.

China was the first country to report COVID-19 cases to World Health Organization and was one of the hardest-hit countries in the early phase of the pandemic. As the world's most populous country, China is home to at least 85 million PWD (China Disabled Persons' Federation, 2021), and nearly half of them are women or girls. Even so, the situation of Chinese WWD affected by COVID-19 was severely under-researched, making it difficult to examine and reflect on their human rights situation and relevant policies or practices.

As the setter of public agendas (McCombs & Shaw, 1972), the grantors of social status (Lazarsfeld & Merton, 1948), the constructor of historical memory, and the watchers of future risks, media play a crucial role in constructing the social realities of WWD (Cai & Xiong, 2021). In this study, we investigated the media representation of WWD in the Chinese context to better understand the relationship between WWD and COVID-19, to reveal the representation strategies of Chinese media, and to support various social subjects (media outlets, government departments, PWD organizations or communities, etc.) to construct a more diversified, equal, and inclusive social environment in the post-COVID-19 era. These subjects can choose to serve either as the target of criticism, the source of policy advocacy and project development (van Zoonen, 1994) or as the foundation for potential dialogue and cooperation.

Literature review

Media representation of marginalized groups

As a significant topic in communication research, media representation refers to constructing the so-called social reality (Chang & Wang, 2016) “by means of selection and interpretation which operate through gatekeeping and according to agendas which are suffused by ideology” (Watson & Hill, 2012, p. 259).

Due to their subordinate positions in social structure, marginalized groups (such as women, PWD, children, older persons, etc.) have always been represented as the Others -- “the outgroups” that deviate from the mainstream social norms (Ni, 1998), which may exacerbate their social exclusion. There are several frequently used representation strategies regarding marginalized groups (Nie, 2010; Ni, 1998): (1) Marginalization, ignoring or looking down upon marginalized groups as a whole or some aspects; (2) Categorization, repeatedly describing some surface characteristics of them and having “a whole range of belief that is anchored in the stereotype” (Gowman, 1957, p. 198); (3) Stigmatization, emphasizing negative comment “that is deeply discrediting” (Goffman, 1963, p. 3) targeted at marginalized groups. “Abominations of the body -- the various physical deformities” (Goffman, 1963, p. 4) mainly refer to disabilities, and are among the types of stigmas.

Media representation of marginalized groups involves a series of selections from perspectives of how language constructs meanings (Ni, 1998) within different dimensions of media text (Braun & Clarke, 2006). On the quantity distribution dimension, media need to select marginalized groups' presence or absence, and foreground or background (Fairclough, 1995). For instance, topics "in the lead paragraph in a press report, are informationally foregrounded" (Fairclough, 1995, p. 119).

On the semantic or explicit dimension, media select and organize the surface meaning of media texts (Braun & Clarke, 2006), such as role allocation and related actions, events, or relationships of marginalized groups (Ni, 1998), which are suffused by ideology (Watson & Hill, 2012). For example, as "a significant component of social structure" (Schaefer, 2012, p. 101), individuals can be categorized into these roles in the private sphere (e.g., daughter, wife, and mother) and those in the public sphere (e.g., medical worker and government official), correlating with the discourse and environment of different marginalized persons.

On the interpretive or implicit dimension, media select the latent meaning of texts that reaches underlying ideas, assumptions, conceptualizations, and ideologies (Braun & Clarke, 2006), often reflected in the reporting perspectives of news coverage. For example, if marginalized groups are consistently described as "responsible agents" of negative actions, then we may assume that such propositional "framing" itself adds to the negative portrayal of such a group, and therefore has an ideological basis (van Dijk, 1995).

Media representation of PWD and women

Since representation has long been an important field of feminist media studies (van Zoonen, 1994), the study of disability as a field of representation has also developed over the last three decades into a coherent and compelling body of critical work (Garland-Thomson, 2006). Both PWD and women "are portrayed as helpless, dependent, weak, vulnerable, and incapable bodies" and beneficiaries of benevolent rescuers' philanthropic actions (Garland-Thomson, 2002).

Specifically, media outlets tend to dehumanize, criminalize, patronize, and medicalize PWD, or treat them as evidence of political achievements (Beauchamp-Pryor, 2011; Cai, 2016). Barnes (1991) summarized 10 commonly recurring disabling stereotypes from English-language mass media such as "social burden," "super cripple," and "sexually abnormal." Mitchell and Snyder (2000) used the term "narrative prosthesis" to refer to "the pervasiveness of disability as a device of characterization in narrative art" (p. 9) which "affirms and shapes discriminatory attitudes" (Garland-Thomson, 2006). Quayson (2007) indicated that "aesthetic nervousness" is seen "when the dominant protocols of representation within the literary text are short-circuited in relation to disability" (p. 16). In the aftermath of the 2007-2008 global financial crisis, British tabloids more frequently described PWD as "folk devils," thus justifying social welfare cuts (Briant et al., 2013). Zhou et al. (2021) argued that Chinese online media tended to portray PWD in the COVID-19 pandemic from three aspects: special groups receiving assistance, devotees actively fighting against COVID-19, and hardworking and self-improving socialist workers. Xiong and Wang (2021) also found that Chinese mainstream media constructed PWD affected by COVID-19 as the Others under the perspective of ableism.

Women have long been subject to "symbolic annihilation" in mass media (Tuchman,1978), and have been portrayed mainly as housewives who serve men, sales promoters who solicit (male) consumers with attractive appearances, and those who dress up for the benefit of men (Hole, 1971; Liu et al., 1997). The COVID-19 pandemic has once again exposed the conspicuous invisibility of women and gender issues in global public health governance (Feng, 2020), whether in developing countries like India, Kenya, Nigeria, South Africa, and China, or developed countries like Australia, the United Kingdom, and the United States. Women were underrepresented as protagonists, sources, and experts in news coverage of the pandemic, of which more than 99% lacked a gender equality perspective (Kassova, 2020; Fletcher, 2021). Although Chinese female medical workers were mainly represented as “lady warriors” or “contemporary Mulan” in actions fighting against COVID-19, the essence of these labels affirms the status of women through the social recognition of masculinity under the dominant patriarchal discourse (Zhang, 2020).

The above-mentioned literature indicates that PWD and women have always been underrepresented and misrepresented in daily life. Moreover, the COVID-19 pandemic, a public health emergency with a short response time and involving an infectious disease with severe and intricate influences on both marginalized groups and media outlets (Wang, 2022), worsened the underrepresentation and misrepresentation of PWD and women to varying degrees.

Media representation of WWD

Su (2016) proposed to emphasize the daily work and life experience of marginalized women (including WWD) from multiple levels such as gender, disability, and an urban-rural dichotomy, and to use intersectionality to assist the women in voicing their views collectively rather than individually. Garland-Thomson (2002) regarded representation as one of the four fundamental and interpenetrating domains of feminist theory and advocated integrating disability as a category of analysis to articulate and foster feminist disability theory.

Situated at the intersection of disability and gender, very limited research can be found on media representation of WWD. Humeira and Nurbaya (2017) claimed that, compared to MWD, media outlets represented WWD as weak, pitied, and highly dependent on other persons. Mother-blaming is ubiquitous in the professional literature about disability, with negative judgments like "indifferent," "hysterical," and "emotional" (Hillyer, 1993, p. 90); and it becomes more complicated when a mother of children with disability is also a WWD (Quayson, 2007). Pompper and Holtzthum (2022) suggested that "Push Girls" (an American reality television) relied heavily on "sex object" and "supercrip" images to represent WWD. In contrast, the representations of Amber and Dooneese (two characters on "Saturday Night Live") "signal freedom and agency regarding their display of displeasing behaviors as physically disabled women" (Hungerford, 2022). Media representation studies about WWD are even fewer in mainland China. Gao and Liu (2016) found that media coverage of Chinese women with hearing disabilities was significantly less prominent than that of men with hearing disabilities, and *People's Daily* tended to portray them as "beautiful angels of the silent world" who won readers' sympathy and admiration.

Based on existing literature, this study attempts to achieve three goals: first, to examine "how disability functions along with other systems (like gender) of representation" (Garland-Thomson, 2002) to construct disability and gender discourse, which potentially affect our perception and practice regarding the interaction of body, identity, and the risk society; second, to compile historical data about the life experiences of WWD in public health emergencies as a reference for future crises based on the "authenticity" of news coverage; and third, to transcend the unevenness of disability and culture studies for being "U.S.- and Eurocentric, white, and middle class" (Davis, 2011) by providing evidence from China, a populous member of the Global South.

Research questions

This paper aims to answer two questions: what are the characteristics of Chinese media's representation of WWD affected by COVID-19? What kind of media politics is reflected in their representation strategies? To arrive at the answers, we pose three specific research questions based on three dimensions of media text:

RQ1: On the quantity distribution dimension, how prominent have WWD been in Chinese media's COVID-19 news coverage?

RQ2: On the semantic dimension, what news facts regarding WWD affected by COVID-19 have been reported by Chinese media?

RQ3: On the interpretive dimension, from what disability or gender perspective has Chinese media covered WWD affected by COVID-19?

Method

To answer the above research questions and facilitate the comparisons among various marginalized groups under a similar analytical framework (Xiong & Wang, 2021), this study applied content analysis, "the systematic and replicable examination of symbols of communication, which have been assigned numeric values according to valid measurement rules" (Riffe et al., 2019, p. 23) and a frequently used method for media representation studies (Krippendorff, 2019) to analyze the news coverage of WWD affected by COVID (hereafter referred to WWD news). The study was operationalized for news coverage featuring WWD affected by COVID-19 as primary or secondary news figures according to their length in the news texts.

Data collection

WeChat is China's most popular social media platform with over 1 billion active users in 2020 (China Internet Network Information Center, 2020). This study selected the official WeChat accounts of 23 representative and influential Chinese media outlets based on their ownership structure and business scope: (1) State-owned full-scope media (*People's Daily*, Xinhua News Agency, CCTV News, and News Broadcast); (2) State-owned health-focused media (Health News, Life Times, and Health Times); (3) Market-oriented full-scope media (*Southern Metropolis Daily*, *Southern Weekly*, *Bing Dian Weekly*, Beijing Youth Reports, The Paper, Ifeng.com, Jiemian.com, *China News Weekly*, Portrait, Sina News, China Business News, *Caijing Magazine*, *21st Century Business Herald*, and Caixin Media); and (4) Market-oriented health-focused media (DXY and Tencent Medipedia).

News coverage from December 31, 2019 to December 31, 2020 were collected, covering the period in which China was hardest hit by COVID-19, the time of national resumption, and the subsequent localized and overseas pandemic. Firstly, our data provider, Shanghai Watch Mdt InfoTech Ltd., collected 52,553 examples of COVID-19 news coverage based on 10 COVID-19-related keywords[1]. Because of the complexity and scarcity of WWD news, two doctoral researchers and one master student majoring in communication studies screened out 169 PWD news samples based on 45 PWD-related keywords[2] through manual filtration. Then the researchers obtained 28 WWD news samples (as shown in Table 1) with the help of keywords indicating female news figures, such as "woman/women," "female," "she/her," "girl," "maiden," "lady," "daughter," "wife," "grandma," "pregnancy,"

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[1] COVID-19-related keywords: Coronavirus Disease 2019 (COVID-19), virus, pneumonia, pandemic, anti-epidemic, Wuhan, Hubei (Province), mask, doctor, medical supplies.

[2] PWD-related keywords: disability, disabled, handicap, barrier-free, visual disabilities (with one synonym), blind person (with two synonyms), white cane, guide dog, hearing disabilities, dysaudia, deaf (with two synonyms), surdimutism, speech disabilities, lalopathy, dumb, physical disabilities, cripple, lame person, wheelchair, crutch, paralysis, cerebral palsy, intellectual disabilities, amentia, Down syndrome, Down baby, psychosocial disabilities, psychonosema, autism (with one synonym), rare disease, "orphan" disease, albinism, osteogenesis imperfecta (with one synonym), scoliosis, amyotrophic lateral sclerosis, myatrophy, Ice Bucket Challenge, "broken in body but firm in spirit" (a Chinese idiom).

“menstruation,” and “gynecology.” The second and third steps were performed under investigator triangulation.

Table 1

The list of 28 WWD news samples.

No.	Title of News Article	News Outlets	Published Date
1	A woman rumored to have climbed down from the 10th floor to buy meat? Here is the response from Hubei's local authorities	Southern Metropolis Daily	2020-02-25
2	Narration from the frontline | The eternity of love lies in the fact that love can transcend life and death	Health Times	2020-02-27
3	A Hubei single mother is asking for help: Her 8-year-old daughter is suffering from a rare disease while the life-saving medicine is only enough for two weeks	Southern Metropolis Daily	2020-02-29
4	Henan's authorities notified that "a peasant woman has been subdued for not wearing a mask"	The Paper	2020-03-01
5	A middle school girl student suicided by taking medicine for having no cellphone for online courses? Her father responded! An investigation has been launched by local authorities	Sina News	2020-03-02
6	A 12-year-old boy played games during online courses that cost thousands of yuan! His mother said his sister with disability is waiting for money to get treatment	Southern Metropolis Daily	2020-03-02
7	A Henan girl who suicided by drinking pesticides is out of danger after treatment. Local villagers have donated to her	Tencent Medipedia	2020-03-03
8	A Henan girl has been rumored to drink pesticides in a bad temper for having no cellphone to attend online courses. Here comes the result of relevant investigation	Southern Metropolis Daily	2020-03-03
9	A girl who didn't have a cellphone for online courses	China News Weekly	2020-03-05
10	A transoceanic rescue: Joining hands for 168 Chinese babies who suffer from PKU (Phenylketonuria)	China News Weekly	2020-04-29
11	Who sold my house in Beijing?	Bing Dian Weekly	2020-06-04
12	Looking forward to knowing each other again: Dementia patients in Dutch nursing homes under the COVID-19 pandemic	Jiemian.com	2020-06-06
13	Stay in the "Lilliputian" or go to your "Brobdingnag"?	Beijing Youth Reports	2020-06-26
14	Let's make this bakery popular!	CCTV News	2020-08-12
15	Let's make this shop popular!	People's Daily	2020-08-12
16	Children who can't enjoy normal foods	The Paper	2020-08-18
17	The extended line of lives	Bing Dian Weekly	2020-08-20
18	She saves money for the hope of getting ideal treatment	Bing Dian Weekly	2020-09-22
19	Indian TikTok influencer lost contact with her millions of Indian followers	Beijing Youth Reports	2020-10-02
20	Looking back on Bing Xin's 120th birthday: A gentle rebel	Southern Weekly	2020-10-05
21	Here is a rope for survivors	Bing Dian Weekly	2020-10-31
22	Some groundhogs-like stories	Portrait	2020-11-06
23	Interview | Xiuhua Yu: Whom did I offend for expressing love to Jian Li?	The Paper	2020-11-13
24	The disappeared "Little Jack Ma"	The Paper	2020-11-27

25	Older persons are being abandoned by high technology? Five ministries cooperate to solve the problem	The Paper	2020-11-27
26	My name is Xiaoqin Fan, not "Little Jack Ma"	Bing Dian Weekly	2020-12-23
27	In a special school, a grandpa accompanied his grandson who has autism for 9 years. Unexpectedly…	The Paper	2020-12-23
28	Those shining ordinary people illuminate the 2020	China News Weekly	2020-12-30

Analytical framework

This study adopted an analytical framework consisting of three themes: quantity distribution, news fact, and reporting perspective, corresponding with the three levels of media text (Braun & Clarke, 2006; Fairclough, 1995; Ni, 1998) and respective research questions.

Specifically, quantity distribution refers to the amount of WWD news samples and their distribution on published date, news location, page position, and length, indicating the presence or absence, foreground or background (Fairclough, 1995) of information about WWD.

News fact refers to the concrete content of WWD news samples on the semantic dimension (Braun & Clarke, 2006). Given that the COVID-19 pandemic is a public health crisis, we focused on examining the roles (Schaefer, 2012) played by WWD -- what roles media outlets allocated to WWD and the problems they faced; what vulnerabilities of WWD and relevant attributions media outlets covered; and the support WWD received or provided -- how media outlets represented the social support for WWD and their resilience during the pandemic. We constructed the categories of each variable (as shown in Table 2) based on precoding and existing categories (House, 1981).

Lastly, reporting perspective refers to the disability or gender perspectives reflected on the interpretive dimension (Braun & Clarke, 2006) of news samples, indicating the ideologies or media politics of the representation of WWD. Since categorization and stigmatization are two frequently used representation strategies imposed onmarginalized groups (Nie, 2010), raising the disability or gender equality awareness of news outlets has always been advocated by programmatic documents such as the United Nations Convention on the Rights of Persons with Disabilities (Article 6 and Article 8) and Beijing Platform for Action (Article 245). We took the operational definition and categorization matrix of a "gender-sensitive news article" (Bu et al., 2019) as a main reference.

We further divided the two reporting perspectives into four categories as below. First, disability or gender equality, which is operationalized as any of the following criteria (Cai & Xiong, 2021): (1) For image-building, the sample explicitly stated WWD's identity as the subject of human rights, rather than merely projecting positive images for them; (2) For perception, it explicitly acknowledged that disability or gender is socially constructed and is a part of human diversity; (3) For attribution, it explicitly recognized that the plight of WWD stemmed from a lack of human rights or inequity in social structure; and (4) For action, it explicitly advocated that social subjects (like media outlets, government departments, PWD organizations or communities, etc.) should take actions to protect the rights of WWD, such as opposing behaviors that undermine their dignity, eliminating disability or gender-based violence, and empowering WWD.

Second, disability or gender-based stereotype, which means a sample used positive or neutral role models to portray WWD, such as "broken in body but firm in spirit," "poor imbeciles," or "ladylike." Third, disability or gender-based discrimination, referred to a sample that either explicitly or implicitly gave negative comments about WWD as a group or their identity, or used other specific stigmatizing terms like "cripple," "midget," and "moron" (Goffman, 1963), or other abelist or sexist expressions, including "PWD are a hazard or burden to society" or "women are simple-minded or hysterical." Fourth, "unclear" -- a sample that does not contain any content that indicates any of the above-mentioned perspectives.

We designed a coding scheme consisting of 15 variables and divided each variable into several categories. We then assigned values to them, as shown in Table 2.

Table 2

Coding scheme of WWD news samples

Themes	**Variables**	**Categories**
Quantity distribution	V1 News location	1=Wuhan; 2=Other cities in Hubei Province; 3=Rural Hubei; 4=Beijing, Shanghai, Guangzhou, or Shenzhen; 5=Other cities in China; 6=Other rural areas in China; 7=Other countries or regions; 8=Unclear
	V2 Page position	1=Front-page; 2=Other places
	V3 Length	1=1,000 or fewer words; 2=More than 1,000 words
	V4 Primary or secondary news character	1=Primary character (who accounts for 50% or more of the length of a news article); 2=Secondary character (whose proportion requirement is 10% to 49%)

News fact	V5 Classifications of disabilities	1=Visual disabilities; 2=Hearing disabilities; 3=Speech disabilities; 4=Physical disabilities; 5=Intellectual disabilities; 6=Psychosocial disabilities; 7=Multiple disabilities; 8=Unclear
	V6 Roles in the COVID-19 pandemic	1=Medical worker; 2=Government official; 3=Community worker; 4=Expert or scholar; 5=Public welfare worker; 6=Other professionals; 7=COVID-19 patient; 8=Ordinary resident; 9=Violator or lawbreaker; 10=Daughter; 11=Wife; 12=Mother
	V7 Information source	1=News figures; 2=Medical worker; 3=Government official; 4=Community worker; 5=Expert or scholar; 6=Public welfare worker; 7=Relative or friend; 8=Others
	V8 Problems	1=Physical problem; 2=Psychological problem; 3=Living problem; 4=Working problem; 5=Educational problem; 6=Financial problem; 7=Affectional problem; 8=Rights problem; 9=Other problems
	V9 Attributions of problems	1=COVID-19; 2=News characters; 3=Other individual; 4=Medical institution; 5=Government agency; 6=Community organization; 7=Educational institution; 8=Social or cultural factor; 9=Others
	V10 Providers of social support	1=Medical worker; 2=Government official; 3=Community worker; 4=Lawyer; 5=Teacher; 6=Public welfare worker; 7= Relative or friend; 8=Stranger; 9=Others
	V11 Types of social support	1=Medical support; 2=Financial support; 3=Material support; 4=Legal support; 5=Psychological support (relieving or eliminating someone's negative emotions); 6=Information or communication support (providing needed information or assisting someone in communication); 7=Technical support (instructing someone to use a device or perform certain operations); 8=Living support (taking care of someone in their daily life); 9=Affectional support (expressing recognition or love to someone to make them more cheerful); 10=Policy or administrative support; 11=Other supports
	V12 Types of self-support (the same as V11)	
	V13 Types of support for others (the same as V11)	
Reporting perspective	V14=Perspective on disability	1=Disability equality; 2=Disability-based stereotype; 3=Disability-based discrimination; 4=Unclear
	V15=Perspective on gender	1=Gender equality; 2=Gender-based stereotype; 3=Gender-based discrimination; 4=Unclear

Reliability

The coding was completed by one doctoral researcher and one master student who are experienced in content analysis and attended targeted coding training to better understand the coding scheme. *Ir* coefficient[3] (Perreault & Leigh, 1989) was used to test the intercoder reliability of V8-V15, the eight relatively subjective variables. In the first round, the reliability coefficients were not ideal, especially V9, V14, and V15. We conducted the second round of intercoder reliability test after discussion and modification of problematic

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[3] $Pa \geq 1/k$; $Ir = 0$, for $Pa < 1/k$ (*Pa* refers to inter-rater agreement; *k* refers to number of categories).

categories, such as distinguishing between a “psychological problem” and “affectional problem,” and clarifying operational definitions like “social or cultural factor” and “disability/gender equality.”

Table 3

The reliability coefficients of V8-V15

V8	V9	V10	V11	V12	V13	V14	V15
0.96	0.81	0.92	0.91	0.98	0.94	0.92	0.92

As a result, all the coefficients (as shown in Table 3) were 0.8 or higher, coming up to the standard of intercoder reliability. SPSS 22.0 was used in data analysis.

Results

Quantity distribution of WWD news

Of the 52,553 examples of COVID-19 news coverage, only 0.05% of them were WWD news. This proportion was less than 20% of the number of MWD news (Xiong, 2022) and also less than the proportion of WWD in the national population (China Disabled Persons’ Federation, 2021). In other words, WWD affected by COVID-19 were severely underrepresented by the 23 media outlets and nearly “absent” in the Chinese media environment.

Given that our data spanned the full year of 2020, one WWD news item appeared approximately every 13 (13.1) days. Only on 23 of the 366 days did the 23 media outlets report WWD news, far less than the continuity of PWD news, of which one news article appeared approximately every two days (Xiong, 2022).

Regarding news location, more than half (53.6%) of WWD news occurred in Chinese urban areas such as Wuhan, Beijing, and Shanghai, and less than one-third (28.6%) occurred in rural areas, whether in or out of Hubei Province. With the COVID-19 pandemic occurring overseas, Chinese media also reported a few (7.1%) WWD news stories in developed countries but showed a lack of attention (3.6%) to WWD of developing or underdeveloped countries.

Among the 28 WWD news samples, 75.0% were headlines, 85.7% had more than 1,000 words, and 67.9% had WWD as primary news figures, which were "foregrounded" in terms of page position, length, and the share of news character. However, given the extremely small proportion of WWD news, their visibility was still extremely low.

News facts reported in WWD news

Roles played by WWD. At first, we counted the classifications of disabilities and found that news figures of women with physical disabilities (28.6%) had the highest frequency, followed by women with psychosocial disabilities (21.4%), intellectual disabilities (17.9%), multiple disabilities (10.7%), hearing disabilities (7.1%), and visual disabilities (3.6%). There were no news figures with speech disabilities. The classifications were "unclear" in 10.7% of the news samples.

Taking the populations of different Chinese PWD (China Disabled Persons' Federation, 2021) as a reference, women with psychosocial disabilities (7.4%) and intellectual disabilities (6.7%) were overrepresented, echoing the common images of "crazy women" and "stupid women" in misogynistic culture (Manne, 2018). In comparison, male figures with psychosocial disabilities (3.5%) and intellectual disabilities (1.4%) were underrepresented (Xiong 2022), projecting overall a rational, stable, and intelligent image.

Meanwhile, women with hearing disabilities (24.2%), visual disabilities (14.9%), speech disabilities (1.5%), multiple disabilities (16.3%), and physical disabilities (29.1%) were underrepresented in differing degrees. As with MWD (Xiong & Wang, 2021), the first three kinds of WWD were severely underrepresented. This might have resulted from their perceived lower news value and difficulties in obtaining and disseminating information to media outlets during the pandemic. In contrast, men with physical disabilities (68.1%) were highly overrepresented, and 78.6% of them were doctors with mild physical disabilities who fought against the pandemic (Xiong, 2022).

Further, we analyzed the social roles played by WWD news figures and compared the results to the corresponding findings of MWD (Xiong, 2022).

Table 4

Proportions (%) of social roles played by WWD news figures (N=28) and MWD news figures (N=144)

	WWD	**MWD**
Roles in the public sphere		
Medical worker	0.0	53.5
Government official	0.0	11.1
Expert or scholar	0.0	0.7
Community worker	0.0	0.7
Public welfare worker	14.3	4.2
Other professionals	32.1	22.9

COVID-19 patient	7.1	2.1
Ordinary resident	28.6	15.3
Violator or lawbreaker	7.1	0.7
Roles in the private sphere		
Daughter/Son	28.6	27.1
Wife/Husband	25.0	20.1
Mother/Father	39.3	11.8

As shown in Table 4, most WWD news figures featured in a positive or neutral social role, with only 7.1% of them playing negative roles as violator or lawbreaker, although this proportion is 10 times higher than the corresponding value of MWD. Except for public welfare workers, WWD were rarely portrayed as filling powerful roles in the public sphere. MWD received more opportunities to be represented in anti-COVID-19 roles, especially as medical workers and government officials. In comparison, WWD's common roles in the private sphere, especially that of mothers, were more frequently covered than that for MWD.

Concluding this part of the study, we examined the information source, asking who had the privilege of defining and constructing specific events or problems. In 53.6% of the news samples, WWD news figures were not the information sources. This was especially for women with psychosocial disabilities (46.2%), hearing disabilities (15.4%), and multiple disabilities (15.4%), indicating they had less discourse power to construct COVID-19-related subjective experience, cognition, and understanding. Correspondingly, government officials (46.2%), relatives (46.2%), and even netizens (46.2%) were endowed with more power to define and construct WWD-related matters in the pandemic, depriving WWD of opportunities to voice their views independently.

Problems faced by WWD. The unequal effects of the COVID-19 pandemic are reverberating along preexisting fault lines and creating new ones (Robinson et al., 2021). All of the news samples mentioned the challenges encountered by WWD news figures. Nevertheless, as shown in Table 5, the preexisting problems were more frequently covered than new problems that occurred after the outbreak of the pandemic. This phenomenon never appeared in media representation of PWD, MWD, or women affected by COVID-19 (Xiong & Wang, 2021; Xiong, 2022).

One potential reason is that the 23 media outlets studied did not notice the various impacts of COVID-19 on WWD. They tended to use the long-existing vulnerabilities of WWD as the indispensable background for their situations in the pandemic. For example, the Sample No. 3 article only mentioned one post-outbreak problem of a girl with tuberous sclerosis, reporting "cheap medicines couldn't be bought while expensive medicines couldn't be afforded because of the lockdown and quarantine during the COVID-19 pandemic." Meanwhile, the journalist presented a series of long-existing problems faced by the girl, including her poor health condition, "being unable to live independently," and the financial constraints of her family. The following findings may resonate with the above analysis.

Table 5

Proportions (%) of problems faced by WWD news figures (N=28)

	Total (%)	**Prior-existing (%)**	**Post-outbreak (%)**

Physical problem	89.3	89.3	17.9
Psychological problem	42.9	28.6	25.0
Living problem	53.6	39.3	28.6
Working problem	28.6	25.0	14.3
Educational problem	32.1	32.1	14.3
Financial problem	46.4	39.3	7.1
Affectional problem	35.7	21.4	17.9
Rights problem	21.4	25.0	3.6
Other problem	57.1	35.7	35.7

The physical problems of WWD were most frequently reported on, especially for older women who had multiple disabilities or underlying diseases. For some WWD, their chronic diseases were expected to worsen due to treatment disruptions in the pandemic, even if they did not contract COVID-19.

The second most covered issue dealt with living problems, which mainly involved disruption of daily life in terms of clothing, eating, housing, and transportation, or the lack of necessities. A 93-year-old woman with multiple (physical, hearing, speech, and intellectual) disabilities had lost nearly all ability to live independently during the pandemic, and “could only take liquid diet by nasal feeding through a gastric tube” (Sample No.2).

The third most covered problem faced by WWD related to financial issues, such as heavy reliance on basic living allowances, rehabilitation training expenses embezzled by family members, inability to afford ultra-expensive drugs to cure rare diseases, and inability to earn money during the pandemic.

The psychological problems of WWD were also frequently mentioned in the samples, which referred to negative psychological states like anxiety, depression, and self-abasement. For instance, Sample No.12 cited the finding of a survey conducted by Alzheimer's Society in which 79% of nursing homes participating believed that the mental health of persons with dementia had been severely damaged in the COVID-19 pandemic. In addition, WWD also faced dilemmas in the domain of affection, such as that related to kinship, friendship, and love. A girl with dwarfism (little people) believed that the reason for her separation from an "able-bodied" boyfriend was that "he needed face ('Mianzi' in Chinese)" rather than a girlfriend with disabilities "under the gaze of outsiders" (Sample No.13).

While almost all the "problems" could be understood as human rights issues, only those involving exclusion, discrimination, humiliation, or infringement of rights by others or rights not fully protected were categorized as a "rights problem" in this study. That is why an older woman with visual disabilities who lost her only property under the "house-for-pension" scam (Sample No.11) was coded as a "rights problem." Another example came from Xiuhua Yu, a famous contemporary poet and woman with cerebral palsy. She has been humiliated as a "slut" or "shrew" because of her bold remarks (Sample No.23).

It is worth noting that the rights problems mentioned in the samples were not directly related to the COVID-19 pandemic. Additionally, compared with problems frequently faced by PWD, those that were more common to women, such as lack of sanitary pads, heavy housework, and domestic violence, were scarcely mentioned in our news samples.

All the samples listed tried to identify the reasons behind the above-mentioned problems, and 67.9% of them attributed the subject's challenges to COVID-19 or the pandemic. Besides that, 71.4% of the samples attributed those problems to specific persons, objects, or events at the micro level, citing WWD themselves, the financial hardship of their relatives, discrimination, or someone's violent behavior. At the meso level, 39.3% of the samples attributed the problems to organizations, such as medical ones that lacked resources and testing capacity and government departments which implemented improper prevention and control policies. At the macro level, 14.3% of the samples involved attribution to cultural or social factors, such as a digital divide, prejudice or discrimination within the mainstream society.

Supports received or provided by WWD. It is noteworthy that the WWD were not only portrayed as vulnerable persons afflicted by COVID-19 but also resilient fighters against the pandemic. Of the news samples, 53.6% described WWD helping themselves and 57.1% described their support of others. However, a much higher proportion of coverage represented WWD as recipients of social support (89.3%). In our news samples, the subjects providing social support to them mainly were relatives or friends (75.0%), government officials (60.7%), medical workers (46.4%), public welfare workers (42.9%), and enterprise personnel (42.9%). Only 3.6% of the samples mentioned support provided by community workers.

Among the forms of support, financial support (64.3%), medical support (53.6%), and living support (46.4%) ranked in the top three, while administrative support (21.4%), psychological support (17.9%), and legal support (10.7%) ranked in the bottom three.

WWD news figures offered relatively more financial support (28.6%), information support (25.0%), and material support (14.3%) to themselves. They also provided relatively more of these supports to others, which are financial support (25.0%), information support (28.6%), and material support (17.9%). However, they rarely provided support in legal, medical, technical, administrative, and other areas requiring more public resources or having a high technical threshold.

In the news samples, WWD have been victims of the COVID-19 pandemic, but some of them had also been proactive survivors and doers. In Sample No.18, several WWD had been actively promoting “the legal system design and policy response to rare diseases.” In Sample No.19, an Indian woman with physical disabilities had been “motivating children in slums to ‘dream big’” by teaching them living and artistic skills. She also provided psychological and information support to release the loneliness, insecurity, stress, and fear of people suffering from the pandemic. However, this kind of sample is quite uncommon.

Reporting perspectives of WWD news

Of the samples, 10.7% adopted a perspective of disability equality, which not only emphasized the strong initiative of WWD but also criticized social prejudice against them or advocated for disability equality. For example, the reporting perspective of Sample No.19 was revealed through the viewpoint of its WWD protagonist: “PWD have always been ignored by the mainstream society, so that’s why I can imagine how many social restrictions and prejudices he (a dancer with physical disabilities) has to break to dance so freely.” In Sample No.22, a female volunteer wrote and shared the stories of persons recovered from leprosy because she wanted to illustrate that they were “individuals with unique personalities, neither a type of people, a suffering group, nor an example in history.” In addition, 7.1% of samples adopted a perspective of gender equality through expressing feminist ideas by quoting the comments of famous women like Qing Wu (such as “woman should always be a human before a woman”) (Sample No. 20), and Xiuhua Yu (Sample No. 23).

The most common stereotypes displayed in the samples were disability-based

(39.3%), where WWD were regarded as “poor imbeciles” who have tragic life experiences and would always be the objects of sympathy, care, or remedy. In Sample No. 27, “a group of children with autism, cerebral palsy or Down syndrome (including WWD)” were represented as setting “the tragic backdrop for the whole story” while “the grandpa (non-disabled)” who gave them caring and warmth was described as their savior, a typical example of this stereotype.

Another disability-based stereotype can be named “weird idiot,” which is commonly found in the samples of women with intellectual disabilities. Take the intriguing representation of Sample No. 24 as an example. The journalist used double-quotation marks (“”) to imply an abnormal and ludicrous “reading” behavior of a woman with intellectual disabilities, without any scientific testimony or information.

Further, 10.7% of the samples involved expressions of gender stereotypes, such as “she gave birth to two sons for Jiafa Fan (Sample No. 26).” In Sample No.13, a news article about persons with dwarfism (little people), the MWD portion focused on men’s career experience and expectation. The WWD part weighed in on affectional topics, or presented content about makeup, dress-up and a plan of “engaging in occupations that can make me beautiful,” revealing a gender-based divide of media representation.

We found 10.7% of the samples involved relatively implicit disability-based discrimination. One of them quoted negative judgments from WWD themselves, describing PWD in terms of “more or less self-abasement” or lacking “high literacy” (Sample No. 21). The other two established unnecessary or inadequate connections between individual deviant behaviors (like evading health examination and taking illegal trips, etc.) and disability identity, the negative implications of which might be extended from individuals to the group (van Dijk, 1995). Similarly, 7.1% of samples involved gender-based discrimination.

Conclusions and Discussions

This study examined the representation of WWD affected by COVID-19 from 23 influential Chinese media outlets and found that WWD were predominantly depicted using neutral or positive images. Some of the media outlets noticed the connection between WWD's long-existing vulnerabilities and post-outbreak problems, presented their resilience to some extent, and reflected little explicit disability or gender-based discrimination, which could be seen as progress compared to previous findings (Cai, 2016). Despite this, deficiencies of the WWD's media representation should be underlined.

Heavily marginalized

Compared with categorization and stigmatization of WWD (Humeira & Nurbaya, 2017; Pompper & Holtzthum, 2022; Hungerford, 2022), marginalization has received less attention from the academic community, but we think it still needs to be monitored as the fundamental concern in the representation system of disability and gender. According to our results, the marginalization of WWD affected by COVID-19 manifested on multiple levels. First and foremost, WWD were ignored or looked down upon as a whole (Nie, 2010), manifesting in limited, low continuity of coverage and resulting in a kind of "symbolic annihilation" (Tuchman, 1978), even within women-related COVID-19 news (Xiong, 2022). Women with disabilities and WWD in Chinese villages and from the Global South were severely underrepresented. The voices of women with psychosocial disabilities were substantially unheard. Last but not least, the 23 Chinese media outlets paid relatively scant attention to WWD's human rights problems, especially those related to COVID-19 and to WWD's particular issues as women.

PWD were far less noticed by Chinese media outlets than other marginalized groups like women, children, and older persons (Xiong, 2022), while gender as a representation category worsened the marginalization of WWD (Xiong & Wang, 2021). Additionally, the suddenness and infectivity of the COVID-19 pandemic and related quarantine measures might have exacerbated the “absent” and “background” of the problems facing WWD and specific subgroups. Factors like news value and barriers during news reporting processes may have also played a part.

Moderately stereotyped

As revealed by this study, only a few WWD news outlets adopted a perspective of disability or gender equality. On the contrary, more than one-third and one-tenth of the news samples used disability-based and gender-based stereotypes, respectively.

MWD were subject to diversified and even capable labels such as “supercrip” whether at usual times or during the COVID-19 pandemic (Barnes, 1991; Zhou et al., 2021; Xiong & Wang, 2021). So were WWD at usual times (Pompper & Holtzthum, 2022; Hungerford, 2022). However, the typical stereotypes of WWD affected by COVID-19 were relatively monotonous and forceless, dominated by descriptions like “poor imbecile” and “weird idiot” (Humeira & Nurbaya, 2017).

Other findings like “WWD were rarely portrayed as powerful roles in anti-COVID-19 actions,” “WWD were more frequently represented as recipients of social support than providers,” and “women with psychosocial disabilities and intellectual disabilities were relatively over-represented” resonated with other stereotypes from various dimensions and aspects.

The result that “the 23 media outlets tended to attribute problems of WWD to individuals rather than social circumstances” could be implicitly related to another stereotype, that is disability is the origin of difficulties faced by PWD. This acts as the "narrative prosthesis" (Mitchell & Snyder, 2000) of news stories.

It is worth noting that the frequency and types of stereotypes of WWD affected by COVID-19 are less than those of women as a whole (Xiong, 2022), both before (Hole, 1971; Liu et al., 1997) and after the pandemic (Zhang, 2020; Fletcher, 2021). The reason may be that WWD's disability identity relatively transcends gender in the Chinese media environment, resulting in the lower social expectation for them as "women," especially during a severe public health emergency. That is why female medical workers were praised as "contemporary Mulan" (Zhang, 2020) who chose to be fighters instead of mothers, while WWD could only play the roles of victims or beneficiaries.

Lightly stigmatized

Although disability and gender-based discrimination (Barnes, 1991; Beauchamp-Pryor, 2011; Briant et al., 2013; Cai, 2016) were not prevalent in media representation of WWD affected by COVID-19, they still appeared in indirect or subtle ways, such as in quotes of self-deprecation expressions from WWD, which may contribute to discriminatory practices like eugenic programs, selective abortion, infanticide, coercive rehabilitation, and domestic violence (Garland-Thomson, 2002).

Another common but routinely overlooked implicit discrimination -- establishing unnecessary or inadequate connections between individual deviant behaviors (especially those violating the anti-COVID-19 policies and measures) and their disability or gender identity -- is also worthy of vigilance. The stigmatization of these identities was exploited as the "prosthesis" of constructing COVID-19-related mainstream discourse and practices, which are harder to recognize and eliminate than explicit ones.

Recommendations

This study suggests redefining the objectified Others (Ni, 1998), transforming the subordinate position of WWD in media representation, and establishing a more equal and inclusive WWD-related discourse in the post-COVID-19 era. Based on the above results, we make the following recommendations for media outlets (including the alternative media of PWD): (1) Increase the quantity of WWD news during a public crisis, especially news about women with visual disabilities, hearing disabilities, speech disabilities, multiple disabilities, and WWD in rural areas and Global South; (2) Boost the independent voice of WWD during a public crisis, particularly women with psychosocial disabilities, hearing disabilities, and multiple disabilities; (3) Focus more on the resilience and contributions of WWD during a public crisis, highlighting their expertise, professionalism, and leadership. For example, an organization of WWD named “Beijing Enable Sister Center” provided adult diapers, Pull-Ups, various necessities, and psychological support for “sisters with disabilities” around China, and spread the voices of WWD to the public during the COVID-19 pandemic (Le, 2020); (4) Pay more attention to the multifaceted impact of a public crisis on WWD, especially their human rights problems and unique challenges as females; (5) Seek to attribute the problems to multiple levels of factors, especially the barriers in social structure, to promote the innovation of cultural environment, and the participation of multi-subjects in the establishment of WWD’s social support network; (6) Adopt or develop reporting projects that advocate disability and gender equality while refusing stereotyping and discrimination in any form. For instance, if WWD’s deviant behaviors during a public crisis have no relation to their disability status or gender, we suggest media outlets keep such information private and use titles like “resident,” “citizen,” or other appropriate descriptions.

These suggestions might be implemented through the following approaches: (1)

Supplement WWD and public crises-related content in textbooks, ethics guidelines, and government regulations involving journalism and communication, or develop specific training or regulating texts; (2) Carry out normalized news reporting training on the basis of above materials while localizing and customizing them according to different subjects and situations; (3) Strengthen and deepen the participation of WWD and their organizations that have a strong awareness of disability and gender equality in every procedure of news reporting. Additionally, WWD and their organizations can also use proactive counter-representation and self-construction to influence the media agenda and the pseudo-environment.

The above conclusions, recommendations, and analytical framework could go beyond the context of COVID-19 and be extended to other future public crises to differing degrees. The analytical framework might also be applicable for studying the media representation of WWD in other countries and regions after the corresponding adjustment, which will be beneficial to horizontal comparisons and relevant collaborations across regions. Considering the limitations of this study, our next step is to improve the depth and complexity of the analysis of news samples, especially in terms of intersectionality and the features of crisis reporting.

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Discrimination Based on Disability in Chinese Legal System and Practice

Xi Jin

Soochow University

Author Note

Xi Jin is a PhD candidate in the law school of Soochow University. He holds a LLM from Syracuse University. His latest publication is “Legal Protection of Audio Description Films for the Visually Impaired — Based on the ‘Marrakesh Treaty’ and China's Practice.” He is a visually impaired, practicing lawyer in China who cares about disability rights.

Abstract

Persons with disabilities in China are still subject to direct or indirect, overt or covert, systemic or non-systemic discrimination in education, employment, banking, transport, mobility, and other areas of life. This paper will analyze such discrimination based on consideration of disability in the Chinese legal system and will recommend changes to improve the status of persons with disabilities.

Keywords: China, disabilities, legal system

Discrimination Based on Disability in Chinese Legal System and Practice

China’s current legal system has been in place for over the past 45 years since the country began its “Reform and Opening Up” policy. Two decades ago, China’s ruling Communist Party announced its strategy of “Rule by Law,” and in 2004, it wrote into the Constitution that “the State guarantees and protects human rights.” In the area of disability rights, China’s ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008 has been followed by evident changes in the country’s laws on disability. An increasing number of new laws and regulations have appeared at different levels. For example, China’s “Law on the Protection of Disabled Persons (LPDP),” first promulgated in 1990, was thoroughly revised in 2008; in 2013, the “Mental Health Law” was passed; the State Council promulgated “Regulations on Disabled Persons’ Employment” and “Regulations on the Construction of Barrier-free Environments” in 2007 and 2012 respectively; and “Regulations on the Education of Persons with Disabilities” and “Regulations on Disability Prevention and Rehabilitation of Persons with Disabilities” were passed in early 2017. Additionally, the Standing Committee of the National People's Congress (2022) published a draft of “Law on the Construction of Barrier-free Environment” (LCBE) for suggestions. The Ministry of Education, Bureau of Civil Aviation, and other departments passed statutes relating to disability within their own areas of responsibility. “Discrimination based on disability,” “reasonable accommodation,” and other concepts started to appear in the wording of China’s laws.

But in marked contrast to this apparent plethora of legal reform, the actual practice of disability rights has remained rather bleak. China’s disability human rights protection level remains relatively poor by international standards and there are still major inconsistencies with the CRPD. In China, persons with disabilities, as well as other disadvantaged groups, are still widely regarded as unwanted, undesirable, or dangerous (Kanter, 1999; Jones & Marks, 1999).

Official Chinese statistics currently put the number of disabled people at around 85 million (United Nations, 2018). According to data from court cases and news reports, this huge population is still subject to direct or indirect, overt or covert, and systemic or non-systemic discrimination in education, employment, banking, transport, accessibility, and other areas of life. There are still numerous barriers to social inclusion and equal participation. This paper will view and analyze discrimination that exists in Chinese laws and practices, why such provisions do not comply with the CRPD, and how to eliminate these issues.

This paper is divided into three parts: the first part discusses the overall Chinese legal system dominated by the medical model, which results in extensive and structural discrimination against persons with disabilities; the second part analyzes the provisions and behaviors within government and other public sectors that constitute discrimination in specific fields, including education, employment, banking, and legal. This second part will also illustrate weak points in the latest legislation, such as the deficiencies of the LCBE. The last part attempts to summarize the challenges of Chinese people with disabilities and find possible solutions.

The legal system dominated by a medical model of disability

The medical model of disability, also known as the deficit model, views people with disabilities as “sick” and in need of medical intervention (Kanter, 2014). The model locates the “problem” of disability within the person rather than in an environment that creates barriers to the full inclusion and participation of people with disabilities (Kanter, 2011).

Under the medical model, persons with disabilities tend to be the objects of legislation regarding medical rehabilitation, charity relief, or social welfare. It is obvious that the current Chinese legal system related to disability is dominated by the medical model (Cui & Chiu, 2020).

Overview of Chinese legal system

The source of law today in China mainly takes the form of statutes. China's legal system can be divided into five levels: (1) the Constitution, occupying the highest position in the legal system; (2) the law enacted by the National People's Congress and the Standing Committee, and is universally binding; (3) the administrative regulations enacted by the State Council, implemented nationally but lower than law in the legal hierarchy; (4) local laws and regulations that are universally binding in administrative districts; (5) rules and regulations, which may be legislated by the State Council's ministries and commissions or local governments and can be relied upon during court adjudications.

It is worth mentioning that China ratified the CRPD in 2008, which means China has an international obligation to legislate in accordance with the CRPD.

Medical model in legal definition and terminology

The medical model is first reflected in the Chinese Constitution. The parts related to disability in the Constitution are stipulated in Chapter 1: the basic rights and duties of citizens. The third paragraph of Article 45 stipulates that the state and society help to arrange the work, life, and education of the blind, deaf, dumb [sic], and other disabled citizens. The verb it uses is “arrange,” which means the work, life, and education of disabled citizens is dominated and controlled by the state and society. The individuals lack the right and freedom to make choices.

At the legal level, the People's Republic of China Law on the Protection of Disabled Persons (LPDP) comprises nine chapters and 68 articles covering rehabilitation, education, work and employment, cultural life, social security, and accessibility. The content and spirit of the LPDP may be regarded as embodying the basic approach of the existing law toward disability rights. But the LPDP is also dominated by the medical model, which is first revealed in the legal definition of disability. Article 2 of the LPDP stipulates that “a disabled person refers to one who suffers [sic] from abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost in whole or in part the ability to perform an activity in the way considered normal. Disabled persons are referred to as those with visual, hearing, speech or physical disabilities, mental retardation [sic], mental disorder, multiple disabilities and/or other disabilities.” The focus is on the "abnormality" of the individual's psychological and physiological aspects, and emphasizing personal physical defects and diseases. The LPDP draws a distinct boundary between persons with disabilities and “normal” people. Even the U.N. Committee on the Rights of Persons with Disabilities (the Committee) takes note of the prevalence of the medical model of disability in both the definition of disability and the enduring terminology and language of the discourse on the status of persons with disabilities.

The effects of the medical model

Such medical model-oriented constitutional terms and legal definitions have deep effects on the whole legal system. Firstly, the laws fail to regulate discrimination based on disability. There is no comprehensive definition of discrimination against persons with disabilities in the LPDP as well as other laws. China does not consistently apply the concept of reasonable accommodation in relation to the principle of non-discrimination. What also concerns the Committee are the contradictions between many local law regulations and the national law regarding the prohibition of discrimination.

Secondly, persons with disabilities in China lack their own civil society to express their own voices. The China Disabled Persons' Federation and its branches, as a governmental sector, almost monopolizes the representatives and resources regarding disability in China. The Committee is concerned that organizations of persons with disabilities outside of the China Disabled Persons' Federation are not included in the implementation of the CRPD.

Thirdly, nowadays, the Chinese official term for "disability," whether in the government sector or legal documents, is "残疾 (can ji)," which means broken and diseased. Compared with the previous term "残废 (can fei)," which means broken and waste,[1] "can ji" seems to reflect some progress, but it still easily evokes negative associations regarding persons with disabilities.

In conclusion, the medical model exists not only in specific legal fields such as education, employment, and banking (as will be critiqued in detail in the following discussions) but also in many people's attitudes toward persons with disabilities. Persons with disabilities are treated as an inferior group, which may create barriers in their fight for equal rights.

Discrimination in specific fields

Discrimination in education

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[1] "Can fei" has been used in Chinese official discourse for a long time and even today still affects some Chinese people's view of disability. For example, the U.N. named the year 1982 "International Year of Persons with Disabilities," which translated into Chinese is "Guo ji can fei ren nian (international broken and waste people year)."

There is no doubt that education is the key for a person to obtain knowledge, communicate with peers, and participate in mainstream community life. In China, the educational system could be divided into two relatively independent systems, general education and special education. The law also requires that "general primary schools and junior middle schools must admit disabled children or juveniles who are able to adapt themselves to life and study there[2]; general senior middle schools, secondary occupational schools, and institutions of higher learning must admit disabled students who meet the state admission requirements and shall not deny their admission because of their disabilities." But, there are high numbers of special schools in China and its policy is to actively develop these schools (U.N. Committee on the Rights of Persons with Disabilities, 2012). In practice, only students with certain kinds of impairments (physical disabilities or mild visual disabilities) are able to attend mainstream education, while all other children with disabilities are forced to either enroll in a special school or drop out altogether.

The first obstacle for students with disabilities to attend general schools is that some schools, especially universities, will refuse admission to students with disabilities as soon as they are aware of the students' disabilities. According to some statistics, the students with disabilities admitted by universities account for only 0.14% of total students (Beijing News, 2019). In 2014, Wan-ling Liu, a student with myasthenia gravis was refused admission by Jiangxia College, although her score on the High College Entrance Examination had reached the admission score line (Chen, 2014). Jiangxia College stated that it based this decision on the fact that Wan-ling Liu could not adapt to studying and living on the campus

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[2] In China, primary school and junior middle school are also called "nine-year compulsory education," which means each student has both the right and duty to accept such education in their school district.

independently because of her disability and the campus's lack of accessibility facilities. Wan-ling Liu is not a unique case. Many schools use the excuse of lack of accessibility to refuse students with disabilities rather than improving their accessibility and accommodations.

In recent years, the Chinese government revised several rules and regulations to promote inclusive education and provide equal opportunities in exams,[3] such as the college entrance examination, graduate examination, and college English test. However, almost no general school has a department like an Office of Disability Services or resource center to coordinate accommodations for students with disabilities, which becomes another roadblock for inclusive education. In other words, students with disabilities can rarely attend general schools unless they can study like other students without extra support. People sometimes forget that merely placing students with disabilities in general schools without accommodating their needs is not true inclusive education. Some schools even tend to suspend students with disabilities. Xiao Zhu, a student with intellectual disabilities, was suspended by his primary school when he was in the second grade (Chan Nian, 2018). The school announced that Xiao Zhu had difficulty following school activities due to his disability. Unfortunately, similar to Jiangxia College, the school blamed the student's failure on his own disability instead of the campus's denial of accessibility and accommodations. This is among the biggest challenges for students with disabilities, preventing them from enjoying inclusive education in China.

Discrimination in employment

Persons with disabilities in China are not only isolated from the mainstream education

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[3] For example, in 2017, the State Council of China amended the People with Disabilities Education Ordinance, which set the principle of improving inclusive education.

system but are excluded from most of the open labor market.

First of all, the public sector, such as the administrative agencies, does not play a model role in recruiting persons with disabilities.[4] Instead, it takes the lead in discriminating against persons with disabilities. A huge obstacle for persons with disabilities to compete for government-employed public servant positions is the requirement of the “physical exam.” In China, for an applicant to be qualified as a public servant, the applicant must pass a paper exam, an interview exam, and a physical exam. Article 19 of the 2005 Civil Servant Recruitment General Physical Examination Standards (Trial) stipulates: “If a candidate’s best-corrected visual acuity is less than 0.8 for both eyes (standard logarithmic visual acuity 4.9) or those with obvious visual impairment of eye disease, the candidate is unqualified.” Article 20 stipulates: “If a candidate’s both ears have hearing impairments that disallow the candidate to hear voices within 3 meters after wearing a hearing aid, the candidate is unqualified.” These two provisions deprive persons with visual or hearing disabilities of the right to become public servants. Such laws constitute obviously direct discrimination, which violates Article 5 and Article 27 of the CRPD.

In another case, Fang Yuan was a low-vision student who graduated from a famous law school. She took the exam to apply for the position of clerk in the Chinese Supreme Court under the public servant system. Although she had no reasonable accommodation for the exam and did not have enough time to read and finish all of the questions in the paper exam, she still successfully passed both the paper exam and interview exam with an extremely high accurate percentage for the questions she could answer. However, she could

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[4] In fact, major developed countries always set government or other public sectors as examples to hire more employees with disabilities, which will encourage the private sectors to employ persons with disabilities actively.

not get the job in the end because her vision was less than 0.8, which is why she failed the physical exam. Fang Yuan's experience is the epitome of that encountered by most persons with disabilities in China. They experience direct discrimination from the existing requirements. China has, however, not established a judicial review system that allows them to challenge these unconstitutional rules.

In addition, the national standard for civil servants impacts the recruitment standards and provincial regulations for other jobs, such as for teachers. Besides discriminating against persons with visual or hearing disabilities, "The Henan Province Teacher Qualification Application Physical Examination Standards and Methods (Trial)" stipulates that "if a candidate's two upper limbs or two lower limbs cannot function; two lower limbs' unequal length is longer than 5 cm; scoliosis is more than 4 cm; muscle strength is below 2; or thorax is significantly deformed," the candidate is not qualified.

In addition, "The Shandong Province Teacher Qualification Medical Examination Standards and Operating Procedures" stipulate that "if a candidate has an upper limb or a lower limb that cannot move or [is] deformed; unsteady gait; a disabled upper limb (especially right hand) that affect the candidate's board writing ability; body deformities such as obvious 'chicken breast,' hunchback, or scoliosis of more than 3 cm; short stature," that candidate is unqualified (Beijing Yirenping Center, 2011). Such provisions appear in almost all provincial regulations related to teacher qualifications, which excludes most persons with physical disabilities from becoming a teacher.

Furthermore, as mentioned above, from the Constitution to laws, the keynote about disability employment in the Chinese government is "arrangement." Those with certain types of disabilities are organized to do the same kind of job. The vocational freedom of persons with disabilities is not respected. The Committee is concerned that "the practice of reserved employment (such as the field of 'blind massage'), … discriminates against persons with disabilities in their vocational and career choices" (U.N. Committee on the Rights of Persons with Disabilities, 2012). In fact, taking visually impaired persons as an example, most are chosen to do the same job – massage. Almost all vocational training for the blind is limited to massage rather than other training that considers individual interests and ability (Ni, 2014). As a result, in many people's minds, massage is the symbol of blindness. Such arrangements and practices are completely against the rights of free choice for persons with disabilities.

The phenomenon of fake employment is another problem in China. A quota policy requires that employees with disabilities occupy at least 1.5% of the total staff of each employer, no matter in the public sector or private sector. Otherwise, an employer must pay a levy for disability employment. Some "clever" employers pay their disabled employees the legal minimum wage and do not need them to work. In exchange, the employers submit information on their disabled employees and apply for an exemption from the levy. In this transaction chain, many agencies are active in matching employers who want to evade the levy with persons with disabilities to earn a commission (Traveling photographer, 2022). On the surface, it appears some persons with disabilities may get basic income without work, but such practices ultimately violate the rights and dignity of all persons with disabilities. Firstly, the quota policy is a kind of affirmative action to promote realization of disabled persons' equal right to work. Besides equitable recruitment, the quota also provides accessibility and reasonable accommodations. However, fake employment is obviously contrary to the purpose of the quota policy. Secondly, fake employment denies persons with disabilities the ability to serve as a talented and capable human resource, rather than stereotyped as incompetent and pathetic. Thirdly, employment is an important way to address disabled persons' social inclusion. But under fake employment, employees with disabilities do not step into an office or have contact with colleagues, blocking their social participation. In short, fake employment is like a glass of toxic cocktail, tasting not bad at the beginning, but ultimately causing long-term harm.

Discrimination in banking

The CRPD explicitly requires its contracting states to take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, control their own financial affairs, and have equal access to bank loans, mortgages, and other forms of financial credit, communicating that banking and other financial services are important in people’s daily lives. However, these requirements are often violated.

In China, persons with disabilities face difficulty not only in accessing advanced banking services such as loans or mortgages but also primary ones such as opening an account or applying for credit cards. For example, Xiao Shi, who has a congenital visual impairment (Feng, 2017), worked since 2005 for a chain of healthcare companies in Changsha, Hunan Province, doing massage and earning a stable income. In September 2016, he applied for a China Guangfa Bank credit card. After the online application was approved, he went to the Hongxing branch of the bank in Changsha to activate the card. The bank informed him that he had to read the risk warning and then sign his name. Xiao Shi said he was blind and could not sign, but the bank insisted on his signature, and rejected his application because of "not being able to read the risk warning and not signing.” The following month, Xiao Shi filed a lawsuit with the Yuhua District Court in Changsha City, requesting a judgment that the defendant issue a written apology to the plaintiff as redress for discrimination based on disability and promise to provide reasonable accommodations to blind people in their business (Xiao, 2017). Yuhua District Court dismissed Xiao Shi's claim.

The court pointed out that as a financial service institution, commercial banks have the freedom in market competition to choose the targets of their financial services. Commercial banks have the authority to exercise discretion and impose strict examination and approval procedures to protect credit safety and customer transaction security. The plaintiff argued that the bank should provide accommodations for completing the signing, such as allowing a recording, photocopying, or fingerprinting. The defendant said these flexible methods did not apply to the plaintiff for credit card activation. Although the defendant adopts far more rigorous methods and standardized review criteria compared to other commercial banks when approving credit card applicants, this was not found to constitute discrimination against the plaintiff or to violate his rights.

The experience of Xiao Shi is not a unique case; instead, most persons with disabilities in China have the experience of being refused in banking, especially when they need reasonable accommodations. Moreover, the court judgment may justify the bank's discrimination based on "financial security" or "freedom of transaction," although China is not a country of "stare decisis" (principle of recognizing prior case decisions). Actually, because of the lack of applicable legal definition for "discrimination," plaintiffs with disabilities can hardly win anti-discrimination lawsuits.

Discrimination in legal capacity

The CRPD clearly stipulates that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. Contracting states shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity. But in the Chinese legal system and judicial practice, there are several illustrations of failure to respect persons with disabilities' legal capacity.

Firstly, China passed the Maternal and Infant Health Care Law ("Eugenics Law") in 1995 (Gomez, 1996). China’s Eugenics Law mandates the forced sterilization of people with “serious genetic defects.” Recently, some congress representatives attempted to submit a bill to restate that each pregnant woman should accept mandatory screening for fetus defects (Jian Liang, 2015). If any fetus is found with a birth defect, the pregnant woman would need to get an abortion. The assumption was that persons with disabilities have no right to exist, which is a complete denial of their legal capacity. This has been compared to the Nazi genocide of Jewish people by reproductive intervention in the 1930s (Kanter & Dadey, 2018).

Secondly, the Chinese civil law system’s current legal guardianship provisions do not recognize the rights of persons with disabilities to make their own decisions and to have their autonomy, will, and preferences respected (U.N. Committee on the Rights of Persons with Disabilities, 2012).

Thirdly, the deprivation of liberty on the grounds of disability is allowed in China. Many persons with actual or perceived impairments are involuntarily committed to psychiatric institutions for various reasons, such as being petitioners. Besides, many persons who live with intellectual and psychosocial impairments and require a high level of support lack adequate resources for their medical and social care and are thus permanently confined at home. For those involuntarily committed persons with actual or perceived intellectual and psychosocial impairments, the “correctional therapy” offered at psychiatric institutions represents inhuman and degrading treatment. In addition, not all medical experimentation lacking free and informed consent is prohibited by Chinese law.

Lack of accessibility

Under the CRPD, accessibility is a basic principle. One specific provision (Cui & Chiu, 2020) requires contracted states to take appropriate measures to ensure persons with disabilities have access, on an equal basis with others, to the physical environment, transportation, information, and communications. In 2022, the National People's Congress of China published a draft of the LCBE for advice, which indicated the rules for a barrier-free environment have been enhanced from administrative regulation to national legislation.[5] The draft made some progress compared with the LPDP, Regulation on the Construction of Barrier-Free Environment, and other previous legislation. For example, the draft expanded the range of beneficiaries of the barrier-free environment from persons with disabilities to any social member in need, especially the elderly. However, the draft still left much to be desired, which could reflect the Chinese legal situation and dominance of the medical model.

Firstly, some provisions in the draft only focused on whether there is accessible facilitation rather than its usability. It is doubtful that such facilitation can really eliminate barriers; sometimes it can even create new barriers. For example, the second paragraph of Article 22 of the draft stipulates that people's governments at or above the county level support the promotion of the installation of elevators or other barrier-free facilities in existing residences. There is no doubt that elevators belong under accessible facilitation, but if an elevator is only equipped with a touch button and not Voice broadcast, it might create a new barrier for visually impaired users. The draft further failed to include accessibility standards for elevators, as well as the accessibility standards for blind roads (Cui & Chiu, 2020). That

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[5] Chinese official legislation uses the terminology “barrier-free environment,” which is approximately equal to “accessibility” under the CRPD.

means the intended beneficiaries can sometimes be harmed by the facilitation.

The second disadvantage of the draft was that it contained too many optional rules. Mandatory requirements are an important feature of law and are often in the form of legal obligations requiring the subject to act or not to act. Its operative term is "shall." Due to various reasons, optional rules occasionally appear in the law as a supplement to mandatory rules. Subjects who violate these rules will not bear the corresponding legal consequences, but the law expects subjects to abide by it or reward those who comply. "Encourage" is a typical term for such optional rules. Based on the characteristics of the law, the number of mandatory rules should be much more than that for optional rules. In the draft, according to approximate statistics, the expression "The state encourages" is used in at least 16 articles, many of which related to important standards in barrier-free environment construction. For example, Article 46 of the draft stipulates that the state encourage cultural, tourism, sports, financial, postal, telecommunications, commercial, catering, accommodation, and other service places to provide barrier-free services such as assistive devices, consultation, and guidance for those with accessibility needs. In fact, during the past years, several lawsuits based on discrimination against persons with disabilities in China resulted from public places' denial of accessible services (Cui & Chiu, 2020). By regarding accessibility as an optional rule, the draft asserts that denial of these services is not illegal, thus depriving persons with disabilities of their rights. Moreover, such optional rules were not only stipulated in the draft of the LCBE but are also widely found in other legislation in China, such as in the LPDP. The majority of Chinese laws related to disability equal rights look only like declarations rather than legal rules.

Furthermore, the draft failed to pave the way for broader use of the judiciary in resolving disputes regarding barrier-free environments. Chapter VI of the draft stipulated the legal liability for violations of the LCBE, but most of them referred to administrative liability. One example states: “The people's government at the same level shall order corrections” and “punish those directly responsible officials.” Based on its openness, neutrality, and procedures, the judiciary often becomes the last resort in resolving disputes. In the past, when exam organizers refused to provide reasonable accommodation, public places denied persons with disabilities’ access to services, or other disability rights incidents occurred, many cases were resolved by appealing to the courts. This does not deny the fact that the administrative approach is indispensable to resolving disputes. But if the LCBE, as law, fails to offer a clear guide, persons with disabilities resort to the judiciary to protect their equal rights. Such rights have not made progress compared with previous legislation.[6] In previous cases regarding discrimination based on disability, the parties and courts often faced several difficulties in determining what kinds of interests were damaged, the amount of loss, which provisions were violated, or the relationship between accessibility and discrimination. The LCBE draft also has not addressed the above issues.

Conclusion

The discrimination against persons with disabilities in China can be divided into three levels as follows. The first level is the direct threat to life, health, or freedom. This includes forced sterilization of people with genetic defects under the Eugenics Law, deprivation of freedom in psychiatric institutions, and medical experimentation without free and informed consent.

The second level of discrimination is the structural exclusion in certain fields, such as

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[6] Administrative liabilities, rather than judicial liabilities, were the primary liabilities stipulated in the LPDP.

education or employment that may substantially affect the development of one’s life. For example, the suspension of Xiao Zhu perhaps led him to stay away from the general education system his whole life. The Physical Exam Standard materially ended Fang Yuan’s public servant career. There has been a court holding that deprivation of employment might constitute economic persecution (Li v. Attorney General of the U.S., 2005). Here, refusing persons with disabilities’ access to public employment or inclusive education because they failed to meet certain “qualifications” can easily destroy one’s life.

The third level is the occasional discrimination in particular affairs, such as in applying for credit cards or traveling by plane. Such discrimination on the surface may no seem life threatening, but when accumulated, can block access to a full life. Should the reason for Xiao Shi’s credit card rejection become commonplace in banking or be imitated by other banks, it would damage persons with disabilities’ financial rights.

To eliminate the above discrimination, we propose a number of recommendations for legislators or other rule-making departments to consider. These also could serve as future directions for policy advocacy:

A. Gradually put an end to direct discrimination from the rules themselves. Abolish the existing physical examination standards, including the Civil Servant Recruitment General Physical Examination Standards (Trial), for entering public service examinations, or at least change the unreasonable restrictions for those with disabilities so that government departments can truly become examples of supporting equal employment for people with disabilities.

B. The law should clearly define and explain such concepts as "discrimination" and "reasonable accommodation" so that "discrimination" can be applied as a legal concept rather than just as a moral evaluation, thus reducing the obstacles in anti-discrimination cases. At the same time, this clarity would make people aware that refusal to provide reasonable accommodation is illegal.

C. There should be more specific regulations in disability law about the legal consequences of violating the law. The single disincentive to violating the disability law is the embarrassment of a lawsuit. Otherwise, the legal consequences for violations can only be found in civil or administrative law. Relatively clear legal consequences could also encourage relevant governments and enterprises to take more seriously their obligation to protect disability rights.

D. The law should raise the mandatory requirements and standards for accessibility construction. Accessible facilities should be mandatory in both physical and information environments. Also, the currently vague idea of information accessibility should be articulated and made a reality.

The law should stipulate rules regarding the violation of equal disability rights and what constitutes discrimination against disability, and support compensation for mental health damage. At present, the law does not impose additional legal responsibility on those who discriminate, thus lowering the cost of violating the law. At the same time, it is very difficult for persons with disabilities to obtain direct economic compensation in public interest disability litigation, which greatly affects their motivation to claim their rights. Of course, such a system could be very controversial.

With regard to persons with disabilities, another obstacle to the equal protection of their rights by law is their tolerance of violations and their unwillingness to assert their rights, leading to their inability to make use of the law. Being unwilling to protect their rights stems from a lack of awareness of their rights. What this reflects is a gap between their recognition of the phenomenon of disability, intrinsic human dignity and worth, and social pluralism, and the spirit of universality communicated by and advocated in the CRPD and other international conventions. Therefore, as important as policy advocacy is empowering persons with disabilities to safeguard their own rights.

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Understanding Parents' Voices in Mainland China

– A Sequential Mixed Methods Study

Yue Wu[1] and Peggy M. Martin[2]

[1]Rehabilitation Science, Rehabilitation Medicine, University of Minnesota

[2]Program in Occupational Therapy, University of Minnesota

Author Note

Correspondence concerning this article should be addressed to Yue Wu,

wu000150@umn.edu

Abstract

This sequential quantitative to qualitative mixed method study explored the impact of regional, cultural, and socio-economic differences on accessibility and people's perception of disability and rehabilitation services. A quantitative survey study was first conducted to collect demographic information and caregivers' perception of rehabilitation services from two rehabilitation centers in two regions known to be distinctively different culturally and socio-economically. Qualitative focus group interviews followed six months later with fifty participants from the survey populations whose children received treatment from two selected rehabilitation centers. The overall question of each focus group was: W*hat is your experience of having a child with disabilities?* Interviews were recorded, transcribed, and translated from Chinese to English. In Vivo coding and emotion coding were applied during data analysis. Five themes emerged from the focus group interviews: (1) being different; (2) feeling vulnerable; (3) being resilient; (4) valuing kindness and support; and (5) accepting disability.

Keywords: disability, regional differences, cultural differences, socio-economic differences, perception

Understanding Parents' Voices in Mainland China

– A Sequential Mixed Methods Study

Services for persons with disabilities have increased in Mainland China. This is reflected in the 2016 report published by China's Central Party Committee and State Council entitled *Blueprint Outline of the Healthy China 2030*. This report, according to the World Health Organization, is the first national level medium- to long-term strategic plan for the health sector since the founding of the People's Republic of China in 1949 (WHO, 2016). The blueprint specifically addressed access to healthcare services and public health equity. The government aimed to improve access to basic medical care and health services to reduce regional health inequalities (Zhuang, 2016). According to the report, new policies would increase disability care for families, increase medical financial aid for low-income people with disabilities, and develop barrier-free medical facilities (Li & Chen, 2020).

Rehabilitation tailored to children with disabilities can help them better adapt to society, gain knowledge and skills, and eventually become valuable contributors to society (Liang & Liang, 2018). In 2014, the Chinese General Office of the State Council published the *Proclamation of the Advancement of the Special Education Promotion Plan of the Ministry of Education and Other Departments (2014-2016).* Through the Proclamation, the government committed to carrying out the 'healthcare and education integration' project and exploring a special education model that integrates education and rehabilitation (General Office of the State Council, 2014). Addressing disabilities is not only a medical concern but also a challenging and costly social, public health, and ethical concern. Consequently, it is important to hear the voices of caregivers about their perceptions and experiences of having a child with disabilities. Moreover, people from different regions with different social economic and cultural backgrounds might have different experiences with rehabilitation.

Due to the country's large territory, various ethnic groups reside in different areas of mainland China and, therefore, have distinct cultural and religious traditions. Because of the uneven distribution of wealth in different regions, socio-economics factors play an important role in the accessibility of healthcare services. Previous studies showed that the top three statistically significant factors affecting rehabilitation accessibility in China are cost, knowledge about rehabilitation, and the belief in therapeutic benefits (Dai, Xue, Yin, & Xiao, 2006). Most people do not understand the importance of rehabilitation, nor do they have information about therapy options and their effectiveness (Dai et al, 2006). In this study, the authors focused on populations associated with rehabilitation centers in two regions in mainland China: Shandong Province and the Ningxia Hui Autonomous Region (hereafter "Ningxia"). Shandong is a coastal province in east China, where the Yellow River created rich land for agriculture. It is the birthplace of Confucius, who had a fundamental influence on Chinese culture and philosophy. Shandong has always been part of China's territory since the beginning of Chinese civilization. The major ethnicity of Shandong is Han, and the traditional religions are Taoism and Buddhism. On the other hand, Ningxia is an autonomous region of the Hui ethnicity, where the primary religion is Islam. Ningxia is upstream from the Yellow River; a sparsely settled, mostly desert region. It was on the route of the Silk Road that connected the East and West trade network. Throughout the five thousand years of

Chinese history, Ningxia has been located far from the political center and has endured constant conflicts between different ethnic groups. The western region is less developed economically, and it is harder for people to access rehabilitation resources (Kwong, 2015). Culturally, traditional thinking has a stronger root in the western region (Chu, 2011).

These two regions were chosen as focus areas due to existing professional connections and access to the healthcare and rehabilitation facilities in these two regions. Moreover, Shandong and Ningxia appear to be appropriate for this comparative study due to their notable differences in geography, location, socioeconomics, development, environment, ethnicity, culture, religion, customs, and lifestyles. Each region contained a rehabilitation facility that agreed to participate in this study. Both facilities serve children with autism spectrum disorder, cerebral palsy, intellectual and developmental disabilities, and hearing impairment. Both facilities were owned by the government, received funds from the central and local Disabled People Federations, and served children from two to fourteen years old. Therefore, children who enrolled in these two rehabilitation centers received intervention at no additional cost to families. The rehabilitation model in both rehabilitation centers requires close parent involvement. Caregivers were required to be in the same classroom with their children to learn strategies and to practice at home with their children. If a child did not cooperate when caregivers were present, the classroom teacher would ask the caregivers to go out and take a video of the session for caregivers to learn what was covered.

This research had both quantitative and qualitative aims. The quantitative aims were to:

(1) Understand the differences of family backgrounds between the two identified regions; and (2) Explore the impact of regional, cultural, and socio-economic differences on accessibility and people's perception of disability and rehabilitation services. The qualitative aim was to better understand the in-depth experience of families caring for a child with disabilities in two different regions of Mainland China.

Caregivers of children with disabilities from all over the world have documented difficulties in the areas of physical health, emotional health, and financial burden (Pilapil, Coletti, Rabey, & DeLaet. 2017; Gilson, Johnson, Davis, Brunton, Swift, Reddihough, & Williams, 2018). Caregivers need support and training to understand their children's diagnoses and provide better care (Scarinci, Erbasi, Moore, Ching, & Marnane, 2018; Spratling & Lee, 2020). However, little research has explored the experiences and perspectives of people from different regions in Mainland China regarding disability and rehabilitation services. The authors suggested that it is important for healthcare providers to have a clear understanding of the impact of cultural factors to provide better care. This sequential quantitative to qualitative mixed methods study compared responses from care providers for children with disabilities between two distinct regions (east and west). These two regions of China were selected because of their regional, cultural, and socio-economic differences. Both quantitative and qualitative phases were drawn from the same population of care providers, but the specific samples differed.

A sequential quantitative to qualitative mixed methods design was used to comprehensively understand the impact of regional, cultural, and socio-economic differences on accessibility and people’s perception of disability and rehabilitation services. As a native of China, the first author understands the cultural customs of the local people. A quantitative survey study took place first to collect basic demographic information and participants’ opinions followed by a qualitative focus group six months later to further understand the participants’ perceptions and experiences. Questions asked in the focus group were informed by the survey study results.

Phase 1 - A Quantitative Survey Study: Factors Affecting Accessibility and Perception of Rehabilitation in Two Regions in Mainland China

Methods

The purposes of the first phase were to understand the differences of family backgrounds between the two identified regions and people's perception of rehabilitation; and to explore the impact of regional, cultural, and socio-economic differences on accessibility and people’s perception of rehabilitation services. An online survey collected demographic information from parents of children attending two rehabilitation centers in two regions that are distinctively different culturally and socio-economically.

Participants

Participants were caregivers of children who were currently receiving services at the two selected rehabilitation centers.

Inclusion Criteria for Parents. The participating parents or guardians were recruited through text invitations by the administrator of each rehabilitation center Parents or caregivers were included if they:

(a) Had a child receiving treatment in one of the two identified facilities;

(b) Currently lived in Jinan, Shandong province or Yinchuan, Ningxia;

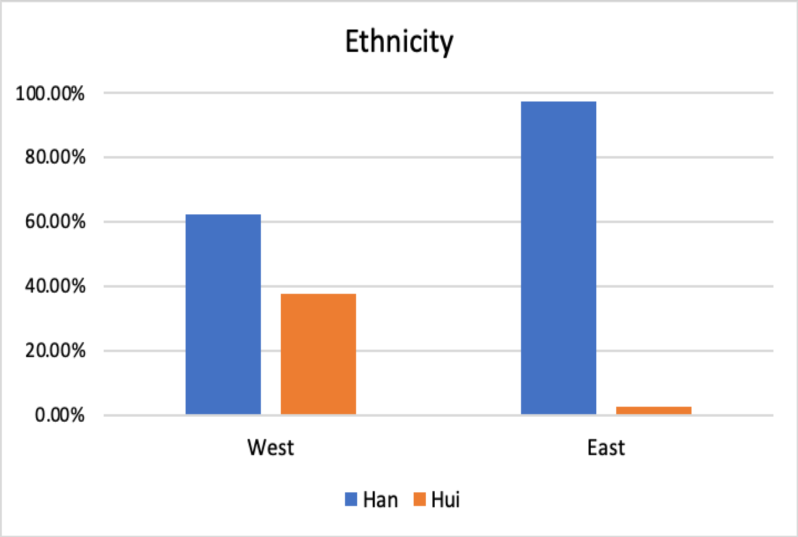
and

(c) Had a child with disabilities limited to cerebral palsy, autism spectrum disorder, intellectual and developmental disabilities, or hearing impairment.

There were 64 caregivers from Yinchuan (hereafter "the west region") and 37 parents from Jinan (hereafter "the east region") who filled out the survey. The survey was written in English and translated into Chinese. Of the participants in the west region, 62.5% were of Han ethnicity and 37.5% were of Hui ethnicity. On the other hand, in the east region, 97.3% of the participants were of Han ethnicity and 2.7% were of Hui ethnicity. A Chi-square test of independence was performed to examine the relationship between ethnicity and region. The relation between these variables was significant, X^2 (1, N = 101) = 15.24, p = .000095. People living in the western region are more likely to be of the Hui ethnicity than people from the eastern region.

Figure 2.1

Ethnicity Ratio of the Parents from the Two Regions



Among the west region participants, one person had no education (1.5%), seven only had an elementary level of education (10.9%), fourteen had a middle school education (21.9%), thirteen had a high school education (20.3%), thirteen had a vocational education (20.3%), and sixteen had a college education (25%). Seventy-eight percent of people had an annual household income less than 50,000 RMB (Chinese currency). Eighty-six percent of parents were in their 20's and 30's at the time of the survey. Among the east region participants, two had a high school education (5.4%), twenty-four had a vocational education (64.9%), six had a college education (16.2%), and five had gone to graduate school (13.5%). Seventy percent of people had an annual household income of less than 50,000 RMB. Ninety-two percent of parents were in their 30s and 40s at the time of the survey. A Kruskal-Wallis test was performed and demonstrated a significant difference of parents' ages between the west and east groups ($p = .017$). The rehabilitation center in the west region served families from a wider geographic area than the one in the east region. In the west region, participants were from a few different provinces. However, in the east region, all participants were from Shandong province, though different cities and suburbs.

Table 2.1

Demographic Information of the Parents from the Two Regions

Region	**Sample Size**	**Ethnicity (n) (Han: Hui)**	**Age**	**Education Level**	**Location**
West	64	40:24	20-30’s	No education - college	Close by regions
East	37	36:1	30-40’s	High school – grad school	Within province

Procedure

The first author took field trips in December 2018 to Jinan, the capital city of Shandong, and Yinchuan, the capital city of Ningxia, to visit the most representative rehabilitation facilities in each city. The author created an online survey through REDCap based on theories in existing literature (Dev & Qayyum 2017; Bapaye & Bapaye, 2021; Yiğitalp, Bayram, & Çifçi, 2021). The survey was distributed to the parents of children with disabilities through the facility administrators. The survey contained 11 multiple-choice questions take took 5-10 minutes to complete (see Appendix). The survey questions focused on the participants’ family background, including their ethnicity, regions of residency and social-economic status, as well as the parents’ perception of rehabilitation services. Due to the incidence of illiteracy in Ningxia, adaptations of the survey were made available, such as having a facility staff read the questions to caregivers, to enable participation. Participants responded to the survey anonymously and no contact information was collected.

Data Analysis

The quantitative survey study data were collected, processed, and analyzed in REDCap. Percentage statistics were generated to describe demographic differences and report service barriers. Statistical analysis was performed on RStudio (RStudio Team, 2020) to compare findings between the two respondent groups. Various statistical tests were performed.

Results

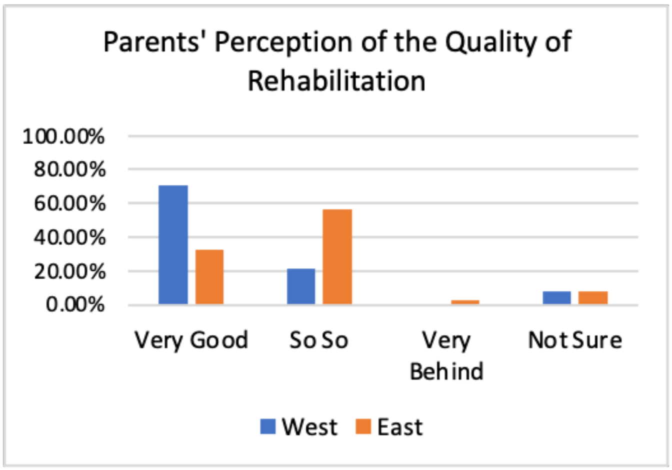
The survey results demonstrated that there were a few major differences between the two regions including ethnicity, educational levels, household income, and perception of rehabilitation. Participants' perceptions of the development of rehabilitation, impact factors, and types of therapies vary between the two regions.

Perception of the Quality of Rehabilitation in the Local Region

The perceptions from the parents on the quality of rehabilitation between the two regions were significantly different. Overall, most participants in the western region perceived their rehabilitation services as "very good," (70.77%), whereas the majority of parents in the eastern region perceived the quality of local rehabilitation services as only "so-so" (56.76%).

Figure 2.2

Parents' Perception of the Quality of Rehabilitation in the Two Regions



Perception of the Quality of Rehabilitation in the Local Region

	West	East
Very Good	70.77%	32.43%
So So	21.54%	56.76%
Very Behind	0	2.70%
Not Sure	7.69%	8.11%

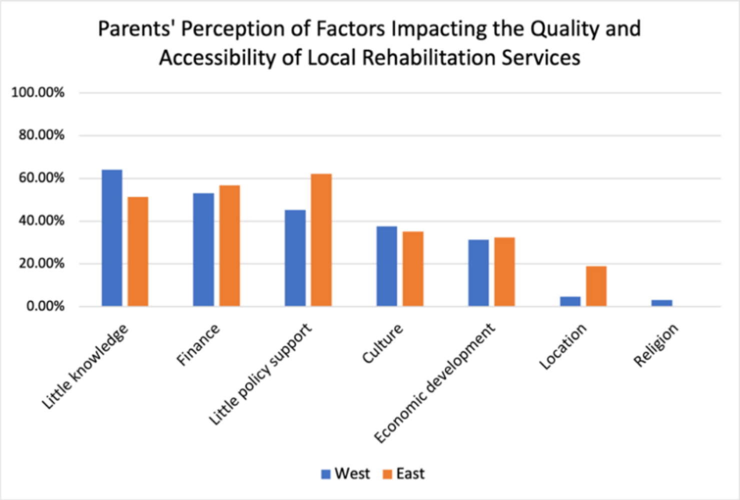
Factors Affecting Quality and Accessibility of Rehabilitation

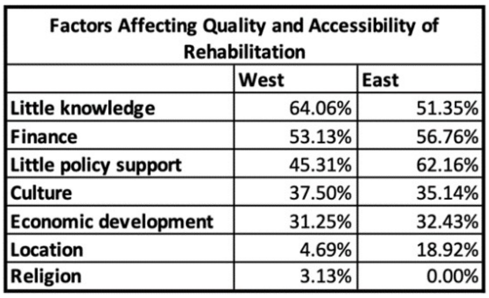
The top three caregiver-chosen factors that affected the quality and accessibility of rehabilitation services are the same between the two regions: “little knowledge about rehabilitation therapy,” “financial,” and “little policy support.” However, the west region respondents chose “little knowledge about rehabilitation therapy” (64.06%), whereas east region respondents chose “little policy support” (62.16%) as the top factor that affected the quality and accessibility of rehabilitation locally. Participants were asked to select all that pertained.

Figure 2.3

Parents’ Perception of the Factors Impacting the Quality and Accessibility of Local

Rehabilitation Services





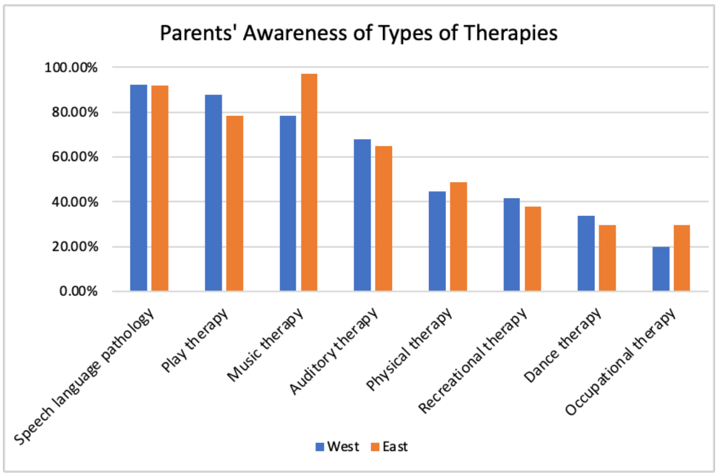
Factors Affecting Quality and Accessibility of Rehabilitation		
	West	East
Little knowledge	64.06%	51.35%
Finance	53.13%	56.76%
Little policy support	45.31%	62.16%
Culture	37.50%	35.14%
Economic development	31.25%	32.43%
Location	4.69%	18.92%
Religion	3.13%	0.00%

Awareness of the Types of Therapies Available for Children with Disabilities

When asked about what types of therapies parents were aware of, the top four types in both regions identified were: (1) speech therapy; (2) play therapy; (3) music therapy; and (4) auditory therapy. The bottom four in both regions were: (1) physical therapy; (2) recreational therapy; (3) dance therapy; and (4) occupational therapy.

Figure 2.4

Parents' Perception of Types of Therapies



Awareness of the Types of Therapies Available for Children with Disabilities		
	West	**East**
Speech language pathology	92.31%	91.89%
Play therapy	87.69%	78.38%
Music therapy	78.46%	97.30%
Auditory therapy	67.69%	64.86%
Physical therapy	44.62%	48.65%
Recreational therapy	41.54%	37.84%
Dance therapy	33.85%	29.73%
Occupational therapy	20%	29.73%

Discussion

To better serve people in rehabilitation settings, it is important to understand the impact of regional, cultural, and socioeconomic backgrounds had on people's experiences and perception of rehabilitation services. The purpose of this sequential quantitative to qualitative mixed method study was to explore and understand the impact of regional, cultural, and socio-economic differences on accessibility and people's perception of disability and rehabilitation services. The survey was designed to collect demographic information and participants' opinions on rehabilitation services.

An association was observed among education and parents' age. As reported by the staff, some caregivers in the west region were illiterate, which made it harder for them to learn information and seek help. On the other hand, most parents in the east region had post-secondary education and had an easier time accessing the information they needed. However, no causal factors were determined in this observation. Many factors may contribute to this phenomenon, for example the cost of living in the east region is higher than that in the west. A household with an income of 50,000 RMB in the western region may live better than a household with an income of 50,000 RMB in the east region. In the western region, participants were from a few different provinces. However, in the east region, all participants were from the local province, though different cities and suburbs. This difference suggested a lack of resources in the western part of China. Policies that favor the development of healthcare in west China are needed to attract health professionals to work in these less-developed areas. Financial support would be another key factor to help upgrade the medical equipment in hospitals to provide better care to patients.

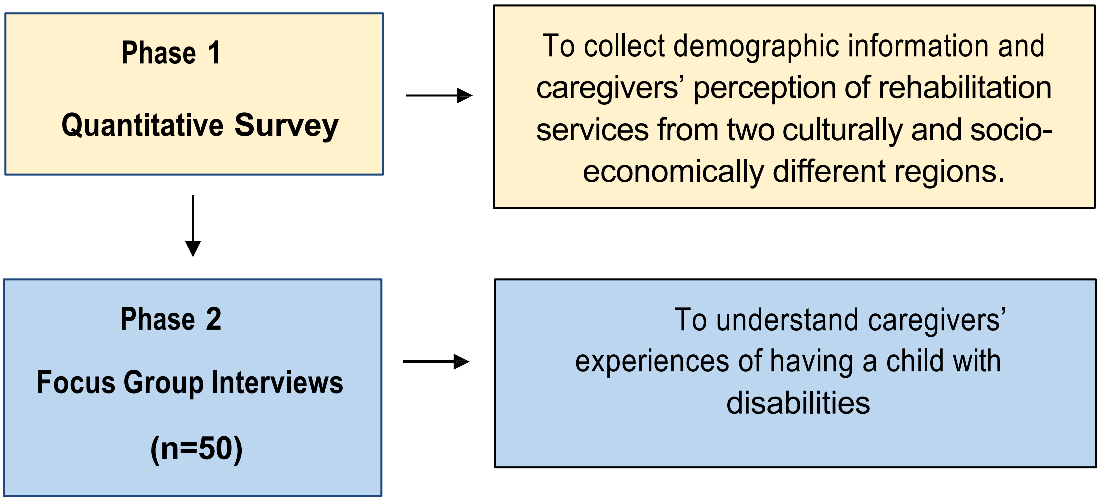
As mentioned before, the western region was relatively lacking resources and that was why participants from surrounding provinces moved to this region for treatment. However, most participants from the western region rated the local development of rehabilitation as "very good." On the contrary, most participants from the east region chose "so-so" even though they had easier access to rehabilitation resources due to the availability of information and their higher educational level. A possible interpretation could be that because of a lack of resources, parents in the west region perceived their rehabilitation services as being "very good" when there were services available. Another interesting finding is that speech language pathology, play therapy, music therapy, and auditory therapy were much better known by participants from both regions than physical therapy, recreational therapy, dance therapy, and occupational therapy, which are typical rehabilitation services in the U.S.

One reason for this difference might be that in China, the definition of each type of therapy is the same as in the U.S.; however, the scopes of practice may differ. Special education teachers at the centers may receive training in physical, occupational, and speech therapy, and may carry out rehabilitation goals in special education classes. In addition, physical and occupational therapy are embedded under the umbrella term, "rehabilitation therapy". Most of the staff would use the principles and techniques of physical and occupational therapy without being certified as physical or occupational therapists. Therefore, parents were not aware of the terms.

The survey study provided demographic information on caregivers in the two regions. The results confirmed the noticeable differences between the two regions culturally and socioeconomically. Moreover, it revealed significant findings regarding participants' perception of rehabilitation and the impact of regional, cultural, and social economic factors. As these findings were limited by the nature of quantitative study, the researchers could not fully understand participants' perceptions. Unanswered questions included how accessibility and differences in perception might affect parents' experiences of having children with disabilities. To better understand this, the researcher then ran a focus group, posing the question: *What is your experience of having a child with disabilities?* There were six-months between Phase 1 and Phase 2 of the study; the primary reason was this was that the researcher was studying in the U.S. and could only return to China for the focus group study during a school break. Moreover, the 6-month ensured the researcher had enough time to analyze the quantitative data and design the focus group study.

Figure 2.5

Procedural Diagram: mixed methods quantitative to qualitative explanatory study



Phase 2 - Parents' Experiences with Rehabilitation in China

Methods

A qualitative focus group study asked open-ended questions to a sample of eastern and western regions participants to better understand their experiences parenting a child with disabilities and their perspectives of rehabilitation. Questions were informed by results of the phase 1 survey study (Wu, 2021) to a different sample within the same population. Both the survey and the focus group studies used the same population and inclusion/exclusion criteria and may reflect some duplication in samples. The staff at the rehabilitation centers recruited twenty-five parents from each facility for the focus group study.

Procedure

Recruitment occurred via a text message sent by an administrator of each rehabilitation center to all parents of current children receiving treatment. The staff sent the recruitment information to parents weekly, starting a month before the focus group starting date. As the majority of mainland China speaks Mandarin Chinese, the recruitment statement was translated into Chinese by the first author. Translated consent forms were also provided. Six semi-structured focus group discussions were then held in the summer of 2019, approximately 6 months after the survey phase was completed. Five focus groups of 5 people each were held in the western region, and one large focus group of 25 people was held in the eastern region. The western region focus groups ran five consecutive days, lasting 60-90 minutes each and located in the same room, with five different participants per group. In the rehabilitation center in the eastern region, one focus group of twenty-five participants was held only once due to time constraints of the center. This focus group lasted 3.5 hours. Each caregiver attended a single focus group. Having five focus groups, 60-90 minutes each, from the western region yielded more text than the one 3.5-hour focus group in the eastern region.

Each focus group began with the primary investigator describing the research question, explaining consent, and responding to questions. Questions included:

- What is your experience of having a child with disabilities?
- What does rehabilitation mean to you?
- What are your hopes for your children in the future?
- How can healthcare services better support your needs?

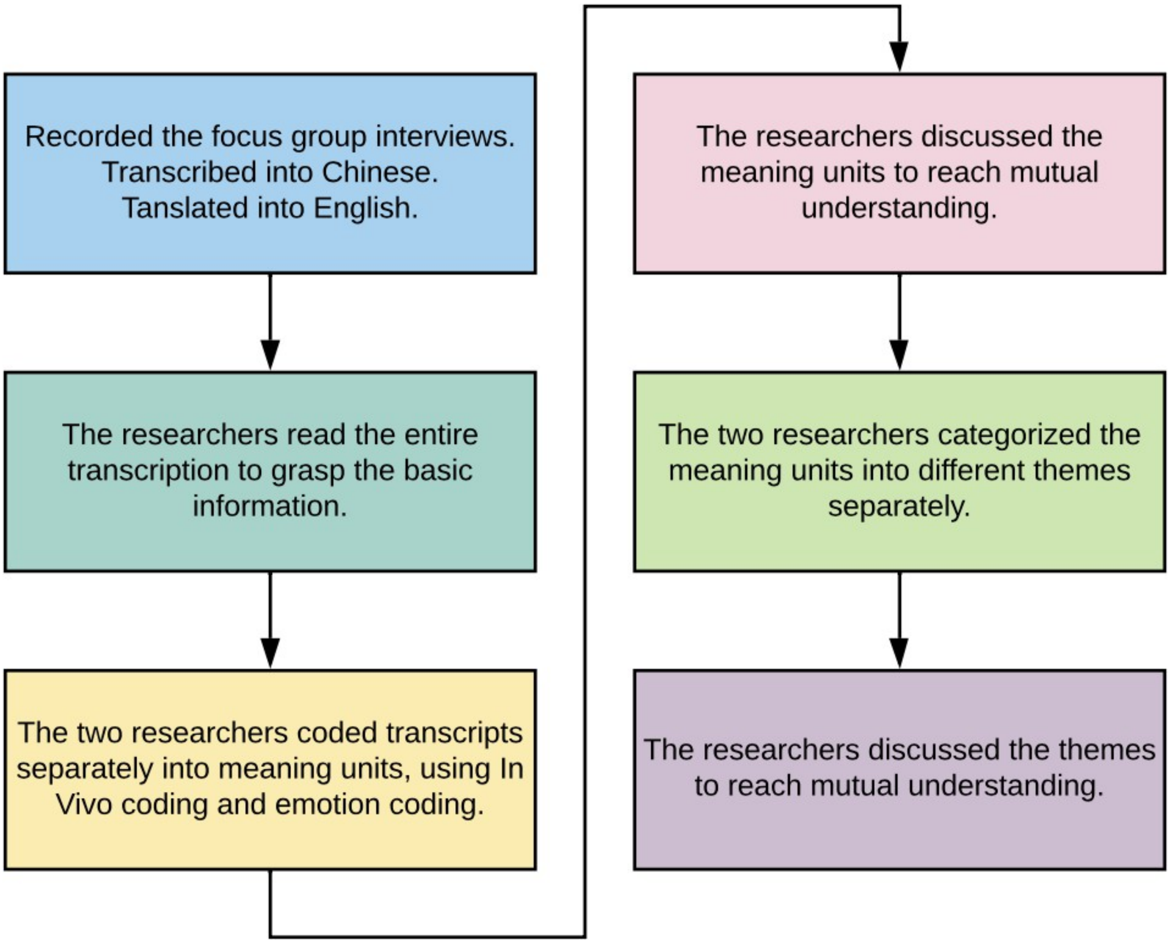
Focus group discussions were audio recorded, transcribed into Chinese, translated into English, and later analyzed for themes. Each participant was given a pseudonym at the time of transcription to ensure anonymity. Transcribed English text from the focus group discussions was selected and labeled as meaning units separately by the researcher and an experienced qualitative researcher, and then compared to ensure agreement. When disagreements arose, researchers discussed until agreement was reached, most often in response to cultural norms.

Data Analysis

The transcribed words, translated from Chinese to English, were the basic form of data used in the qualitative focus group study (Miles, Saldaña, & Saldaña, 2014). Reverse translation (from English to Chinese) was applied to ensure original Chinese translation was accurate. The first author approached each interview using an open stance to prevent leading participants toward answers. The descriptive information compiled during the focus groups was coded into meaning units. In Vivo coding (Miles, Saldaña, & Saldaña, 2014) and emotion coding (Miles, Saldaña, & Saldaña, 2014) were applied in this study. In Vivo coding uses the words from the participant's own language directly as codes (Miles, Saldaña, & Saldaña, 2014). This coding strategy helped to capture existing group cultural categories. For example, one participant said “The child’s father does not want him. He felt that having such a child would not be acceptable.” The researchers coded the meaning unit as “having such a child would not be acceptable.” Emotion coding “provides insight into the participants’ perspectives, worldviews, and life conditions” (Miles, Saldaña, & Saldaña, 2014). For example, one participant said, “I was so angry that I was grinding my teeth.” The researchers coded the meaning unit as “so angry grinding teeth.” In Vivo coding focuses on participants’ exact language while emotion coding pays attention to participants' emotional language to reflect their perspectives. After coding each individual focus group transcript, themes were categorized across all focus group discussions. To reduce their influence, both researchers openly discussed personal biases about rehabilitation in China before analyzing data. Strategies used to reduce bias included using the participants’ own words to describe a theme, finding agreement between the two researchers who independently read and identified meaning units first separately, and the final assignment of a meaning unit by agreement between the two researchers.

Figure 2.6

Data Analysis Procedure

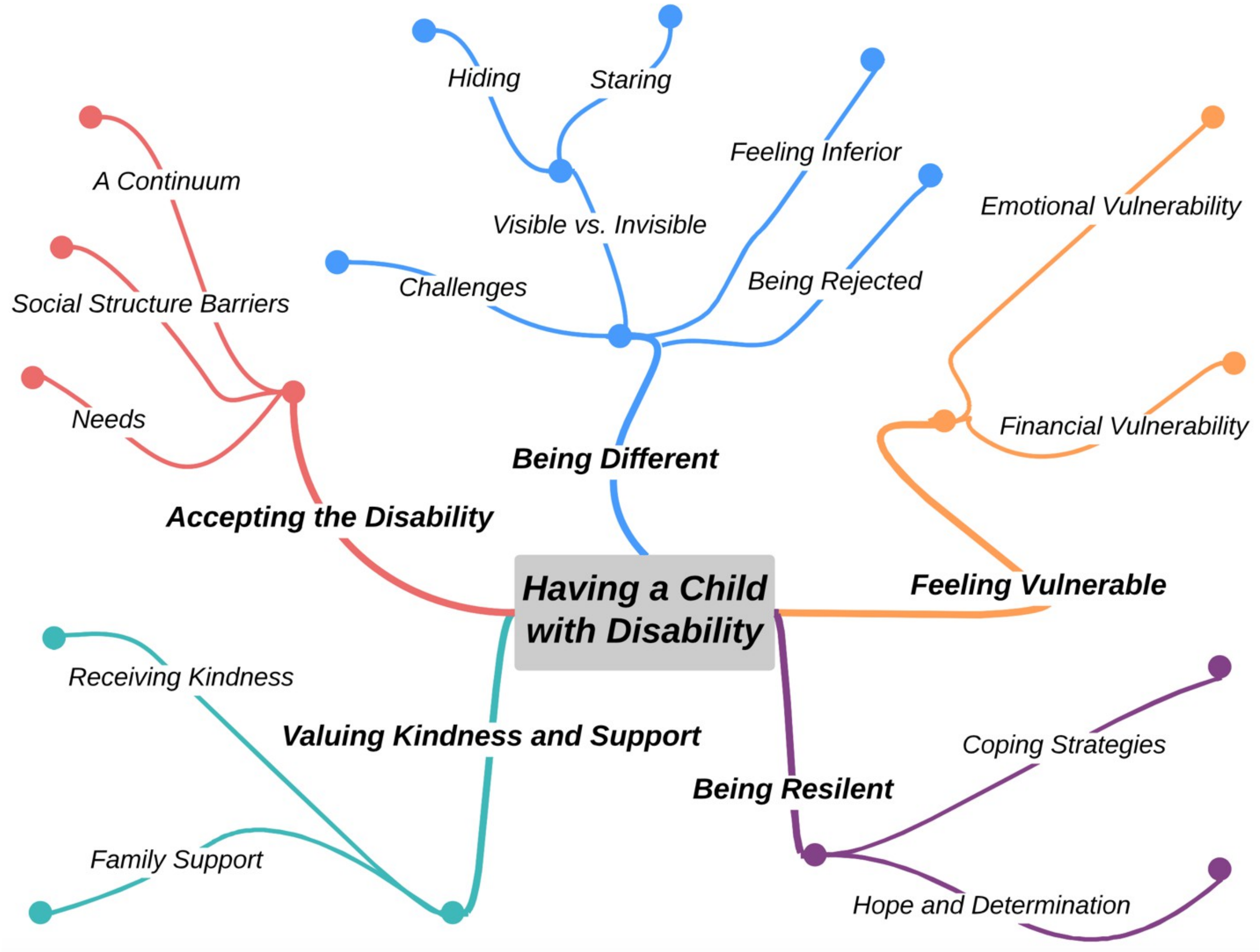


Results

The following key themes emerged from the words spoken by focus group participants: Being Different, Feeling Vulnerable, Being Resilient, Valuing Kindness and Support, and Accepting the Disability.

Figure 2.7

Themes that Emerged from the Focus Group Interviews



Being Different

The presenting symptoms of a neurodiverse child are different from a neuro-typical child. Jie said that her little girl “sometimes laughs so loudly and screams. Other caregivers realize that there is something wrong with her.” Caregivers observed that some people saw their children but pretended not to; others would stare at their children. According to Jie, “sometimes other caregivers look at my child strangely.” Children who have cochlear implants may easily draw people’s attention. Ting mentioned that “sometimes when I take my son out, someone will ask him ‘What are you wearing? Do you have a hole on your head?'" Sometimes, families, neighbors, and strangers' reactions to their children made caregivers feel inferior. Jie shared an incident when her daughter attended a community dance class and pulled another girl's hair. The other girl's grandma came and slapped her daughter's hand, "What are you doing? Why are you touching my granddaughter and making her hair messy?!" Jie wept and said, "I cried that time." Qiang also reported that once, when he heard other children calling his son a derogatory name, "I was so angry that I was grinding my teeth."

Physical and behavioral differences make disability visible. Emotional and social behavioral challenges that make children with disabilities different can result in inappropriate attention and comments from community members. As a result, caregivers of children with disabilities may experience feelings of inferiority and rejection because of how people treat their children.

Feeling Vulnerable

Caregivers experience both emotional and financial stresses due to social stigma, lack of support, and limited accessibility to public rehabilitation services, and financial hardships. Some participants expressed feeling emotionally vulnerable. Su, a grandparent said, "As the grandma, I feel that my daughter has been depressed in the past two years because of stress. I think that having such a child makes caregivers feel ashamed." The stress parents experience may also have a negative effect on their temperament. "My husband was always very patient. But now, because of our child, he loses his patience very easily," Zhen said.

As Dong pointed out, "caregivers are deeply anxious and desperately need help."

Caregivers wanted more information about how they could help their children at home: “I don't know where to start when I get home, how to teach my child.” Wen spoke of her own stress about this: “I have a headache every time I think about this. Where do I take her afterwards [after she ages out of rehabilitation services]?” “Rehabilitation is not something short-term,” Yan said, “We can hardly afford the private treatment centers.” Limited availability and access to public rehabilitation centers, resulted in some families leaving their homes to move to a different city. Such was the case with Ran’s family: “We are not local, so we have to rent an apartment which brings economic pressure.” For families that did not have grandparents able to watch the child, parents negotiated working and child watching duties, often not working outside of the home at the same time. These families reorganized their schedules to cope with the situation. As Ling described: “Usually my husband comes home after work and stays with our child and then I go to work.” Li agreed: “One parent will go out to earn money and the other takes care of the child, or one of the parents switches to night shifts to take care of the child during the day.” With one parent staying home with the child, the household income is basically cut in half.

Caregivers in this study were vulnerable both emotionally and financially. Participants expressed feelings of loneliness, desire for family and community support, and concerns about the high cost of services to help their children with disabilities.

Being Resilient

Caregivers developed a variety of coping strategies, including self-care. Ling said, “If you think too much about the future, you will put too much pressure on yourself. It is good just to live one day at a time.” Other caregivers used coping strategies such as talking to colleagues, going to movies, planning family vacations, and shopping. “I play sports with my neighbors as a way of venting and relaxing… I think, as parents, our attitude is very important. Attitude determines altitude,” Lin said. Jia described another way of coping, “The way I handle it is that the more you look at my son, the more I stare at you.” Hong tried another option, “I would try to bring my child to say hello to others, try to be friendly first. If you are friendly first, others will be friendly to you.” Caregivers frequently brought up hope: “I also want to have hope and I feel that I must change my mindset. If I have a good attitude, I can pass positive energy to my child,” Zhen said. Regardless, they are determined to provide the best to their children, as Pu said, “There is no other way. I will use all my strength to raise my grandson.” “It will get better and better as long as..... we all look after our child,” Jia echoed.

Caregivers developed different coping strategies in dealing with their stress of daily life. Some reported “thinking too much,” some reported doing fun things with family and friends, and some learned how to confront injustice. Caregivers expressed their hope and determination, eager to provide the best support for their children.

Valuing Kindness and Support

Another theme that arose from the focus group discussions was how participants valued kindness and support those caregivers received. Unlike resilience, which comes from within, kindness and support were provided to individual caregivers by external sources. Kindness and support included kind words from a neighbor, support from family members including the grandparents' involved in taking care of the children. Lan described, "In the community, most people who see such a child [with a disability] will sympathize with his parents. They feel that the parents will be with this child for a lifetime" (Qing). Others commented that the kindness and encouragement from neighbors and strangers were heart-warming and let the caregivers feel "there are more good people in the world." Qiang described, "A lady in her 50's in our neighborhood is very kind. My child goes to visit that lady every day at noon." This kindness is also mutual, Qiang continued, "The lady said to me, 'Look, your son's heart is clear. I talk to him, and he knows me.' My son knows that only this lady talks to him, so he loves her back." Jia, another participant responded, "Our neighbors are very good. When they see us, they say, 'The child is much better now.' These words are so warm."

The compassionate words from others and practical help from family members are important to caregivers of children with disabilities. They became the fuel to keep them going and provided hope for the families that "there still are more people who are kind."

Accepting Disability

The perception of rehabilitation is caregivers' opinion related to rehabilitation, including what rehabilitation is to them, how they use rehabilitative concepts in their daily lives, what rehabilitative goals they want their children to achieve, and barriers in the long-term rehabilitation process. At the beginning, many caregivers, particularly in the rural areas, had little knowledge about early childhood development. "There are no similar children around. I never knew what autism, developmental delay, or Down syndrome was. We didn't know what the milestones of a child’s development are and when a child should talk,” Jie said. Some caregivers seek information on their own to continue the rehabilitation process. Lin creatively used his knowledge of rehabilitation and took every opportunity to help his children gain functional skills: “My son’s hobby is like mine. We love to fix things. Sometimes I take out some old devices for him to play with. I use this to develop his fine motor skills.”

Caregivers expressed need for greater support to help better integrate their children into society. Ye, a parent from the eastern region stated, “Social acceptance is not enough, and it is difficult for children to integrate. Caregivers identified a lack of service options and professional support. Yao stated, “We parents read books or watch videos to learn about rehabilitation… still we lack professional support.” Social structure change and legislative support are common requests of caregivers. They realize individual efforts are not enough to support their children’s long-term rehabilitation. Dong stated “We need assurance for our children’s future. We don't have a sense of security right now.” Jing followed, “I hope there will be more organizations for the children to go to later. I hope that with the development of our society, there will be a public care institution that will give caregivers a break.” Although, rehabilitation services and policies have come a long way in mainland China, there are still many needs to be addressed.

In answering the overarching question: *what is your experience of having a child with a disability,* caregivers expressed and elaborated on their experiences of being different, feeling vulnerable, being resilient, valuing kindness and support, and accepting disability.

The similarities and differences between the eastern and western regions are discussed in the following section.

Discussion

The qualitative results supported previous research on caregivers’ experiences of physical, emotional, and financial strains, as well as the needs of support programs and skill training (Schulz & Sherwood, 2008; Goudie, Narcisse, Hall & Juo, 2014; Pilapil, Coletti, Rabey & DeLaet. 2017). Caregivers need continuous education and training in facing and addressing new situations as they manage the care of their children at home (Spratling & Lee, 2020). Findings from the current focus group study confirmed the needs of respite care, sustainable programs, and skill training in better serving children with disabilities and their caregivers.

Care providers from various countries describe similar experiences, yet culturally nuanced (Jones, Ward, Hodkinson, Reid, Wallis, Harrison & Argent, 2016; Tennant, Allana, Mercer & Burns, 2022). According to previous research, families who are affected by disabilities experience stress and financial hardship; however, the support they receive contributes to their resilience (Farrell & Krahn, 2015). A phenomenological study on caregivers’ experiences in Swaziland found that parents experience “challenges at work, home, school, and in the community such as emotional stress, failure to cope with the children’s disability and financial challenges” (Thwala, Ntinda, & Hlanze, 2015). The study also suggests the need for parental training programs and government policies to ensure the children’s welfare.

Two ways of thinking about rehabilitation emerged from the focus group discussions. The medical model of rehabilitation focuses on skill-development, such as improving language, social communication, and emotional regulation skills (Marks, 1997). On the other hand, the social society's attitudes towards disabilities, providing social structures, and adapting the environment to better support individuals with disabilities (Marks, 1997). Caregivers supported rehabilitation at home by incorporating new information into their children's daily activities. Some participants demonstrated their understanding of "family shared occupation" and acted like amateur therapists (Pickens & Pizur-Barnekow, 2009; Sachs & Nasser, 2009).

Limitation and Future Research Directions

The interpretation might be biased because of the first author's familiarity with the east region of this study. However, in-vivo coding was used to preserve participants' essential meaning and prevent biased interpretation. Because both the quantitative survey study and the qualitative focus group study drew from the same population, there might be bias in the results. Another limitation was that different focus group formats were used in the two regions and this difference might bias results towards the west region where five smaller focus groups occurred.

Future studies may look at gender differences about the perception of rehabilitation in greater depth. This current study combined and analyzed the data from both east and west regions. Future studies might want to just look at one region at a time to compare the difference of experience in different regions. This study also inspires other study questions.

For example, why people under the same circumstance have different experiences? What are the factors that contribute to that? As the field of rehabilitation is rapidly developing in mainland China, the authors anticipate that people's access to and perception of rehabilitation services will change accordingly. A longitudinal or follow-up study might be worth conducting to capture the development and progress of rehabilitation services in mainland China.

Conclusion

This mixed method study provided a comprehensive view of how caregivers who have children of disabilities from two culturally, socially, and economically different regions viewed rehabilitation services in mainland China, and how these differences impacted their experiences of having a child with disabilities. Despite all the differences between the two regions, caregivers' experiences have some consistently similar themes. The east region, more culturally open and economically developed, had better access to more rehabilitation services compared to the west region. Moreover, their perception of rehabilitation services was more sophisticated; that is, rather than focusing on immediate rehabilitation needs, they were concerned about developing long-term legislative changes. The results suggest the needs for continued coping strategies for managing care, enhanced public education to reduce stigma and misunderstandings towards disabilities, and the existence of long-term care plans supported by disabilities legislation.

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Community-like Institution and Institutionalized Community:

Reflection on the Implementation of Article 19 of the CRPD in China

Yi Huang

Shenzhen Autism Society, China, Raoul Wallenberg Institute of Human Rights and Humanitarian Law, Lund University, Lund, Sweden

Author Note

Yi Huang has a PhD in law from the University of Leeds and is now the director of Shenzhen Autism Society (in China). Applying a legal-anthropology approach, her research interests lie in international human rights law, rights of persons with disabilities, comparative law and legal culture. She is currently visiting research in Lund University, Sweden. Address: Room 305, Shenzhen Autism Society, Ju Zhihui Building, West Nigang Road, Shenzhen, China

Abstract

With a major focus on the implementation of Article 19 of the Convention on the Rights of Persons with Disabilities in China, this paper examines the key elements of community that empower people with disabilities to live and, more importantly, participate and be included in the community.

Keywords: disabilities, community living, Convention on the Rights of Persons with Disabilities, China

Community-like Institution and Institutionalized Community:

Reflection on the Implementation of Article 19 of the CRPD in China

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes the equal rights of all persons with disabilities (PwDs) to independent living and inclusive life in the community. Central to Article 19 is the call for empowering support for PwDs to have autonomous choice and control over their lives, advancing the core human rights values of equality and dignity (Committee on the Rights of Persons with Disabilities, 2017).

The last decade has witnessed advancements in implementing Article 19, as well as debate and misunderstanding around it. In particular, given the close relationship between Article 19 and the western discourse on deinstitutionalization, both concepts of “independent” and “community” have been subject to cultural incompatibility in the Asian context, including in China, where institutionalization arguably never existed (Fina et al., 2017; Hayashi & Okuhira, 2008). Apart from the cultural differences regarding deinstitutionalization, existing literature has suggested a common experience shared by PwDs in both Western and Asian contexts: a sense of alienation pervading their lives even after living in the community for quite a long time (Milner & Kelly, 2009; Wang, 2013).

Based on this background, the core research question raised in this paper is what should be the key elements of community that empower PwDs to live and, more importantly, actually participate and be included in the community. This question will be examined by using the “weak cultural relativism” proposed by Donnelly (1999, 2007) as a lens for understanding the potential tension between the universality of Article 19 as a piece of human rights law and the cultural differences that may influence its implementation. The analysis will mainly focus on the implementation of Article 19 in China, drawing on an extensive review of literature, relevant policies, and publicly available secondary material such as reports of practice, records of conferences, and news accounts.

A brief review of the theoretical and normative framework of this paper will be given in section 2. A comparative study of how community is conceptualized in Western and China's contexts will be given in section 3. An analysis of recent attempts in China regarding the right of PwDs to community living and relevant community-based services will be presented in section 4. Further discussions of the key elements of an empowering and supportive community will be given in section 5, followed by a conclusion and issues for future research in section 6.

Section 2: Theoretical and Normative Framework

Theoretical framework: The universal human rights law in a cultural relative context

The implementation of international human rights law inevitably creates a debate between universalism and cultural relativism (Mertus, 1999; Reichert, 2006). This debate encompasses two key issues: one is how to ensure that international human rights law is understood in the way it should be when interpreted in different sociocultural contexts (Legrand, 1997; Watson, 1983; Zola, 2005). The other is how to strike a balance between human rights law and local cultures to avoid human rights laws becoming hegemonic. (Michaels, 2013; Michele Graziadei, 2006).

The debate between universalism and cultural relativism has pervaded Article 19 discussion since the very beginning of its drafting process, manifested by skepticism and criticism from a cultural perspective. A typical example of this is the concern raised by people from Asian countries as to why living independently should be a human right. In some Asian countries, it is considered preferable for people to always live with their families, and underlying this is the cultural emphasis on the value of family. Therefore, there was the argument that Article 19 was incompatible with Asian culture (Hayashi & Okuhira, 2008; Yan et al., 2014). As will be discussed later, such an argument is subject to the criticism that Article 19 is misunderstood and shows how Article 19 as an international human rights law is embedded in the debate over universalism and cultural relativism.

There is extensive literature regarding the debate of universalism and cultural relativism regarding international human rights law. However, going deeply into this is beyond the purpose of this paper. Selective arguments from both sides will be reviewed in the following sub-sections to set the theoretical framework for the discussion in this paper.

The universality of international human rights law

Those who argue for the universality of international human rights law have pointed out, first of all, that human rights can be regarded as an abstract concept of rights that one enjoys simply because one is human (Donnelly, 1982; Hastrup, 2001; Shany, 2013). This is a kind of global consciousness reinforced in the process of globalization (Mertus, 1999).

In addition, Donnelly (1984, 2007) advances the idea of international legal universality, which means that when human rights' values are codified into international human rights law, it acquires a certain degree of substantive universality. Through ratification, state parties accept that the list of human rights in the law should be universal and implemented at the domestic level. While a violation might not deprive state parties of their legitimacy under international law, it can influence political legitimacy.

These two points partially respond to the concerns of hegemony as they explain that human rights are a kind of consensus formed in the trend of globalization and accepted by the states.

Further, van Dijk (1995) advances the idea of functional universality, which refers to the creation of international monitoring mechanisms, such as the Committee on the Rights of Persons with Disabilities (CRPD Committee), and its accepted competence to ensure that human rights law is universally implemented by state parties. This point partially responds to any misunderstanding of international human rights law by showing that there are monitoring mechanisms responsible for the proper interpretation and implementation.

Cultural relativism and variation

Cultural relativism and universalism are not an absolute dichotomy; hence those who acknowledge the significance of cultural context do not necessarily deny the universality of international human rights law.

Örücü (2002) employs an interesting metaphor which explains the traveling of law in different contexts as a process of transposition, tuning, and fitting. Applying the process of transposition to the implementation of international human rights law means that the sociocultural context at the national level should be well studied and the international human rights law should be adapted in a way that suits the local context. The process of transposition is considered an important step because the cultural context will have an essential influence on how human rights law is understood and applied in domestic legal reasoning. As an arguably more important reason, Merry (2009), based on her empirical study of the implementation of international human rights law in several different sociocultural contexts, points out that the cultural aspect should be seriously considered because human rights law should be translated into the version that local people can understand, accept, and use.

Donnelly (1984, 2007) distinguishes between strong and weak cultural relativism. Strong cultural relativism takes the position that human rights are culturally determined.

Weak cultural relativism proceeds from the presumption of the universality of human rights law, and culture is seen to play a role in checking the potential excesses of universalism. In a similar but more specific view, Merry (2009, 2010) disaggregated human rights into three levels, namely, human rights value, the rights framework, and the expression of human rights ideas. She argues that cultural variation should be weak and happen only at the level of the expression of human rights law and ideas. The values underlying human rights law, on the other hand, should be firmly insisted on rather than altered to fit the local culture. She advances an even stronger argument that when part of the human rights value conflicts with the local condition, human rights law should have the power and capacity to challenge existing social conditions by providing a radically different frame of thinking.

The universality of Article 19 and the socio-cultural context of China

The approach of weak cultural relativism is adopted in this paper. This means, firstly, the discussion proceeds from the assumption that Article 19 of the CRPD should be universal. The meaning, implication, and value underlying Article 19 are universal and shall be firmly adhered to when it is implemented in China at the national level.

Second, the importance of the sociocultural context is recognized in this paper. An in-depth study of China’s social-cultural aspects is included in the discussion because repackaging and presenting the universal meaning and value of Article 19 in a culturally sensitive way is regarded as an essential step in implementation at the national level. Only with this step can Article 19 go from paper to practice and be mobilized by local people, especially those most vulnerable and in need of rights protection. In cases where human rights’ values conflict with the local context, which may be inevitable, this paper tends to agree with Merry that the human rights values should be upheld and serve as a different frame of thinking for local people.

Normative framework: Article 19 and General Comment No. 5

Article 19's call for living independently and being included in the community is referred to as the normative framework in this paper. The article recognizes the equal right of all persons with disabilities to independent living and community inclusion (Committee on the Rights of Persons with Disabilities, 2017), and calls for empowering different forms of support, including deinstitutionalization strategies, accessible community facilities, community-based and individualized assistance, and raising of public awareness (Committee on the Rights of Persons with Disabilities, 2017).

Informed by the functional universality proposed by van Djik (1995), General Comment No. 5 issued by the CRPD Committee should be one of the most important sources for understanding Article 19. Two concepts are essential to understanding not only the text but also the meaning, implication, and value of Article 19 regarding independent and community living.

The term independent in Article 19 is interpreted quite clearly. According to General Comment No. 5 (Committee on the Rights of Persons with Disabilities, 2017), independent living means exercising choice and control over one's life and making all decisions concerning one's life. Based on this interpretation, the term independent refers to the independence of personality, emphasizing personal autonomy and self-determination, rather than living alone or carrying out daily activities by oneself. The interpretation in General Comment No. 5 also serves as a response to culture-based criticism, as mentioned previously, by clarifying that the recognition of and emphasis on independence does not mean the isolation of a person from their families or others.

The meaning of the term community is relatively less clear. The General Comment No. 5 defines what is being included in the community without defining the term community itself. The definition of being included in the community is presented from the perspective of accessibility, ranging from the accessibility of various places and facilities to the accessibility of public and specialized support services and political and cultural events (Committee on the Rights of Persons with Disabilities, 2017, para. 16(b)). In addition, community-based independent living arrangements are described as lacking the "defining elements of institute or institutionalization" (Committee on the Rights of Persons with Disabilities, 2017, para. 16(c)). Given such an interpretation, the image of community is arguably drawn by the method of exclusion, i.e., listing the defining elements of an institution first and defining community as not having these elements. Described in this way, the community is still a relatively abstract concept and thus subject to various and arbitrary interpretations in different sociocultural contexts.

Community in different socio-cultural contexts

Current literature and practice illustrate that the image of the community can be very different in different contexts.

Community in the Western context

In the literature of the Western context, the conception of community is usually constructed in the context of deinstitutionalization. The typical institution is usually thought of as places like the asylums described by Goffman (1961), prison-like and totally controlled, with a low quality of life and limited access to the outside world. Community is somehow conceptualized as anywhere outside the asylum walls (Boelé, 2017; Milner & Kelly, 2009).

Defining community in this way has been criticized from several perspectives. The first and most straightforward criticism is that the community is thus reduced to a geographical area. As long as the place does not look like the segregated environment historically experienced by disabled people, it is recognized as the community (Autistic

Minority International, n.d.; Boelé, 2017). The policymakers emphasize spatial presence over other indicators of community inclusion, and services and support provided in line with such policies further entrench the significance of the geographical dimension of the community (Milner & Kelly, 2009). As some critics have pointed out, the battle to move out of institutions has been fought and won, but the personalized needs, aspirations, and quality of life of the person after moving out of the institution have still not been adequately considered (Cummins & Lau, 2003).

Related to this point, another criticism raised is that too much emphasis has been put on the presence of PwDs in ordinary spaces and community life. The value of places shared by PwDs and relationships between peers are always undermined (Amado et al., 2013). Reflected in this practice is that community-based services tend to be steered toward mainstream locations instead of to places chosen or defined by PwDs where they have more psychological safety and a sense of belonging (Boelé, 2017; Milner & Kelly, 2009). The outcome and effectiveness of community-based services are evaluated exclusively by indicators of objective integration and do not address the realm of personal experience. Measures to support the development of social capital or a sense of community for PwDs are largely absent (Cummins & Lau, 2003).

More importantly, as Cummins & Lau (2003) found, PwDs may define community in an abstract way, as the place “out there,” i.e., outside their home or day center. They do not define the community from the perspective of how they belong to it. This further indicates that decades after deinstitutionalization, PwDs remain absent from intimate social and interpersonal relationships. The presence of such relationships is precisely how community integration should be characterized. It is necessary to question whether PwDs should be forced to integrate into the so-called community.

Community in the sociocultural context of China

In comparison with the implementation of Article 19 in the Western context, the most obvious difference with China, as well as most East Asian countries, is that there are not many walls of asylum to fight against. In China, the traditional and culturally justifiable practice is that PwDs are cared for by their families at home. Although changing socio-economic configurations have raised challenges for families, the whole society, including the government, policymakers, and majority of citizens, have shown a consensus to maintain the tradition of family care. Such consensus can partially find its root in Confucian cultural heritage (Chui, 2007). Because of such practice and lasting consensus, most PwDs in China are at least physically in the community with their families rather than in an institution.

It is worth questioning whether the community in such culturally based practice refers conceptually to the same community advocated in Article 19. To answer this question, it is helpful to refer to the meeting of the CRPD Committee on August 17-19, 2022, to review China's state report. During the review, a Chinese representative confirmed to the CRPD Committee that most PwDs in China spend most of their lives in their community, followed by the explanation that they have difficulty moving around. It is not hard to see that the community in this context is not what is advocated by Article 19.

The community without service or support

Although China has and is still building segregated institutions to serve PwDs, the elderly, and unsupported children, it has not experienced a phase of large-scale institutionalization as in the West. On the other hand, the service provided for PwDs and their families to support their community living is underdeveloped (Yamaki & Yamazaki, 2004). Consequently, PwDs are forced into total dependence on their families. The burden of care is thus imposed on families, which may last a lifetime. A lack of services or support has, directly or indirectly, produced some extremely tragic cases in the superficially ordinary community. Two cases were selected to understand the possible consequences when PwDs live in the community without service or support.

One was first reported in January 2022 by a video blogger, according to a China Daily report (Wei, 2022). A woman who claimed to be diagnosed with mental illness was locked up in a mud hut with a chain around her neck. According to subsequent news reports, she had been chained by her husband for several years. Her husband explained that she had mental health issues and would hurt people. She had given birth to eight children, the oldest one now an adult. The woman's husband and children lived in a room next door. More than one year since the first report on her, many questions, including her real name, where she was originally from, and whether she voluntarily gave birth to eight children, remain unanswered publicly. The government blocked information about her soon after outrage about her case ensued on the Internet.

Many issues were raised, not only regarding the rights of PwDs but also domestic violence, rape, and human trafficking. What is pertinent in the current discussion is that the woman was hospitalized only after her situation became public. Prior to that, she had lived in an apparently ordinary community. Neither was she kept in an inaccessible place, as everyone in the village knew about her; the original video showed that the blogger could talk to her without interference by others. However, no one in her community had helped her. This contrasts with a typical case of institutionalization. In the case of a person in a segregated institution, the straightforward way of support may be to take him or her out of the institution, while in the woman's case there did not seem to be an "out there" for her.

Another case was first reported at the end of January 2020, the beginning of COVID-19 in China. A young man with cerebral palsy died at home after his father, who was his only caregiver, was infected and quarantined in the hospital for six days. It should be noted that the young man died not in a segregated institution but in the community where he and his father had lived for quite a long time. It should also be noted that he was not abandoned or fully neglected. According to the following reports and information collected from local civil society organizations, people in the community as well as the local government had tried to help him during his last six days. It turned out, however, no one in the community was familiar with him and thus no one knew how to take care of him.

Is institutionalization a desirable response?

Against the social context analyzed above, the large-scale, government-managed institution is sometimes considered the ideal response for care, especially by the families of PwDs. In China, the government has been investing resources in building new institutions for PwDs in recent years. However, the demand for institutional beds far exceeds the supply.

It has been observed that most existing institutions prefer to admit old people or people with physical impairments rather than those with psycho-social or developmental disabilities. Comparing the demand for institutionalized services to the reluctance of the institutions to accept many PwDs suggests that the families and even some PwDs themselves constitute the primary driving force for institutionalization rather than community-living in China. However, such observation does not, and should not, lead to the conclusion that institutionalization is the justifiable and desirable approach to protecting and promoting the rights of PwDs. It is important to note that the attitude of PwDs and their families can be, to a large degree, explained by the lack of access to information regarding either the empowering support of independent and community-living or the dark side of institutionalization.

It is equally important to recall the theoretical framework analyzed in section 2, which makes clear that the meaning, implication, and value of Article 19 will be firmly adhered to through this discussion. Nor should the cultural context be used to defend a failure or reluctance to implement Article 19 at the national level. Accordingly, the question is not whether the right of PwDs to independent and community living should be promoted in China, but how to do it by considering the existing sociocultural context.

The development of community-based services in China

One question recurring in the literature, especially those by scholars from East Asia, is what can a region without a phase of institutionalization learn from the western version of deinstitutionalization? (Chou, 2019; Hayashi & Okuhira, 2008; Wang, 2013). The major answer in both literature and practice is the importance of developing community-based services to support PwDs as well as their families to live in the community.

Main types of community-based services in China

Currently, there are two main types of community-based services in mainland China. One is the day center. The center is usually located in the community and provides services for adults with disabilities during the day. PwDs can go to the center, participate in some activities or have rehabilitation training. The main intent behind this kind of service is to support PwDs to leave their own homes and have a more normalized daily routine. Some day centers may also claim that they aim to support PwDs in their transition to a more independent life by teaching them skills for work and independent living.

The other is the community living residential service. The residents share an ordinary home or house in the community and assistants are available to support them in their daily lives (Chou et al., 2008). Each home provides accommodations for up to six residents, most with intellectual or mental disabilities. The service aims to help those who used to live with their families become more independent. The service also supports those who had been living in institutions for a long time return to the community. For the purpose of promoting normalization and community inclusion, the community homes are supposed to be in lively neighborhoods with convenient access to public transportation, public services, and leisure, cultural, and recreational activities. However, recent years have witnessed the difficulties faced by service providers in finding good locations for community homes. One of the reasons is that the rent, especially in large cities, rises every year. To make the community home affordable, some service providers must locate the community homes in relatively isolated neighborhoods away from the city center. Another reason, which raises more concerns, is that public acceptance of PwDs living in the community is still low. According to a report issued by Shenzhen Association of Persons with Psychosocial Disabilities and Their Relatives and Friends (2021), although the majority of the public recognize the right of PwDs to live in the community, only a few of them are willing to live in the same neighborhood with PwDs. Many community homes have shared the same experience of complaining neighbors, exclusion by the neighborhood, or even evictions by landlords. To avoid such situations and the difficulties resulting from frequent relocation, some service providers tend to locate the community homes in relatively remote neighborhoods to ensure that the PwDs do not disturb and are not disturbed by other people.

These types of services are technically categorized as community-based because, first, they are provided within the community rather than in a segregated institution. Second, community-based resources are more or less mobilized. Third, these services at least appear to offer PwDs some degree of choice. In comparison with times when there were no services, these options have brought about some good changes; it is not difficult to highlight individual cases that demonstrate the effectiveness of the services.

Existing research also suggests that such community-based services are better than traditional institutional service. Shenzhen Association of Persons with Psychosocial Disabilities and Their Relatives and Friends (2021) issued a research report on the needs and status of housing and living services for people with psychosocial disabilities in Shenzhen in 2021. The research team, including eight PwDs, observed both a government-run segregated caring institution and community living residential facilities managed by civil society organizations. The team's report noted that while the fees of these two forms of services are similar, the community living residential services provide PwDs better conditions and more diverse daily supports, and thus perform better in ensuring and improving the quality of life of PwDs than the government-run, segregated caring institution.

However, it is still questionable whether these community-based services lead PwDs to fully participate in independent and inclusive community living. Community living residential services, as observed in both mainland China and Taiwan, can to some degree improve the quality of life for PwDs, especially in comparison to those who used to live in a large institution. However, most PwDs are still not provided with the opportunity to freely engage in various activities or have their own life choices (Chou et al., 2011; Shenzhen Association of Persons with Psychosocial Disabilities and Their Relatives and Friends, 2021; Shenzhen Autism Society, 2021). The lack of freedom of choice is even more obvious in the day centers. The activities and services provided in day centers are similar to each other in terms of content, type, and time arrangement (Shenzhen Autism Society, 2021). Although PwDs are not required to follow a fixed schedule, it turns out that most PwDs in fact follow relatively rigid daily routines, and almost all activities are centered in their homes or day centers. The services do not facilitate their more diverse participation in the broader community.

Community-like institution and institutionalized community

In addition to community living residential services and day centers, some relatively new ideas for PwD community living attempt to reshape the concept of community in China. The first is community-like institutions as advocated and promoted mainly by parents of people with developmental disabilities. A group of parents has already co-funded the purchase of land in an East China suburb and one community-like institution is under construction. Most of the parents aligned with this service model have demonstrated the awareness that living in the community is important to a person's well-being. On the other hand, they hold a strong belief that PwDs, especially those with developmental disabilities, are not capable of living independently in the community. Building a community-like institution would provide an ideal, realistic option. Based on a blueprint described by parent leaders, the institution will occupy a huge space and be equipped with facilities such as special schools, hospitals, supermarkets, parks, restaurants, and cinemas that would be available in a typical community. PwDs and their families can live together and be cared for in the community-like institution, which will be accessible and meet their needs.

The second concept, as tentatively called in this paper, is an institutionalized community. The idea is that one organization would provide all-inclusive services to PwDs and their families in the community, ranging from the assessment of needs to monitoring and evaluating the quality of the services. The organization would provide a wide variety of substantive services such as day care, residential services, vocational rehabilitation training, personal assistance, and financial management. Such an all-inclusive service is also proposed and advocated for by parents of people with developmental disabilities, together with some insurance companies that are interested in providing financial management services to the families. One leading parent association in China has started a pilot project with the strategic step of registering several branch organizations or companies with different names that can provide various services. It thus appears that these services are provided by different and unrelated actors. The project also has different facilities in multiple parts of the community to demonstrate that PwDs are given choices in a range of services.

Currently, both attempts at community living are driven by families of PwDs, especially parents of adults with developmental disabilities. Leading parents play key roles in advocacy, fundraising, and policy lobbying. In very few cases, a local government or Disabled People's Federation may provide limited support through, for example, government purchase of services. In general, however, there is no clear, stable government policy or financial support from the top down to back these efforts. Parents of people with severe disabilities and families of those who have already demonstrated capacity to live independently in the community are active in the development of these two ideas. Given both the Chinese culture's emphasis on the collective value of the family and the traditional practice of family care, the endorsement especially of parents has largely established the rationale and legality of these two ideas. As can be argued, the process in shaping and developing these services is paternalistic and excludes elements of personal autonomy and self-determination of PwDs, essentially in contradiction to Article 19.

It is critical to note that both ideas discussed above are proposed and advocated with reference to the human rights-based discourse on community living, although they run counter to the right to community living elaborated in Article 19. Thus, this indicates how the concept of community can be understood or misunderstood given the social-cultural context. Moreover, the ideas illustrate that an asylum in this era can be built without walls if embedded in the community with every service a person receives fully controlled. The oppressive structures and power relations that exclude PwDs from the community can exist even in a country without a history of institutionalization. From this perspective, a key issue to focus on in implementing Article 19 in China is to actively counter such institutionalizing structures and power relations.

Re-think the relational dimension of the community

The comparison between the right of PwDs to independent and community living in the West and in China reveals one fact: despite the differences in the history of institutionalization and other cultural aspects, PwDs in both contexts share a common experience of social distance in the community. That is, even if PwDs physically stay in a community, some are not included or do not have a sense of belonging in the community. Social distance addresses the core research question of this paper, which is examining the key elements of community that empower PwDs to live and, more importantly, participate and be included.

Geographically, a safe and friendly living environment as well as accessible public facilities and services are undoubtedly essential for PwD community living. The General Comment No. 5 (Committee on the Rights of Persons with Disabilities, 2017) made clear that accessibility of the environment, facilities, and services is one of the defining elements of an inclusive community. The current policy development in China, specifically public consultation in drafting the Law on the Construction of an Accessible Environment by the National People’s Congress, manifests some efforts in this regard. This new legislation will provide more clarity regarding the right to an accessible environment, which should enable PwDs to better navigate public facilities and services and potentially spark awareness-raising around the right of PwDs to equally participate and be included in the community with others.

The geographical dimension of community is, however, not sufficient by itself. Based on the discussions in previous sections, we argue in this paper that the concept of community should include a relational dimension, which is key to empowering and supportive living.

Community-based relationships should, in general, be equal, mutual, and dynamic, and feature at least the following three defining elements. First, the relationship should be person-centered with two interrelated aspects. One is that the relationship should be defined by the PwDs rather than by experts or professionals. Others should not decide which community PwDs will integrate into or what counts for meaningful community inclusion. In particular, the public should avoid devaluing the relationships developed by and between PwDs themselves in assuming that associations with non-disabled people are superior (Cummins & Lau, 2003). The other aspect is that the community relationship should enable PwDs to express their own needs for support or services. Professional assessments of needs or capabilities based on stereotypical scales and indicators reflect a pattern of institutionalized practice and translate into unequal power and control over PwDs (Adams et al., 2015).

Second, meaningful connections and a sense of belonging are even more important features of a community than its geographic location. These connections can be established with other members of a community as well as with those outside a specific location if they share trust, understanding, interests, or common experiences. Such connections are important as it creates a sense of belonging within a community. In cases where PwDs need assistance, meaningful connections can translate into resources of natural support (Wilt et al., 2021). PwDs can autonomously mobilize such support rather than seek help every time from professional services providers. In this way, the community-based resources become the resources of PwDs rather than of the service providers or experts. PwDs are thus empowered to make their own choices about how they want to participate in community life.

Third, community-based relationships should be interactive, co-defined, and established by PwDs and their supporters. The relationship between PwDs and their supporters in the community can change over time. It may start with a relationship between an assistant and the one being assisted, and then change into either a more formal employer-employee relationship, or a more informal peer and friend connection (Yamaki & Yamazaki, 2004). Considering the dynamics of the relationship, what is important is not what it looks like at a given moment but whether it can lead PwDs to live with autonomy and opportunities for participation in the community.

Conclusion and advice for further research

With a major focus on the implementation of Article 19 in China, this paper examined the key elements of community that empower PwDs to live and, more importantly, participate and be included in the community. The theoretical framework of the discussion was established in section 2 with reference to the debate about universalism and cultural relativism as it relates to international human rights law. Informed by the approach of weak cultural relativism, the discussion assumed the universality of Article 19, and the socio-cultural contexts of China were studied for the purpose of examining the universal human rights values underlying Article 19 in a culturally accessible way. A comparative study of how community is conceptualized in western and China's contexts was offered in section 3. The analysis showed that community without effective support can be dangerous to PwDs. However, institutionalization should not be considered a desirable response. The development of community-based services in China was analyzed in section 4. By illustrating how oppressive institutionalizing structures and power relations that exclude PwDs from the community can be shaped by community-based services, the discussion points out that a key issue in the implementation of Article 19 in China is countering such institutionalizing structure and power relations. Drawing on the discussions in previous sections, this paper asked a core research question: what elements of a community empower PwDs to live and, more importantly, actively participate and be included in a community? This question is answered in section 5, which examines community-based relationships that are equal, mutual, and dynamic and that characterize an empowering and supportive community.

This paper has several limitations. First, it focused on how Article19 and the right to community living is interpreted in a human rights law framework and in sociocultural contexts. People with different kinds of disabilities or impairments may have fundamentally different needs when enjoying and practicing their right to community living and this is essential to the comprehensive understanding of both Article 19 and the human rights approach to community. This paper did not explore this aspect in sufficient depth.

Second, given the literature referenced and the practice observed in this paper, the analysis mainly reflects the situation in urban areas in China. There may be significantly different circumstances in rural areas regarding how the concept of community is understood and how the right of PwDs to live in the community is practiced, both of which were not sufficiently explored in this paper. Third, the full implementation of Article 19 requires reflection on and modification of domestic law and policy and practice as well as constructive dialogue among PwDs, practitioners, and policymakers. This paper, however, did not expand on the future direction of relevant domestic policies.

All of these aspects while not adequately explored in this paper should be given more attention in future studies. In addition, this paper pointed out that the future research should go beyond the institution-community dichotomy and put more emphasis on the nature of the relationship underlying the various services provided for PwDs to support their independence and community living. There are three more specific suggestions for future research. First, the implementation of Article 19 in China can still draw from the experience of both western countries, such as Sweden, Canada, and Denmark that have a long history of promoting independent living, and East Asia neighbors, such as Japan. Second, in recent years some disabled people organizations, especially those co-established by PwDs in their 20s and 30s, have developed various kinds of peer support and online groups for activities, information exchange, and experience sharing. Most of these are not traditionally defined services in geographical communities but may contribute new insights into the relational dimension of community, thereby meriting further exploration. Third, Article 19 and the promotion of inclusive community are intrinsically connected to several other components of human rights, such as the rights to legal capacity, health, education, and employment. Further research is needed from a cross-cutting lens to examine the right of PwDs to community living in conjunction with other important equity issues in other arenas.

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Consciousness Awakening and Technology Enabling - A Case Study of Self-Supporting of Persons with Visual Impairments in Inclusive Higher Education[1]

Cong Cai[1], Fengming Cui[2] , Xiaoming Chang[3]

[1]One Plus One Disability Group; Doctoral Student, Communication Department, University of Chinese Academy of Social Science, China

[2]Harvard Law School Project on Disability, Harvard University, United States

[3]Nanjing Normal University of Special Education, China

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Abstract

This case study investigates the experience of students with visual impairments in pursuing equality in inclusive higher education in China through the assistance of technology. It analyzes the development of higher education for persons with disabilities from segregation to inclusion, addresses attitudinal and environmental barriers to the equal participation of persons with disabilities, and shows the impact of local organizations of persons with disabilities on promoting equal rights in inclusive education through professional support and strategic advocacy work. Through an in-depth case study of a student with visual impairment who underwent college and graduate studies, the study's results indicate her problem-solving approaches to overcome barriers to independent living, academic achievements, and full inclusion in social activities. This study reveals the urgent need to develop systematic disability support in higher education institutes to promote equal participation in inclusive education.

Keywords: Inclusive higher education, students with visual impairments, disability awareness, accessibility, organizations of persons with disabilities

Consciousness Awakening and Technology Enabling - A Case Study of Self-Supporting of Persons with Visual Impairments in Inclusive Higher Education

On June 30, 2022, Jiangbo Liang, an applicant with visual impairments, received an admission letter from the Graduate School of Tsinghua University. This news attracted extensive media coverage. Many media outlets used headlines such as “25 Years of Perseverance,” “25 Years of Pursuit,” and “A Dream of Tsinghua University Becoming True” to honor the long journey undertaken by a person with visual impairments to be accepted by a regular university. However, these statements also drew awareness to the rights of persons with visual impairments to higher inclusive education. Coincidentally, Jiangbo was born in 1985, the prime year that people with disabilities in China were institutionally allowed to receive higher education due to the *Notice on College Enrollment and Graduation Assignment of Disabled Youth*, issued by the PRC Ministry of Education and other government agencies in February 1985. This policy stipulates that “if all candidates possess the same moral and intellectual conditions, they should not be denied admission solely because of disability.”

A focal point of the news reports on Jiangbo’s admission to Tsinghua University was the accessible format of testing he had taken. Some reported that “a computer-based test that employed a screen-reading software speaks 20 times faster than the normal speaking rate” (Jing, 2022). This description of testing technology drew newfound attention to the additional barriers that students with visual impairments must navigate throughout their university admission processes and their completion of college.

Moreover, reports on Jiangbo’s testing software speaking “20 times faster” than normal sparked another round of discussion among persons with visual impairments. To facilitate understanding, some college students with visual impairments produced an audio-containing speech 20 times faster than normal. Only static electricity could be heard in this audio; nobody with visual impairments could actually understand it. Apparently, the reporting on the testing technology was not factual, which raised a new concern. Though exaggerations like these contribute to an image of the visually impaired “having superpowers,” they confuse practice and interaction of persons with visual impairments with technology in higher education. Moreover, they obscure discussions on—and potentially hinder—the construction and development of inclusive education support systems.

This case study is based on the long-term professional as well as experiential background of the authors. The principal author has visual impairments and has been a leader of a representative organization of persons with disabilities for more than a decade. To promote disability human rights in China, he has collaborated with different sectors, especially academia, to support students with visual impairments in inclusive higher education since 2015. Furthermore, based on their accumulated practical experience, the authors are deeply aware of the importance of transferring individual cases of support to system-wide constructions for all students with disabilities in higher education settings. This case study is conducted for this purpose.

This study addresses the following questions: 1) How do students with visual impairments utilize information technology to foster accessibility and inclusion in higher education? What are the challenges? 2) How do universities, students with visual impairments, and organizations of persons with disabilities interact in inclusive higher education institutions? What are the implications of such interaction for promoting inclusive higher education?

Historical Background and Current Conditions of the Development of Higher Education for Persons with Visual Impairments in China

Restrictions and Rejection Persons with Visual Impairments Experiences in General Colleges and Universities (1949–1987)

Research indicates a general but elucidating picture of the history of higher education and its impact on persons with disabilities before 1977:

> For a long time after the founding of the People's Republic of China, the government policies for persons with disabilities mainly inclined to the living care of the injured soldiers in war. Educational policies emphasized on elementary education and increasing the enrolment rate of children with disabilities. Coupled with the destruction of the entire higher education system due to the Cultural Revolution, prior to the 1980s, the government had neither issued a special policy on higher education for persons with disabilities nor had it made corresponding education statistics on the disability category. The education at different levels was of low quality, and most persons with disabilities were excluded from the education system. (Li & Fu, 2015)

In September 1977, China reinstituted the national college entrance examination, which had been suspended for ten years. Higher education was considered exclusive to the elite, open only to a small percentage of students through a merit-based admission system including an annual examination. Meanwhile, correspondent system construction was underway. However, the physical examination system became an obstacle for persons with disabilities to pursue college and university admission. The 1979 *Standards and Implementation Rules of Physical Examination for College Attendance (1979 Rules, hereafter)* became the basis of the physical examination system for college admissions. The core of the *1979 Rules* was to list health conditions for rejection and restricted candidates from selecting specific majors based on the results of a physical examination conducted after admission. Restricting rules dominated the policy. For example, in addition to rules for rejecting people with certain infectious diseases, there were very strict rules for rejecting students with visual impairments, involving the following ineligibility provisions:

> 20. Persons who have been diagnosed with glaucoma are ineligible for college attendance (glaucoma patients who have been asymptomatic for over two years after surgical treatment, with normal intraocular pressure, and visual acuity or corrected visual acuity of at least 1.0 in each eye are eligible for admission). Persons with congenital or traumatic cataract, whose visual acuity per eye or corrected visual acuity is above 1.0, are eligible for admission.
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> 21. Persons with diagnosed retinal and optic nerve diseases affecting vision (whose binocular visual acuity is less than 0.7) are ineligible for admission.
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> 23. Persons with a combined corrected visual acuity of less than 0.8 in both eyes are ineligible for admission (including persons with one eye blind and the other eye's corrected visual acuity less than 0.8).

The *Standards and Implementation Rules of Physical Examination for College Attendance* in 1980 refined these rules and specified the circumstances under which a person may be ineligible for college enrollment or not be admitted to a particular major. Although the standards for visual impairment have since been adjusted, eligibility guidelines on the annual admission examination have yet to be eased. Consequently, there are still various barriers for persons with visual impairments to attend colleges and universities. For instance, Article 5 stipulates that "persons with visual acuity of less than 0.8 per eye are ineligible for any major in the arts, such as film, theater, or vocal music".

This physical examination standard for college attendance actually excluded all visually impaired persons. According to the *Standards and Implementation Rules of Physical Examination for College Attendance*, launched in 1979 and 1980, even the lowest level of visual acuity is far higher than the mildest level of low vision (Level 2) in China's visual impairment assessment standards. According to the visual impairment standard in the first national sample survey of disabled persons in China in 1986, second-degree low vision is "best corrected visual acuity of the good eye equal to or better than 0.1 and less than 0.3." According to the visual impairment standard of colleges and universities in the same period, "if the sum of the corrected visual acuity of both eyes is lower than 0.8, the candidate cannot be admitted." Even in 1985, the admissions physical examination standard was only slightly reduced to "if the sum of the corrected visual acuity of both eyes is lower than 1.0, the candidate cannot be admitted," which still disqualifies most visually impaired people.

Policy improvements began to loosen restriction for persons with physical disabilities. For example, on February 25, 1985, the Ministry of Education and other government agencies issued the *Notice on College Enrollment and Graduation Assignment of Disabled Youth*, stipulating that the relevant education and labor departments "should not deny admission of disabled youth solely because of their disabilities," and "the disabled candidates enrolled by colleges and universities should be assigned jobs by the state according to their majors after graduation." In the *Notice*, however, "the disabled candidates" clearly refers to "those with physical disabilities (without further deterioration), who can take care of themselves and whose disabilities do not affect the study in their enrolled majors and the work they will do after graduation." Candidates with visual impairment were still ineligible for higher education. These restrictions persisted until the establishment of the College of Special Education at Changchun University in 1987.

Formation of the Separate Exam and Admission System as a Dominant Alternative (1987–)

At a time when general higher education was not opening its doors to most persons with disabilities, Changchun University's decision to establish colleges and universities specifically for disabled persons was monumental. The College of Special Education of Changchun University became the first institution in China to admit students with visual impairments in 1987 after eight years of preparation. Bolin Gan, a member of the China Association for Persons with Visual and Hearing Impairments National Committee, spearheaded this institution. During a prior study tour in Yugoslavia, Bolin Gan found that "all blind and deaf people in Yugoslavia are required to receive education. In contrast, the Deaf and the Blind in China do not have a university, and they even have no junior college" (Tian, 2014).

However, Gan's pursuit of disability equal education sought to establish a separate university specifically designed for persons with disabilities. His efforts greatly shaped China's higher education for visual impairments towards the pathway of establishing separate exams and admission systems for a long period of history. Nevertheless, although Changchun University became a comprehensive general university and its College of Special Education now comprises one part of its campus, education through the College was, and has remained, isolated. For instance, its range of majors is limited to subjects such as acupuncture and massage, rehabilitation therapy, music performance, and piano tuning; furthermore, its teaching and living accommodations are all located separately.

It is worth mentioning that, beginning in 1986, the idea of placing students with special needs into regular classrooms received attention due to the global influence of integrated education and the need to increase the enrollment rate of students with special needs in China (Zhang & Yang, 2018).

Meanwhile, in 1987, Bailun Xu, the founder of the *Journal of China Children with Visual Impairments Literature*, who also happened to have visual impairments, began collaborating with the local government to explore how to provide basic education to children with visual impairments by placing them in regular classrooms. To achieve this goal, he used the platform of the Golden Key Education Research Center for Visual Impairments to mobilize funding, human resources, ideas, and technology (Lv, 2017).

Therefore, the initial development of education for the visually impaired was driven by key persons with visual impairments. They endured, however, the Separate Examination and Admission System of high education (Dankao Danzhao 单考单招, the Separate System) since its formation. Horizontally, there have been schools that have retained the Separate System policies for visually impaired persons: the Special Education College of Beijing Union University and the School of Special Education of Binzhou Medical University, for example, have set up the Separate System programs for the visually impaired. In addition, schools, including the Guangzhou University of Chinese Medicine and the Shandong Vocational College of Special Education, have also opened junior colleges – specializing in acupuncture, massage, and music – for the visually impaired. Vertically, some universities also apply the Separate System policies to their graduate programs based on undergraduate education. For instance, in September 2014, Beijing Union University was approved to develop a special master’s degree program in Clinical Medicine (Traditional Chinese Medicine, TCM), becoming the first special master’s program for persons with visual impairments in China.

Sporadic Practice of Inclusive Education under the Separate System (2002–)

Since the turn of the 21st century, a few higher inclusive education practices have emerged in China, despite enrollment still being conducted through the Separate system. For example, in 2002, Shanghai allowed students with visual impairments who graduated from Shanghai Schools for the Blind to learn in regular classrooms at Shanghai Normal University through the separate process. Later, East China Normal University and Shanghai Second Polytechnic University also began to accept students with disabilities and offered majors, including special education, English, and social studies to students with disabilities who were permanent residents in Shanghai according to the household registration system in China. Moreover, since 2005, the College of Special Education of Changchun University has explored a second minor program for students with disabilities and opened three minor programs, such as Special Education in 2005, English in 2008, and Chinese Language and Literature in 2012 (Changchun University, 2021). In 2016, Nanjing Normal University of Special Education also made a breakthrough by introducing a major in the Department of Applied Psychology for students with visual impairments through the Separate System (Nanjing Normal University of Special Education, 2016). Ultimately, these sporadic practices laid the foundation for promoting inclusive higher education for persons with visual impairments, as discussed in the following section.

The Development of Inclusive Higher Education for Persons with Visual Impairments and Parallel System between Special Education and General Education (2014–)

China’s inclusive higher education remains a parallel system between the Separate System and regular college entrance examinations, with the Separate system still playing a dominant role.

China ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008. During the negotiation process of CRPD, China revised its 1990 Law on the Protection of Disabled People (LPDP). The revised law entered into force in July 2008. Article 7 on Barrier-Free Environment states “where visually impaired persons take various entrance examinations, occupational qualification examinations and appointment examinations held by the state, Braille or electronic examination papers shall be provided to them, or special workers shall be arranged to offer assistance.” The 2012 Regulations on the Construction of Accessible Environment Article 3 reinstates this provision. On paper, the laws have removed barriers for persons with disabilities to take the Gaokao for regular higher education. In reality, before 2014, although many students with visual impairments had the opportunity to participate in the regular college entrance examination, they encountered challenges in the support system for testing and admission. Thanks to the joint efforts of policymakers, experts, and different groups of people with disabilities, students with visual impairments could apply for reasonable accommodations for taking the regular college entrance examination beginning in 2014. As a result, a limited number of students with visual impairments took the regular college entrance examination and entered general universities (Han, 2016).

Two specific policies contributed to this advancement towards inclusive higher education. The first is the national policy, *the Plan for Promoting Special Education (2014-2016)*. The paragraph concerning higher education states that higher education should “create conditions to actively enroll candidates with disabilities who meet the admission criteria, not to deny them on the basis of their disabilities; and provide assistance for people with disabilities to receive adult higher education” (General Office of the State Council, 2014). The second one is the *2014 Regulations on the Enrollment of Students to General Higher*

Education Institutes issued by the Ministry of Education in March 2014. It mentioned that "examination authorities at all levels should facilitate equal registration for examinations for persons with disabilities. For example, when a blind person takes part in the examination, the blind examinee should be provided with braille test papers, electronic test papers or special assistance from staff" (Ministry of Education, 2014).

These policies paved the way for people with disabilities to take the Gaokao with needed reasonable accommodations. Among them, Jinsheng Li, a blind man from Henan Province, got his first braille test paper for the national college entrance examination. Similarly, Yaodong Zhang, a candidate from Gansu Province, used large-print papers to take the college entrance examination and was admitted by the Hubei University of Chinese Medicine—becoming the first student with visual impairments to pass the college entrance examination and to be admitted by a general university. Thus, this year marked the "Prime Year of the College Entrance Examination for Blind People" (Lin, 2014). In celebration of this historical advancement, an organization of persons with disabilities (DPO) initiated the "selection and evaluation of top 10 disability rights events in China and pointed out: "the effects of and gaps between the 2018 LPDP and the 2014 MoE Policy (OnePlusOne, 2014). This social, political, and legislative context in China is a necessary background for this article. There is a dire need to explore different pragmatic and effective pathways beyond law analysis for equal participation of persons with disabilities in promoting inclusive higher education through analyzing the practice of inclusive higher education for persons with visual impairments.

In 2015, the Ministry of Education and China Persons with Disabilities' Federation promulgated the *Administrative Regulations on the National Unified College Examination for Persons with Disabilities (Provisional)* and, after two years of trial implementation, finalized the *Administrative Regulations on the National Unified College Examination for Persons with Disabilities* in 2017. It also published three annexes, including the *Practical Operational Points of National Unified College Examination for Persons with Disabilities*, the *Application Form for Reasonable Accommodation for Persons with Disabilities to Apply for the ×××× National Unified College Examination (Sample Form),* and *Provincial (District and City) Notice of Application for Reasonable Accommodation for Disabled Candidates to Participate in the ×××× National Unified College Examination (Sample Form).* These documents provide practical and specific instructions for reasonable accommodations for people with disabilities, including those with visual impairments, to take the national college entrance examination (Ministry of Education & China Disabled Persons' Federation, 2017).

Reasonable accommodations for the visually impaired candidates covered in these documents include, among other things, "braille test papers, large-print test papers (including large-print answer cards), or regular test papers for candidates with visual disabilities"; "blind writing pens, braille writing tablets, braille drawing instruments, rubber mats, braille typewriters without storage, electronic vision aids without storage, blind canes, desk lamps, optical magnifiers, and other assistive devices or equipment necessary for answering questions"; a 50% extension of testing time for "specified for the subject; candidates with special difficulties in writing, such as visually impaired candidates using large-character test paper or ordinary test paper"; and a 30% extension of testing time for candidates whose "upper limbs cannot write normally due to cerebral palsy or other diseases, and candidates without upper limbs based on the total exam time specified for the subject."

Despite this progress, electronic test papers necessary for some students with visual impairments were not included (Wang, 2014). Furthermore, although accommodations for the college entrance examination underwent improvements, the number of students with visual impairment who have applied for braille exam paper in the CEE since the first implementation of reasonable accommodation in 2014 is very minimal compared to the total number of students taking the CEE in the same year (Hu, 2022, p. 97).

Moreover, many visually impaired candidates still lack the confidence in taking examinations and requesting accommodations due to the fundamental inadequacy of basic education. Moreover, factors such as limited selection of areas of study and employment opportunities, weak transitional policies for inclusive education at different levels, and negative traditional attitudes toward disability also contributed to the lack of participation in the examination (Cai, 2018).

This restricted acceptance of students with disabilities in colleges and universities, a limited offering of majors and programs, and inadequate preparation within colleges and universities continue to hinder the advancement and quality of inclusive higher education for students with disabilities (Lei et al., 2017). Consequently, despite the ease of the regular college entrance examination, higher education for persons with disabilities is still dominated by the Dankao Danzhao system. The regular college entrance examination is not an option for most persons with visual impairments. However, the parallel system of special education and general education in higher education has undergone an imbalanced development and persisted. Thus, achieving quality, inclusive higher education remains a challenge.

Therefore, this article aims to analyze the enduring efforts and achievements of pioneers of inclusive higher education in an environment with a limited support system to respond to two urgent challenges: the first challenge is to meet the critical needs of persons with disabilities for support to take the Gaokao; the second need is to introduce the views of persons with visual impairments into the research of system construction for inclusive higher education. The article aims to contribute to efforts to close the gaps between the promises in law and policy and the reality of meaningful, inclusive higher education.

Literature Review

Support systems for providing reasonable accommodations to students with visual impairment in universities vary worldwide. For example, based on a longitudinal study in the United Kingdom, researchers proposed a framework of support to facilitate learning environment to enable students with visual impairments through the “notion of progressive and mutual accommodations” to address challenges of support (Hewett, Douglas, Mclinden, at el., 2020, p. 754). Some study in Australia indicates that learning environments in higher education remain focused on adjustments at the individual levels with inadequate efforts to remove attitudinal and organizational barriers (Collins, Azmat, & Rentschler, 2019). Other studies rightly emphasize the importance of transitional programs to prepare students with disabilities for inclusive higher education (Morina, 2017; Getzel & Thomas, 2008). A study in Thailand through interviewing a group of blind students reveal the issues of inaccessible campuses, awareness issues of teachers, and inconsistencies in policies (Bualar, 2017). Despite the wide range of studies on students with visual impairments, Wang & Takeda (2022) point out that there have been inadequate ones on support services in China and further suggest that learning contents, methods, and purposes form the three principles for supporting the academic lives of students with disabilities. Given the unique context we discussed above, there needs to be appropriate ways to explore the development of a support system for disability-inclusive higher education in China.

When policies on the participation of persons with disabilities in the general college entrance examination were issued in 2015, there was no practical experience to follow in China on how to support the participation of persons with visual impairments and their integration into campus life on an equal basis. Therefore, in 2016, six universities in China, including Changchun University, Beijing Union University, Wuhan University of Technology, Sichuan University, Nanjing Normal University of Special Education, and Zhengzhou University of Technology, were selected to carry out pilot work on inclusive higher education for students with disabilities. Among them, Changchun University, Beijing Union University, and the Zhengzhou University of Technology had previous experience in Dankao Danzhao and separate college running; the Wuhan University of Technology and Sichuan University had experience enrolling students with disabilities for inclusion in their programs; Nanjing Normal University had both features. However, a closer review of research on relevant topics finds few results related to inclusive higher education for persons with visual impairments.

By analyzing the working texts of the China Disabled Persons' Federation and the Ministry of Education in six domestic universities piloting higher inclusive education for people with disabilities, scholars found that "the pilot universities have made progress in admission, support for academic study, campus life and support for transition into employment. However, they face challenges in many other aspects, including establishing the enrollment process, meeting the special needs of students with disabilities, constructing inclusive campuses, and forming transitional service systems" (Zhang et al., 2020). In terms of school support services, "at present, much of the research on inclusive higher education in China focuses on the accessibility of the physical environment. Many studies have pointed out the problems in public spaces such as outdoor roads, surrounding areas of buildings, and leisure places in colleges and universities, as well as indoor learning places such as classrooms and libraries. However, the problems are mostly raised from the principle of the barrier-free design itself – that is, without consideration of users' feelings and thoughts – and lack the perspective of students with disabilities on problem-solving in a learning environment still full of barriers. Moreover, the existing studies pay limited attention to indoor living places, such as constructing barrier-free environments in dormitories" (Wang & Zhang, 2017).

More importantly, there is a considerable lack of research on developing an inclusive culture in school environments. It has been pointed out that "awareness raising of inclusive education is still an urgent issue to be addressed" (Zhang, 2015). Other studies, based on the experience of students with disabilities, have pointed out that in an "inclusive" environment, college students with disabilities face many difficulties and challenges due to the lack of special education support and services at all levels (Wang, 2019). Students with disabilities are not passive objects but active subjects. More research is needed from the perspective of students with disabilities in coping with these challenges.

Other studies have paid attention to information accessibility in online courses for college students with visual impairments (Cai, 2020). These studies pointed out the impact of differences in technology application on the academic performance of students with visual impairments; they found that these students engage in technology empowerment and overcome barriers in online learning through mutual support in their community and raised the issue of inadequate awareness and support for these students in developing their technological skills. However, these studies have not linked such issues to developing higher education to explore the comprehensive application of information technology and the positive action of students with disabilities.

It is worth noting, however, that some studies emphasize the role of systematic support of university libraries for students with visual impairments and proposed "promoting the improvement and development of the support service for students with visual impairments in Chinese university libraries from the systematic, institutional, environmental, resource and emotional dimensions” (Yuan, 2019). Overall, few studies have examined how organizations of people with disabilities and college students with disabilities can, collectively and individually, use existing technologies and resources to break barriers to meaningful, inclusive practices, and increase disability rights awareness in general.

In August 2015, One Plus One Disability Group, a civil society organization of people with disabilities, held its first workshop on “Support Services for Inclusive Higher Education for Persons with Visual Impairments.” The workshop brought together experts and scholars in visual impairment education in China, college students with visual impairments who had been admitted to college via regular college entrance examinations, and staff from the admissions offices of various colleges (One Plus One Group of Disability, 2015). The workshop explored ways to support the equal participation and campus integration of students with visual impairments to promote the construction of systematic support.

Subsequently, in conjunction with public welfare foundations, professional colleges, and institutions, One Plus One established training sessions on disability rights awareness for schools and admitted students with visual impairments, campus adaptation assessment and training protocols, career planning consultations, and support for reasonable accommodations and accessible materials production. In addition, its signature program, the “Golden Cane Pre-College Program for the Visually Impaired,” has had positive impacts by motivating researchers to make schools an inclusive, as opposed to isolated, environment for visually impaired students (Wang et al., 2020). However, beyond One Plus One’s intensive support, topics focused on college students with visual impairments and practices of self-empowerment have not yet received attention.

This article aims to fill that gap. On the one hand, it hopes to address the lack of research on accommodation support for students with visual impairments in higher inclusive education and – on the other hand – provide guidance on how to empower visually impaired college students to participate in and integrate into campus life fully. A support system for students with visual impairments in higher education is still under development in China. This research can also shed light on how to empower students with visual impairments to pursue success on campus during this transitional time of encountering barriers and the typical role DPOs in achieving this outcome.

Research Methodology and Design

Rationale for the Research

According to Feng (2022), to generate initial investigation on a specific issue is the main goal and strategy of such case study as well as the significance of methodology. This is a case study through which the authors attempt to explore in-depth of the experience of a student with visual impairments in inclusive higher education, her challenges, strategies of problem solving, and support she receives. Its goal is to focus on the specific and typical case in order to gain an in-depth and concrete understanding of the lived experience of students with visual impairments in inclusive higher education and reveal contextual barriers for prompting future research inquires and attention to the issue under discussion.

According to Scott (2014), a deep exploration and thick description of small-scale social life can be utilized to generate broader cultural interpretations (p. 760). This case study fits right into this category in the context where limited number of students with visual impairments can make their way into general higher education only in the past decade. As the implementation of the new *2023 PRC Law on the Construction of Accessible Environment* is under discussion on the ground, how this law protects the rights of persons with disabilities in inclusive higher education is an important topic in the field. There is tremendous value and urgency to understand the experience of these students in their universities through "craftwork" (Yin, 2014, p. 28) of case studies.

Data Collection

A semi-structured interview method was used in this study. The interview mainly focused on the challenges facing persons with visual impairments, problem-solving methods, and factors affecting the choice of methods in general higher education. Questions were adjusted or expanded flexibly according to the interviewees' answers. The recordings were transcribed after the interviews. The participant reviewed the transcribed data. Data analysis was carried out with the help of interviewer.

Participant/Interviewee Q, a student with visual impairments, was selected as the participant for this case study. Q is a female second-year graduate student with congenital visual impairment. She is currently diagnosed with "Visual Disability - Level 1," with tubular vision and residual vision. She is unable to read with her vision and can travel independently. She enrolled in a local school for the Blind at eight, then moved to another school for the Blind in the provincial capital city. After graduating from junior high school, she enrolled in a school for the Blind in a city outside her province. In her senior year of high school, she passed the Dankao Danzhao system and enrolled in a university's inclusion program after graduating from high school. In her senior year in college, she took the national postgraduate examination and was admitted to a corresponding major in another general university.

Q has experience studying at schools for the Blind, having entered a general university for undergraduate studies through the Dankao Danzhao system and a general school for graduate studies through a national examination. Her undergraduate university is one of the six pilot universities of inclusive education in China and had already begun accepting students with visual impairments the year before Q was admitted. Q was not the only student with visual impairment in the same department. However, she is the first and only student with visual impairments in the university for her graduate program. Her experience at both institutions has differed; her ability is constantly increasing as she gradually moves into a general education environment. As a graduate student, she is more active in seeking support and more mature in her strategies. As a result of her undergraduate experiences, she can better deal with the interaction with the graduate campus environment and develop transferable strategies. At the same time, Q has been in contact with organizations of people with disabilities since she started her undergraduate studies – having participated in training and received support – which has increased her understanding of the impact and role of such organizations.

Data Analysis

Currently, there exist no inclusive higher education resource centers or disability offices for students with disabilities in universities in China. Therefore, students with disabilities need to seek support from their universities or social resources. Q divides the core challenges faced by college students with visual impairments into three categories: independent living, academics achievements, and full inclusion in extracurricular life and activities.

Independent Living

To Q, pursuing independent living is also a journey of awareness-raising both for herself and her environment through her rigorous advocacy and active participation. A problem-solving attitude and approach turn to focus on solutions rather than problems. In the global history of independent living, disability rights movement activists began in the United

States in the 1970s, when a group of college students with physical disabilities faced a challenging campus and community environment and advocated for rights in equal participation. The social model of disability emphasizes the removal of environmental barriers and the provision of appropriate support to ensure the equal rights of persons with disabilities, which is consistent with the concept of independent living and has become an essential theoretical basis for the latter (Dejong, 1979, as cited in Marinelli & Orto, 1984, p. 43). From the concept of independent living and integration into the community in the Article 19 of the *UN Convention on the Rights of Persons with Disabilities (CRPD, hereafter)*, the protection and promotion of the fundamental rights of persons with disabilities in education, employment, and health should be based on “living independently and being included in the community” (Liu, 2014).

Q participated in disability rights awareness raising training held by One Plus One Disability Group. She noted, “I think that the most useful thing was the disability rights awareness-raising training because it helped me understand my rights and encouraged me to always fight for it.” Q has always been pursuing independence. She is sensitive to barriers that hinder her independence and has also developed strategies for action to eliminate them.

Mobility Independence

Q often experienced “overprotection” from the university and volunteers assigned to her during her undergraduate study. For example, her activities outside the dormitory area were required to be always chaperoned by students without disabilities. “They arranged for students to take turns to accompany us. It was fine in the dormitory, but we couldn’t go outside without them.” This system was designed by an upper-class student who served as Q’s deputy head teacher. “We fought for [the system’s removal], but our efforts were futile.

The university only listened to the head teacher and the deputy head teacher. Understandably, they worried about our safety and the consequences they might bear." This problem was not solved until Q observed a training session on the *CRPD* held in the reading room when she was studying there.

She and several of her classmates with visual impairments actively sought help from One Plus One, the training session's organizer. After several negotiations, One Plus One acted as a third party to provide an assessment report and support plan for students with visual impairments. One Plus One then held a training camp – the Golden Cane Pre-College Program for the Visually Impaired – for college students with visual impairments at their university to hone their independent mobility skills. Students without disabilities were involved throughout the training to improve their understanding of the capacity of those with visual impairments.

The impact of the support plan and training allowed Q to gain the freedom to navigate around independently. During her graduate studies, Q prepared a needs form to communicate with the university before her entrance, emphasizing her mobility independence and ability to address barriers in her school environment independently. Consequently, through her efforts and the university's support, she navigated the campus independently. Most importantly, Q leveraged technology as often as possible to facilitate her mobility independence, in accordance with her own goals, and requested available human resources simply as necessary.

Q found that her graduate campus's interior buildings and roads were clearly marked on the mobile map. This attribute made her adjustment to the campus environment smooth:

"My mom spent a few days with me at school. At first, I planned to get a bunch of stickers, asked my mom to go with me and put up all stickers in places where I would go frequently. Later, I found out that the campus map and buildings were very clear on the mobile GPS. I asked my mom to follow me. I took the phone to navigate, activated Gogo city function on the app, listened to the phone announcing the surrounding buildings, and then double checked with my mom. That's it!"

However, there were still accuracy issues with GPS navigation. Therefore, after her mother left, Q still requested volunteer support to accompany her as she familiarized herself with her campus environment. Luckily, it took much less time for her to become familiar with the environment. In addition, due to the disconnected and poorly paved tactile paths on campus and the limited accuracy of the navigation app, it took Q extra time to find the entrance once she approached the building. Her more significant concern, however, is her use of a navigation app developed specifically for the visually impaired that relies on outdated data and could face service suspension any day. This threat could curb Q's mobility independence; hence, she has been following discussions on social networks for college students with visual impairments.

Campus Life

To travel independently on and off campus, Q mainly relied on using a GPS and asking for help navigating. However, there were still some barriers to her campus life, the most prominent being dining. She faced the following three main dining issues:

The first obstacle pertained to reading the menu. The undergraduate school Q attended was small, so she could remember most of the dishes in the canteen; however, when she got to the graduate school, there were so many windows in the dining hall that she couldn't remember all the dishes. "I asked my classmates to read the menu at each window, recorded it on my phone, and converted it into a document with a speech-to-text software. I could order by looking at the menu before dinner."

The second obstacle pertained to finding a seat, which is still difficult for her to do. During her undergraduate study, Q usually dined with her classmates with visual impairments and had little issues. Q requested the university to reserve a seat at her most frequented canteen before enrolling as a graduate student. Despite her efforts to communicate with the canteen, the canteen failed to secure her a seat. "One canteen owner is really nice and allowed me to post a sticker. However, the cleaning service kept removing the sticker the next day. On another occasion, the canteen may have been rearranging the dining tables and, therefore, moved my labeled table to somewhere else." This problem has not been fundamentally solved, and as such, Q's ability to independently navigate the canteen relies on the will of others: "It really depends. This one canteen, every time I go, a staff member will take me to my seat. But this might not be the case in a different place."

> The third obstacle is that accessibility issues have been ignored when the university implements technological improvements, resulting in greater accessibility barriers: We cannot use the self-service machine to recharge the campus card, and there is no manual window. Every time, I have to ask someone for help.… During my undergraduate years, I could take a shower by swiping my card in the dormitory. When I swiped my card, water started flowing, and when I swiped it again, the water would stop. Later, when the school introduced payment methods such as QR code scanning and Apple Pay, I couldn't shower in the dorm anymore. This is also true with the boiled water machine. I have to stop getting water by clicking on my phone. I still have a little vision, and every time I want to stop fetching water, I have to scramble to find the button on my phone that stops the flow of the boiling water. The totally blind students cannot get boiled water at all, and I have to help them.

Academic Achievements

Due to the limitation in accessing appropriate support services, Q decided to make choices for her learning and focus on what mattered the most to her. Her ability to use technology for problem-solving helped promote her independence and participation, but it also indicated the gap in the support system to be addressed. Q dreamed of becoming a Chinese teacher when she was a child. However, as she was applying to college, she could not take the general college entrance examination because her file was removed, making it impossible for her to register:

> I actually called to double check if my file would be removed earlier, and the reply was no. So I took the Dankao Danzhao first to secure a college admission. But my file was removed just before the general college entrance examination happened, and I couldn't even print my registration pass. In the end, I wasn't able to take the examination. This hit me so hard because I worked very hard and didn't even get a chance to prove myself.

Although Q did not like her current major in her college, she still expected to get a higher-level degree and realize her dream of becoming a teacher. Therefore, she studied diligently and had been preparing for the postgraduate entrance exam since her junior year. In the process of achieving academic achievement, she encountered the following barriers:

Production of Accessible Learning Materials

Currently, no appropriate mechanism exists to provide accessible learning materials for students with visual impairments in China. Although Q's undergraduate university built a reading room for the visually impaired, it did not initially provide them with suitable learning materials. “The last batch of students with visual impairments did not have accessible textbooks and learning materials, and they had to rely on teachers’ PPT materials to study.” Later, due to the assessment and training partnership with One Plus One, the staff in the reading room for the visually impaired learned that the Golden Cane Pre-College Program was producing accessible electronic textbooks for college students with visual impairments in many regions. Through learning from One Plus One, the staff began to organize volunteers on campus to provide accessible textbooks for Q’s class in the same way. “They set up a volunteer club (I think it was called the Aurora Club) to produce electronic learning materials for us. By the time we got the textbooks, however, it was the end of the semester.” During her graduate studies, Q communicated with the university in advance and got a promise from the library that it would produce accessible textbooks for her. “But I didn’t ask them to do it much mainly because it was too slow. I couldn’t wait to read these textbooks, and I just couldn’t wait.”

> After years of practice, Q learned an effective method of obtaining textbooks: First, look for textbooks online. Online textbooks are comprehensive and can be found directly in electronic form. If they are unavailable online, I pay for PDF versions through some channels that look for books on behalf of others. It seems that they also look for such books in various online libraries. If they still can’t find it, I’ll buy such books, and then use the CamScanner app on my phone to scan, which can also directly identify text basically without errors. At home, I asked my younger brother to acquire books for me. We used a scanning cloth to hold the book in place and scan, which was pretty fast.

Textbooks with graphics and formulas, on the other hand, cannot be recognized with software or read aloud in a linear fashion. In this case, Q would ask her mom for help. “I normally record on the computer the page number; then, when I get home, I say to my mom: “Mom, read the lines and pages!”” Based on this experience, Q was able to read many materials in preparation for her graduate school entrance exams.

Classroom Learning and Sharing

At present, college teaching has been largely electronic, and teachers prepare PPTs during lectures, which is convenient for students with visual impairments. However, because it is difficult to simultaneously listen to lectures and the sound of reading PPT by the Voice Reader on the computer, Q usually requests the teacher to send the PPT to her in advance so that she can familiarize herself with the content and progress. “Teachers in her program are generally willing to share PPTs with all students, but they don’t make the format of the PPT accessible. For example, it is impossible for me to read screenshots and formulas, and the machine recognition results are poor.” In addition to the accessibility issues of the PPTs, the teaching habits related to visual capacity can also cause problems during the presentation. “I’ve reminded them, but they often forget, and still say to students, “please look at this or that.” I have no idea what the teacher is referring to.” In Q’s opinion, however, her interaction with teachers and classmates can still overcome these nuisances. “I don’t really feel comfortable about bringing them up all the time. If it’s important, I’ll ask about it in private.” However, when she audits the courses of other departments, Q would feel more comfortable asking the teacher for the PPT. Sometimes, if she communicates with the teacher, the teacher asks other students to share electronic files of course material with Q.

Student sharing is a vital engagement process in both undergraduate and graduate classes. To prepare her for sharing in class, Q may ask her classmates for help with the design of her PPT to enhance its visual effect. “I draft the content into a document and then ask my classmates to design the PPT. There is no need to make the PPT very beautiful. I just ask them to help with the template. After all, it would be difficult for me to do it anyway. My teacher set up a volunteer group for me, so that I can get assistance when I share such needs in the group." Q may face challenges, however, when using the PPT for her presentation. "Actually, I was curious about how I could control the PPT by myself while looking at my notes and introduce the content to the group. Usually, I can only listen to the document by myself, and then ask my classmates to help me switch the PPT slides."

Tests

Testing at the higher education level is flexible, and teachers have greater power to decide how to do it. Therefore, it is less difficult to make testing accessible, such as through electronic test papers and computer-based answering with a braille dot reader. Her undergraduate university has purchased braille computers, braille dots, braille printers, and other devices. Her graduate school initiated collaboration with the China Braille Press to rent braille computers and small braille printers for her daily use, but they were used infrequently.

For Q, the barriers come from two main sources: firstly, quantitative research courses that require the operation of SPSS software – which is not accessible – on a computer. During her undergraduate period, the teacher would ask students to finish the test at home by operating the software independently and then submitting the results. Consequently, Q completed the test with the help of classmates. "I asked my classmates to do it for me. Our teacher didn't really care about the process. The software didn't support accessibility anyway. So the teacher had to allow me to finish the test this way." This way of completing the exam also influenced Q's attitude towards the course: "I probably won't be doing much quantitative research in the future, so I just need to know the concepts." The second barrier comes from the national examinations, such as the CET-4, CET-6 and teacher qualification certificate examinations. To apply for reasonable accommodations for these exams, Q is required to communicate with the relevant examination authorities. There are already braille papers and large-print papers for CET-4 and CET-6. As for the teacher qualification certificate examination, only some cities have opened pilot programs for persons with visual impairments.

Extracurricular Learning

Q has high expectations for her study and plans her extracurricular schedule well. Her undergraduate school set up a special reading room for students with visual impairments, so it was easy for her to find seats to study. During her graduate studies, she communicated with the university and requested a special seat in the library. However, she needed to study with a computer and hoped to protect her ears, so she tried to minimize her use of headphones. Aware that the computer loudspeaker could disturb other students, she applied to learn in a separate study room. “That room was originally a small activity classroom. Only my card could be swiped to open this activity classroom. I studied alone in this classroom. To take breaks, I also prepared a quilt and a pillow.”

Full Inclusion in Extracurricular life and Activities

Q’s participation in extracurricular life and activities revealed the limitations of technology and a much deeper problem – attitudinal barriers. Unlike segregated blind schools, there many extracurricular possibilities on campus, including auditing other schools’ courses, attending various academic lectures, participating in student associations, and applying for teaching assistant and research assistant positions. Students must also participate in internships in their junior and senior years and during their second year of graduate school. Here, Q faces three main barriers: information access, activity participation, and interrelationship with others.

Information Access

Information access posed the biggest challenge for the equal participation of people with visual impairments. Based on her rich experience with computers and smartphones, Q has a variety of solutions to deal with the challenge. “The biggest problem is the verification code issue while logging on the school website. I communicated with the university about this. They replied that it was difficult to add a voice verification code, but there used to be a way to scan WeChat QR code to log in, and they could add the feature back to me. That hasn’t been done yet. But that's okay, I just ask my classmate to read it for now.” Because of the complexity of the university faculties and clubs, Q is challenged to get information from multiple sources. “There’s not much content on the university website. Each faculty, department, or club has its own WeChat official account. There are so many official accounts we need to follow.”

Activity Participation

Due to the university’s openness, Q is free to sit in on classes in other departments. However, when it comes to signing up for clubs or seeking internships, Q still encounters barriers. “Most recruiters don’t know how to deal with me, I guess. I once signed up for a psychology club but got turned down on the grounds that the people in charge said that the courses involved drawing pictures a lot and said that I wouldn’t fit.” In Q’s opinion, the main problem is still the inadequate awareness of disability equality and inclusion among students. As a result, the typical reaction is still rejection rather than providing reasonable accommodations to people with visual impairments to participate equally. The same is true in finding internship positions. “We did our internships in positions offered by the undergraduate university, because the university didn’t provide a suitable co-op program. Later, I learned to seek opportunities online, such as Boss Zhipin. The job openings were all pretty interesting.”

Interrelationship with Others

In addition to the aforementioned needs, Q also encountered other barriers in campus life. The biggest barrier is the development of social relationships. On one hand, Q did not consider herself a social person. On the other hand, Q also felt the distance between persons with and without visual impairments. “I feel like I’m not in the same world as everyone else. Especially when everyone likes to share expressions and emoji while chatting, I can’t join them at all. I was often forgotten during club activities.” Q had classmates with visual impairments at the undergraduate level, and they formed a group for the visually impaired in the class; however, during her postgraduate studies, there has been only one student with visual impairment in the university. As a minority, she did face interpersonal troubles. Some researchers have noted that “students with visual impairments in colleges and universities have a strong connection and strong mutual support for each other,” but that “this strong connection pattern of high intimacy affects their campus integration with college students without disabilities and, indirectly, their social inclusion” (Yuan, 2019).

However, there is a possibility of reverse causation in this relation. It seems that the tight connection of students with disabilities among themselves is a passive connection due to challenges in interpersonal relations development in the process of being included in campus life revealed in Q’s case. Therefore, Q believes that the important thing is not to provide psychological support or interpersonal skills intervention but to have broader disability awareness training on campus to promote an inclusive and accepting environment. Q hopes that the Golden Cane may play the role of providing professional training for this purpose.

Nevertheless, from the authors' practice and experience, there are also barriers for the university to promote disability consciousness training at a holistic level. Moreover, in Chinese culture, it still takes effort to raise awareness and understanding of disability rights.

Results and Recommendations

In the context of inclusive education, constructing a support system for college students with disabilities from a macro perspective has received extensive attention. Discussion topics cover comparative studies of the international experience and local practice. The former includes, for example, the perspective of "the support system of higher inclusive education for college students with disabilities in the United Kingdom and its inspiration," from which the researchers propose that "China can build an inclusive higher education support system of values, regulations and policies, teaching practices and accessibility construction to create an inclusive campus" (Pang, 2020). Conversely, the latter suggests that "China should support college students with disabilities to complete their studies by establishing a leadership department, setting up a counseling center, and developing policies" (Ma, 2012).

However, Q's experiences demonstrate the difficulty in coordinating and constructing support systems for students with disabilities. The fundamental issue underpinning this difficulty is the lack of understanding of inclusion and the lack of willingness of each stakeholder to promote inclusion. Raising awareness of disability rights and promoting understanding of disability is still largely regarded as charity work rather than a form of disability expertise. Consequently, the leading and professional role of organizations for persons with disabilities hasn't received sufficient recognition. Yet, as the number of students with disabilities entering general universities grows, the demand for change is even more urgent. Given this, it is necessary to explore what strategies should be adopted to ensure the substantial equality and participation of students with disabilities and promote the development of support systems.

During her undergraduate and postgraduate studies, Q faced challenges related to independent living, academic achievement, extracurricular activities, internships, and interpersonal development. Her main problem-solving strategy is to use technology to remove obstacles and improve her own problem-solving skills, supplemented by seeking temporary help from people close to her. However, even when she seeks human help for a specific matter, she eventually turns it into an opportunity to use technology to tackle problems herself. This compromised choice is due to the extra burdens and reliability issues inherent in seeking human help. For example, the scanned materials might be delayed or incorrect; the human support might not be available and stable; and she also doesn’t want to be considered as a troublemaker or incapable by requesting necessary help, a result of environmental marginalization and discrimination against persons with disabilities that also shape her decision-making process.

Compared to negotiating with people, in this situation, using technology by herself for problem-solving is a much easier endeavor. However, technology can only solve some of the problems. She still must seek help from others. Her list of human resources for help begins with those close to her, such as family members and people in close relationships. Her experience in college and graduate programs indicate that system support from the school is missing. There is random support she has to pursue at times. Compared to the coordinators and service providers her school sent, family members and close friends were more available and handier and also understood her needs better, hence offering more appropriate help.

Although she has not yet been able to participate and integrate into campus life fully, she managed to have main academic achievements and life autonomy. This aspect fully demonstrates the low awareness of the capacities of persons with disabilities and of their rights to equal participation. This low awareness explains why her ability to realize full inclusion is undermined.

We do not intend detract from the direction of promoting inclusive higher education for persons with visual impairments to a technology-centered approach from removing social barriers and oppression by overemphasizing the importance of ICT to breaking down barriers. We also don't intend to undermine the significance of technology in its current conditions either. Neither technology nor human support should weaken or undermine the fundamental role of students with visual impairments as rights bearers. Behind their role play is the awareness raising of disability rights, enabling them to seek pragmatic support when structural support is missing effectively. Random choices are always limited. However, for students like Q to have full and equal participation, developing a support system through the active involvement of these students themselves is crucial. They should not be treated as passive receivers of support.

In conclusion, the authors present the following recommendations for promoting the development of higher inclusive education:

First, re-recognize the active role of college students with disabilities, raise awareness of their rights as rights holders through disability rights training, and prepare them to be stronger advocates of inclusion through active engagement in a school environment.

Second, improve the digital knowledge of college students with disabilities so that they are equipped with the ways of thinking, abilities, experiences, and methods necessary to use technology for problem-solving. This will enable them to solve practical problems and make good practices when they encounter temporary obstacles that are difficult to remove.

Third, establish a support network for college students with visual impairments so that their positive experiences can flow horizontally among their peers and be passed vertically between their predecessors and younger generations. Furthermore, this support network will ensure that students with visual impairments can get psychological support while solving practical problems.

Fourth, recognize the important role of disability organizations in promoting inclusive higher education, provide system support for them to play their professional and leadership role in disability support for students and university awareness enhancement, and develop regular partnerships with them for inclusive higher education.

Conclusions

In 2017, Xiang Wei, a candidate from Gansu Province, wrote a letter to Tsinghua University, hoping he would be accepted and his mother could accompany him. At that time, Tsinghua University's reply – "*Life is hard, but please choose to believe*" – caused widespread, heated discussion on the Chinese Internet. Amid the praises, Cong Cai, wrote an article criticizing Tsinghua University for not responding to the accessibility needs of this student using a wheelchair from a systematic support perspective (Cai, 2017). From a macro perspective, this is an expression consistent with the idea advocated by disability organizations. It also implicitly criticizes the student for not requesting accommodations but rather indicating his willingness to address barriers himself. Given mounting difficulties in the system over the recent years and the persistent practical needs of students with disabilities in higher education, the authors recognize that Xiang Wei had written letters requesting to study at Tsinghua University accompanied by his mother to pursue equality in an environment full of obstacles. Meanwhile, Q faced slow responses from her university and thus actively developed a set of strategies to handle accessible textbooks through the Internet and information technology.

Calls for inclusive higher education for disabled persons are not the focus of empty studies, nor do they garner external attention; hence, it is important to observe the experience of college students with disabilities. Students with disabilities are not objects that can and should wait to receive support but rather living testimonies of the power of inclusion in the development of higher inclusive education. They are not the objects rescued by technology, but rather subjects who actively choose to use and engage technology in a range of meaningful ways: in solving their problems, they also drive forward the process of inclusion at large. Only by recognizing these key points, allowing college students with disabilities to stand at the center of inclusive higher education in China, and providing support for their further awareness and self-empowerment can their value and significance be noticed – thereby laying the foundations for full, practical equality and inclusion.

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Inclusive Education in China:

From Policy to Implementation to On the Ground Experiences

Helen McCabe[1] and Tian Jiang[2]

[1]Education Department, Daemen University

[2]Warner School of Education, University of Rochester

Author Note

Helen McCabe, PhD, BCBA is an Associate Professor of Education at Daemen University. She has conducted research as well as provided training and support to teachers and families of children with autism in China for over 20 years.

Tian Jiang, MS, BCBA is a doctoral candidate at the Warner School of Education and Human Development, University of Rochester. Jiang's work involves training teachers and parents on implementing ABA-based strategies, and advising policymakers on creating initiatives which suit the Chinese context.

Correspondence for this article should be addressed to: Helen McCabe, Education Department, Daemen University, Amherst, NY 14226 hmccabe@daemen.edu 716-839-8201

Helen McCabe: https://orcid.org/0000-0001-5692-186X Tian Jiang: https://orcid.org/0000-0003-0616-0921

Abstract

Inclusive education rights in China are increasing, yet gaps remain between policy and practice. Increasing access to inclusion (*suiban jiudu*) is important. To understand policy implementation, this qualitative study examined how families experience the schooling of their children with disabilities. Results demonstrate that children's rights to inclusive education are recognized, though a stronger support system is still needed.

Keywords: inclusion, inclusive education, policy, China

Inclusive Education in China: From Policy to Implementation to On the Ground Experiences

Commitment to the right to inclusive education in China has increased in policy and practice over the past few decades. Many scholars reference the Salamanca statement, which stated that children should have access to inclusive education with accommodations (UNESCO, 1994), as an important origin of this work in China (Du & Feng, 2019). Moreover, since China signed the Convention on the Rights of Persons with Disabilities (CRPD) in 2008, despite ongoing limitations, disability policy has evolved and increasingly positively impacts inclusion and disability rights (Zhao & Zhang, 2018).

Despite increasing calls for equal educational opportunity and for promoting rights to inclusive education (Zheng at al., 2019), there remains a gap between policy and the realization of rights (Xu, 2020). School enrollment rates remain low, with 69% of school-age children with disabilities enrolled in school in 2017 (China Daily, 2018). Increasing access to general education has long been an important channel to expand school enrollment in China, in the form of *suiban jiudu* (Huang & Wu, 2021; Xu, 2020; Zhu & Wang, 2011).

Suiban jiudu has been translated as “Learning in Regular Class” (LRC), meaning educated in the same class as typically developing peers (Su et al., 2018). *Suiban jiudu* was first mentioned in government documents in 1987, followed by the 1994 Trial Measures for Carrying Out *Suiban Jiudu* for Children and Adolescents with Disabilities (1994 Trial Measures) (Huang & Wu, 2021; National Education Committee, 1994). By 2016, about half of students with disabilities who were in school were educated in special education settings, and half were in general education settings through *suiban jiudu* (Guo & Deng, 2021; Yin, 2016). (In this article, *suiban jiudu* is used when referring specifically to practices in China, and inclusion is used when referring broadly, or when it is specifically used in policy).

Current policy emphasizes increasing the enrollment of students with disabilities in general education settings (*yingsui jinsui*) (Guo & Deng, 2021; MOE, 2020). Yet policies also limit inclusion, because many policies state that only children with the ability to adapt to general education settings may attend (Xu, 2020; National People's Congress, 2006; 2008; State Council, 1994). Moreover, the language is vague, with no standard criteria for what "ability to adapt" means.

This article examines how inclusive education policies are implemented in China, as demonstrated by how families experience the schooling of their children with autism spectrum disorder (ASD) and other developmental disabilities. Research questions include: How have parents experienced the process of seeking, securing, and maintaining educational opportunities for their children, particularly in general education settings? How do their experiences confirm or differ from what is recommended by policies?

Literature Review

In order to analyze participant experiences with inclusion within the policy context, literature and policies related to special education and inclusive education/*suiban jiudu* were reviewed, including an overview of *suiban jiudu*, examination of the rights provided by policies, and analysis of policy limitations.

Suiban jiudu and Inclusive Education in China

Suiban jiudu is the practice of educating students with disabilities in general education classrooms, integrating two separate systems of special education and general education (Xiao, 2005). It has been described as a localized model of inclusion, combining inclusive education practices in other countries with the local Chinese context (Guo & Deng, 2021; Huang & Wu, 2021; Xu & Jia, 2020). The term *ronghe jiaoyu*, inclusive education, has been used recently in policy documents. For example, the Action Plan for the Development and Improvement of Special Education in the 14th Five-Year Plan (2021 Action Plan) calls for exploring models of inclusive education and better integrating general and special education for more effective and equal educational opportunity (State Council, 2021).

Rights to Education in Policy

Several laws and policies in China provide important foundations for the right to inclusive education (See Table 1). The 1986 Compulsory Education Law, the 1990 Law on Protection of Persons with Disabilities (Protection Law) (National People's Congress, 1986; 1990), and the 1994 Regulations on Education for Persons with Disabilities (State Council, 1994) all called for the right to nine years of compulsory education. Regarding inclusive education, the Protection Law and 1994 Regulations both indicated a continuum of options, with children to be placed in general or special education classes based on their disability category and "learning receptiveness." The 1994 Regulations mentioned *suiban jiudu* in general education, special education classes at general education schools, and special education schools (National People’s Congress, 1990; State Council, 1994).

Table 1

Policies Relevant to Inclusive Education

Year	Policy (Chinese)	Policy (English)	Issued By
1986	中华人民共和国义务教育法	Compulsory Education Law	National People's Congress
1990	中华人民共和国残疾人保障法	Law on the Protection of Persons with Disabilities	National People's Congress
1994	残疾人教育条例	Regulations on Education for Persons with Disabilities	State Council
1994	关于开展残疾儿童少年随班就读工作的试行办法	Trial Measures for Carrying Out the Work of *Suiban Jiudu* for Children and Adolescents with Disabilities	National Education Committee
2006	中华人民共和国义务教育法	Compulsory Education Law (Revised)	National People's Congress
2008	中华人民共和国残疾人保障法	Law on the Protection of Persons with Disabilities (Revised)	National People's Congress
2009	关于进一步加快特殊教育事业发展意见的通知	Notice on Opinions on Further Accelerating the Development of Special Education	State Council
2010	国家中长期教育改革和发展规划纲要（2010-2020年）	National Medium- and Long-Term Educational Reform and Development Plan	National People's Congress

2014	特殊教育提升计划	Special Education Improvement Plan	State Council
2016	普通学校特殊教育资源教室建设指南	The Guidelines for Building Special Education Resource Classrooms in Ordinary Schools	Ministry of Education
2017	第二期特殊教育提升计划	Second Phase of Special Education Improvement Plan	State Council
2017	残疾人教育条例	Revised Regulations on the Education of Persons with Disabilities	State Council
2020	教育部关于加强残疾儿童少年义务教育阶段随班就读工作的指导意见	Guiding Opinions of the Ministry of Education on Strengthening the Work of *Suiban Jiudu* in Compulsory Education for Children and Adolescents with Disabilities	Ministry of Education.
2021	十四五特殊教育发展提升行动计划	Action Plan for the Development and Improvement of Special Education in the 14th Five-Year Plan	State Council

The revisions of the Compulsory Education Law and the Protection Law continue to state that children and adolescents with disabilities have the right to education, including at general education schools for some (National People’s Congress, 2006, 2008). The Revised Regulations on Education for Persons with Disabilities in 2017 called for promoting *inclusive* education (*ronghe jiaoyu*) in general education as the main channel of instruction (State Council, 2017b; Yang, 2022; Xu & Jia, 2020). Zhao and Zhang (2018) note that these education regulations moved closer to the ideals of equal opportunity and inclusion. Updated laws and regulations state that schools cannot refuse school-age children “who have the ability to receive general education and *suiban jiudu*" (National People's Congress, 2006, 2008; State Council, 2017b).

Three Action Plans for the Development and Improvement of Special Education (State Council, 2014, 2017a, 2021) also promote school acceptance. The First Action Plan called for expanding the scope of compulsory education through *suiban jiudu* and resource rooms, as well as special schools and home-based education for children with significant disabilities. At the conference of the Second Action Plan, the "zero reject" principle was emphasized, with local education authorities called on to enroll every student with disabilities. This did not mean placement in inclusive education, but rather individualizing placements according to "one person, one case," including a continuum of services from home-based to general education. This plan promoted *suiban jiudu* in nearby schools as the priority placement for children with disabilities (Li, 2017; State Council, 2017a). Currently, the third Action Plan continues to promote school enrollment, inclusion, and differentiation of instruction (Ding, 2021; State Council, 2021). In addition, an inclusion-relevant concept, *yingsui jinsui* (for those who should *suiban jiudu*, promote it as much as possible), was noted in the 2020 Guiding Opinions of the Ministry of Education on Strengthening the Work of *Suiban Jiudu* in Compulsory Education for Children and Adolescents with Disabilities, to increase the enrollment and quality of *suiban jiudu* instruction (Ding, 2021; Huang & Wu, 2021; MOE, 2020).

Support Systems and Role of Special Education Schools

A strong and effective inclusive education system requires support systems. Provision of support for students with disabilities in general education in China is included in many policy documents. The 1994 Regulations noted that assistance should be provided in general education settings according to student needs and, when possible, schools could provide individualized instruction or "tutorial classrooms" (State Council, 1994). The 1994 Trial Measures suggested tutorial rooms, staffed with part- or full-time tutoring teachers with special education training, to work with students and assist general education class teachers in individual planning and assessment (National Education Committee, 1994).

Special education schools and resource classrooms are currently both important sources of support for *suiban jiudu* in China (Yang, 2022). The function of special schools is shifting to comprehensive support services, including overseeing s*uiban jiudu* and resource rooms (Huang & Wu, 2021; MOE, 2016; Xia & Xu, 2017). Special education schoolteachers are called on to periodically serve general education schools as itinerant teachers*,* provide training and consultation, and support students receiving home-based education (State Council, 2009, 2017b). In the National Medium- and Long-Term Educational Reform and Development Plan (2010-2020), in addition to a goal of providing special education schools in all localities with over 300,000 people, there was also a goal to grow the scale of *suiban jiudu* and special classes, in order to increase compulsory education enrollment (State Council, 2010; Xu & Jia, 2020; Zhu & Wang, 2011).

Qualified staffing is essential for effective support in inclusive education, and the Revised Regulations on the Education of Persons with Disabilities (Revised Regulations) call for staffing resource rooms with teachers who have special education backgrounds (State Council, 2017b). The Second Action Plan calls on local authorities to hire specialized resource teachers for students with disabilities (State Council, 2017a; Zhang & Lu, 2020), specifically including "public institution tenure track" (*bianzhi*) teachers and professionals (Ding, 2021), which is very important and encouraging.

All three Action Plans (State Council, 2014, 2017a, and 2021) expanded the number of children obtaining compulsory education (Xu & Jia, 2020; Liang et al., 2015) and provided guidance on improving support for inclusion (Yang, 2022; Yin, 2016) including the promotion of resource rooms and resource centers. While this is promising, the Guidelines for Building Special Education Resource Classrooms in Schools also addressed problems including shortage of resource teachers and ineffective resource classrooms (Huang & Wu, 2021; MOE, 2016).

Policy Limitations on Inclusive Education Rights

While policy context since the 1980s has demonstrated a commitment to rights to educational opportunities and inclusive education, beginning in the mid-1980s there has been a phrase in policy documents indicating restrictions on access to *suiban jiudu*. Many policies state that children with disabilities may be included in general education classes if they have the ability to do so (e.g., National People's Congress, 1986, 1990, 2006, 2008; State Council, 1994, 2017b). The Compulsory Education Law states that schools “shall accept school-age children and adolescents with disabilities who are able to receive ordinary education, to *suiban jiudu*,” and notes that failing to do so would be corrected or sanctioned (National People's Congress, 1986; 2006). The 1990 and Revised Protection Law and the 1994 and Revised Regulations use similar language, including requiring that children are able to “adapt to the study and life” of general education elementary and middle schools (National People’s Congress, 1990, 2008; State Council, 1994; 2017b).

Both rights and restrictions for individuals with significant disabilities in particular are also noted in the First Action Plan and the Revised Regulations. These policies describe home-based education for students with severe disabilities “who need special care and are unable to attend school” (State Council, 2014, 2017b). This fits with global practices of a continuum of services for students with disabilities, from less to more restrictive. However, determining a child’s ability to learn and adapt in school “according to type of disability, degree of disability… school-running conditions and other factors” (State Council, 2017b) leads to decisions based on categories and local resources, and not on individual needs.

Another potential restriction in policy language is in the 2020 Guiding Opinions of the Ministry of Education on Strengthening the Work of *Suiban Jiudu* in Compulsory Education for Children and Adolescents with Disabilities, which calls for expanding *suiban jiudu opportunities* to all who should be included (*yingsui jinsui*) (MOE, 2020). Although policies related to disability and education demonstrate increasing recognition of inclusive educational opportunities, the concept of *yingsui jinsui* is vague about who “should” be included, and the term “*sui*” (follow) indicates a hierarchical division between students with and without disabilities. In *suiban jiudu* practice, children with disabilities attend general education classrooms but, while some have school status (*xueji*) there, others have their school status at the local special education school. Thus, *suiban jiudu* implies a hierarchy, where typically developing students are full members of the class while others are “following along” with the class (Guo & Deng, 2021).

Regional Development and Policy Language

Uneven regional development of opportunities results from practical differences based on context and vague policy language. Vague language means “the right to inclusive education is a ‘can’ instead of a ‘must’” linked partly to limited resources (Zhao & Zhang, 2018, p. 134). Regarding contextual differences, the third Action Plan notes that development follows regional economic and population differences (State Council, 2021). Vague national policy is followed by regional implementation documents, which inevitably differ, and may overlook some policy goals (Ren & Wang, 2020). Of course, needs differ across regions, and implementation guidelines are not precise. More practical and implementable policies are needed (Fang, 2019; Xia & Xu, 2017).

Policies, Institutions and Human Experiences

Recent policies make clear that more attention is being paid to the rights to education for children with disabilities, including to attend both special and general education settings.

An understanding of the lives of people impacted by those policies can provide a snapshot of how policies are being implemented, in the context of the boundaries, limitations and strengths of local educational institutions. We took a unique approach here by focusing mainly on policy documents themselves for the literature review, in order to then consider families' experiences with their children's schooling as on the ground outcomes of these relevant policies.

Methodology

Part of a larger study targeting teachers and parents, this qualitative study examined 11 parents' experiences with inclusive education for their children with ASD and other developmental disabilities. Specifically, we examined discourse surrounding access, opportunities, and challenges in inclusive education. Qualitative research "generate[s] knowledge grounded in human experience (Sandelowski, 2004)" (cited in Nowell et al., 2017, p. 1) which was appropriate for the focus of this study. Qualitative research design included open-ended semi-structured interviews conducted via WeChat.

Participants, Recruitment, and Interview Protocol

A Qualtrics survey was posted in WeChat parent and teacher groups that the first author belongs to, and on that author's "moments" WeChat page. Participant criteria included being a parent of a child with ASD or other developmental disabilities who attended general education schooling at the elementary school level. Initially, 56 people with complete contact information responded and 11 parents met the criteria. Nine parents had children with ASD, and two parents had children with other developmental disabilities. (See Table 2)

Table 2

Participant Information

Participant	Child's age	Gender	Location	Official Roster or Suiban jiudu
Parent 1	13	Boy	Handan, Hebei	Suiban jiudu
Parent 2	13	Boy	Taiyuan, Shanxi	Suiban jiudu
Parent 3	10	Boy	Nanjing, Jiangsu	Official roster
Parent 4	16	Girl	Suide, Shaanxi	Suiban jiudu
Parent 5	9	Girl	Jinan, Shandong	Suiban jiudu
Parent 6	7	Boy	Beijing	Suiban jiudu
Parent 7	12	Boy	Nanjing, Jiangsu	Suiban jiudu
Parent 8	16	Boy	Zigong, Sichuan	Suiban jiudu through 6th grade
Parent 9	10	Boy	Wuhu, Anhui	Official Roster
Parent 10	13	Boy	Wuhu, Anhui	Official Roster
Parent 11	8	Boy	Zhuzhou, Hunan	Suiban jiudu

Regarding inclusive education and access to education, sample interview protocol questions included: What was the process of gaining access to your child's school? Share your experience in interacting with school administrators and teachers. What supports are provided for your child in the classroom/school? All interviews lasted approximately one hour and were conducted in Mandarin Chinese, the native language of participants, by the first author.

Data Analysis

After transcribing all interviews, they were translated into English for analysis. Thematic analysis used an inductive approach, generating codes and examining emerging themes (Braun & Clarke, 2006). Analysis of the codes used the constant comparative approach (Glaser & Strauss, 1967; Miles & Huberman 1994). Some codes included "process of getting into school," "barriers to inclusive education," and "perspective on educational placement." Both authors transcribed, translated, and reviewed the data. Specifically, through an iterative process of conducting interviews, coding, defining, reviewing and refining themes (Braun & Clarke, 2006; Lincoln & Guba, 1985; Nowell et al., 2017), themes emerged to explain the phenomenon of gaining access to, and experiences in, inclusive education.

Results

The increasing focus on *suiban jiudu* and inclusive education in educational policy in China is promising. Despite limiting language, rights to education for children with disabilities are mentioned directly in important laws and regulations. Here we present a snapshot of families' experiences of policy implementation on the ground, through listening to the voices of parents of children with disabilities. Themes from data analysis include recognizing children's rights to education; the need to demonstrate ability and qualifications, and a subtheme of gaps in support systems; and concern for the impact on the teacher and the school.

Recognizing Children's Rights: Rights to Education in General Education

Many of the participants discussed and recognized that their children had rights to education under current policies. However, they had a range of experiences that demonstrated regional variations and varied impacts of policies. For example, Parent 11 explained:

> It's not easy finding a school that can accept him. Public schools have to admit children, but admitting and accepting are different, and requires cooperation with schools and teachers.… It's difficult for a child like him to truly integrate into the environment. There's basically no inclusive education; it's stuck at the policy level.

"Stuck at the policy level" indicates the challenges that schools face when they do not have the support systems in place to effectively teach a student with autism. For example, Parent 5 also noted that, though the Action Plans call for support systems like resource classrooms and teachers, "but now we basically don't have any." Though most participants were aware of educational policies, they remained worried: "When we went to elementary school, we were always worried about being rejected by the school" (Parent 3).

Despite hesitation and institutional limitations, participants' experiences demonstrate that schools recognize children's rights to education, including in general education. When Parent 6 registered her son for school, she said, "I knew the school couldn't refuse him … in developed areas like Beijing and Shanghai, at least physically, it should be well implemented. In other words, the school may not want to admit a child, but the child must be admitted." Parent 6 further explained, "Now the country also has laws and regulations, and 'zero reject'…. My household registration is here, so … the school cannot refuse him." Similarly, two other children were easily accepted by their local schools. Parent 9 recalled, "The teacher found out he has Asperger's … [though she was unsure] she didn't say he can't come. They let him come to school … they didn't say … he can't adapt to this (environment) ... and thus reject him, it didn't happen." Even in middle school, Parent 7 said, "The country has a policy. Now, the middle school can't reject you, they have to accept you. We can attend a nearby middle school."

Parents in multiple cities reported experiences of schools that hesitated but did not reject their children. Parent 7 explained, "For us to enter general education school wasn't easy…. China hadn't … said [schools] must accept unconditionally." Parents worked with schools to find solutions, including parents accompanying children to school *(peidu*) and signing responsibility waivers. For example:

> Because our home is in this district, we signed up for this school ... it's just according to where you live. If you meet those conditions, you can sign up and attend ... [but he was very disruptive and they called us in after the first day] ... the teacher's meaning

> was, they don’t want this child, they were rejecting him. But after all, we’re from the area, and now inclusive education has begun, it’s being promoted. It’s called ‘zero reject’. And we parents persisted, we wanted to stay here, we’ll figure out a way, whatever problems exist … if something happens, we parents are responsible, that is, it has nothing to do with the school. So we signed the guarantee letter (Parent 2).

Given the logistical challenges faced by schools in implementing inclusion, even given the recognition of and desire to provide those rights, one strategy used by several parents to convince hesitant schools was through connections. Parent 4 explained, “The principal knew we came here after attending another school and didn’t want to accept her.” Though she was rejected by several teachers, her relative was a teacher there, so she transferred to the relative’s class, following the relative “up and down grade levels.” Parent 1’s son also gained access to general education through family connections at school. Parent 2 noted that being from a smaller town was helpful; they “found an acquaintance to go with us to sit at the principal’s house” and then kept building a good relationship with the teacher, which helped the teacher to be understanding and the process to be smoother. Parent 8 recalled:

> I told the teacher when he was in the first grade [he has autism], because…if I don't say it, the teacher will find out. When I told them, at first, they didn’t want to admit him. They were afraid, what if problems come up…? So we asked friends, and used connections to talk to the principal. That’s how we were admitted.

Reaching out personally was often helpful in seeking access to school and, in one case, parents pleaded their case to other parents for an equal right to education. Parent 9 shared that, after her child demonstrated challenging behavior one day, “The next day many parents’ response … was [to write in a group WeChat] about not letting him attend school.” She and her husband responded in the group, writing, “Every child has the right to nine years of compulsory education…. If as parents you don't have your child … attend school near your home, that’s against the law. It’s his right, you’re depriving him of his rights.” Then, the other parents stopped complaining and trying to kick him out.

Parents noted both the right to education, and the need to be qualified: “At age 7, I didn’t delay his starting school, because I think he’s a person in society, he should keep up with society’s rhythm. His ability is insufficient, so I definitely chose to accompany him (*peidu*).” Parent 5 also recommended letting the school know one’s child’s strengths. When enrolling her daughter for *suiban jiudu*, she told them about her child’s disability, and, “…never did they say they would reject us … I think parents should be fully prepared. Our child may have insufficient abilities, but we also highlight her strengths…. Let them know she has a certain learning ability first.” The teacher was understanding, and the principal admitted them to *suiban jiudu* as soon as they got the hospital disability certification.

Demonstrating Ability and Qualifications

In practice, results demonstrate that the right to attend general education was not seen as a given. Parent 5, while pleased with her school’s accepting her child, did not interpret policies to mean that everyone should be accepted in general education: “Some parents feel that since it’s compulsory education, a school must accept me. I have never felt there’s any ‘must’... if your child cannot adapt to the environment, nobody said they have to accept you.” Her child was quiet and followed teacher instructions, positively impacting her admission. Similarly, Parent 7 explained “China hasn’t … said you must accept unconditionally. When you enter school there’s an interview, and if a child has some abilities that aren’t good, they will recommend that you attend a special school.” This understanding echoes policies, many of which clearly state that, in order to be accepted for *suiban jiudu*, students must demonstrate receptivity to general education, including the ability to adapt to school. Parent 7 shared, “Actually, it’s not easy to get into regular school. The problems faced by my child to get into general education school were quite numerous, because of the expectations of a child’s abilities.”

Many parents mentioned enrollment interviews that were used to demonstrate qualifications for admission. Parent 9 recalled, “For the enrollment interview he passed everything. Plus during the interview they didn’t find anything different about him so we didn’t worry that he wouldn’t be able to be enrolled, and we didn’t talk to the teacher about [the child’s disability] in advance.” Some delayed the interview and enrollment, including Parent 2:

> ...because at the time I felt he had a lot of deficiencies, so we delayed a year. After delaying a year, we registered. He passed the interview, and that afternoon we were

> very happy, but on the first day they discovered his problems. Originally, I felt he had improved, and that we could hide (his disability).

Similarly, Parent 1 delayed enrolling her son in school until age 10, because “He didn’t have the ability to attend school at age 7 … even if I accompanied him.” By age 10, he had gained motor and behavioral skills, but several schools rejected him due to safety concerns. Finally, through connections they found a school. Regarding the child’s school status, Parent 1 explained, “We talked about the issue of setting up his school status” and then her son was registered as a *suiban jiudu* student with school status at the local special education school.

Interview data showed that, even if a student enrolls under *suiban jiudu* status, they must perform at a certain level in class. Thus, for students with more significant behavioral or learning needs, “if the family doesn’t have anyone appropriate to accompany (*peidu*) … attending school [general education] is difficult, so what can you do? The child must attend special school. In other words, [government policy] gives you the opportunity to attend school, but if you can’t adjust to the school’s atmosphere, then you must attend a special school” (Parent 7). Parent 3 said, “We worried about being rejected because, before us, many children like this were rejected by general schools because children need an interview before going to school. When the teacher sees you have a problem, many schools refuse to accept you.” In her situation, her child did not pass the interview but was still allowed to attend at first; when he had difficulties the first day, “The teacher called me…and said they needed me to accompany him [*peidu*].”

Lack of Support in General Education

Related to the need to be qualified was the reality that general education settings experienced by the participants in this study lacked the support needed by students with disabilities. Given this issue, when considering the results, it is important to remember that institutional limitations on the ground, in addition to policy, are factors impacting families’ experiences. Many parents accompanied their children in school [*peidu*] for all or some of their schooling, because they needed individual classroom support. Parent 7 explained that, although her city had policies against schools rejecting children with disabilities,

> They accept these children, but there’s not enough support provided. Although there are some resource rooms, and *peidu* teachers, that's for very few students. The majority [of support] is still parents or someone hired by parents. The country doesn’t provide resources like this.... In China, in terms of resources, it’s still not enough. So we have this slogan, and this model, but actual implementation isn’t solid yet.”

Thus, she said, for many children with disabilities, if a family “can’t find someone to go with them, they must attend special school.”

Regarding policies and the related school support, Parent 6 reflected that regulations are clear now, but “everything has just begun, the school doesn’t know what to do…. There are more than 40 people in a class and one head teacher…. So it’s impossible for teachers to have extra energy to take care of our children. Not to mention they lack technical and professional support.” This parent researched local regulations and found that special education schools in her city had resource centers “to support *suiban jiudu* students” and successfully advocated for a resource teacher to go to her son’s school twice a week for two hours to provide individual classes for him.

While Parent 6 found support from a resource center in Beijing, due to her knowledge of the law and advocacy efforts, and being located in a major urban center, others had less support. Parent 9 commented, “I really need special education support, but this school isn’t equipped with [that]. It’s just a typical classroom and teaching. So my child cannot keep up with the group … so I’m thinking if there were a special education teacher, how great that would be!” Without support, she continued, “this kind of environment is also wasting his time” (Parent 9). Because of this lack of professional support, Parent 10 focused on her child’s progress compared to himself, rather than keeping up with the class, because in her own understanding and experience, “there’s no resource classroom in China.”

Suiban Jiudu **Decisions: Considering the Impact on Class and Teachers**

Most parents noted that their children could not keep up in class and they worried about teachers’ and administrators’ attitudes. This concern was because low grades would lower the class average, thus impacting teachers, whose evaluation is tied to student performance (Liu & Zhao, 2013). This was a major consideration in deciding on registering for *suiban jiudu* status or not. The goal for Parent 5 was to be in the school environment: “We just want her to improve. Such an environment may help her … but we don't want to burden teachers too much." Parent 10, whose son had regular school status, explained:

> Although my child isn't *suiban jiudu,* he cannot keep up academically…. So if this impacts the teacher, it's not fair to the teacher…. We'd feel a lot of pressure…. After communicating, the principal said the child [child's scores] won't enter into the class average, so now the teacher is very relaxed about his studies.

Parent 4, concerned about the impact on the teacher and school, described her strategy: "They say our child lowers the scores ... she's on the official school roster, so she participates in exams. I'm afraid she'll bring the scores down, so I never allow her to take tests."

To avoid having a negative impact on the class average, some parents chose *suiban jiudu* status. Parent 8 said, "His examination results aren't recorded towards teachers' performance because he's a *suiban jiudu* student." Similarly, Parent 7 said, "I signed him up as *suiban jiudu*, and I said to the principal, if you have requirements of teachers regarding assessment, then we'll register as *suiban jiudu*. I don't want to give any teacher or the school additional burden." Demonstrating the hierarchical nature of *suiban jiudu* versus official school status, she continued, "If they had no such requirements then I wouldn't sign up as *suiban jiudu*." Parent 1's son also enrolled as a *suiban jiudu* student at the general education school, with school status at the special school.

Discussion

Scholars point to progress towards educational rights for children with disabilities, as well as room for improvement in *suiban jiudu* in China (Ren & Wang, 2020; Xu, 2020; Zhao & Zhang, 2018). We investigated parents’ experiences gaining and maintaining access to educational opportunities for their children with disabilities. By examining relevant policies, followed by parents' voices, we considered how these experiences illustrate the impact of policy and implementation in their lives. The themes of recognizing children's rights, the importance of demonstrating ability, and *suiban jiudu* decisions made by parents and schools resonate with issues in literature. Together, these findings point to the importance of developing a support system to ensure effective implementation and expansion of inclusive education. Indeed, the experiences of parents and children are impacted both indirectly by policy as well as more directly by institutional resources, practices, and challenges on the ground.

The Right to Effective Education: Placement Options

Many parents in this study referred to “zero reject,” explaining that policies give children the right to attend local elementary schools. Scholars have noted that this concept originates from western concepts of inclusive education (Xiao, 2003; You, 1997) and, within policy documents, positively impacts inclusion (Sun et al., 2020). In China, *suiban jiudu* has been described as the main channel of special education, so that most students with disabilities should be in general education schools (Zhu & Wang, 2011), while special education schools are transitioning to both educate children directly and support an inclusive education system (Xia & Xu, 2017; Yang, 2021).

At the other end of a continuum of placements, increasing attention to the educational rights of students with significant disabilities is noted (e.g., State Council, 2014, 2017b). Though the ability requirement clauses exclude this population from *suiban jiudu,* policies call for other means of providing compulsory education, including special schools and home-based education, for those previously excluded. Though not an inclusive or equal opportunity, this demonstrates an important range of options. Yang (2019) points out that promoting inclusion, constructing special schools, and efforts for home-based education are linked, so this is a way to take the strengths of both systems, and explore collaboration to promote inclusive education. A focus on collaboration between general and special education is essential and there is enormous potential through the development of resource centers within special education schools to truly “give full play to the respective advantages of general education schools and special education schools” (Yang, p. 9) in a way that fits China’s context. In other words, the development and new roles of resource rooms and resource centers may serve as an important factor in removing systemic barriers between general education and special education schools. They can continue to serve in their distinct roles but, with more collaboration between the two, more supports might be introduced into general education schools.

Accessing and Succeeding in General Education

From comments about accessing school, beliefs on what their children needed to be ready for school, and efforts to avoid having a negative impact on teachers and classes, analysis of the interviews found parents understood that children should demonstrate qualifications to enroll in general education schools, whether with official school status or *suiban jiudu* status. Access to general education was not assumed, and many parents knew that policies do not guarantee the right to inclusive education for all (Zhao & Zheng, 2018). Thus, parents communicated with principals and teachers to gain access, and frequently provided support including accompanying children to school, sitting beside them, and providing academic and behavioral support (authors, 2023).

Indeed, many policies continue to limit *suiban jiudu* to children who do not require support in a classroom (National People's Congress, 1990, 2008; State Council, 1994; 2017b), demonstrating a continued phenomenon where students do not all have a right to attend general education schools, but rather must demonstrate that they have qualifications to attend independently. Requiring students to demonstrate ability is linked to the lack of special education support systems in general education. Classrooms do not typically differentiate instruction (Li, 2022) and parents reported that individualized support is rare; this may be linked to the large class size, little to no special education support available in schools, and traditional group instructional practices in China. The CRPD states that, in realizing the right to inclusive education, "Persons with disabilities receive the support required, within the general education system, to facilitate their effective education" (United Nations, 2006). If children must demonstrate a certain ability and adaptability to school, the responsibility seems to be on them to demonstrate qualifications, rather than on schools to provide individualized accommodations. Thus, students still are rejected or, once enrolled, may soon drop out (Xu, 2020). To understand why policy is implemented as it is, we must look at institutions in society. Between policy and family experiences are conditions on the ground, such as the separate special and general education systems and schools, allocation of resources and large class size, and limited supports in general education schools. This organization of educational systems is one important factor making effective implementation of inclusive education difficult.

Support System Challenges

The results of this research indicate that, while there are many policies promoting *suiban jiudu* and inclusion, and schools and teachers are increasingly willing to admit students with disabilities, a significant challenge of providing needed support remains. Institutional limitations, such as staffing, create barriers. Because there is often not enough staff, and not enough staff with special education backgrounds, such as special education classroom teachers, resource room teachers, or classroom assistants, it is difficult to effectively include students with disabilities. Our interviews demonstrate that parents are grateful for their children's schooling opportunities, though children cannot keep up on their own. Some authors argue that, due to a lack of formal support mechanisms, some children included in general education are still just "sitting" in class (*suiban jiuzuo*) and not "learning" in class (*suiban jiudu*) (Ding, 2021; Xu, 2020; Zhu & Wang, 2011).

The systematic establishment of a high-quality support system for inclusive education is a needed key step in the development of *suiban jiudu* (Xu, 2020; Yin, 2016). Special schools are slowly transferring their role to provide needed expertise and guidance for inclusion (Xia & Xu, 2017; Yang, 2021). As general and special education systems collaborate more, special classes are also important and serve as an important bridge in general education schools (Yang, 2022). Support systems require new staffing allocations in general education schools, and new roles for special education schools and teachers. While, typically, general education schools do not have special education full-time staff (*bianzhi*), it is promising that policies specifically note that in schools with *suiban jiudu*, the needed professionals and resources should be provided. Effective inclusion requires full-time special education teachers, and teaching assistants, to collaborate in general education settings (Ding, 2021; Xu, 2020).

In this study only one family was supported by a resource center, though policies indicate the new function of special schools as a resource center, which should oversee resource rooms staffed with resource teachers (State Council, 2021; Xia & Xu, 2017; Zhu & Wang, 2011). This would bring two separate systems together, rather than adding new special education expertise and full-time staff hired directly by the general education school. Relying on existing special education resources may be efficient, but it should be noted that special education schools have a heavy responsibility to continue providing education within their own schools, as well as supporting and guiding other schools' *suiban jiudu*. This transformation is still in its early stages, with some special and general education school leaders not fully aware of this and how it impacts them (Yang, 2019).

Interdisciplinary collaboration is a key ingredient for successful inclusion. In China, collaboration between general and special education, across levels of schooling, and between education systems, health systems, Disabled Persons' Federations, and civil affairs systems, is needed (Xu, 2020). Within schools, teachers who are well-trained in the field of special education, based in general education schools, are essential, as are more resource classrooms (Xu, 2020). Having professional special education teachers within schools and classrooms is essential to meet the diverse needs of children, including more individualized education and instruction (Li, 2022; Xu, 2020).

Limitations and Directions for Future Research

The goal of this qualitative study was to understand families' experiences with inclusive education within China's policy context. We recruited widely without limiting by region. Yet policies are vague, leading to inconsistent implementation (Guo & Deng, 2021) and, because local regions implement policies according to their specific situation, there is variation in how parents experience these policies. Future research might focus on families in one geographic area or compare experiences across two areas. In addition, the ages of participants ranged from 7 to 16. Focusing on students closer in age would provide a clearer picture of the most current situation. Another limitation related to participants is the lack of inclusion of students' experiences from their own perspectives. Including interviews with the children, in the manner of communication that is accessible to them, should be included in future studies. Regarding observation and direct observation of students' experiences, data was collected during the period of COVID-19 when travel was very limited, thus ruling out any classroom observation.

Future research should examine inclusion both in the classroom, as well as from a leadership perspective. Examining classroom experiences in more detail should include students' experiences with peers, curriculum, and overall school supporting systems. Children with disabilities are being educated in general education through *suiban jiudu*, and scholars and parents call for special education supports, so it is important to understand children's classroom experiences. Observational research, in collaboration with schools, would provide a foundation for developing supports appropriate to the present Chinese context. As another perspective, future research should also examine school leaders' experiences with inclusive education, to understand their decision-making in implementing policies. It is important for teachers, principals, policymakers, and researchers to better examine the quality of education that students receive, and work together to design effective inclusive education opportunities.

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The Past, Present and Future:
Hukou as a Social Status and Its Impact on Chinese Disabled Migrant Workers' Social Mobility in the Labor Market

Cunqiang Shi[1] and Debbie Foster[2]

[1] Bangor University

[2] Cardiff Business School, Cardiff University

Abstract

Liberalization has transformed the economy in China, but legacy policies such as the *hukou* system undermine free movement of labor and embed discrimination in the labor market. Opportunities for social mobility are restricted for all migrant workers, but this article argues disabled migrants experience a specific form of ghettoization.

Keywords: disability, employment, *hukou* discrimination, China.

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Over the past four decades the rights of Chinese disabled people have attracted increased public attention because of the establishment of disability advocacy institutions, such as the Chinese Disabled People's Federation (Stone, 1998), and the Chinese government's ratification of the United Nation's Convention on the Rights of Disabled People (UNCRPD). Despite this interest, however, disabled people do not appear to have benefited significantly from rapid urbanization and modernization in China. And, as this article demonstrates, they have been particularly disadvantaged by the legacy of past policies that continue to perpetuate social-spatial disparities in employment (Liao et al., 2016; Zhao & Li, 2019). The consequences stemming from the legacy of the *hukou* system, a means of categorizing the population as well as monitoring and controlling migration, is one such example. This essay argues that, not only is the *hukou* system unsuited to a reformed labor market, but its operation has doubly disadvantaged and divided disabled people, operating as an obstacle to their economic independence and identity as a group.

The *hukou* system is a form of household registration, and although there is evidence that it is detrimental to all migrant workers' social mobility (Song, 2016; Wang et al., 2021), little is known about the specific experiences of disabled migrant workers as a sub-category. By drawing on 48 semi-structured interviews with disabled people in China examining their labor market experiences, this essay addresses this gap in current literature. It will illustrate the ways in which the *hukou* system shapes an individual's social status and interacts with the socially and culturally constructed category of 'disability' within a Chinese context.

After examining the discriminatory impact *hukou* has had on disabled people as a socially disadvantaged group in China, the essay then considers social, educational, and employment disparities that are disproportionately faced by disabled migrants. This population is likely to face direct and indirect discrimination. Finally, the article highlights the contradictory legacy of the *hukou* system and the drive for labor market liberalization. As such, it argues that the tensions between the past and present have particularly disadvantaged disabled migrant workers, negatively impacting their access to economic prosperity.

The Legacy of the Planned Economy: The Historical Context of *Hukou*

The *hukou* system was originally intended as a social status identification system. It enabled the state to differentiate citizens during the Maoist centrally planned developmental era (1949-79) for purposes of controlling the national migration flow from rural to urban areas (Greenhalgh & Winckler, 2005). The consequences of its continued application to citizens in the modern era, however, are often not fully appreciated (McElroy & Yang, 2000; Chan, 2010). What was essentially viewed as a functional dualistic socioeconomic structure implemented by the Chinese Communist Party has in contemporary China created significant inequalities. This is particularly true in relation to access to education, healthcare, and employment between urban and rural citizens (Qi et al., 2015), evident in patterns of geographical inequality. The liberalization and marketization of the Chinese economy has involved a significant relocation of migrant workers from rural to urban regions. The original purpose of *hukou* as a migration control policy, therefore, no longer appears to be served. Instead, it could be argued that this has actively created social divisions by limiting equal access to employment opportunities. Wang et al. (2021) suggest that, despite several reform attempts by the government to reduce *hukou*'s effects on social mobility, *hukou* has continued to play a major role in discrimination in the Chinese labor market. We will examine new policies and rules aimed at addressing urban-rural integration.

***Hukou,* the Ableist Discourse of Citizenship and the Myth of Meritocracy**

Rapid economic growth, the need to relocate labor, and an acceleration in urbanization have led to migration from the countryside to cities. However, this labor migration has created the so-called "floating population" of more than 200 million people; these individuals do not have local *hukou* but are resident in cities (Chan, 2010). Among disabled people in the population, 76.7% have the status of rural *hukou* (Ling et al. 2018), which is concerning when contrasted with a national urbanization rate of 64.72% in 2021 (State Council of the People's Republic of China, 2022). Thus the probability of disabled people who move to cities making up a high proportion of those with urban *hukou* is low. Despite no official data on the urbanization rate of the disabled population, it can be reasonably assumed that lack of accessible infrastructure in transportation and barriers to enter the urban job market disadvantage disabled people's social mobility in China.

When migrating to a city, disabled workers place themselves at significant risk because of the mismatched *hukou* of their original hometown and their current residential emigrating city (Xiao et al., 2018). This mismatched *hukou* status has excluded migrants from local service provisions such as healthcare and vocational training, which are particularly important if migrants wish to increase their competitiveness in the job market.

For migrants who wish to settle in cities, there are, however, two potential ways to obtain urban *hukou*. The first option is through urban expansion: people who live in suburban areas might be granted urban *hukou* in exchange for their land ownership (Wu & Zheng, 2018). This is a lottery system because citizens do not have any control over the scheme. The second method is a so-called ‘merit-based’ selection system. *Hukou* is used to attract talent and investment into regions, but in reality, it is mainly wealthy, educated people who are selected by local government to qualify as there are strong connections between education and income inequality (Xu et al., 2018). Disabled people are less likely to be selected under these criteria as many have not attended mainstream schools and, if located in rural areas, are materially disadvantaged. Furthermore, critics suggest that, under this scheme, local government takes over the role of employers in judging the value of laborers, which in turn contributes to regional inequalities as fiscally richer cities are more likely to attract the most ‘able’ and ‘talented’ migrants than poorer ones (Cooke & Wang, 2019). This classification of migrants on an individual's economic contribution and education will favor wealthy and educated citizens over those more likely to have socially-economically disadvantaged *hukou*.

The Marginalization of Disabled People in the Labor Market as Consequence of *Hukou*

Although the *hukou* policy is applicable to everyone in China, it has particularly negative implications for disabled people and their social mobility in the ever-changing labor market. The way *hukou* distinguishes between rural and urban citizenship is an indicator of access to social-economic opportunities and resources and should be regarded as an important contributor to one's social status, something associated with birth and social position. In the Chinese context, research suggests the employment rate among disabled urban citizens is statistically significantly higher than that of their rural counterparts (Liao et al., 2016). This suggests status advantages from possessing urban *hukou*.

To understand *hukou* as part of an individual's social status and how it marginalizes disabled people in the labor market, several Chinese contextual characteristics need to be considered. The *hukou* system is particularly associated with individual households or families. Existing research on the role of the family's economic and social position in influencing disabled people's career choices suggests a substantial gap between rural and urban households (Fisher & Jing, 2008). In urban areas, the annual income of households with and without disabled members is substantially different (14,505.9 yuan [≈US$ 2,000] vs 24,564.5 yuan [≈US$ 3,500]), with the gap being narrower in rural regions (6,971.4 yuan [≈US$ 1,000] vs 7,913.1 yuan [≈US$ 1,140]). In addition, due to the lack of state financial support to accommodate medical or physical adjustments, households with disabled members are likely to shoulder the 'extra cost of disability' (Loyalka et al., 2014).

Hukou also determines a citizen's access to educational opportunities and choices, as most public schools only admit students from their local communities. Urban, disabled people are more likely to receive higher quality education, which in turn provides more opportunities in the job market, as educational qualifications are a main criteria for career success in China (Xu et al., 2018).

The kinship oriented social relational tradition in China, along with the dualistic urban/rural socio-economic structure, likely further disadvantage disabled people in the labor market. The Chinese concept of *guanxi* or social ties, often forged from informal social relations, enhances a person's social capital and has been shown to be significant in networking and progressing careers (Chen & Volker, 2006). *Guanxi* is based on an exchange of favors among social members in the circle to which they belong (*quanzi*); it is predicated on the belief that such exchanges will improve the collective interest of the group by connecting social resources possessed by members (Bian & Ang, 1997). Interdependence and mutual obligations are, therefore, core features of *guanxi* based on belonging to a social group (Bian & Logan, 1996). *Guanxi* can interfere with what should be neutral recruitment and selection decisions (Whyte & Parish, 1984), career progression (Bian & Ang, 1997) and social relations at work (Chen & Volker, 2016). Furthermore, because of the unbalanced economic and political structure that has been influenced by differences in *hukou* status, urban citizens tend to have more powerful *guanxi* networks than rural migrants, who tend to have fewer favors to offer in exchange for access to a valuable *guanxi* network (Gold et al., 2002). This is likely to have a significant impact on disabled migrant workers in the labor market who could find themselves doubly disadvantaged by the absence of urban *hukou* and, because of their poor social integration, reduced social capital.

Current debates about the *hukou* system in China have not considered the experiences of disabled people as a group, especially those who are migrants from rural areas or smaller cities. If reform of the *hukou* system is to take place, it is important disabled people's voices are included; the qualitative data presented here helps illuminate the diversity of those experiences.

Research Questions and Methodology

The previous section provided contextual background for considering *hukou* as social status of Chinese citizens and its impact on disabled people's social mobility in China's contemporary labor market. To bridge the knowledge gap identified, the following research questions are posed:

- Are the lived experiences of disabled people in China affected by their social-spatial status? If so, how?
- What impact has the *hukou* system had on the social mobility of disabled people in the Chinese labor market?

A qualitative approach to data gathering was adopted to give Chinese disabled people opportunities to highlight their lived experiences in the labor market based on their different *hukou* status and its impact. It is important to acknowledge that the emancipatory nature of this study is to identify and address disabling barriers that all disabled people face in Chinese society, with a specific objective of delivering disabled people's voices to a broader audience.

Forty-eight semi-structured interviews were conducted in late 2019. The participants' demographic backgrounds were mixed with variations in education experience, gender identity, employment status and *hukou* status. Details of each participant can be found in the table below. Except for one informant who refused to reveal their *hukou* status, there were 19 urban *hukou* holders and 28 participants with rural *hukou*. Among the 48 participants, 28 had migration experiences. This can provide a meaningful insight into the role of *hukou* for disabled migrant workers.

Table 1
Summary of research participants

Interviewee Number	**Gender**	**Age Group**	**Education Level**	**Employment Sector**	***Hukou* Type**	**Province of *Hukou***	**Current Residence Province**
1	Female	31-35	Postgraduate - Master's	Private	Urban	Chongqing	Chongqing
2	Male	36-40	Bachelor	Private	Urban	Beijing	Beijing
3	Male	26-30	Bachelor	Private	Rural	Zhejiang, Wenzhou	Zhejiang, Hangzhou
4	Male	26-30	Postgraduate - Master's	Student	Rural	Gansu, Jiuquan	Shanghai
5	Female	21-25	Bachelor	Private	Urban	Ankang, Shanxi	Shanghai
6	Female	26-30	Postgraduate - Master's	Public	Rural	Jiangxi, Shangrao	Shanghai
7	Female	21-25	Bachelor	Student	Urban	Jiangsu, Wuxi	Jiangsu, Nanjing
8	Male	18-20	Primary school	Private	Rural	Shandong, Dezhou	Shangdong, Dexzhou
9	Male	31-35	Bachelor	Private	Rural	Hubei, Xiaogan	Beijing
10	Female	26-30	Vocational College	Private	Urban	Xinjiang, Kuerle	Beijing
11	Male	21-25	Bachelor	Private	Rural	Shandong, Weifang	Beijing
12	Female	26-30	Bachelor	Private	Urban	Jilin, Tongthua	Beijing
13	Female	31-35	Postgraduate - Master's	Government	Urban	Shandong, Jinan	Beijing
14	Female	26-30	Bachelor	Public	Rural	Zhejiang, Shaoxing	Zhejiang, Shaoxing
15	Male	26-30	College	Private	Rural	Zhejiang, Shaoxing	Zhejiang, Shaoxing
16	Male	31-35	High school	Unemployed	Rural	Zhejiang, Taizhou	Zhejiang, Taizhou
17	Male	26-30	Middle school	Private	Rural	Fujian, Fuzhou	Fujian, Fuzhou
18	Male	26-30	Postgraduate - Master's	Private	Rural	Hunan, Loudi	Hunan, Loudi
19	Male	26-30	No formal education	Private	Rural	Hunan, Zhangjiajie	Hunan, Changsha
20	Male	26-30	Vocational College	Public	Urban	Hunan, Changsha	Hunan, Changsha
21	Male	31-35	Primary school	Unemployed	Urban	Guangdong, Heyuan	Guangdong, Heyuan
22	Male	31-35	Middle school	Private	Rural	Hunan, Huaihua	Guangdong, Dongguan
23	Male	31-35	High school	Private	Urban	Guangdong, Zhanjiang	Guangzhou, Guangdong
24	Female	26-30	Bachelor	Private	Rural	Jiangxi, Xinyi	Guangzhou, Guangdong

25	Male	36-40	Primary school	Private	Urban	Guangxi, Binyang	Guangxi, Binyang
26	Female	26-30	Vocational College	Private	Urban	Shanxi, Linfen	Sichuan, Chengdu
27	Male	21-25	Bachelor	Private	Rural	Shanxi, Ankang	Shanxi, Xian
28	Male	31-35	Bachelor	Private	Rural	Shanxi, Baoji	Shanxi, Baoji
29	Female	21-25	No formal education	Unemployed	Rural	Gansu, Pingliang	Gansu, Pingliang
30	Male	26-30	Postgraduate - Master’s	Public	Rural	Hebei, Hengshui	Yinchuan, Ningxia
31	Female	26-30	Vocational College	Private	Urban	Shanxi, Taiyuan	Shanxi, Taiyuan
32	Male	26-30	Vocational College	Public	Rural	Hubei, Huanggang	Hubei, Wuhan
33	Male	26-30	Vocational College	Private	Rural	Hubei, Qianjiang	Hubei, Wuhan
34	Female	36-40	Vocational College	Public	Urban	Jiangxi, Xinyu	Jiangxi, Xinyu
35	Female	21-25	Vocational College	Unemployed	Urban	Guizhou, Xingyi	Guizhou, Xingyi
36	Male	26-30	Postgraduate - Master’s	Student	Rural	Nemenggu, Huhehaote	Nemenggu, Huhehaote
37	Male	26-30	Bachelor	Private	Urban	Gansu, Jiayuguan	Gansu, Jiayuguan
38	Male	21-25	Bachelor	Student	Urban	Hunan, Loudi	Jilin, Changchun
39	Female	26-30	Postgraduate - Master’s	Student	Rural	Sichuan, nanchong	Guansu, Lanzhou
40	Male	21-25	Middle school	Private	Urban	Guangdong, Guangzhou	Guangdong, Guangzhou
41	Male	26-30	Bachelor	Unemployed	Rural	Zhejiang, Hangzhou	Zhejiang, Hangzhou
42	Female	21-25	Vocational College	Public	N/A	Shanxi, Changzhi	Shanxi, Changzhi
43	Male	26-30	Bachelor	Private	Rural	Guangdong, Jiangmen	Jiangsu, Taicang
44	Female	31-35	Postgraduate - Master’s	Government	Urban	Heilongjiang	Chongqing
45	Male	26-30	Vocational College	Unemployed	Rural	Xinjiang, Qilian	Xinjiang, Qilian
46	Female	21-25	Bachelor	Student	Rural	Anhui, Suzhou	Jiangsu, Wuxi
47	Female	26-30	Postgraduate - Master’s	Private	Rural	Jiangsu, Xuzhou	Jiangsu, Suzhou
48	Female	26-30	Bachelor	Private	Rural	Fujian, Zhangzhou	Fujian, Xiamen

Research Findings

Findings revealed that the most apparent effect of *hukou* status is the source and extent of social support that a disabled citizen can access. Uneven development and the Chinese government’s focus on improving urban areas are both reflected in rural participants reporting comparatively less social support related to their impairment. The consequence of this for disabled people living in rural areas is greater dependency upon family as well as limited choice of alternative sources of support. Findings also suggest family support is unpredictable and dependent on the goodwill and financial circumstances of each household. This is illustrated by examples from interviews with disabled rural citizens below. These two interviewees had different educational experiences, qualifications and family support that affected their career opportunities:

> *I was born in an extremely poor village … having a child like me caused my parents a great deal of financial pain … but they have faith in supporting my education, and I could not achieve a postgraduate degree without their dedicated support. (Interviewee 6)*
>
> *It used to be 600 yuan [≈US$ 85] a year in order to [receive an] education, but my family could not afford it… so I had to drop out of middle school, and now I have no work. (Interviewee 21)*

In contrast, disabled interviewees that possessed urban *hukou* reported receiving or having access to some local government funding making them less dependent on their families, although the amount of financial support was dependent upon location and *hukou* status. In an economically developed region with a relatively rich local council, disabled people reported receiving significant financial support to help them live independently.

According to Interviewee 41, a worker who has lived in various cities, the amount of money disabled people can receive from the government in a rich region like Zhejiang (where he currently lives), can be up to 2,000 yuan a month. This is about ten times what he could get in his original town. In addition to welfare benefits, disabled workers can also claim tax reductions when working in cities. Interviewee 23, for example, works in Guangzhou (a highly international city) and refers to a substantial personal income tax reduction. In contrast, interviewees from rural areas or less developed cities mention few supportive tax or fiscal benefits.

In addition to differences in support based on residential and *hukou* status, disabled migrant workers who do not have local *hukou* are likely to experience higher costs when commuting in cities, despite the better accessibility of the public transport system. For interviewees who had migrated from a rural region or smaller city to economically prosperous cities like Shanghai and Beijing, many reported positive experiences with accessibility when commuting using public transport. Furthermore, it is likely these benefits will be further enhanced for disabled city dwellers because of legal commitments to continue to improve the accessible built environment. Nevertheless, increased accessibility comes at a cost to those who travel frequently, consuming a significant proportion of their monthly income. Many disabled employees also reported being in low-income jobs, which meant they had to live on the peripheries of the city. Disabled residents with local urban *hukou*, by contrast, could apply for a travel pass from the local council, which can be used for claiming discounted travel fares.

The other significant disadvantage reported by interviewees who were migrants in cities without local *hukou* was their lack of access to social security provisions. As migrant workers without local social contacts (*guanxi*), participants also tended to be concentrated in low aspiration, labor-intensive jobs. This could put their health at greater risk than non-disabled workers as many disabled workers need to manage pre-existing impairments; it also meant access to social security was more, not less important. Interviewee 10 worked in a call center, for example, where shifts were pre-arranged by managers. She was constantly concerned about her health because of the intensive nature of her work but tried not to be absent:

> *Generally, we are not supposed to take sick leave because it will cause significant disruption to other team members… if I become sick (which I try to avoid), I essentially force other colleagues to take on more work. And I cannot afford the huge medical bills if I got sick; it could easily cost me a couple of month's salary (Interviewee 10)*

Other disabled migrant workers without local *hukou* reported similar worries about their financial vulnerability due to their exclusion from local social security schemes (see interviewees 6 & 22).

Social relations, or *guanxi*, were found to be important for disabled employees and had a moderate but important connection with *hukou* status. Interview findings suggest that urban citizens are more likely to have more influential *guanxi* as they are more likely to be connected with urban employers. Interviewee 31 (a woman with a visual impairment) who has urban *hukou* in her city used her *guanxi* network to her advantage to secure her job at a local healthcare organization:

> *I applied for a job in a public hospital … I was initially rejected, with the excuse that 'we do not need people on this job anymore', but later the decision was overturned*

> *because I managed to use my guanxi to contact the senior manager in the hospital … then I was told that I could work for the hospital. (Interviewee 31)*

This suggests that privileges derive from urban *hukou* and are interrelated with linkages to a *guanxi* network that 'outsiders' cannot access. Disabled migrants are likely to be disadvantaged by the absence, not only of access to this network, but also lack of social integration as disabled workers. As migrant workers from rural areas, many participants had only socialized with their local communities and reported that they found it difficult to establish *guanxi* networks in urban workplaces due to the lack of common topics to talk about with colleagues:

> *My social circle is very small, so I have limited access to resources, and I am unable to have fruitful conversations with others…this made me hugely marginalized because I am not popular at work. (Interviewee 22)*

The role of *hukou* in social relations is relatively indirect. Participants with rural *hukou* reported few kinship connections in urban cities. This became a major barrier for many who experienced hardship and social exclusion in their attempt to seek and secure employment opportunities. Insecure employment status and poor social networks were problematic for disabled migrants, and interviewees shared their experience of facing further barriers in attempts to obtain local urban *hukou.* Firstly, the meritocratic standard used to award *hukou* was more likely to disadvantage disabled people because of education inequalities. According to interviewee 41, who is campaigning for education equality, the number of disabled people who graduate from a higher education institute is significantly lower than non-disabled people:

> *From 2015-to 2018, only 20,000 disabled students entered higher education (including special education), but the number of total students is 20,000,000. That means only 0.1% of new students are disabled, and only 1% of disabled people can enter higher education. (Interviewee 41)*

It is clear by examining the demographic characteristics of the interviewees that education plays a significant role in upgrading social mobility in the labor market. Those originally from urban cities tend to have higher educational qualifications that allow better opportunities to secure employment. Despite most participants in this study having some higher education experience (including vocational colleges), only two interviewees (both having worked for the civil service) were able to obtain local urban *hukou*. This may indicate a general perception of employers that disabled workers as less desirable.

In addition to the need for educational qualifications, there are financial barriers associated with claiming urban *hukou.* The experience shared by interviewee 23, who is considered to be one of the higher earners among the participants, demonstrates his concerns related to settling down in Guangzhou:

> *In most Chinese cities, a standard requirement for claiming a local Hukou is that you have to pay the social insurance for a consecutive period of time and possess a*

> *house.… In my current city, for people like me from the rural area without a good education and with poor income, it is nearly impossible for us to claim the local Hukou. (Interviewee 23)*

For those interviewees in low-income jobs where many disabled participants were located, few paid social insurance. This is because many urban job contracts are non-permanent. Interviewees thus reported a general lack of employment security; the state disability employment legislation (2007, article 12), which is intended to encourage employers to hire disabled people, in effect, does this at the expense of their employment rights.

The findings from interview testimonies collected by this study suggest that, although *hukou* acts as a nationwide barrier to migrants, it is likely to confer additional disadvantages on disabled people. This study found restrictions were financial, social, familial, and educational. Whilst these might also be relevant to some non-disabled migrants, for disabled people in a society where stigma and marginalization is still prevalent, this means opportunities to obtain urban *hukou* are limited even further.

Discussion and Conclusion

Previous research about the Chinese *hukou* system has largely focused on non-disabled migrant workers (Whalley & Zhang, 2007; Bosker et al., 2012). Quantitative studies have highlighted spatial and social disparities among the disabled population (Liao et al., 2016), but there have been few qualitative studies that have documented the lived experiences of disabled migrant workers and have tried to understand the generic mechanisms behind the phenomenon of what can only be described as a form of ‘disability ghettoization’.

A key argument advanced in this paper is that the Chinese *hukou* system is not only a household registration system and a means of evaluating migratory patterns; it is a signifier of social status and identity, as well as a determinant of access to employment opportunities and social mobility. While recognizing that disabling barriers, most notably negative social attitudes, can be experienced by all disabled people across the country, evidence from qualitative interviews in this research suggests disabled migrants face additional disadvantages. Moreover, the dualistic structure of the *hukou* system, by spatially and socially excluding disabled people, illustrates how enduring economic, social, and cultural factors in Chinese society contribute to the continued devaluation of disabled people’s labor.

Findings suggest that, in urban job markets, migrant workers are more likely to be concentrated in low skilled manual work in small and medium sized cities. This is despite such jobs often being viewed as unsuited to disabled people because the jobs are physically intensive and little consideration is given to adapting the jobs. In big cities such as Shanghai, Guangzhou, and Beijing, nevertheless, this study suggests that disabled people fared better where they were able to access white-collar jobs in the growing knowledge economy, which required educational qualifications. The intersecting role of education and *hukou* in determining opportunities in the labor market is important. Existing evidence and data from this study suggest disabled people continue to face significant educational barriers, particularly in rural, but also in urban regions (Xu, 2018). As China’s economy transitions and more highly skilled sectors develop, there is a possibility that there will be more opportunities for educated disabled people to enter white-collar knowledge jobs. For this to happen, however, not only do the inequalities *hukou* places on access to education and training need to be addressed, but the current education system that promotes segregation and stereotyping needs to be reformed through a better understanding of how it is shaped by ableist attitudes and values.

This exploration of how *hukou* interacts with family, social, and economic factors, also highlights the ways in which *hukou* contributes to the creation of a two-tier labor market among and between disabled people. Disabled people with urban *hukou* in large cities have the benefits of a more accessible built environment and greater access to public resources from local councils to support their education, health and vocational training (although this may be insufficient). Meanwhile, disabled migrant workers from rural locations are more dependent on private and family resources, yet this familial capital in an urban labor market is likely to be less influential (Bian & Ang, 1997). The formative experiences of disabled migrants are often shaped by rural life, segregation and ‘misplaced paternalism’ (Foster & Hirst, 2020), all of which are not helpful in their attempts to penetrate urban networks.

A major stumbling block to a fully liberalized labor market, which requires free movement of labor, is the so-called ‘meritocratic’ process of awarding *hukou* to migrants (Qi et al., 2015). It was found that the income threshold for claiming urban *hukou*, especially in bigger cities, is extremely high and beyond the reach of most disabled migrants concentrated in low status jobs because of their poor educational qualifications. The ‘meritocratic’ system of awarding *hukou* could be said, therefore, to have been ‘created by the ableist and for the ableist’ (Wu & Zhang, 2018); such a system favors the ‘ideal’ (non-disabled) worker who is always ready to work in a standardized job with standard qualifications (Foster & Wass, 2013) and perceived as being able to contribute to local economic development (Zhang, 2007). Disabled migrants are less likely to fit within this ‘ideal,’ and their rights to settle in cities are, therefore, often denied.

It should be noted that urban *hukou* may also have created unintended consequences, including contradictions between central and local government policies on disabled people’s employment. Relatively high welfare payments made by local government to disabled people with urban *hukou* in mega cities may discourage them from entering employment where low paid work is their only available option. Furthermore, *hukou* plays an uneven role in the national disability employment quota scheme: only disabled people with local urban *hukou* employed by companies are acknowledged by local government as counting towards meeting quota total. The incompatible fiscal structures of central and local government are the source of this problem, but the consequence is that the aims and objectives of the national quota system are undermined by its implementation at local level. Abolishing *hukou* nationwide might address these anomalies, but even so there would need to be better local incentives for employers to provide improved vocational training and employment opportunities.

Findings from this research substantiate those of other authors, e.g., Song (2016) and Wang et al. (2021) have argued that the current *hukou* system creates labor market discrimination, reinforcing the position of already socially marginalized and disadvantaged groups. In terms of the future, a draft Barrier Free Environmental Development Law (2022) is welcomed because of its potential to improve public accessibility, but its impact is likely to be uneven, with urban rather than rural areas (where most disabled people reside), benefitting most. Furthermore, in 2022 a new policy, the 14th five-year new urbanization implementation plan, was proposed by the central government and is intended to ease the *hukou* awarding restrictions in small-medium cities (< 5 million population). The new points-based *hukou* awarding system in mega cities (>5 million population), nevertheless, still uses education qualifications, type of employment, income, and possession of real estate as criteria, and is likely to continue to disadvantage disabled migrants. It is essential, therefore, that China, as a signatory member state of the UNCRPD, safeguard disabled people's rights, at a very basic level, to equal access to education, regardless of family situation or *hukou* status. If future disability discrimination law is to be effective, we also argue it must be enforced evenly across geographical regions to ensure equal opportunities are available to all, regardless of location or position in the labor market (Zhang, 2007).

Several methodological limitations reduce the applicability of the findings from this study to other contexts. The participants involved in this research were relatively well qualified in terms of educational background and are not fully representative of the disabled population in China. It should be noted, however, that despite the over-representation of educationally qualified disabled people in this study relative to population, many reported experiencing a labor market glass ceiling; this may indicate the power of *hukou*-based discrimination but almost certainly also illustrates disadvantages associated with being disabled. Another limitation of our discussion is that it mainly focuses on the migration flow from rural to urban regions, rather than disabled migrants' experiences of moving from smaller urban towns to larger cities. Further research on such disabled workers would enhance the understanding of those whose social mobility may not be hugely restricted by *hukou* status and might also further reveal the relative impact of being disabled.

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Note

In this article, the UK social model of disability is used, and as such, we refer to "disabled people." This model makes a distinction between a person's impairment (or medical condition) and barriers in society (physical, attitudinal, sensory) that disable people. Disability in this respect is seen as belonging to society, not solely the individual. This terminology contrasts with the people-first language often used in the United States, i.e., "people with disabilities."

The exchange rate applied between Chinese yuan and U.S. dollar in this article was based on May 12, 2023 data.

Why Can't Deaf-Mute People Be Cadres?:

Disability Advocacy and Bureaucracies in 1980s China

Di Wu

Massachusetts Institute of Technology

Author Note

Di Wu is a PhD candidate in the History, Anthropology, and Science, Technology, and Society (HASTS) program at Massachusetts Institute of Technology (MIT). Her research and practice focus on the relationship between disability, labor, and technology in contemporary China. She worked extensively on disability inclusion programs as a professional in China and holds a Master's from the University of Oxford.

Abstract

Analyzing official disability magazines, this article argues that China's state-sponsored disability organization in the 1980s curated a space for persons with disabilities to publicly express grievances, among which labor was a central concern. This history shows that intensified bureaucratization may have marginalized persons with disabilities within the very institution meant to serve them.

Keywords: disability advocacy, bureaucracy, labor

"Why Can't Deaf-Mute People Be Cadres?": Disability Advocacy and Bureaucracies in 1980s China

In 1986, three workers from Jinan Wire Drawing Factory wrote an angry letter to *Voices of the Blind and the Deaf*, the official magazine run by the China Association for Blind and Deaf-Mute People (hereinafter, "the Association"), the precursor of today's state-sponsored disability organization, the China Disabled Persons' Federation (hereinafter, "the Federation"). Their anger was directed at their city government's human resource bureau, who rejected all the deaf candidates recommended by the factory for promotion. Although the majority of the factories with over 500 workers had the presence of disability, they claimed none of the leaders were disabled. "Why can't deaf-mute[1] people be cadres?" they asked (Du et al., 1986, p. 2):

> "They all met the conditions for cadreship. It is so unfair to shut them out! Bullying and humiliation based on deafness and muteness belonged to the Old Society. Shockingly, such a scene reappeared today! […] The municipal human resource bureau claimed that this is the decision of the provincial bureau: because they are deaf-mutes, because they have physiological defects. According to this view, all cadres of our country must be muscular and strong. People who have a disability are not wanted. When did our country set such criteria [?]"

The letter received eager support from the magazine. Not only did the editors make it the first story of the journal issue, but they also supplemented a commentary criticizing the local human resource bureau. Titled “Please Respect Their Equal Rights,” the commentary deplored (Xin, 1986, p. 2):

> “Higher-level leaders do not approve so I cannot do anything. This is a blatant and helpless excuse. The truth is, if you don’t approve in the first place, why would the higher-level? Socialism granted disabled people equal rights, which is a hundred times better than capitalism. Unfortunately, due to feudal mindsets and prejudice, equal rights are more or less discounted in reality.”

The publicity of this story resulted in speedy resolution of the case (Z. Li, 1988a). It is unclear whether the staff writer had a disability, though at least one complainant did. Nevertheless, this case marks a distinctive genre in the official publication of a state sponsored association — it explicitly claimed to represent the voices of people with disabilities and openly criticized government violations of the rights of disabled people, an act increasingly unthinkable today. I use the term “advocacy” as a shorthand to describe such content that facilitated claim-making for or by disabled people. Although propaganda made up vast majority of the magazine, roughly 3% of its pages were routinely dedicated to advocacy.

Analyzing advocacy cases in this official publication, this article shows that the state-sponsored disability organization in the 1980s curated deliberate space for people with disabilities to publicly express grievances. Advocacy, however limited, existed within the institutions of the state rather than a separate realm, as the disability rights activists strive to carve out today. Sandwiched between the dramatic decades of the Cultural Revolution (1966–1976), and the watershed reforms of the late 1980s, events in the early 1980s leading up to the establishment of the paradigmatic national institution — the Federation in 1988 — has received limited attention from scholarship on disability in China.

This article presents a prehistory of the Federation and the contemporary disability rights movement. The magazine offers a rare window into state-sanctioned disability advocacy in the 1980s, among which labor was a central concern. Market reforms disrupted the socialist labor structure of workers with disabilities, rendering in flux their livelihood, identity, and social relations that were previously organized through the workplace. Meanwhile, disabled readers of the magazine, mostly deaf people, displayed great ownership over the official platform and leveraged it to negotiate their new place in a transitioning society. Institutionally, the shifting discourse of the magazine over the decade, and its eventual takeover by the Federation from the Association, revealed how intensified bureaucratization of the disability cause may have ironically marginalized people with disabilities within the very institution meant to serve them, and corroded its advocacy potential.

History in and of the Official Publication

China’s disability rights movement, as led by persons with disabilities based on principles of the social model of disability (Shakespeare, 2013), is often considered to be prompted by the state's ratification of the *United Nations Convention on the Rights of People with Disabilities* (CRPD) in 2008 (S. Huang, 2019; C. Zhang, 2017). Indeed, the CRPD created a momentum for grassroots disability activists to leverage the civic space and international cooperation for making explicit claims about rights and anti-discrimination in areas including education, employment, and accessibility, with uneven success (Cui et al., 2019; S. Huang, 2020; Y. Huang & Chen, 2022; Z. Ma & Ni, 2020). Despite the tightening of civic space in recent years, associational life and grassroots networks by and for people with disabilities continue to exist (Dai & Hu, 2022; S. Huang, 2022).

With the exception of Kohrman (2005), most scholarship on the political subjectivity and organizing of people with disabilities began with the pivotal year of 1988 (Hallett, 2019; S. Huang, 2021; Stein, 2010), when the Federation was established. The Federation was the brainchild of Deng Pufang, Deng Xiaoping's son who was injured and disabled during the Cultural Revolution. Indeed, the Federation symbolizes enormous state commitment to disability issues, and heralds a dramatic intensification of bureaucracies and associational life for people with disabilities. This article seeks to contribute to the still scarce knowledge about institutional and self-advocacy prior to the Federation. The earlier days of the Association also present a different variant of state-led disability initiatives than the Federation.

The Association had a tumultuous history (see Figure 1). Formed in 1960, it was built on merging two preexisting groups — the China Welfare Society for the Blind (founded in

1953), and the China Welfare Society for the Deaf and Mute (founded in 1956) — initially under the Ministry of Internal Affairs and the Central Relief Office. The Association's work was halted during the Cultural Revolution, as "welfare" became associated with reactionaries. Some staff members were persecuted, injured, and even killed (Kohrman, 2005, p. 226). It was only until 1978 that the State Council resurrected the Association as a bureau of the Ministry of Civil Affairs (MOCA). In 1988, the Association and the China Disabled Persons' Welfare Foundation jointly formed the Federation (China Disabled Persons' Federation, n.d.). Since then, five special associations representing people with visual, hearing, physical, intellectual, and psychosocial disabilities have been established, operating as internal departments of the Federation (X. Wu & Wu, 2022).

In January 1980, the Association launched its official magazine — *Chinese Deaf People*, later renamed as *Voices of the Blind and the Deaf* (hereinafter, "Voices") in 1986. Despite the dual constituencies of the Association, representing both blind and deaf people, its magazine had a strong focus on deaf audiences.[2] Its main readership consisted of the Association's staff members at all administrative levels, the MOCA, special education professionals, and deaf people. *Voices* defined its mission as "promoting the guidelines and policies of deaf-mute work, sharing experience, communicating information, and guiding work based on practice" (The Association, 1986, p. 32), as well as "reflecting deaf people's

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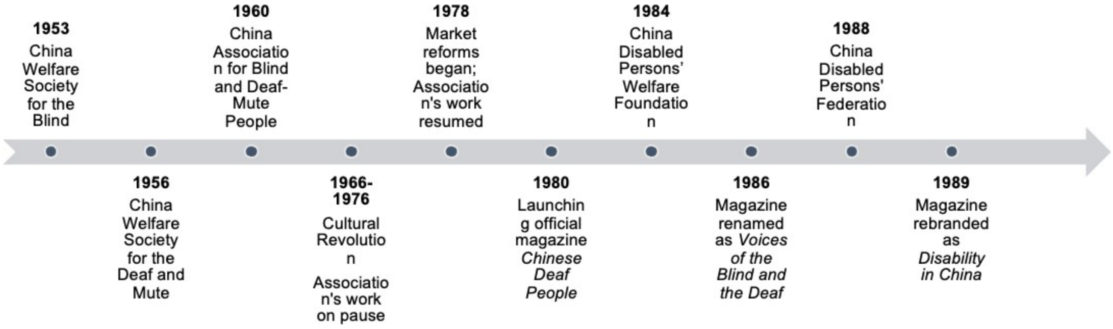
voices, and protecting deaf people's rights" (Z. Li, 1985, p. 1). This latter set of goals, which I code as advocacy, is the focus of the study.

Figure 1

Timeline for the Association's key milestones



Methodologically, I draw on the official magazine of the Association as a historical primary source, and critically examine the content and discourse of the official texts. Rather than dismissing them as mere propaganda, I see propaganda as an object of inquiry that offers insights into, as Emma Stone puts it, "what *should be* in an ideal China," regardless of the intention or implementation (Stone, 1998, p. 54). In this case, the official magazine represents what the Association perceived as its ideal role. This study systematically reviewed the magazine from 1981 (the earliest issue available) to 1988 (the last issue before it was rebranded into a different publication) based on the collections of Harvard-Yenching Library, including 51 issues with 1,945 pages in total.[3]

For coverage that expressed grievances to, exposed misconduct of, or sought redress from the state — termed as "fighting against discrimination and neglect" (Voices, 1982, p. 31) in the magazine's words, I coded them as "advocacy." I use page size as a proxy for importance. Articles typically take up a whole page (n=1), half a page (n=0.5), or 1/3 page (n=0.3). I counted 50.3 pages as covering advocacy, amounting to 3% of the total magazine pages. I then conducted a close reading of all the advocacy cases and organized them based on their dates, themes, complainant, objects of blame, and claims for redress. The magazine advocated for a variety of themes, including labor, education, residential status, housing, marriage, rehabilitation, discrimination, and crimes against/by disabled people. Based on frequency, I categorized three most significant clusters of claim-making that generated multiple rounds of dialogue in the magazine, signifying their resonance with the audience's common concerns as well as the self-perceived political priorities of the Association. In the following analysis, I unpack these three clusters of significant claims, namely — labor, sociality, and criminality.

Labor: From Welfare to Profit

Labor is at the center of the magazine's advocacy. 44% of the pages coded as advocacy are related to the employment of people with disabilities. Debates included the lack

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of career development for disabled people, “fake employment” by factories, and discrimination against deaf and blind workers. These cases illuminate the intense clash between the socialist welfare system and the new market economy.

China’s market reform since 1978 induced dramatic changes in labor and welfare regimes. The “iron rice bowl” status enjoyed by once permanently employed state employees began to be replaced by labor contracts in the early 1980s (Lee, 2007). Institutional guarantee of welfare benefits also dissolved as the state retreated from welfare provision through the socialist “work unit” (*danwei*). Lay-offs, bankruptcies, loss of benefits, and mistreatment of workers in all types of enterprise gave rise to wide-spread labor disputes since the 1980s (F. Chen, 2003).

Among workers affected by the reform were disabled people working at welfare enterprises. The welfare enterprises, first set up in the 1950s for disabled veterans, allowed those deemed with work capabilities to participate in industrial work. Welfare factory workers reportedly “[received] the same wages as other workers and have access to free health care and sick leave” (Dixon, 1981b, p. 69). A proud sign of “socialist superiority,” labor during the Mao era was considered a revolutionary tool to redeem the value of people with disabilities, transforming their “crippled and useless” (*canfei*) bodies into active contributors of socialism (Dauncey, 2020).

The reform preserved the shape of this legacy but altered its nature. The Mao-era welfare factories “placed welfare before factory,” and expected little economic value from their production (Stone, 1998, p. 203). By contrast, Deng Xiaoping's reform sought to transform these factories into competitive, viable businesses. Since the mid-1980s, eligibility to operate welfare factories expanded, together with tax incentives, giving rise to a decade-long boom of welfare enterprises (Shi, 1999). But the new factories generally hired a smaller proportion of disabled workers, and the priorities shifted from welfare to profit (Stone, 1998).

As a result, despite the soaring number of welfare factories in the 1980s (H. Liao & Luo, 2010), workers with disabilities were experiencing a decline in their rights. The magazine was quick to address these concerns. In 1982, Shihan Li, a deaf intellectual and Deputy Chairman of the Association, published a two-page opinion on this problem. He noted that market competition threw many factories out of business, and "under the mechanisms of value and profit, some social welfare factory productions developed disabled people out of jobs, especially blind people" (S. Li, 1982, p. 2). The 1980s also witnessed a stark increase in petitions (*xinfang*, or "letters and visits") by disabled people, according to the magazine. One of the key drivers was livelihood hardships during the reform (Wang, 1988).

The magazine publicly criticized fraudulent practices in welfare enterprises that disadvantaged people with disabilities during difficult times. In the first issue of the 1986 new edition, the magazine spent a whole page discussing the issue of giving blind workers "long holidays," referring to practices in which factories hired disabled people on paper but did not assign them actual work and only paid them minimally. This was discussed as a common issue across the country, causing noticeable protests (*shangfang*) by disabled workers (Voices, 1986c). Later that year, the magazine launched a series of reporting about welfare fraud in Wenxi County, Shanxi Province (Jing, 1986, p. 3): some factories enjoyed the tax benefits of welfare enterprises but did not hire enough disabled workers; some exploited disabled workers as cheap laborers; and some failed to care for disabled workers and treated them as burdens. The magazine's commentator accused these factories of "profiting privately from welfare enterprises, wiping oil off of disabled people, and taking advantage of the state" (Yue, 1986, p. 2). The story led to the inspection and restructuring of seven factories in Wenxi within a year (Jing, 1987), which the magazine proudly attributed to their constructive criticism (Voices, 1987).

It is worth noting that the magazine's narrow focus on welfare enterprises reflected more its intended audience than the general experience of people with disabilities during this period. Organizing work was one of the key mandates of the Association (China Association for Blind and Deaf-Mute People, 1984). The disabled people featured in the magazine were almost exclusively workers of state-owned industries, ranging from steel, paper, oil, automobiles, to cement, metal, and sewing. In reality, by 1987, half of the country's "employable" disabled people were still unemployed (Z. Li, 1988b). Among those employed, less than half worked at welfare factories even at its peak in the 1990s (J. Huang et al., 2009). The perils of reform-era welfare factories, nevertheless, crystalized broader social turbulences spurred by the drive for profit and the retreat of the state.

Welfare enterprises began waning in mid-1990s due to tightened regulations, partly in response to fraudulent practices (Stone, 1998). Instead, employment quota became the main policy incentive to create jobs for persons with disabilities (J. Huang et al., 2009). Yet "fake employment" practices exposed by the magazine four decades ago remain rampant today (J. Liao, 2020). It is symptomatic of a competitive job market that lacks equal education opportunities and infrastructures for meaningful inclusion but abounds in deeply entrenched views about the worthlessness of persons with disabilities.

Sociality: The Erosion of Community Space

The socialist *danwei* functioned as a crucial anchor of economic and social activities. Typical *danweis* were state-owned, urban work units in the public sector that provided shared communal facilities and a range of benefits in addition to a secure job (Lu & Perry, 1997), which had an all-encompassing impact on its members' every aspect of life. For this reason, labor was more than a means to income; it was the core mechanism through which all kinds of social relations — between workers, workers and factories, and workers and the state — were forged. The reform created a vacuum. Since early 1980s, discussions about what to do "beyond the eight hours" of work began emerging in the magazine. The dissolution of old-style welfare production *danwei* had an impact beyond the loss of livelihood. It removed a key space for social life of disabled factory workers, to whom alternative opportunities for sociality became ever more important.

In a 1982 "Reader's Voice" column, the magazine published a letter from six disabled people in Jinan City, Shandong Province, demanding their social club to be returned (C. Wu et al., 1982). Run by the local Association, the club was the only activity space for blind and deaf people in the city. Since the Cultural Revolution, it has been occupied by a government bureau. Accordingly, the letter complained,

> "[T]he blind, deaf, and mute lost the space for gathering. Everyone could only spend their leisure times at home, bored and frustrated. [We] cannot learn knowledge, cannot understand the current affairs of the country, and cannot participate in cultural and sports activities. How very sad! Under such circumstances, people have no choice but to mess around, wander away, start gambling or even become a criminal."

The letter presented the takeover of community space as a common problem, citing that clubs in many other places have been returned. Indeed, similar problems occurred in Taiyuan City, Shanxi Province. The year 1986's very first story was a detailed report on the occupation of Taiyuan Association's clubs by the military since the Cultural Revolution. The military allegedly refused to implement the municipal government's decision to return the space. The journalist asked (Voices, 1986d, p. 3):

> "Doesn't our *Voices* magazine want to speak for blind and deaf-mute people, and protect their legitimate rights? Then please publish this letter, and urge the Beicheng District military to implement Taiyuan government's decision and return the houses immediately."

Once again, the magazine responded enthusiastically. They added another strongly worded commentary on the same page, titled “It’s Time to Take Actions.” The commentator accused the military of being corrupted by Cultural Revolution-style anarchist mindset, ignoring central Party directories, and indifference towards disabled people, against the socialist spirit. Mocking the military’s mentality, the author deployed bold, colorful language (Voices, 1986a, p. 2): “You have witty plans; I have solid rules. You have policies; I have counter measures. You make your decisions; my ass is still firmly sitting here.”

The seemingly inappropriate language made it even more striking how the Association felt it was appropriately within its position to publicly shame other state organs in its official publication on behalf of people with disabilities. This emotionally charged condemnation paid off. Two years later, the magazine announced that the Taiyuan club reopened. Not only did it recover spaces for reading, gaming, studying, and entertainment — it got better. It now had a match-making office (Y. Ma, 1988).

Indeed, love was a big part of the story. Throughout the decade, letters and questions about romantic life and marriage never ceased to appear in the magazine. Inquiries typically centered on the difficulties of finding love as a disabled person. Although these inquiries did not carry the same political significance as other claims made, they reveal the shifting social conditions in which intimate relationships and collective deaf identity were made possible.

Multiple deaf readers noted how welfare factories were essential spaces for them to meet other deaf people, and potentially, their future life partners (He, 1982). Rural deaf people, they claimed, worked on separate farms and never had a community (Damin, 1984).

Now, as employment became less concentrated in cities, conventional space for deaf encounters also eroded. Meanwhile, the magazine became a virtual space where (mostly) deaf men could post advertisements looking for deaf women, and deaf women could seek advice about their love life. A multi-coverage debate took place around the question “Can deaf-mute and able-bodied people get married?” (Zhu, 1982) Although the discussions are mostly supportive of such relationships, the exoticism and excitement in the debate was indexical of the relative segregation of deaf communities, and a somewhat defined deaf identity whose difference from hearing people needed explicit overcoming.

Criminality: Moral Panics about Outcasts

As the state retreated from planning for all aspects of lives, people with disabilities inside and outside the state factory system sought to explore new sociality and cultivate their own space. While factories and clubs were considered legitimate places worthy of the magazine’s support, activities beyond the reach of state control were starting to cause moral panics.

In this section, I analyze a distinct cluster of social dialogues that took place in the magazine — deaf people as “criminals” — triggered by the phenomenon of deaf people selling paintings and gambling. Since 1982, the magazine launched a multi-coverage discussion about deaf painting-sellers, inviting readers from all sides to comment on the issue. It was the most extensive single-topic debate throughout the magazine’s history. No other subject received such coverage of back-and-forth readers’ correspondence about the pros and cons of the phenomenon. Although the magazine eventually took the official stance of harshly condemning painting-selling, a few deaf readers were able to exploit the space and defend their fellow deaf comrades. This case shows the limited extent to which alternative voices were tolerated, and demarcates the boundary of the Association's advocacy.

Since early 1980s, stories about "deaf-mute people" using fake credentials to forcefully sell high-priced, low-quality paintings began to circulate. These sellers would often carry a fake recommendation letter from their *danwei*, travel to other cities, pirate paintings, and refuse to leave until someone purchased the paintings. These stories sparked heated debate about the morality of the sellers. Most reader comments considered selling paintings a dishonest way of earning, a crime of "cheating the state and the collective," and a symptom of "capitalist liberalization" (A. Chen & Wang, 1982, p. 8). The sellers were said to have stable jobs in factories but tempted by higher profits (Nanjing Association, 1982). Their lifestyles were perceived as greedy, vagrant, and promiscuous (Voices, 1983b). Painting-selling was therefore considered a sign of indolence that betrayed the proletarian work ethic and socialist morality of altruism, diligence, honesty, and frugality (Dixon, 1981a).

A few readers did express sympathy for the painting-sellers. An eighth-grade deaf student from Nanchang City, Jiangxi Province, for example, raised the question of limited work opportunities for deaf people and projected their own insecurities (Deng, 1982, p. 9):

> "In my opinion, after a deaf-mute student graduates, without a job arranged, he has to continue being dependent on his parents. When he thinks of the burden of his parents,

> his mind cannot be at peace. […] I guess after I graduate, I won't find a job immediately either. What to do? I am very worried about my future now. So I hope to hear your thoughts."

Other proponents defended painting-selling as a legitimate source of income under the market economy, a means to proliferate arts and creativity, and a form of "self-help through production" (*shengchan zijiu*) that ultimately would reduce the burden of the state.

Interestingly, even those against painting-selling repeatedly stressed the importance of work and the responsibility of the state. They blamed the factories for letting the workers "fall out" and not "properly arranging deaf-mutes' life and production" (Wei & Lu, 1982, p. 29). They urged the sellers to return to their production unit and demanded the state to educate and help the deaf outcasts settle (A. Chen & Wang, 1982; Zhao, 1982). The Party Secretary of a Beijing factory proposed that the solution was to "occupy the battlefield outside the eight hours" (Meng, 1982, p. 11). If factory leaders kept deaf workers engaged after work with education, sports, and entertainment, the argument went, delinquent deaf workers could be transformed. Another commentary stated that leadership was all that mattered. Some deaf workers were able to resist the temptation because the Party and state leaders cared enough to ensure them proper job placements and political education (Yin, 1982).

These arguments all pointed to the same anxieties about the state's loss of total control over disabled workers' lives. Deaf criminality and labor were two sides of the same coin. Without a full-blown state arrangement for one's life inside and outside work, deaf people were expected to either be forced to fend themselves through criminal activities or be allured by capitalist egotism. Life was imagined as either entirely under the auspices of the Party-state, or completely off the rails. There was no middle ground. The existence of mobile, enterprising, and self-serving deaf people was unsettling. It contrasted starkly with the model worker figure who was always obedient, loyal, and altruistic (Dauncey, 2020). The agency displayed by the deaf painting-sellers also threatened to dismiss the paternalistic relationship that the state presumed to have with its people, particularly those with disabilities (Z. Ma, 2020). Though some deaf readers managed to advocate for their peers through the debate, the magazine's eventual denouncement of deaf painting-sellers marked the limit of the Association's advocacy. It drew the line where its disabled constituencies were not demanding entitlements granted by the state but were seeking to break free from state control.

Discussion: Evolving Disability Bureaucracies

In January 1989, shortly after the establishment of the Federation, the magazine was overhauled and refashioned to match the new political alliance between people with different kinds of disabilities and their representatives. No longer called *Voices of the Blind and the Deaf*, the new title of the magazine became *Disability in China*. The change was more profound than a mere rebranding. After 1989, voices of disabled readers almost entirely disappeared from the pages. Discussions of specific identity such as deafness or blindness were replaced by the new official category of *canji*, an umbrella term for all kinds of disabilities. Individual stories gave way to abstract opinions. More significantly, the content of the magazine shifted from a diverse range of real-life issues that deaf and blind people presumably cared about, to a narrower focus on the priorities of professionals working on disability, such as statistics, rehabilitation, special education, and international events. In other words, the magazine — representing the official voice of the Federation — transformed from a magazine *for* people with disabilities, to one that is *about* them.

This discursive change reflected a broader institutional shift. With the birth of the Federation in 1988, the former Association effectively dissolved. Some of their staff became cadres of the Federation. Five new associations representing people with different types of disabilities — visual, hearing, physical, intellectual, and psychosocial — were gradually established. On paper, the Federation is the formal alliance of the associations. In reality, the five special associations are subordinate to the Federation. With a handful of full-time staff, and a frugal annual budget between 300 USD and 30,000 USD allocated by the same-level federations, their power has practically relegated to organizing a few social activities every year (Sun & Ding, 2016).

Though both are state-sponsored mass organizations, the politics of the Federation and its precursor Association differed in subtle ways. A legacy of Leninist regimes, mass organizations typically function as “a transmission belt through which the Communist Party is able to reach a particular constituency of the people” (Judd, 2002, p. 16). The double duty of serving the Party and serving the constituency is considered theoretically compatible. In practice, mass organizations are often “unequivocally biased towards the state” (X. Chen & Xu, 2009, p. 651), working more towards top-down policy implementation than bottom-up interest representation (Unger & Chan, 1995; Dreyer, 2008). While the Federation states its mission as “representing, serving, and managing” all disabled persons, its representational function is often enacted by forceful collective actions that threatened local stability (X. Chen & Xu, 2009), and limited to issues of existential value to its institutional or financial status (Kohrman, 2005), such as resisting the ban of motorized tricycles.

The Association similarly privileged Party voices over people’s. But its representational efforts were also evident in its readers’ reactions. Deaf readers, in particular, displayed genuine ownership over the magazine. When the magazine changed its name from *Deaf People in China* to *Voices of the Blind and the Deaf*, some deaf readers questioned why “squeeze us deaf people together with blind people” and mourned the loss of “a dedicated publication of our own” (Zeng, 1986, p. 27). Readers earnestly critiqued the magazine for too much party-line views and positivity, and they demanded to see the complexity of real lives (Voices, 1983a). Overall, the Association’s proactive support for selective claims of disabled people appeared systematically in its official magazine, despite the small scope. Compared to the Federation, the Association exercised more discretion in publicly criticizing (mostly local level) government bodies and challenge discriminatory practices.

Why did the Association routinely allow advocacy by and for people with disabilities in the 1980s? The magazine’s own discourse offered some clues. First, rights-protection was a more explicit mandate of the Association. In multiple occasions, the magazine stressed its own purpose as to "fight against thoughts and actions that discriminate against and neglect deaf people, and correctly reflect reasonable and feasible demands of deaf people"; to "protect the legitimate rights of deaf-mutes, and counter social discrimination" (Z. Li, 1985, p. 1); and to "reflect the voices […] and defend the rights of blind and deaf people" (Voices, 1986b, p. 32). Reflecting upon the magazine's history in the very last issue of *Voices* before the rebranding, the former Director of the editorial department, Zhiqi Li, who later became a Federation official, proudly remarked on the magazine's rights-protection efforts. Despite the tiny proportion, he devoted more ink to advocacy than any other columns of the magazine. He referred to the publication of five readers' letters in 1981 as a major progress, "a heartening step that the magazine took to protect the legitimate rights of deaf people" (1988a, p. 2). Even today, the three core functions of the five associations are "representing, serving, and rights-protection," one word different from the Federation's "representing, serving, and managing" (Y. Zhang, 2021).

Second, the institutional status of the Association was weaker than the later Federation. Early in 1990, thirteen readers wrote to the magazine, asking "can disabled people ourselves form a disabled persons' federation?" (Pan et al., 1990, p. 8) To this, the magazine responded that federations must be approved by the government and cannot be formed by individuals. Federations are "semi-governmental and semi-civil" (*banguan banmin*), said the magazine, and individuals can only form "associations" constituted of the people (as opposed to the state), and apply to become local federation's group member. The response highlighted the distinction between “association” and “federation,” the former more akin to interest groups and the latter more aligned with the state. Increased state investment elevated the institutional status of disability affairs, but paradoxically, may have subjected the Federation to more compliance with state agenda and stricter political scrutiny.

Most importantly, as the official representative body of disabled people in China morphed from associational groups to professional bureaucracies, their personnel makeup also changed. In 1990, two deaf readers asked the magazine whether deaf people could work in the Federation. Having taking leadership positions at a municipal Association for over twenty years, they were puzzled by “why people like us who have worked on disability affairs for a long time cannot join the Federation” (P. Zhang & Guan, 1990, p. 8). In response, the editor affirmed that in principle all disabled people are welcome, but with conditions:

> “The Federation is different in nature from the former Association. The Federation is a semi-governmental semi-civil public institution [*shiye tuanti*]. Staff of the Federation are working state cadres. Generally, to work at the Federation, one must first be a state cadre. […] We believe, as the society progresses, and the quality of disabled people improves, more and more disabled people will work in their own organization.”

This interaction revealed the marginalization of disabled people in the new Federation meant to serve them. The magazine’s editorial team had deaf staff such as Wen Damin, Li

Shihan, and Fu Zhiwei (Z. Li, 1988a) and blind staff like Li Dafang (D. Li, 2013). The Association also had many active staff members with disabilities. Similarly, the special associations today are typically staffed by people with the kind of disability they represent or their relatives and are closer to local disability communities than the Federation (Y. Zhang, 2021). By contrast, vast majority of the Federation's staff are able-bodied civil servants with no interest in disability. The few disabled staff are more likely men with less severe physical disabilities, preferably veterans, whose number was kept low for efficiency and obedience (Kohrman, 2005). Once a people, disability now means a career (*canjiren shiye*). The bureaucratization and professionalization of disability affairs in late 1980s successfully elevated disability to national significance, but at the same time, it seems, ironically pushed many former disabled cadres out, and diluted its advocacy mandate with able-bodied career bureaucrats representing state interests.

No doubt, the Association's relative freedom to speak up was also a product of the socio-political environment. The 1980s, up until 1989, is known for its unprecedentedly liberal political atmosphere. Media began breaking the convention of only covering good news (Chan, 2002) and critical reportage of societal problems became a popular genre (Lei, 2018). Discourses about "rights" began rising in official media after 1978, and the state eagerly promoted notions of law and rights to help address social and economic crises triggered by the reform (Lei, 2018). The magazine functioned as a *de facto* platform for petition — a mechanism for voicing grievances with long history in imperial China, and routinely facilitated by the modern state since early 1990s (X. Chen, 2011). In this sense, advocacy by state institutions like the Association is not surprising given China's long tradition of state mobilization of the masses (Perry, 2002). What is worth noting is the institution's own evolution — from a state-affiliated interest group to a hegemonic bureaucracy — one that is increasingly considered by today's activists as a barrier, not just a blessing, to disability rights.

This article does not intend to overstate the shift in disability politics or exaggerate the space for advocacy in the 1980s. The institutional changes have been subtle and oscillating. The claims made through the magazine were predominantly individual grievances rather than collective action, framed in official rhetoric and moral terms, and directed at local rather than national actors, with no intention to question the overall system. Further, the magazine only captured a meager fraction of disabled people's voices. In the magazine's own accounting, its maximum readership was 20,000 nationwide (Yan, 1988). The 1987 National Disability Census also suggested high rate of illiteracy and semi-literacy (68%) among people with disabilities (Stone, 1998), which means only a small literate disabled elite could make claims through the magazine. Advocacy was still the exception, not the norm, in the official publication throughout the 1980s. This article sheds light on what these exceptions were and what made them possible.

Conclusion

Surveying official publications of the precursor of China's state disability agency, this article analyzed three significant domains of state-sanctioned advocacy during the 1980s — labor, sociality, and criminality. Fair treatment in welfare enterprises and access to social activities and space was considered legitimate claims that disabled citizens and their allies could make through official channels. Yet deviation from state-approved space such as factories and social clubs could lead to moral panics about the criminality of people with disabilities. These articles revealed the texture of daily lives of people with disabilities amidst the dramatic social and economic transformations in the 1980s. Reforms in the labor regime destabilized working disabled people’s livelihood, identity, and social relations that were interwoven with their workplaces. This pushed more people with disabilities into a competitive labor market without equal education or meaningful inclusion, sowing seeds for contemporary disability activism. The publication’s discourse also alluded to the nuanced difference in state approaches to disability issues between early 1980s and now. As disability affairs moved from the associational end toward the governmental end of the spectrum, the institution that claimed to represent disabled constituencies seemed to have also lost its edge for advocacy.

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Footnotes

[1] "Deaf-mute" (*longyaren*) was a common term used by the magazine to refer to all people with hearing impairments. I follow the magazine's original language when translating its quotations. In my analysis, I follow the readers' tendency to refer to themselves as "deaf" (*long*), "blind" (*mang*), or "disabled" (*canji*) during this period.

[2] Two other disability magazines co-existed with *Voices* — *The Blind Monthly*, which dates back to 1954, and *Spring Breezes*, run by the China Disabled Persons' Welfare Foundation since 1984. But *Voices* is the official mouthpiece of the Association and later the Federation.

[3] A few issues were missing from the collection accessed by the author, including 1981-1, 1987-1 to 3, and 1988-2.

The Importance of *Guanxi* for Parents of Children with Autism: A Study of Social Capital in Navigating School Resources

Hui Zhang[1] and Diana Arya[2]

[1]University of California, Santa Barbara

[2] Department of Education, University of California, Santa Barbara

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Abstract

Studies relating to the impact of power imbalances between parents and school actors have increased in recent years. Yet, there remains little insight into the nature of such imbalances from a parent perspective in non-Western countries such as China. Drawing from Bourdieu's Social Capital framework from the 1960s, we analyzed audio-recorded interviews with 16 parents of children identified as autistic living in one of four provinces across China using interpretative phenomenological analysis. Specifically, we analyzed the expressed processes and strategies, e.g., personal connections with key school officials ("*guanxi*" in Mandarin) that participating parents used to advocate for inclusive education services. Our findings suggest a parent's use of social capital (in the form of guanxi) surpasses explicit national policies as an effective strategy for garnering adequate services for their child. Such unspoken power dynamics between schools and parents reveal significant implications for equitable access to educational resources. In making more visible the parental perspective from a less-understood region of the world, we aim to support a deeper understanding of the often-hidden tensions that emerge when parents seek support for their children with disabilities.

Keywords: Inclusive Education, Parental Advocacy, Social Capital, Guanxi, Interpretative Phenomenological Analysis

Previous research on parental advocacy for children with autism highlights the importance of cooperative engagement between parents and schools to provide optimal support for children with disabilities, yet findings from such work suggest that parents are viewed as less-than-equal members in such collaborative efforts (McCabe, 2007; Su et al., 2020). Furthermore, parents of children with autism report greater difficulties gaining access to school and specialized care than parents of children with other disabilities (Burke & Goldman, 2015). Given that the current prevalence of autism among school-aged children in China is around 1% (Sun et al., 2019), a substantial proportion given China's population, it is crucial to build constructive parent–school collaboration to fulfill the rising educational demands. In addition, regional surveys indicate that less than 10% of children with autism attend regular schools, while the remainder attend special schools or do not attend school (Xiong & Sun, 2014; Xu & Zhu, 2016). Parents report that public schools fall short in providing adequate support to families with children on the autism spectrum, noting the extreme stress and challenges in advocating for their children’s rights to an inclusive education that allows their access to regular classrooms (Cui, 2016; Hu, 2020). However, only a handful of these studies have investigated the imbalance from the perspectives of parents, and even less is known about such issues outside the western hemisphere. Zhao and Huang (2017) conducted one of few available studies about parents of children with disabilities in China and the inequitable access to inclusive education (i.e., integration into regular classroom contexts) that is explicitly outlined in the nationally adopted model called *Learning in the Regular Classroom* (hereon referred to as the LRC model). These educational scholars found that 77% of participating parents living in western China were unfamiliar with and were never informed about the LRC model by administrators and teachers (Zhao & Huang, 2017).

The LRC model is widely recognized as both the beginning as well as the most predominant model of inclusive education in China (McCabe, 2003; Xu et al., 2018). It was first introduced in 1994 by the National Education Commission of the People’s Republic of China (renamed the Ministry of Education in 1998, a department under the State Council) through a policy titled “The Measures of Implementing Learning in Regular Classrooms for Children and Adolescents with Disabilities” (the Measures). The Measures proposed that public schools should include students with disabilities in mainstream classrooms and suggested that the LRC model be the primary education model to serve students with disabilities (McCabe, 2003).

However, the LRC model's structural flaws and rhetorical muteness about inclusivity have greatly impeded its implementation. First, it was not a law issued by means of the supreme powerhouse (the National People’s Congress and its standing committee) supervising the legislation at various levels in China (Law, 2002). This means that on a legislative level, the LRC model does not legally bind public schools to provide proper free education to students with disabilities, as IDEA (Individuals with Disabilities Education Act, 1990) does in the United States. (Deng & Poon-McBrayer, 2004; McCabe, 2003; Deng & Pei, 2009). Rather, it is more of a solution plan to address the international trend of mainstreaming and inclusion, as well as the domestic necessity of increasing the enrolment of students with disabilities (Deng & Poon-McBrayer, 2004; McCabe, 2003; Deng & Pei, 2009). Second, due to political and cultural differences, the core values of inclusive education embedded in IDEA, including equity and diversity, have never been the rhetorical emphasis in implementing the LRC model (Deng & Pei, 2009). Different from the rights-based inclusive education system aiming at providing appropriate and free public education to students with disabilities in the United States, the LRC model aims at providing students with disabilities a possible solution, as Deng and Pei described in their work about the LRC model, “to give most children with special education needs in China an opportunity to go to school” (2009, p. 319).

Although previous works shedding light on parental advocacy under the LRC model in China have been published (e.g., McCabe, 2007; Cui, 2016), empirical studies zeroing in on this topic are scarce compared to those focusing on summaries (e.g., McCabe, 2003; Xu et al., 2018), teachers' general attitudes towards inclusive practices (e.g., Qu, 2019; Su et al., 2020), and the availability of classroom support for students with disabilities (e.g., Ge & Zhang, 2019; Xiong & Sun, 2014).

As such, parents' concerns and experiences relating to their advocacy efforts remain largely unknown. In this study, we adopted Holcomb-McCoy and Bryan's definition of advocacy: any actions that “influence public attitudes and enact and implement laws and public policies” (2010, p. 263). In the context of parent advocacy, it consists of acquiring educational resources and opportunities within the LRC model for their children with autism.

We conducted an interview study to learn about the experiences of parents who have advocated for inclusive education services for their children identified as autistic. Bringing such underexplored voices to the forefront, in our opinion, is necessary for fostering more equitable and inclusive practices in school communities. This is especially true when focusing in on parent advocacy in the less explored context of China. Previous studies reveal that parents are no less immune to inequitable challenges than parents in other countries, and that cultural particularities, such as guanxi, have shaped the strategies used for gaining access to educational resources (Xie & Postiglione, 2016).

Guanxi (pronounced gwon-shee) is an idiom in China that refers to the personal connections or relationships embedded in every aspect of Chinese culture and societal life (Gold et al., 2002). This term is defined as a multifaceted concept that refers to the art of networking to achieve a particular goal (Liu, 2020; Xie & Postiglione, 2016). Guanxi is predominantly explored in the context of business administration and marketing, with some connection to political and social sciences (Gold et al., 2002). As Ruan (2016) suggested in their study on school choice, the inequities of compulsory schooling, including the marketization of public education, have led to the presence of tuition fees that have increased since the late 1990s (Ngok, 2007). Such inequities have created a tumultuous, unstable ground that Chinese parents must navigate with great caution, necessitating the strategic use of guanxi to garner educational access for their children (Ruan, 2016).

Guanxi is not a cultural phenomenon unique to China. Previous researchers have reported similar parental strategies in other countries. For example, upper- and middle-class parents in the United States demonstrate stronger ties with school officials, hence gaining greater benefits for their children compared with those from working-class families (Coleman, 1988). Sociologist and philosopher Pierre Bourdieu (1986) characterized such societal privilege as *social capital*; individuals activate their social network to gain social advantages or benefits for a variety of reasons, including support for their children. Bourdieu explained that access to such networking tends to be limited to those sharing the same social circle or class, hence privileging institutional familiarity or membership while excluding those who might benefit even more from such enrichment or resources. Bourdieu's observations of such social action echo the theories by Chinese scholars who have connected social status with relational practices across various sociocultural contexts (e.g., Chen, 1999). For research focusing on guanxi-based social relationships in China, the social capital lens has been used to explain how individuals can draw resources, such as the information, trust, and control benefits of interpersonal dynamics (e.g., Gold et al., 2002; Gu et al., 2008). Scholars believe that to study social capital in Chinese societies, researchers are suggested first to understand and look through the concept of guanxi (social relations) (Bian, 2017; Gold et al., 2002).

Bourdieu (1986) viewed social capital as a form of power that one used to gain respect and access to tangible resources shared within a particular social group. Trainor (2010a) applied this framework in their analysis of parents' utilization of social capital in advocating for their children. By interviewing participants from various cultural and social backgrounds, Trainor found that advocacy efforts were not always effective and that parents gained more knowledge about the importance of using social capital (e.g., personal relationships with experts or teachers). Trainor also implied that the success of such advocacy efforts depends largely on the coherence between home and school; hence, teachers are less likely to dismiss parents and their children when they share cultural affiliations. Parents' reliance on expert opinions and advice from their social circles also played a significant role in the successful procurement of school services at school.

The uses of social capital in Chinese society reflect a different picture; researchers are generally interested in the use of guanxi within a context heavily influenced by traditional, Confucian values and beliefs that emphasize the concept of “reciprocal obligations and indebtedness” (Liu, 2020, p. 454). Guanxi has a cultural connotation like social capital in that it is a form of power used to gain access to certain resources; however, it is distinct from social capital in that, despite the facts that guanxi and social capital both reflect the real and potential resources that may be derived through network interactions and that they both emerge from the investment of individuals seeking to develop advantageous social relationships, guanxi refers to a two-way obligation formed through the exchange of favors to each other, which serves as an incentive for people in China to practice social relations (Bourdieu, 1986; Huang & Wang, 2011; Ruan & Chen, 2020). In the literature, guanxi is frequently mentioned as a form or variant of social capital in China that refers to resources derived through interpersonal interactions and having values that the participants can access (e.g., Yang, 2002; Qi, 2013).

While there is some understanding of the cultural influences of guanxi and how it is used to gain access to valuable educational resources, there is less clarity about parents' perspectives on such societal dynamics when striving to advocate for their children, particularly those identified as autistic. There is more information about teachers' attitudes toward inclusive education; Qu (2019), for example, found that teachers in China viewed inclusion as *correcting* or *fixing* errors for children rather than making accommodations or adjustments according to learning needs and styles. Hence, inclusive education, according to Qu, seemed little more than being physically present in the regular education classroom. By digging deeper for the possible roots for this mindset in Chinese teachers, the author concluded that the teachers' non-inclusive values were embedded within a collectivistic mentality that values assimilation and homogeneity over individual development (e.g., *just look like you belong; they can't really learn anyway*). According to Qu, such a mindset reflects a socialist agenda in modern China that harkens back to the Confucian value of being average, not standing out among the collective. Most studies on parental advocacy of children with autism, particularly in China, do not provide this kind of analysis of parents' experiences and views when advocating for the right to education for their children with autism. Zhang and colleagues (2021) conducted a review of studies on parents' use of social capital in China and discovered that most articles published between 1996 and 2018 (176 articles, 73%) involved only quantitative analysis, with only 37 articles (15%) qualitative studies including interviews. Further, the 37 qualitative pieces excluded accounts relating to guanxi and its practices in educational contexts (Zhang et al., 2021). As such, our qualitative study on parental experiences and views about their lobbying efforts on behalf of their children identified with autism will provide missing information about the impacts of inequitable school practices in China.

Thus, the purpose of this study is to understand Chinese parents' efforts and associative perspectives when advocating for their children with autism. Using the lenses of social capital theory (Bourdieu,1986) in the form of guanxi, we analyzed 16 parent interviews to address the following research question: What are the experiences and perspectives of Chinese parents advocating for their children to gain access to inclusive education? Specific lines of inquiry stemming from this general research question include: In what ways is the notion of social capital, or its localized form in the context of China, guanxi, represented in parent experiences and perspectives? How does the employment of guanxi relate to social capital theory, as proposed by Bourdieu and other researchers?

Given the pandemic conditions during this study, all recruitment and interviewing took place in online spaces.

Methods

Participants and Recruitment

Parent participants were selected according to purposeful sampling criteria (Patton, 2015). Purposeful sampling is a technique widely used in qualitative research to identify and choose information-rich cases for the most effective use of limited resources (Patton, 2015). The sampling involves identifying and selecting individuals or groups of individuals who are exceptionally knowledgeable of or experienced with a phenomenon of interest. In addition to knowledge and experience, Spradley (2016) noted the importance of availability, willingness to participate, and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner. Thus, two criteria were used when recruiting parent participants: (1) those with intimate knowledge of and active participation in their children's education; and (2) parents of school-age children (six to 15 years old) who have been diagnosed with autism.

Table 1. Participants' Background Information.

Total number of participating parents	16	**Number of children described in parent interviews**	17
Women	15	Girls	3
Men	1	Boys	14
Educational background of parents		Ages 5–7	5
Attended college (no degree)	5	Ages 8–12	9
Bachelor’s degree	4	Ages 13–14	3
Master’s degree	5	**Annual Household Income (USD)**	
Doctoral degree	2	$8,000–$15,000	1
Parents’ age		$15,000–$31,000	6
30–39	12	$31,000–$46,000	1
40–49	4	$46,000–$62,000	3
Employment background		$62,000–$77,000	3
Unemployed	4	$77,000–$155,000	2
Employed part time	3		
Employed full time	9		

Interview Protocol and Procedures

Previous research has shown that demographic information, including age, gender, etc., is essential in gathering qualitative information (Alase, 2017). As such, before interviews, demographic questionnaires were sent to participants, enabling the researcher to pre-determine the demographics of respondents to the survey. Institutional Review Board (IRB) approved this study in November 2019 (protocol number: 91-19-0826), and data collection happened after the approval date. Since IRB mandated that all interviews and consent forms be in the first language of participants, all interviews were conducted in Chinese (Mandarin) and by the first author. Each interview lasted from 30 to 60 minutes in the form of an audio call via Weixin, which was recorded on the consent of participants. Consent forms in Chinese were obtained from all participants before the interviews. Excerpted transcribed responses by participants (identified by first and last name initials) were translated into English for accessibility.

A widely used social media app in China, Weixin was used when the first author conducted semi-structured interviews with parents online. In the semi-structured interviews, parents were mainly asked about: 1) experiences before school age, such as diagnosis, early symptoms, and early intervention; 2) experiences with school, including enrollment, accommodations at school, and incidents that happened in the process; and 3) parents' expectations from school and for the future of their children. Most of the questions were open-ended, and follow-up questions were asked based on each participant's responses.

Our study began prior to the onset of the pandemic, and, as such, questions directly related to the current global pandemic were not included. That stated, none of the parents raised any particular concerns or issues associated with the pandemic in efforts to gain inclusive educational access for their children.

Interpretive Phenomenological Analysis

As suggested by Merleau-Ponty's philosophy, a person’s perception must always be interpreted in the context of the ground where it happens (Sohn et al., 2017). To understand the parents' perspectives toward inclusive education, we used the interpretive phenomenological analysis (IPA) method by giving careful attention to what emerged in participants' narratives regarding their cultural beliefs about concepts such as the right to education equity.

Instead of developing a new theory explaining how parents interpret their experiences of school participation of their children with autism, this study aims at unfolding meanings hidden underneath the narratives of participants' experiences (Sohn et al., 2017). It is proposed that IPA researchers utilize open-ended interview methods to elicit descriptions of participants' life experiences without relying on preset values.

Social capital theory served as our theoretical lens when interpreting parents’ experiences. Bourdieu (1986) defined capital as a collection of symbolic components such as abilities, preferences, temperament, dress, demeanor, material possessions, and credentials, all of which index one’s status in society. Bourdieu identified three dimensions of capital—economic, cultural, and social—all of which seem to play a vital role in home–school relations (Trainor, 2010b). Among the three forms of capital, social capital (i.e., the ability to access resources via social networks to accomplish specific goals) seems the most relevant to the Chinese concept of guanxi, which is a unique Chinese idiom for social networks that serve as a tool for establishing access to social resources (Chen, 1999; Xie & Postiglione, 2016).

When using IPA as an analytical method for a qualitative study, researchers are advised to develop approaches in accordance with their research objectives (Alase, 2017). As a result, the authors utilized a three-step analytic strategy to evaluate the data from parents about their experiences with the LRC model via the theoretical lens of social capital and its indigenous construct, guanxi. The authors began by reviewing the original transcripts of parents' interviews and drafting memos on excerpts pertaining to parents' guanxi-related experiences under the LRC model. Second, the authors emphasized the similarities and differences in how parents approached and utilized guanxi in their advocacy experiences. In this phase, comparable extracts were grouped to establish focused codes. The last step consisted of combining focused codes based on their relevance to the issue of social capital and its existence in the for m of guanxi in the context of China, as well as developing themes based on the second step. Table 2 illustrates examples of themes and codes.

Table 2

Examples of Codes and Themes

Themes	Focused Codes	Texts (Examples)
Theme 1: Parents are aware of the importance of guanxi	Guanxi is important in parents’ navigation under the	“If you don't live in this school district, you need to

and widely practice it.	LRC model. Parents are not passively accepting guanxi; rather, they actively seek it.	find a guanxi, you know, as we Chinese say, a guanxi matters most.” (CXD, mother of eight-year-old girl diagnosed with autism) “I would say [the school accepted my child] mainly because I work there, and I know them all…I think that is the major reason.” (GDK, mother of eight-year-old boy diagnosed with autism) “It all depended on my husband to find guanxi via his networks.… If you don't do that, you will be like a blind person in the darkness, and it is still common in China that everyone looks for guanxi to get things done.” (MY, mother of five-year-old girl and 13-year-old boy, both diagnosed with autism) “So, I started to work on [looking for guanxi] a year before school age, and it worked well, and I found the principal who graduated from the same university as I did.” (TC, mother of eight-year-old boy diagnosed with autism)

Theme 2: Parents are hesitantly requesting accommodation and services under the schooling arrangement through guanxi.	The academic performance to be covered under the LRC model is of high importance.	“I think if a child cannot catch up with the progress with his class, then he should go to a special school because it would be beneficial to everyone…. My son could keep up with the class academically, so I wish he could stay in the regular school.” (QW, mother of 11-year-old boy diagnosed with autism) “I wish my son could stay in the regular classroom, but he is too bad in academics, and if he stays, he will interfere with others…and that is not the kind of pressure he or I could take in the end.” (GSC, father of 11-year-old boy diagnosed with autism)
	A cooperative and submissive strategy is needed when facing disagreement with schools.	“As parents, we need to do whatever we can beforehand so that our kids can stay safe and not be a burden to teachers or school.” (CXD, mother of eight-year-old boy diagnosed with autism) “I would say never file a complaint to their supervising sections…It would wind up against parents in the end and

		increase the negative impression to both parents and children.” (GDK, mother of eight-year-old boy diagnosed with autism)
Theme 3: Social status matters in the practice of guanxi	The implicit premise behind an effective advocacy experience is a similar social circle.	“That principal graduated from the same university as I did, and we have common friends … and he has been accommodating for me to get my son into his school.” (TC, mother of eight-year-old boy diagnosed with autism) “I wasn't happy with his former school, so I found out about a private school for children from Christian families, and we contacted one of our sisters in that church, and he was admitted right away.” (FA, mother of 10-year-old boy diagnosed with autism)
	The implicit reason behind unsuccessful advocacy experience is a different social circle.	“And he gave me an excuse, saying the decision has nothing to do with his disability, but I know the true reason; he does not want this burden at his school, and we have no guanxi with him.” (LHX, mother of 13-year-old boy diagnosed with autism)

	“I know it was because of my guanxi with this principal because I know another mom came to the principal and asked for enrollment for her son, but the principal didn't agree.” (TC, mother of eight-year-old boy diagnosed with autism)

Findings

The social capital theory framework developed by Bourdieu (1986) helps interpret parents' approaches to special education participation. According to Trainor (2010b), although this framework does not necessarily illuminate specific methods in which parents interact with schools in terms of service or accommodation, it could explain the transformation of capital into an opportunity (Trainor, 2010b).

In the following sections, three themes emerge from parents' experiences when they tried to create educational opportunities for their children with autism: 1) Parents are aware of the importance of guanxi and widely practice it; 2) parents are hesitantly requesting accommodation and services under the schooling arrangement through guanxi; and 3) social status matters in the practice of guanxi.

Awareness and Uses of Guanxi

Most (14 out of 16) participants talked about either seeking guanxi or maintaining good guanxi with schoolteachers or principals to achieve schooling arrangements or better accommodation for their children with autism. Responses indicated that parents are fully aware that the personal connections between parents and principals and other applications of guanxi can be powerful tools for accessing public education under the LRC model. Although parents had complaints about doing so, they still practiced guanxi actively during interactions with school actors. Parents whose social network consists of school principals were more likely to place their children in public schools. In other words, the successful procurement of inclusive education was perceived to be largely dependent on guanxi rather than the formal written requirements of the LRC model.

As prior studies on Chinese cultures have suggested, guanxi serves as a substitute for public policy in Chinese society and plays a crucial role in social lives (Xin & Pearce, 1996). Furthermore, by establishing a personal bond, the guanxi between the parties provides the basis for trust. It thus forms a source of stability in reaching any bilateral or multilateral agreements.

“If you don't live in this school district, you need to find a guanxi, you know, as we Chinese say, a guanxi matters most,” said CXD, mother of an eight-year-old girl diagnosed with autism and full-time caregiver at home.

“I would say [that the school accepted my child] mainly because I work there, and I know them all…I think that is the major reason,” said GDK, mother of an eight-year-old boy diagnosed with autism and teacher at a local elementary school.

The two statements suggest parents were aware of the importance of guanxi in arranging school for their children. Talking about the arrangement via personal connection instead of official channels, they expressed dissatisfaction and concerns about the wide use of guanxi in schooling.

“It all depended on my husband to find guanxi via his networks…. If you don't do that, you will be like a blind person in the darkness, and it is still common in China that everyone looks for guanxi to get things done…. I wish there will be no room for guanxi in the future, and I wish there will be a transparent system that will guarantee the enrollment to school,” said MY, a local government official and mother of a five-year-old girl and a 13-year-old boy both diagnosed with autism.

While some parents expressed their concerns about using guanxi, more parents accepted it as a valuable mechanism to get things done.

“If you want your kid to get into public school, you just need to find a guanxi to get it done, or your kid [needs to] just behave so well that they won't find [the autism],” said XH, mother of a seven-year-old boy diagnosed with autism and founder of an organization providing private training and therapy for children with disabilities.

“So, I started to work on [looking for guanxi] a year before school age, and it worked well, and I found the principal who graduated from the same university as I did,” said TC, mother of an eight-year-old boy diagnosed with autism.

TC, as a university professor, revealed that she undertook a great deal of planning to cultivate and establish guanxi with possible elementary school administrators before her son started school, as he had been expelled twice from kindergarten owing to a lack of connections, or so she believed.

However, getting an unofficial arrangement with a school only seemed to relieve immediate pressures without resolving issues. Due to the unpredictability and randomness of utilizing guanxi in the process, parents must still face the challenges and uncertainty of their children's long-term educational future.

"My major worry at this point is what to do after elementary school. Where could he go? I could not go with him anymore, right?" said GDK, mother of an 8-year-old boy diagnosed with autism.

This quote is from a mother who works at the same elementary school her son is attending. Although she admitted the benefits of using guanxi, she worried this benefit could not last after her son graduated.

Findings reveal that while parents were aware of the importance of guanxi and actively practiced it in making informal arrangements in schools, they were also aware that the outcomes of using such social capital were neither reliable nor transparent. As such, parents maximized their efforts to fit into the environment while avoiding confrontations.

Hesitancy in Requesting Accommodations via Guanxi

Different from what Trainor (2010a) found in parental knowledge and expertise in advocating for children, parents in this study indicated a tendency to be reluctant to request accommodation or services. Such reluctance seems to stem from the fear of being kicked out of school altogether.

"His dad will send him to school late because we don't want him to interfere with the other students in the classroom…. The morning classes are major ones so, in doing that, it will make the teachers' burden of class management much less and won't irritate other parents," said GDK, mother of an 8-year-old boy diagnosed with autism and a teacher at a local elementary school.

Only two parents in this study expressed that schools should offer services and accommodations to their children. They expressed a positive attitude in communication with schools about the LRC model for their children. However, they believed the model is more of a favor the school offers for the rest of the parents. Most parents (14 out of 16) indicated that if a student with disabilities could not perform well academically, they agree that a particular school would be a better choice.

"I think if a child cannot catch up with the progress with his class, then he should go to a special school because it would be beneficial to everyone…. My son could keep up with the class academically, so I wish he could stay in the regular school," said QW, mother of an 11-year-old boy diagnosed with autism and full-time caregiver at home.

"I wish my son could stay in the regular classroom, but he is too bad in academics, and if he stays, he will interfere with others … and that is not the kind of pressure he or I could take in the end," said GSC, father of an 11-year-old boy diagnosed with autism and advocate for children with autism.

The statements from these two parents suggest that, even though parents are trying hard to get a place in the regular classroom for their children, they prioritize not bothering others over their children's benefit from learning in the school, and they think academic performance is the key to get accepted by the regular classroom settings.

When asked about the strategy parents were using to communicate with schools to solve disagreements, disputes, or concerns regarding their children's education, most of them indicated the importance of being cooperative with the school. According to them, the least appropriate strategy to redress the grievances to the school was to act confrontational and ask for extra services.

“As parents, we need to do whatever we can beforehand so that our kids can stay safe and not be a burden to teachers or school… There was a kid in our school, and his parents did no intervention before school, and that kid ended up being suspended,” said CXD, full-time caregiver at home and mother of an eight-year-old boy diagnosed with autism.

“I would say never file a complaint to their supervising sections…. It would wind up against parents in the end and increase the negative impression to both parents and children … and I suggest parents do not bear too many hopes for a school to educate every child as equal,” said GDK, mother of an eight-year-old boy diagnosed with autism and teacher at a local elementary school.

Responses from parents suggested a preference for taking a cooperative strategy instead of requesting the right to address their concerns with schooling.

Social Status Matters in the Practice of Guanxi

Even though most participants reported guanxi as a significant source of social capital when they advocated for the service right of education for their children, their efforts were not always successful.

“Initially, the principal agreed, and then he changed his mind, and no matter how hard I tried to convince him my son won't be a troublemaker in the class, he just refused me … and he gave me an excuse, saying the decision has nothing to do with his disability, but I know the true reason: he does not want this burden at his school, and we have no guanxi with him,” said LHX, mother of a 13-year-old boy diagnosed with autism and local government official.

“Why do I know [that my son was admitted to a local public school] because of guanxi? Because I know there was another mom who came to the principal and asked for enrollment for her son, but the principal didn't agree,” said TC, university professor and mother of an eight-year-old boy diagnosed with autism.

Some parents indicated what helped their efforts to find guanxi: examples included similar social status and circles, their occupations, educational background, or membership in religious organizations.

“That principal graduated from the same university as I did, and we have common friends…and he has been accommodating for me to get my son into his school,” said TC, university professor and mother of an eight-year-old boy diagnosed with autism.

“I wasn't happy with his former school, so I found out about a private school for children from Christian families, and we contacted one of our sisters in that church, and he was admitted right away, said FA, full-time caregiver at home and mother of a 10-year-old boy diagnosed with autism. When asked if this school is just for children from Christian homes, she replied, “Yes, you must have at least one parent who is a Christian at that church, and you need to have a referral."

GDK, a local elementary school teacher, responded negatively when asked if other children in similar circumstances to her son were ever admitted to the school where she works. "No. In my school, I had never seen someone admitted under the LRC model. I believe my son was the first. My colleague and principal knew my son early and wanted to assist me." As indicated previously, GDK was concerned about her son's future when he graduated from the school where she works because this advantage may not persist through high school.

The expressed experiences and values of participating parents reveal acknowledgment and hesitancy about the uses of guanxi for gaining school resources for their children. Responses also indicate some anxiety about advocating for their children over and above the common good of all students at their children's schools. Hence, the most prevalent form of guanxi used with school actors seemed to be one that capitalized on or fostered social relationships to garner services for their children.

Discussion

We aimed to gain a deeper understanding of inclusive education efforts for children with autism from a parental perspective within China. Limitations in recruiting participants for our study included the fact that the only available mode of contact (online networking) excluded parents who lack access to online resources or were uninterested in online networking. In addition, as all participants in this study were Han Chinese residents living in cities with a per capita GDP ranking among the top ten in China. Parents' perspectives from other ethnic groups were omitted from this study. Studies on Chinese ethnic differences suggest that the dominant Han Chinese culture cannot adequately represent the entire Chinese population in terms of contextualized cultural practices (Deng et al., 2016). Consequently, our findings may not be generalizable to parents from diverse cultural and socioeconomic backgrounds in China. Another limitation was the relatively small sample size with an unbalanced gender ratio (15 females vs. one male) recruited for our study, which precluded our ability to make any generalizations or group-level claims (e.g., parents with younger vs. older children, or male parents vs. female parents). Given these limitations, we view this study as an initial phase of a larger exploration to make visible what parents of children with autism in China may experience and try to do to gain access to inclusive education services under the LRC model.

Findings from our analysis offer some insight into the challenges that parents in China—even those within the top socioeconomic sphere—face when advocating for inclusive education opportunities. Analytic uses of the Bordieuan capital lens have been instructive in previous studies on probing home–school collaborations (Bacon & Causton-Theoharisa, 2013; Trainor, 2010a). As such, we took up this framework as a guide for our analysis. Three major findings emerged from our exploration of recorded interviews with 16 parents of children with autism in China, each of which is addressed in turn.

The Perfunctory and Powerless Nature of Inclusive Education Policies in China

According to prior research, although the LRC model marked the beginning of inclusive education in China and has been recognized as the most popular form of providing education for children with disabilities in China, the inadequacies of this model at the legislative level have rendered it ineffective in achieving its goal of compelling public schools to provide free education to children with disabilities, as illustrated by the accounts of parents in this study. Our participants expressed their reticence in referencing laws or other litigation-related information with school actors during their advocacy efforts. Instead, all parents stated their reliance on guanxi, which seemed to align with the socially framed transactional practices typically observed in Chinese business contexts (Chen, 1999). Fostering positive social connections with school leaders and teachers seemed to serve as the most important strategy for gaining acceptance and support for their children. The national LRC model that explicitly outlines a family’s rights to inclusive education seems to have been deemed by participants to have little purchase in negotiations between parents and schools, regardless of the severity of their child’s disability. Participants also seemed to recognize the inequitable power dynamics that placed them in a subordinate position within the educational system, unable to make or influence any decision relating to their children's placement at school or their accommodations. Such parental recognition contrasts with Trainor’s (2010b) finding that inequitable access to services relies more on the type and severity of disabilities than parental involvement with school actors.

Apologetic Positions for Receiving Favors from Schools

In contrast to what Bourdieu and other related theorists suggest about the purposes and functions of social capital, participants expressed reluctance in making any explicit requests for accommodations or resources for their children. The common theme among all participants reflected the importance of not bothering others because of their child. This principle seemed to stem from a realistic concern that explicit requests for service and accommodations would be deemed as signs of social dissatisfaction, hence burdening school actors. Responses also indicated that parents use a self-deprecating tone when speaking with school leaders and teachers about their children. Such phatic displays from parents shaped their requests to resemble what one would do when asking for a favor out of moral kindness with no references to the rights that schools are dutybound to support. All but two participants expressed a belief that the right to educational access is conditional on the capabilities of their children rather than being a mandatory right. Parents seemed more concerned about not interfering with other children’s progress in the classroom than whether their children could gain access to the classroom.

This finding of parental concern for the whole over their own children’s rights to educational resources is consistent with findings from prior studies that revealed a Confucian mindset when interpreting or referring to disability rights (Poon-McBrayer & McBrayer, 2014; Qu, 2019; Yu, 2008). For example, Poon-McBrayer and McBrayer (2014) found in their study of parental advocacy practices in Hong Kong that there was a strong aversion to making confrontations during interpersonal interactions with school authorities; parents usually adopted a cooperative and gentle manner during such meetings to pave the way for the future negotiation with school actors.

Exclusivity of Guanxi in Social Circles

While all participating parents had a household income in the top 10% in China, there was a range of educational backgrounds and professional standing among respondents in our study. Findings from our analysis moderately suggest that parents with similar social circles with principals, especially those with a higher professional status—those with highly regarded professions occupations such as being doctors, university teachers, or government officials—may be more successful in obtaining educational opportunities for their children. While our sample does not support any conclusive findings, such a pattern aligns with prior research on the vital role that parents' socioeconomic status plays in gaining educational access for their children (de Boer et al., 2010; Trainor, 2010b). In this light, guanxi is similar to the notion of social capital of Bourdieu (1986) in that it results from investment by individuals striving to form beneficial social relations, yet with more emphasis on professional roles and identities than on wealth itself. For example, one of our participants who worked for a school had been successful in getting her son enrolled. Another participant, who was a government official, made use of her position to support the school that subsequently ended up accepting her son.

Responses from participants indicated that guanxi in the context of parental advocacy is not a simple connection between individuals; successful connections have much to do with the social status that is built from one's ability to build positive relationships with school actors and the ways in which professional identities are leveraged. This finding echoes the previous research on guanxi in Chinese society, which largely focuses on business practices. Such studies highlight the importance of guanxi for establishing social order during business dealings, which is exclusive to outsiders of a particular class (Chen, 1999). Our participants also suggested that educational access is not equally accessible to all and that the higher one's social status, the more likely a schooling arrangement can be reached for children with autism. Such sentiments align with Bourdieu's (1986) description of memberships within social networks based on one's social status as well as Ruan & Chen's (2020) notion of guanxi as reflecting "horizontal exclusiveness" (p. 709).

Implications from our study highlight shared values of social capital (in the form of guanxi) in gaining and maintaining access to educational services for children with disabilities, regardless of a family's legal rights. On the one hand, the networks that control our everyday lives operate in a similar manner no matter where we reside (Westlund et al., 2010). Yet, on the other hand, because of the way we organize ourselves as well as operate in networks, our whole perception of the world is formed by the social networks embedded in culture; such networking has an important impact on the manner in which individuals and communities interact with one another (Kwok et al., 2019; Paton et al., 2013). For example, even though researchers in several countries have observed the use of social capital by parents of children with autism as a means of advocating for educational rights, unlike parents in Western countries, the use of policies and laws seems far less acceptable in garnering services for children with autism in China.

One of the most significant findings from our study is our participants' seemingly unwavering concern for the whole school community and the possible impact their child may have on the school's capacity to serve all children. These concerns appear to reflect a deeply entrenched cultural norm of social harmony, which may inadvertently absolve schools of their mandated responsibility to provide inclusive education for children with disabilities. Such a finding is a stark contrast with western countries like the United States, in which litigious discourse surrounding individual rights is unavoidable (Lalvani & Hale, 2015). Future explorations of recently immigrated parents to the United States may reveal to what extent such cultural differences may influence advocacy efforts.

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The Formation of the Deaf Community in China, 1887-1945

Shu Wan

Department of History, University at Buffalo

Abstract

Based on memoirs, newspapers, and other historical materials, this article foregrounds National Association for the Deaf People ("中华聋哑协会") in the formation of the Chinese deaf community before and during the War of Resistance (1937-1945). In addition to the proliferation of Chinese sign language studies, this article examines the extent to which the formation of deaf-only businesses, deaf people's participation in wartime mobilization, and the proliferation of deaf education contributed to the consolidation of the deaf community in China.

Keywords: deaf history, deaf education, deafness, deaf community, China

The Formation of the Deaf Community in China, 1887-1945

In June 1937, a group of deaf Chinese people convened in Shanghai to inaugurate the first nationwide deaf organization in China, the National Association for the Deaf People (“中华聋哑协会”), which will be referenced by as “Association” hereafter (Anonymous, 1937). In Republican China, many social and political organizations, each holding different concerns, bubbled up in urban Shanghai. For example, the Chinese Communist Party (CCP) was founded in 1921. Unlike the CCP, which eventually became the sole hitherto-dominant political party in Chinese society, the Association was less influential.

The current research regarding deaf history in China is dominated by the work of linguists and deaf education scholars. The first publication on this issue was contributed by the Chinese linguist Zhou Youguang (周有光) in the 1980s (Zhou, 1980, pp. 209-216). Alison Callaway’s *Deaf in China* (2000) and Richard R. Lytle, Kathryn E. Johnson, and Yang Jun Hui's "Deaf Education in China" (2005) explore the roles of the Chefoo School for the Deaf and sign language in the development of deaf education in China (Callaway, 2000, p. 98; Lytle, Johnson, Yang, 2005, p. 461). Following in their footsteps, Sarah Dauncey examines deaf education as a component of “special education,” Han Lin studies “the Shanghai variant of Chinese Sign Language” and its origin in deaf schools in the early twentieth century, and Mark McLeister explores the marginalization of sign language throughout the history of deaf education in China (Dauncey, 2017, pp. 290-313; Lin, 2021; McLeister, 2018, pp. 220-237). This concentration on the interwoven history of sign language and deaf education has predominated academic writings on deaf history in China.

This article supplements previous studies by examining the formation of deaf-only businesses, deaf people’s participation in wartime mobilization, and the proliferation of deaf education. Along with well-studied use of sign language, they all contributed to the consolidation of the deaf community in China. Focusing on the formation of the deaf community before and during the War of Resistance (1937-1945), this article explores the role of the Association in the evolution of the deaf community based on memoirs, newspapers, and other historical materials.

The first section of this article examines the proliferation of deaf education in early twentieth-century Chinese society. Shu Wan's article "Annetta T. Mills and the Origin of Deaf Education in China" casts light on the influence of Western missionaries on the introduction of the American pattern of deaf education into China between the 1880s and 1910s (Wan, 2021, p. 85). In the first decades of the twentieth century, an increasing number of Chinese educators in alliance with alums of Mills' school were devoted to Chinese-owned institutions of deaf education. The proliferation of private deaf schools paved the way for the formation of the Shanghai-centric deaf community. Deaf education was essential to the construction and consolidation of the emerging deaf community, characterized by the inauguration of the Association in 1937.

After examining the evolution of a loose network of deaf educators and well-educated deaf people into a national deaf community before the War of Resistance, the second section turns to the influence of the national crisis on deaf people, especially those who were impoverished and living in precarious circumstances. In 1938, the Association began to publish its official magazine titled *Yin Duo* (《喑铎》), which has as an English title, *News for the Deaf and Dumb* [sic]. Its editors and contributors were well-educated deaf people. To inform the deaf audience of the newest happenings in their community, the magazine's content ranges from coverage of deaf events and everyday life to deaf people's artworks and controversial issues in their community. Reviewing its initial issues between

1938 and 1939, this section argues that well-educated deaf people were foremost concerned with providing education and accommodation for deaf refugee children, saving poor deaf people from economic hardship, and displaying their talents in fine art. Overall, well-educated deaf people attempted to help the impoverished members of their community, which led to a “deaf-help-deaf” culture.

A National Network of Deaf Schools

For the modern Chinese nation, deaf education is not considered an indigenous practice but rather something imported from the West in the late nineteenth century. In 1887, American female missionary Annetta T. Mills founded the first deaf school in Chefoo, which encouraged the proliferation of deaf education in China during the following decades (Wan, 2021, p. 93). Most of the deaf educators in China maintained direct or indirect connections with Mills’ school for the deaf. Concerned with the proliferation of deaf education accompanied by the expansion of its network, this section examines the early history of the deaf community in China between the foundation of Mills’ school in Chefoo and the inauguration of the Association in 1937.

Mills’ success encouraged the Chinese to dedicate themselves to developing deaf education. Zhou Yaoxian (周耀先), the parent of two deaf children, launched the first Chinese-owned deaf school, the Shiruiting (石瑞亭) Deaf School, in Hangzhou. Zhou’s early life is unclear and not well-documented, but his contribution to deaf education was recorded in local gazettes. According to the *Gazetteer of Education in the Zhejiang Province*, "in 1914, the private Zhejiang Christian College's faculty member Zhou (whose surname was also spelled as Tse in some historical records) launched a deaf school in Shiruiting in Hangzhou. It was sustained for over a year but closed because of Zhou's death” (Yu, 2004, p. 449).

Within this school’s short life, Zhou's enterprise conveyed the important influence of the Chefoo School for the Deaf on the formation of deaf education in China. The school’s teachers consisted of graduates of Mills’ School, including his son, Zhou Tianfu (周天孚) Wan, 2001, p. 94). Mills' and Zhou's schools were interconnected in the network of deaf education.

Zhou’s school was revived after receiving external financial support in the 1920s. In 1922, the China Christian Independent Church’s (CCIC) leading pastor, Yu Guozhen (俞国桢), announced a plan to build a new Puhui Deaf School. Under his leadership, the CCIC was one of the most influential indigenous churches in 1920s China, which "had over 100 member churches, an annual national meeting, and full bylaws, in addition to its own newspaper” (Bays, 1991, p. 310). Claiming to continue Zhou's passion for promoting deaf education in China, Yu moved the school to Shanghai and hired Zhou Tianfu as a staff member in the new school (Anonymous, 1992, p. 9). In light of Zhou’s experience in the two Chinese-owned deaf schools, the Chefoo School for the Deaf also played an important role in expanding the network of deaf education.

Zhou’s and Yu’s schools were not the only two institutions in the Chefoo-centric network of deaf education. The Qunxue Society (群学会)-affiliated Deaf School in Shanghai offered an example. Unlike the Chefoo School for the Deaf and its offspring institutions organized and supervised by deaf people and/or educators, the Qunxue Society was founded during the proliferation of study societies in late Qing China. Unlike those organizations, which featured intense participation in political activism leading to the 1911 Revolution, the Qunxue Society was constantly concerned with promoting modern education to enlighten ordinary people, including those with hearing impairments. In 1920, the Society launched its affiliated deaf school (Sun, 1997, p. 853). Its maintenance relied on funds raised from the civil society in Shanghai and personnel trained in the Chefoo School for the Deaf.

Aside from pastor Yu and the Qunxue Society, many individuals and institutions took an interest in supporting deaf education. According to a journalist's survey in 1939, there were thirteen deaf schools in China at that time, of which three were located in Shanghai. Among the remaining ten schools, four of them were located in cities near Shanghai, including Nanjing, Nantong, Hanxian, and Wuxian. Most of them were financially supported by successful entrepreneurs and charitable organizations instead of the municipal or national governments (Anonymous, 1939).

Despite the absence of the public sector's support for the proliferation of deaf schools, Qing and early Republican bureaucrats were not ignorant of its progress. In the early history of the Chefoo School for the Deaf, local officials expressed their passion for developing deaf education. The provincial governor in Shandong visited Mills' school, watched her "miracle" in educating deaf children, and donated to the enterprise personally (Wan, 2001, p. 93). Parallel to this local bureaucrat's eagerness to encourage Mills' enterprise in Shandong, officials in the remaining parts of China also advocated for the development of deaf education. In 1903, a local official in Guangdong, Wang Junhe, "proposed to build a blind-mute school ... enrolling crippled children and youth" (Anonymous,1903). Three years later, the influential Chinese politician-entrepreneur, Zhang Jian (张謇), visited the blind-and-deaf school in Kyoto. He became aware of the value of deaf education, which motivated him to take a petition to Emperor Guangxu (Zhang, 2016, p. 29). In his letter, Zhang articulated the importance of founding deaf education to promote the modernization of Chinese society (Liu & Zhang, 1992, p. 51). However, both Wang's and Zhang's proposals did not receive support from the Qing court.

Considering their association of deaf education with the modernization of Chinese society, the official support for deaf education should be situated in the New Policies reform from the last decade of Qing China. Reacting to the exacerbated national crisis after the Boxer Protocol in 1901, the Qing court changed its conservative stance toward a modernizing Chinese polity and society. According to Kristin Stapleton, "the New Policies reform launched in the final decade of Qing rule reflected the concern about national strength” (Stapleton, 2000, p. 4). As an important component of the agenda for enhancing China’s national strength, the old Confucianism-centric and civil service exam-embedded educational system was gradually replaced by the new school system. Modern school education covered the marginalized population such as “deaf people [who] were excluded from the traditional school system in China” (Yuling, 1932). A similar observation motivated Mills' self-dedication to the education of deaf Chinese people in Chefoo.

Long before the inauguration of Mills’ school in Chefoo, the Chinese had an opportunity to obtain first-hand knowledge of American deaf education in the 1840s. Before his active participation in the Self-strengthening Movement in the 1870s, the Chinese Yale alumnus Yung Wing stayed in the house of William Gallaudet, the latter of whom presided over the National Deaf-Mute College, which later evolved into Gallaudet University. However, there was no evidence that Yung discussed any subject with the host regarding the development of deaf education in America (Wan, 2021, p. 87).

When New Policies reformers visited Japan in the 1900s, these successors of Yung documented their strong impression of Japanese deaf education. As the member of the delegation, Yang Fei (杨芾), recorded in his diary, “(I), Zhong Fan, and Mian Hai went to the blind-and-deaf school in Koishikawa (in Tokyo) ... those deaf and blind students study together in the same classroom.… After studying in the school for several years, those deaf and blind children could learn skills for survival, which is a benevolent policy" (Yang, 2014, p.46). Aside from Yang Fei, other late Qing officials visited the blind-and-deaf school in Tokyo and similarly returned with a strong impression of the advancement of deaf education in Japan (Lü, 1999, p. 78). Their encounters with the Japanese pattern of blind-and-deaf education profoundly influenced the direction of deaf education in China. In 1905, the Qing court publicized its reform plan for the "new school system," which combined deaf and blind education in building blind-and-deaf schools instead of the American deaf-only pattern introduced by Mills.

The distinction between Japanese and American patterns could be traced back to the different origins of deaf education in the two nations. In the United States, the pedagogy and practices of deaf education originated in France. According to R. A. R. Edwards, "in the antebellum period, the bilingual-bicultural approach to deaf education became the common standard of deaf education and was in fact the American innovation in a system of education largely imported here from France" (Edwards, 2012, p.3). By contrast, the origin of deaf education in Japan was complex. Following the U.S. Navy officer Commodore Matthew C. Perry's "arrival of the Black Ship" at Kanagawa harbor in 1853, the appearance of deaf education in Japan was associated with the Europeans. According to a report in *The Association Review*, "On May 22nd, 1875 ... at the house of Dr. Fauld, an English physician of Tokyo … Dr. Burchardt, a German-American Lutheran missionary, formed an Association for furthering the instruction of the blind. On May 26th, 1884, the school was thrown open to the deaf people, and its name was changed accordingly" (Anonymous, 1900, p. 190). Attributed to those advocates' German and British backgrounds, the pattern of combining blind and deaf education became prevalent in late-nineteenth-century Japanese society.

Reacting to Chinese intellectuals' and officials' eagerness to follow the Japanese pattern, Japanese deaf educators also contributed their ideas to the heated dialogue about developing deaf education in China. In 1912, the president of the Blind-and-Deaf School in Tokyo, Nobuhachi Konishi, published an article in Chinese to introduce the past and progress of deaf education in Japan. Besides telling the founding story of deaf education characterized by the collaboration between Japanese people and Western missionaries, Konishi ended his writing with the suggestion of developing a Chinese-owned enterprise of deaf education. "(You may) consider sending Chinese blind and mute students to study in Japan or hiring graduates of deaf and mute schools in Japan, who are versatile and skilled as teachers to work in China" (Konishi, 1912, 15). Following Konishi's suggestion, a few of the Chinese graduates from Japanese blind-and-deaf schools returned to China and worked as teachers in the Jinzhou Blind-and-Deaf school founded in 1932 (Anonymous, 2001, p. 176). Parallel to Mills' introduction of the American pattern of deaf education into Chinese society, the Japanese pattern of combining blind and deaf education influenced the progress of deaf education and its expanding network in China.

Despite the coexistence of the Japanese and American patterns in the early history of deaf education in China, their shared trait – reliance on government sponsorship – rarely affected their Chinese counterparts. Both the Qing and Republican governments did not place a high priority on deaf education in their budget. Until the War of Resistance in 1937, the only public deaf school was located in the capital city, Nanjing. Meanwhile, private deaf schools received limited state funds. For example, the Beijing Deaf School was entrenched in economic hardship in the 1930s. Before the War of Resistance, the school received a small number of subsidies. "The Hebei province government appropriated 200 yuan every month, and the Social Security Bureau in Beijing provided 30 yuan each month" (Anonymous, 1934, p. 48). In sum, the provincial and municipal governments could offer 2760 yuan to the school each year. This amount was insufficient for the maintenance of the school, which required 7000 yuan a year (Anonymous, 1934, p. 48). The deficit mainly relied on enrollees' tuition and donations from civil society.

The influence of economic hardship on deaf education in China was prominently embodied in the trajectory of Zhang Jian's enterprise. As mentioned above, Zhang attempted to convince the Qing rulers of the importance of deaf education but failed. This frustration did not discourage his passion for educating deaf and blind children in China. After a few years of arrangement and fund-raising activities, Zhang was determined to build a deaf school in 1916 (Anonymous, 2000, p. 176). In tandem with other private deaf schools in China, the maintenance of Zhang's school mainly relied on the profit of his business Dah Sun Cotton Mill, which was one of the largest textile factories in early twentieth-century East Asia. Despite Zhang's implementation of the Japanese pattern of building a blind-and-deaf school, his enterprise also benefited from graduates of the Chefoo School for the Deaf. However, when Zhang's business encountered a deficit in the 1920s, he failed to seek financial aid from the local and national governments in support of his enterprise. Thanks to his reputation in Chinese calligraphy, Zhang was able to sell his artworks to fund his blind-and-deaf school (Liu & Zhang, 1992, p. 17).

However, the outbreak of the War of Resistance in 1937 disrupted the development of deaf education but prompted the emergence of the deaf community. On April 1st, 1936, well-educated deaf people "in Nanjing, Shanghai, Beijing, Tianjin, Shandong, and Sichuan" convened in the Xinshijie Restaurant in Shanghai. They discussed arranging the first national deaf organization in China (Anonymous, 1936). Following the inauguration of the Association in 1937, its leaders took their endeavor to strengthen the connection among nodes on the deaf education network and other deaf poor people who were unable to access education and were consequently excluded from the "network." As shown in the subsequent section, the Association's agenda successfully consolidated the deaf community in wartime China.

Focusing on the early history of Chinese-owned deaf education, this section discusses the frustration and financial difficulties that well-educated deaf people encountered in their dedication to deaf education. Attributed to a shortage of governmental appropriation, those advocates had to seek financial support from local society. It rendered Shanghai – the city characterized by the largest civil society in early twentieth-century China – the center of deaf education. Confronting a set of challenges, they still successfully promoted the proliferation of deaf schools, accompanied by the extension of its network between 1914 and 1937.

Despite the coexistence of the Japanese deaf-blind and American deaf-only patterns, Chefoo School for the Deaf played an important role in the promising growth of deaf education in China. This school's alumni were employed in various Chinese-owned deaf schools, which blurred the line between the different patterns of deaf education. Furthermore, the school offered a "common ground" for the consolidated network of deaf schools. Their affiliates became the major force in the emerging deaf community in 1936. The following section switches to well-educated deaf people and their efforts to strengthen the connection between the deaf people of different backgrounds.

Forging a Wartime Deaf Community

1937 was a vital year in modern Chinese history, being the first year of the War of Resistance and the Japanese military's occupation of China's capital Nanjing. This was followed by the catastrophic Nanjing Massacre in December. In the same year, a group of well-educated deaf people convened in Shanghai for the inauguration of the Association in

June. Its inaugural chair announced the plan of action, including "building a wartime deaf school for refugee children," "seeking a solution to deaf people's unemployment," "arranging an art exhibition of deaf artists' works," and "undertaking a national survey of deaf people's general condition' (Anonymous, 1937). Concerned with the Association's mission of advocating the interest and well-being of deaf people in China, this section illustrates the wartime transition from a loose network of deaf education to a concentrated deaf community between 1938 and 1945.

One month after the inauguration of the Association in Shanghai, the War of Resistance burst out, during which time the Japanese military assaulted the Marco Polo Bridge in Beijing on July 7. As a consequence of its weaker military power in comparison with the invading force, the Chinese national government lost control of several major cities on its East Coast. Before the end of this war's first year, Shanghai and the capital city Nanjing fell to the Japanese military's occupation. The exacerbated national crisis unavoidably affected the progress of deaf education. For example, Fu Ya School (福哑学校)became at risk of bankruptcy. As reported in *Shen Bao* (《申报》) at the time of occupation, "owing to the outbreak of the War of Resistance in the mid-year (of 1937), the (Fu Ya School's) fund-raising activities (for its maintenance) were entirely interrupted. Moreover, because the campus was located in the battleground, the operation of the school was impacted" (Anonymous, 1943). When relocating to the International Settlement in Shanghai, "all deaf education-related devices and facilities were damaged by the war" (Anonymous, 1943). Other deaf schools in Shanghai and its nearby regions were also profoundly impacted during the war. For example, the only public deaf school in Nanjing was relocated to the wartime capital Chongqing until 1945. Along with the relocation of the public deaf school and its affiliates to the Great Home Front, the Association reached out to Southwest China. In

1939, many well-educated deaf people relocated to Sichuan, and seeing that there were already deaf living there, they “sent a request (to the Association’s leaders) for building a branch there” (Anonymous, 1939).

However, the closure of these deaf schools affected their enrollees’ access to deaf education. After all, many, including both deaf and hearing people, could not relocate to the Great Home Front in Southwest China. Among those people who were reluctant or unable to depart the East Coast, some of the Association’s leaders and active members left for Shanghai, the wartime “lonely island.” As mentioned above, most parts of Shanghai had been occupied by the Japanese military before the end of November 1937. However, the territories in the International Settlement under French, American, and British control took exception and exemption from the occupation until the outbreak of the Pacific War in 1941. The special status of Shanghai sheltered domestic and international refugees, including the deaf Chinese people, during wartime. Taking Sun Zuhui (孙祖惠) as an example, “after Hangzhou fell to the Japanese military's occupation, he and his family ... relocated, via Shanxing and Ningbo, to Shanghai” (Anonymous, 1938). Likewise, another deaf person began his memoir essay by documenting his journey to Shanghai as a refugee. As quoted in a deaf person’s remark in *Yin Duo,* “after the Japanese military assaulted Zhejiang province, the best part of the Western Zhejiang almost all fell to its occupation. I had to relocate to different places frequently” (Anonymous, 1938). Witnessing the damage done to deaf education by military conflict, well-educated deaf people made all efforts to arrange a wartime school. After raising adequate funds and finding a locale for the campus, the Association’s leadership succeeded in building the wartime school in late 1938. A couple of active members of the Association, including Lin Jimu (林吉姆), took charge of teaching in the school, which enrolled over ten students (Anonymous, 1938). The wartime school, which then changed its name to the

Association's affiliated school, successfully sheltered those deprived children as war refugees.

Moreover, the deaf Chinese people remained unemployed in large numbers. Before the War of Resistance, unemployment partially tied to the Great Depression was a severe problem in China (Mitter, 2010, p. 100). The situation could be significantly worse for the deaf people. According to a deaf person's testimony, "my efforts to seek survival and to find a job for a few years led to disappointment" (Anonymous, 1937). In the wartime environment, the deteriorated job market hindered deaf people's entrance into occupations. Consequently, "when a deaf and mute person takes their first step to be integrated into hearing society, he would like to seek a 'rice bowl' in competition with the large army of the unemployed, which is not easy at all" (Anonymous, 1938). The frustration deaf people encountered in wartime was prominently embodied in Lin Jimu's experience. As mentioned above, Jimu served as a teacher in the wartime deaf school. However, his services in the school were terminated when its precarious financial situation worsened in the 1940s; he finally became homeless in 1941 (Anonymous, 1941). Eventually, information about his later life disappeared from historical records. Lin's experience was not alone but represented many deaf people's encounters with the wartime crisis. In Shanghai, many deaf people became homeless and were forced to shelter in the Association's office. For those whose livelihood was at risk, "the Association intended to introduce them to refugee asylums, which could harbor them from vagrancy" (Anonymous, 1938). However, this temporary measure could not entirely solve the unemployment affecting poor deaf people.

Unlike those degraded to the status of war refugees, the majority of the Association's leadership and active members were exempted from economic hardship. These members typically benefited significantly from their wealthy families. As [He] Yuling (何玉麟) noted, "those wealthy deaf-mute children's father and older brother may send them to school for education or invite tutors to teach them at home" (Yuling, 1932). As mentioned above, the founder of the first Chinese-owned deaf school, Zhou, hired his deaf sons as teachers. Likewise, some wealthy deaf people worked in their families' businesses. As for well-educated deaf people employed by the non-family-owned business, their employment was attributed to their education. However, "except those residing in big cities who may have more education opportunities, most of the deaf children in the lower class wasted their time in vain" (Yuling, 1932). As mentioned above, the pre-1937 network of deaf people consisted of deaf schoolteachers and alumni but excluded "uneducated" deaf people who were often unemployed. In mid-1938, it was reported an increasing number of unemployed deaf "came to the Association and asked for charitable aid" (Anonymous, 1939). Encountering exacerbated unemployment among poor deaf people, the Association's leadership opened their business "Zhi Yong Fine Art Cooperative." It aimed to "solve the unemployment issue" by only hiring poor deaf people (Anonymous, 1939, p. 5). Despite this cooperative's similarity to the tradition of poorhouses in the West, its spontaneity and self-sufficiency – being managed by well-educated deaf people and providing work opportunities to their poor counterparts – distinguished them from those government-run charitable enterprises.

Besides building the "deaf-help-deaf" culture in forging the deaf community, the Association also arranged a fine art exhibition to display deaf artists' talents. This choice of fine art as the exhibition's theme was attributed to the fact that occupations of most well-educated deaf people were predominantly related to painting (Anonymous, 1939, 13). Their preference originated in Mills' School. When she introduced the American pattern of deaf education into China, Mills highlighted the integration of deaf children into mainstream society through vocational training (Wan, 2021, p. 95). Chinese-owned deaf schools "inherited" the tradition. However, unlike the emphasis on the skills of printing and weaving in Mills' school, those Chinese-supervised deaf schools paid attention to arts education. According to a deaf student in Hangzhou, "[my deaf school's] curriculum mainly consists of those art-related subjects, including calligraphy and painting … students also take an interest in these subjects. So, their achievements in fine arts are superior to [hearing] students in other schools" (Anonymous, 1936). This youth was not alone in the desire to study fine arts. A large proportion of the Fu Ya School's placement for graduates was in fine-arts-related professions (Anonymous, 1943). For those deaf artists, the exhibition of their artworks could showcase their talents.

During their preparation for the exhibition, the Association's leadership took advantage of the network of deaf education by contacting deaf artists and collecting their artworks. The deaf people in "the Beiping Private Deaf-Dumb [sic] School, Jinzhou Deaf-Dumb School, Yantai [Chefoo] Deaf-dumb school, the Association's affiliated Deaf-dumb School, Shanghai Fu-ya School, and some famous artists" contributed their works (Anonymous, 1939). In light of multiple deaf schools' active participation in its preparation, the exhibition exposes the Association's achievement in facilitating a scattered deaf network into a closely connected deaf community. In the meantime, a group of deaf people in Tianjin succeeded in arranging a five-day exhibition of "deaf calligraphy and paintings" in July 1938 (Zude, 1938, p.5). The deaf cohort in Tianjin was well-known inside the national deaf community for their social activism and for bridging between deaf people and hearing society. Their exhibition reportedly attracted over 200 visitors daily, mainly young students (Zude, 1938, p. 5). Income from tickets helped relieve the Tianjin deaf community's financial stress; the regional deaf exhibition also fostered the Association leadership's determination to accelerate their steps in arranging the exhibition of the deaf Chinese people's artworks and achievements. Ultimately, thanks to the collaboration between well-educated deaf people in Shanghai and their colleagues across China, the two-day exhibition was very successful. Despite being held during wartime, it still attracted over 1000 guests in January 1939 (Anonymous, 1939). Contrary to prevalent perception of deaf people as somehow a burden on hearing people, deaf people's talents in fine art displayed their "usefulness" during the national crisis.

Parallel to their efforts to demonstrate deaf people's potential to become brilliant artists, the Association's leadership also raised funds to support their national military on the front of the War of Resistance. In October 1939, they succeeded in "raising 32 silk-cotton vests and donating them to soldiers on the front," as well as "deploying Association's members Lin Jimu and Zhang Yiwan" in providing voluntary service to the Chinese military in defense of the Chinese nation (Anonymous, 1937). In alliance with their hearing compatriots in confronting the national crisis, well-educated deaf people succeeded in demonstrating their capacity for saving not only their fellow deaf people but also the Chinese nation.

The last project listed on the Association's agenda was to conduct a national survey of the deaf population in China. For a long time, the concrete statistics of the deaf Chinese population and their demographic distribution remained a puzzle. Based on the percentage of deaf people who were taken into the general population of the United States, Mills estimated that "there are nearly four hundred thousand deaf people in that great empire, almost as many as there are in all the rest of the world" in 1905 (Mills, 1905, p. 458). Despite their inaccuracy, statistics were frequently referenced by Chinese hearing and deaf in reasoning about the severity of deafness in China later on. For example, Yuling stated that "assuming our country has four hundred million people, I may estimate there are at least four hundred thousand deaf people in China, which is a striking number" (Yuling, 1932). Likewise, the statistics were referenced with modification in Dai Shishi's (戴师石) speech at the inauguration of the Association. "According to the survey across the world, deaf people take around one-thousandth of the general population. In light of China's worse sanitation than Western countries, we suppose there are four hundred and fifty thousand deaf people in the nation" (Anonymous. 1937). Not satisfied with the accuracy of Mills' estimate, the Association's leaders were motivated to conduct a national survey of deaf people's demographic distribution and living situations in China. They planned to "report the collected and sorted statistics to the government to facilitate its plan for providing charities to deaf people" (Anonymous, 1939, p. 4). However, this project encountered frustration and roadblocks in the wartime environment.

Despite its purpose of providing statistics for the national government's reference, the undertaking of the survey still relied primarily on deaf people's spontaneous efforts. Thanks to the proliferation of deaf education and the expansion of its network, the leadership of the Association could collaborate with its nodes, deaf schools across China, to undertake the survey. Multiple deaf schools and their teachers took active roles in contacting other deaf persons in their regions and collecting information from them (Anonymous, 1939, p. 11).

Unfortunately, the extended and exacerbated national crisis hindered this projects' progress. The Association suspended the project in late 1939. According to its announcement, "owing to the political tumults in the War of Resistance, so our Association decided to, after the war, continue to conduct a nationwide survey and to reach out to" poor deaf people in rural areas (Anonymous. 1939, p. 4). Despite the difficulty in the wartime environment, the Association still made significant progress on the project. Before the suspension of the survey, 1000 copies of questionnaires were sent out, and over 960 answers were returned.

The Association’s active member Yu Weng took charge of analyzing the statistics. He reported his initial conclusion: most deaf people were unemployed, and these unemployed deaf people were predominantly uneducated (Anonymous, 1939, p. 12). The result resonated with the Association’s mission to create a cross-class deaf community, which motivated their further engagement in helping poor deaf people.

The Association played an essential role in blurring class lines inside the deaf community. During the national crisis, well-educated deaf people made efforts to provide “poor relief” to their impoverished counterparts, transforming the well-educated deaf-centric network into an inclusive deaf community. With an intense concentration on facilitating the employment of deaf individuals and their community’s self-sufficiency, the Association’s leadership forged a national deaf community.

Conclusion

This article primarily reviews the early history of deaf education and the formation of the deaf community in early-twentieth-century Chinese society. The War of Resistance catalyzed the creation of a cross-class alliance between well-educated deaf people and their poor counterparts. The leaders of the deaf community in China prioritized reform for the community's poor members and their integration into hearing society.

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Disabling Crisis:

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

Juan Miguel Ortega-Quesada

International Organisation for Migrations

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

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

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; DelVecchio 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, economistic, 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 agentive 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 agentive 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.

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Time is Running Out for People with Disabilities

Sujal Manohar

Baylor College of Medicine

Author Note

Sujal Manohar is a first-year medical student at Baylor College of Medicine interested in the intersections of the arts and medicine. She graduated summa cum laude from Duke University in 2020 with degrees in neuroscience and visual arts. In 2020-2021, she served as a Hart Fellow and AmeriCorps Artist in Residence at Imagine Art. View more of her creative work at sujalmanohar.com.

Abstract

The two drawings included were informed by experiences teaching drawing to artists with disabilities. Through their stories, the artists described problems many people with disabilities encounter daily.

Keywords: disabilities, artists, teaching

Time is Running Out for People with Disabilities

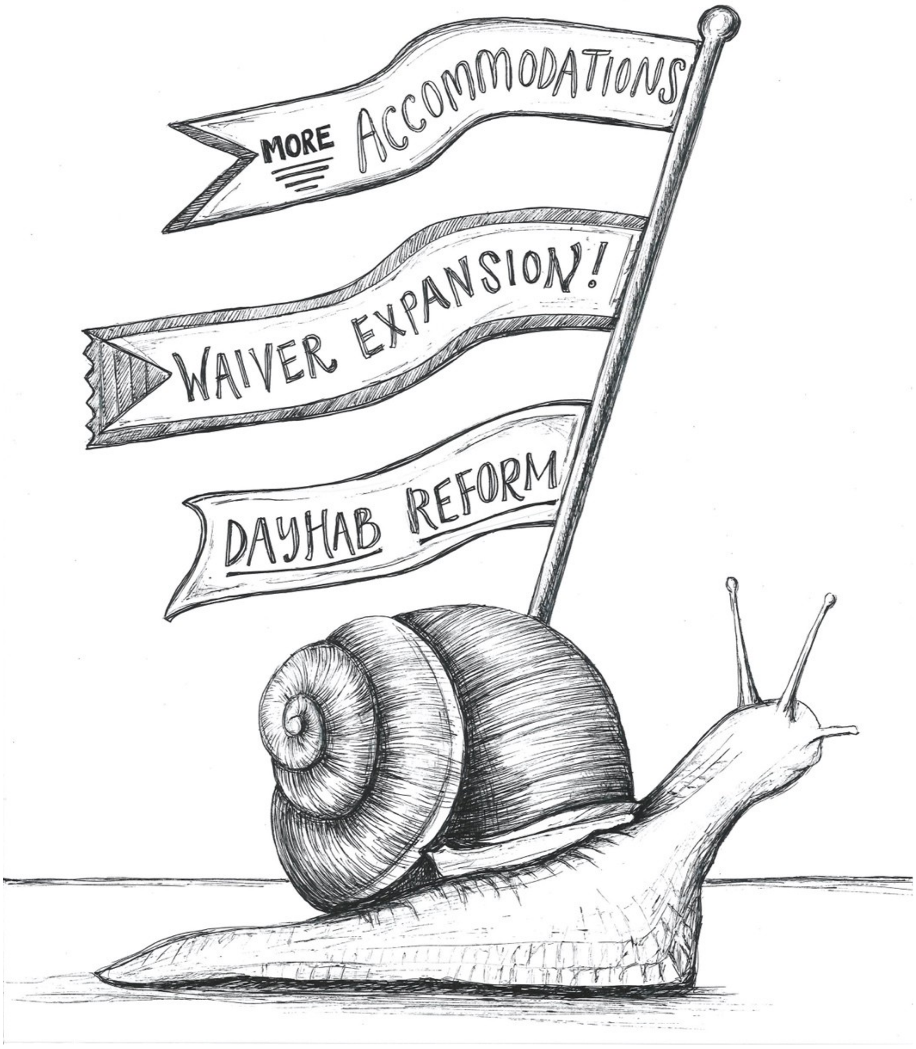
Many times, your students can be your best teachers. As I shared drawing techniques with artists with disabilities at Imagine Art, a nonprofit art studio for people with disabilities in Austin, Texas, the artists with whom I worked taught me about systemic challenges facing many people with disabilities. These interactions directly influenced the themes of these art pieces.

For example, many artists highlighted their challenges with Medicaid waiver programs which provide financial assistance for in-home services, such as occupations offering repetitive tasks with limited opportunities to learn new skills (“Daytime Habilitation in Texas,” 2018). Artists have also struggled with receiving appropriate accommodations for daily activities.

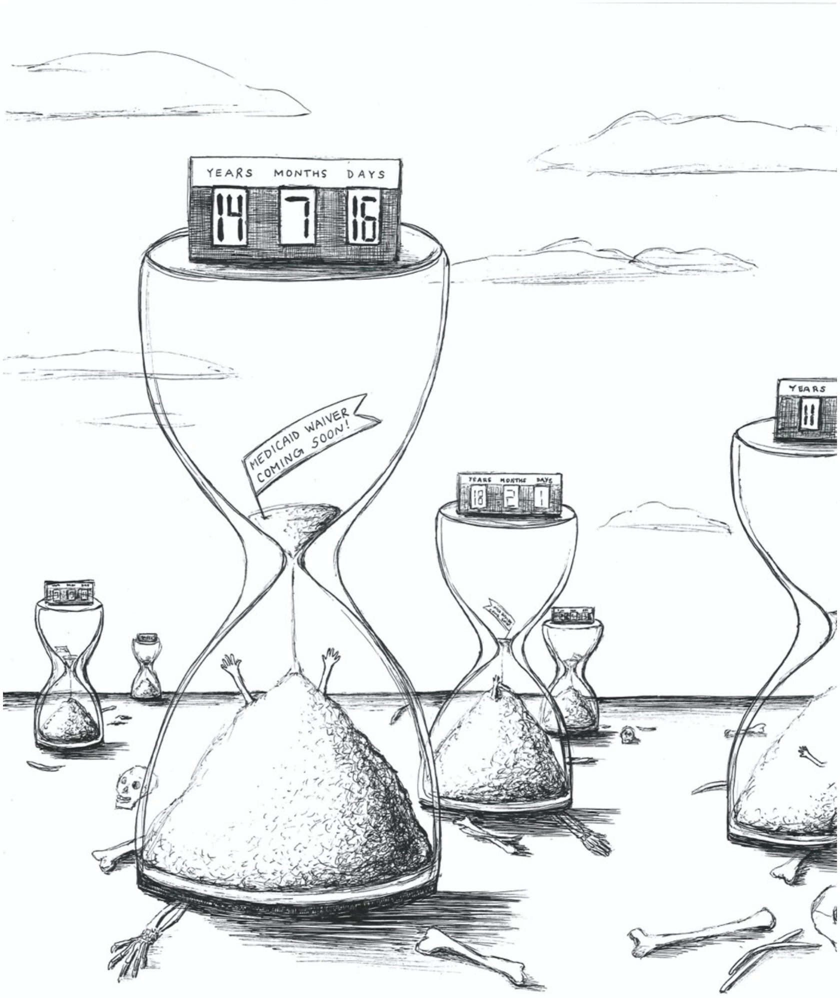
In the first piece, “The Pace of Progress,” the snail advertises reform of support systems for people with disabilities, symbolizing the overall slow pace of progress. The next drawing, titled “Waiting for Waivers,” depicts the numerous people with disabilities who remain on Medicaid waiver waitlists for decades. Unfortunately, some do not live long enough to receive benefits (“Case for Inclusion 2020 Key Findings,” 2020). Each hourglass represents one individual waiting for a Medicaid waiver spot; as years go by, the sand in the hourglass buries them. The ground is littered with the skeletons of people who never received the services they desperately needed.

These pieces are connected to my larger body of work exploring the intersections of the arts and health (found at sujalmanohar.com). I have previously created artwork about health conditions, such as mental illnesses and asthma and allergies, depicting the stories and experiences of people affected by illness. My interactions at Imagine Art opened my eyes to the broken support system for people with disabilities, inspiring me to create artwork on this topic. As a future physician, I am interested in utilizing the arts as a tool for health advocacy and patient engagement.

The Pace of Progress



Waiting for Waivers



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Multimedia

Spirit and Sport Explores the Intersections of Sport, Religion, and Disability

Kara Ayers[1,2] and Breanna Coleman[3]

[1]University of Cincinnati Center for Excellence in Developmental Disabilities,
Cincinnati Children's Medical Center

[2]University of Cincinnati College of Medicine

[3]Independent Researcher

Abstract

This book review of *Spirit and Sport: Religion and the Fragile Athletic Body in Popular Culture* by Sean O'Neil (2022) examines the intersection of disability, sport, and religion. O'Neil utilizes storytelling to describe how the acquisition of disability, often through trauma, translates to intense examinations of faith and the utilization of sport as a demonstration of humanity.

Keywords: disability, sports, religion

Spirit and Sport Explores the Intersections of Sport, Religion, and Disability

Spirit and Sport: Religion and the Fragile Athletic Body in Popular Culture by Sean O'Neil is a contemporary exploration of the intersections of disability, sport, and religion. As O'Neil's first book, this publication utilizes an engaging storytelling approach paired with O'Neil's experiences as a hospital chaplain and cancer survivor to invite readers into a shared exploration. *Spirit and Sport* raises essential questions about the frailness of mortal human bodies and the role of their creation in understanding our bodies' limitations. From this central question, O'Neil layers perspectives on disability and sports to emphasize the impressive strength of the human body.

O'Neil begins *Spirit and Sport* by describing the personal experiences and observations that led him to write this book. He then introduces readers to a web of interconnected stories of people who are either born disabled or became disabled later in life. Following these profiles, O'Neil examines the stigma surrounding anxiety and depression among professional athletes through themes of enchantment and coincidence. Finally, O'Neil defines the interdependence and intersectionality of these topics, including the social costs of stigma and ideas of the natural world that fail to consider aspects of faith. The book's concluding chapter brings these topics together to discuss the reality of perspectives of disability interconnectedness and how viewpoints of popular culture are often misleading.

Spirit and Sport adds to the field of disability studies, which has long been criticized for its lack of practical application. Not the first to explore this intersection, edited books like *Sports, Religion, and Disability* (Watson & Parker, 2016) and *Theology, Disability, and Sport* (Watson, Hargaden, & Brock, 2020) utilized chapters by multiple authors, in contrast to O'Neil's more cohesive but singular perspective approach. These books and similar works indicate a growing interest and invite further questions about the intersectionality of disability, sport, and religion.

While the strength of *Spirit and Sport* is its coverage of well-known profiles in a novel way, it fails to do so with a clear sense of the positionality of the author. Readers learn O'Neil has anxiety, depression, and Body Dysmorphic Disorder (BDD). With brevity, O'Neil notes his skin cancer diagnosis but describes the experience in more depth in editorials (O'Neil, 2018). Readers are provided glimpses of O'Neil's view of disability but not the whole picture. Does O'Neil identify as disabled or does he view disabled people as those he offers ministry through chaplainship or those profiled in his book? This distinction seemed a missing piece if understanding of O'Neil's beliefs throughout this work is to be achieved.

From a practical stance, *Spirit and Sport* is not an easy read for those relatively new to these concepts. Topics are sometimes introduced with few examples and the writing style, and at times felt like it could benefit from greater fluidity. While the book presented intersections among disability, sport, and religion, it lacked intersections regarding race, ethnicity, gender identity, sexuality, etc. Diversity of disability type is also missing with no coverage of intellectual disability. Traumatic acquisition is also portrayed as the primary course of experiencing disability rather than the markedly different experience of congenital disability (Bogart, 2014). While intermittently, *Spirit and Sport* touches on some of these intersections, it could have used further explanation of how these additionally marginalized groups coincide with disability.

Parts of *Spirt and Sport* are quite dense. Given this, it is recommended as a supplement to academic texts, which will provide a foundational understanding of some of the concepts discussed in O'Neil's book. Students in various fields, including healthcare and sports disciplines, welcome the addition of profiles shared through storytelling to enhance their learning and bring to life concepts like resilience and personal faith. This book excels at utilizing this approach while inviting new questions about what the future of these intersections may hold. While readers will undoubtedly bring their own beliefs, experiences, and convictions to these topics, everyone can find a connection to the triumphant human spirit in the face of adversity.

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The United Kingdom Government's Creation of the Personal Tragedy Model of Disability

Jason Olsen

Disability Research Specialists

Author Note

I have no conflicts of interest to disclose. Correspondence concerning this article should be addressed to Jason Olsen, Ulster University, Jordanstown, Newtownabbey, BT37 0QB, United Kingdom. Email: Olsen-J@ulster.ac.uk

Jason Olsen https://orcid.org/0000-0002-9562-3758

Abstract

This article utilizes data obtained through twenty qualitative interviews with disabled people as its base. Findings from this research indicate that efforts by the United Kingdom's Government, and its devolved parliaments, to shame disabled people into work have heavily contributed to more stigma and prejudice being perpetrated against them. It explains how one of the ways this was accomplished was by modifying the personal tragedy *theory* of disability. This theory conveys that the marginalization of disabled people is a naturally occurring part of the social process formed through society's suppositions about what disability means. This is different from the personal tragedy *model* of disability. This model employs targeted and deliberate acts often employing public opinion data to drive campaigns for policy changes that can result in the further marginalization of disabled people in society. This piece explains how this model has been created, why it was employed, and how it has impacted disabled people's lives. Recognizing this model as a true antithesis to progressive models of inclusion can hopefully aid in preventing its application in other areas.

Keywords: disabled, personal tragedy model, stigma, United Kingdom

The United Kingdom Government's Creation of the Personal Tragedy Model of Disability

> "The imposition of stigma is the commonest form of violence used in democratic societies…[It] can best be compared to those forms of psychological torture in which the victim is broken psychically and physically but left to all outward appearances unmarked" (Pinker, 1971, p.175).

Disability continues to be "one of the most stigmatized identities across cultures and across history" (Bogart, 2018, p. 594). This can mean that disabled people have continuously "been defined largely in terms of what they are not able to do - employment, education, and being part of 'normal society' (Roulstone and Prideaux, 2012, p. 3)." Investigating how those in power use these stigmas to their advantage can assist in preventing the expansion of negative stereotypes and lessen their influence and impact on disabled people. The research conducted conveyed that this was much needed in the UK where disabled people have, "felt disenfranchised, pilloried by the media as being 'workshy' or 'scroungers' and targeted by politicians, government, by 'them', with welfare cuts and 'beat the benefit cheats' campaigns" (Walker et al., 2013, p. 228).

In total, twenty qualitative interviews were conducted with disabled people in 2019 /2020 (prior to the COVID-19 pandemic). Each interviewee spent approximately 60-75 minutes discussing their lived experiences as a disabled person in the UK. Reflexive journaling, audio recordings and transcripts from these interviews were coded utilizing NVivo. These codes morphed from initial categories to encompass others. Some were expanded, and others were contracted. This was done as the researcher codified the data and relistened to interviews. This process was conducted by following the criteria for a good thematic analysis as defined by Braun and Clarke's 15-point checklist (2006). It also met the five actions utilized by Charmaz (2014) to identify a study that used grounded theory. As a result, 9 nodes and 32 sub-nodes were finalized into overarching themes.

Interviews covered numerous topics with stigma being identified as the largest barrier participants felt they faced in every aspect of society. About a quarter of participants specifically used the word stigma while others used words to describe UK society like prejudiced, abusive and bigoted. They also cited it as a place that was crushing, humiliating, marginalizing, demoralizing and whose populace enjoyed "slagging off" (i.e., insulting) (Lexico Dictionaries, 2019) disabled people. Participants stated that the stigma they faced increased in parallel with the implementation of the "benefit cheat" narrative implemented by the UK government and its devolved parliaments.

Stigma in the UK

Goffman's book, *Stigma: Notes on the management of a spoiled identity,* defines stigma as "the situation of the individual who is disqualified from full social acceptance" (Goffman, 1990, p. 9). This situation usually emerges when evidence is shared, either voluntarily or involuntarily, during social interactions. During these interactions one participant recognizes, in the person they are interacting with, "an attribute that makes [the person] different from others in this category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak" thus reducing the person in the mind of the person being encountered "from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is also called a failing, a shortcoming, *a handicap*" [emphasis added] (Goffman, 1990, p. 12). While the term handicap has mostly been socially eradicated in the UK, and the term disability has been adopted, this name change does not mean that the stigma associated with having a disability has lessened. The UK, with its own unique history of social class division, has stigmatized and marginalized disabled people by subjecting them to pity, shame and even extermination (Stiker, 1999).

This may be surprising to some as the UK may be considered the home of the social model of disability. This model states that the inequalities disabled persons face result from how society is constructed and not because of one's impairment (Union of the Physically Impaired Against Segregation, 1975, discussed later). Despite this, disabled people in the UK still report that disability stigmatizes them for significant social differentiation and into the underclass of UK society (Barton, 1996). Disabled interviewees revealed that this stigma carries with it discreditation to their social value, creates social barriers that often prevents them from succeeding, and is pervasive throughout every aspect of their experiences in UK society.

While it may be true that the pervasiveness of stigma around the globe has led to the understanding that "stigma is a common, and even defining, aspect of the disability experience" (Bogart et al., 2018, p. 595), interviewees conveyed very clearly that the rhetoric around disability and other direct efforts employed by the UK government was directly correlated with an increased experience of stigma and discriminatory attitudes in their daily lives. In essence, the UK government not only guaranteed that stigma would be a defining aspect of disability in the UK, but that having this stigma would ensure that "to be disabled is to be discriminated against" (Barton, 1996, p. 13).

The Implementation of the Personal Tragedy Model of Disability

In 1974, a group of disabled activists in the UK brought forth the social model of disability (SMD). Created by the Union of the Physically Impaired Against Segregation (UPIAS), the SMD made a clear distinction between what constituted an impairment and what constituted a disability. They defined impairment as “lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.” Making a special point to note that “physical disability is, therefore, a particular form of social oppression” (Union of the Physically Impaired Against Segregation, 1975, p. 20).

Oliver and Barnes (2012) emphasized the power that the SMD brings to bear on society. It means that if disability is a social construction, attention can be shifted “to disabled people’s common experiences of oppression and exclusion and those areas that might be changed by collective political action and social change” (Oliver and Barnes, 2012, p. 22). The identification of this provides opportunities for removing barriers to inclusion and resisting socially oppressive policies. Unlike the personal tragedy theory of disability, the SMD does not see impairment as a personal tragedy. Rather, it sees it as a naturally occurring part of the life cycle. It sees the failings of inclusion, not upon the person with the impairment, but rather on the things that impose these restrictions. The barriers arise from society’s failure to appropriately organize a society that creates structures designed for the full social inclusion of all its populace. Whether it is transportation, physical access to locations, segregated education, or other barriers to inclusion, it’s the lack of planning that results in disabled people facing the discrimination institutionalized throughout society (Oliver, 1996) and not the disabled person's tragic fate or their internal failings. The SMD has encouraged progress for disabled people in the UK and across the World.

This is much different from the personal tragedy model (PTM) of disability which emerged as a caricature of personal tragedy theory. The personal tragedy theory (PTT) of disability depicts those who are born with, or who acquire disabilities later in life, as victims of fate or sin and who warrant pity. Historically this ethos was often rooted in religious principles and ideologies that required its believers to demonstrate kindness and generosity towards disabled people through charitable giving and works.

Like other theories, the PTT provided “a proposed explanation whose status is still conjectural” (Dictionary.com, 2022). In the case of disability, the PTT was used to explain easily why disabled people were often impoverished. It was much easier for the populace to comprehend that someone had “bad luck” than to grasp the immensity of the social barriers disabled people faced to be fully included in society. Some may argue that this is still an issue today.

Historically, governmental bodies had no impetus for action as the PTT often relegated care for disabled people to religious and charitable organizations. This allowed governments to keep monies in their coffers while others cared for, or exploited, members of the population they were elected to represent. This changed slightly in later years as society created a social safety net for various people in society, including disabled people. It was this group, and these monies, the UK Government targeted when it took the PTT of disability and turned it into the PTM of disability. Modelling can be defined as, “to form or plan according to a model” (Dictionary.com, 2022). Unlike the PTT, the PTM does not root tragedy within violations of religious ideologies, but rather within disabled people’s personal failings. One such example is the framing of disabled people as possessing no work ethic, a consequence of which is their dependency on benefits. This explanation assigns blame without addressing the existence of systemic social inequalities and barriers that many disabled people face when seeking to obtain or maintain employment.

What makes the PTM even more damaging than the PTT is that it eradicates the ethical mandate that disabled members of society, who clearly face disadvantage, should receive help from those not disadvantaged (Sharma and Dunay, 2016). This article will demonstrate how the UK government utilized the PTM in conjunction with data to create a replicable model that can be used to vilify and further marginalize targeted groups of people. This model utilizes governmental powers, and media outlets, to influence public opinion. It encourages its populace to view disabled people as tragic victims of fate.

Here, the hegemonic power of the government is displayed as its ability to alter social and political ideologies (Gramsci, 1971). Through the lens of Gramsci, we also see that hegemony is truly politically established and as such political bodies can choose to make concessions to their allies (e.g., bankers, media outlets, and professional organizations) to disseminate the kinds of knowledge it needs for government ideologies to alter personal ideologies to the point that they become seen as common sense and absolute truths. This means that authoritative bodies can indeed manipulate the epistemology of the populace's view on disability and disabled people.

As shown throughout this article, the UK government has created and initiated a process so that it could lessen, or remove entirely, its financial obligations to disabled individuals. To accomplish this, it encouraged people to see disabled people as tragic victims of their own flawed morality who do not deserve support. As Morris found in 2011, the UK government's drive to implement a newer and cheaper benefits system, capitalized on its efforts by using a corrupted version of the social model which claimed that the governments goals were to incorporate the concepts of "independent living," "user involvement," and "co-production" into its supports system (Morris, 2011) but in reality, served to undermine these topics. What they were using instead was the PTM. The PTM is not a model that can be used to advance disability rights but recognizing the power that it can provide to oppressive forces can aid in creating appropriate countermeasures to it. First though, must be the recognition that the ability of a government to implement a model of oppression like the PTM validates that although models of disability can be utilized to better understand disability in society, to discuss ways to challenge social structures and to form groups of epistemic resistance, they can also be used as oppressive devices that harm and exploit people.

While Lawsone and Beckett (2020) may be correct when they state that the social model and the human rights-based models can work well in tandem to improve human rights for disabled people, advocates, and researchers must also identify models that work to counteract these efforts.

The Commitment by the UK Government to Increase Disability Stigma

> "The easiest thing in the world for those in power is to simply blame the individual -for their poverty, their unemployment, even their own illness" (Ryan, 2019, p. 197).

While the creation of stigma can be due to various social constructs and social influences, interviewees for this project report that challenging the stereotypes that result from this stigma has become even more problematic due to extensive negative representations of disabled people by politicians and then in the media. Prior to the UKs Conservative-Liberal Democrat Coalition Government (2010-2015) media representations of disabled people were often used to present them as unusual members of society who warranted pity, fear or admiration (Barnes and Mercer, 2010). The use of these views legitimized the inabilities of disabled people in the minds of the populace, highlighting disabled people's inferiority and justifying their exclusion from society (Barton, 1996). However, after the emergence of the Coalition Government, this rhetoric towards disability was reported as taking a darker tone. The newer version, which Valentine and Harris (2014) deem the "demonization of dependency," questions the deservedness of disabled people to receive benefits and other socio-economic supports. The framing of this issue conveys that it is not illness, impairment, disability or discrimination that keeps disabled people from employment, rather it constructs a narrative that disabled people simply do not wish to take responsibility for their own lives and to fulfill their duty to contribute to society. Integrated into this argument is that *non-disabled* people are being mistreated. They are framed as good, hard-working citizens, who take personal responsibility for the success of the country, while disabled people are framed as unfairly receiving special treatment from the state. This framing concludes that non-disabled are justified in their prejudices against disabled people because, based on these presuppositions, disabled people have perpetuated injustices against them (Valentine and Harris, 2014).

The expansion of this narrative by the UK coalition government can be seen in its introduction of austerity in 2010 and through the rhetoric it utilized to justify it. "Austerity is a form of voluntary deflation in which the economy adjusts through the reduction of wages, prices, and public spending to restore competitiveness, which is 'supposedly' best achieved by cutting state's budget, debts, and deficits" (Blyth, 2015, p. 2). One of the ways the government sought to apply this austerity and to lessen public spending, was to target the social benefits disabled people receive.

But how was the populace convinced that it was okay to stop spending monies on a population often categorized as vulnerable? It began in 2010 with what Clark and Newman called the "alchemy of austerity," an approach that allowed politicians to lay the foundation for government retrenchment with the consent of its population (Clarke and Newman, 2012). Like most quality campaigns of consent, the coalition government's efforts began with discourses that protected themselves and their interests. The government's approach was not just about blame avoidance for bailing out the UK banks, it was also about blaming people for the financial hole that resulted from them doing so. This was done through “a reworking that has focused on the unwieldy and expensive welfare state and public sector, rather than high-risk strategies of banks, as the root cause of the crisis” (Clarke and Newman, 2012, p. 299).

During this time the British Attitude Survey reported that public opinion was shifting away from the belief that government should attempt to deliver a more equal society through income redistribution. This was due largely in part to incorrect inferences being made by the public about fraud, which had been supported by general misinformation, both of which contributed to unfavorable public opinions about those on benefits. This included the lowest public support ever previously seen for increasing government spending on disabled people who cannot work. As an example, in 1998, of those who responded, 74% wanted to see more spending on benefits for disabled people who cannot work. By 2011, this number had steadily dropped to 53%. The same report showed other changes in perceptions well. This included the highest response on record of people agreeing that benefits are too high and discourage work (62%) and the lowest number of respondents agreeing that benefits are too low and causing hardship (19%) (NatCen, 2011). People in the population also believed that benefit fraud ranged between 50% and 70% (Briant et al., 2011), an estimate exponentially higher than the Department for Work and Pensions (DWP) actual figure of 0.7% (Department for Work and Pensions, 2012). This may have contributed to politicians feeling secure in their approach to targeting those previously deemed as warranting support.

These incorrect beliefs about welfare fraud were not challenged as inaccurate by politicians. Instead, a greater emphasis was placed upon the welfare state as the cause of the UK’s financial woes. The coalition government’s prime minister at the time, David Cameron, gave numerous speeches which almost always focused on the topic of personal responsibility. As just one of the numerous examples, in his presentation at the Conservative Party conference in 2010, Prime Minister David Cameron stressed that the nation's future would be determined by individual responsibility and by how much effort was given by responsible individuals to hold to account those whom they deemed as irresponsible in their actions (Cameron, 2010).

Cameron's speech specified that the state of the nation "is not just determined by the government and those who run it. It is determined by millions of individual actions – by what each of us do and what we choose not to do," adding later, "your country needs you" (Cameron, 2010). Cameron stated that this was to be a large national transition "from state power to people power. From unchecked individualism to national unity and purpose." In this discourse, he added that success would come from building a nation "of doers and go-getters, where people step forward not sit back, where people come together to make life better ... A country defined not by what we consume but by what we contribute" (Cameron, 2010). This rhetoric was a calling for a cut in spending and a focus on fairness. One part of this speech added that,

> "Fairness isn't just about who gets help from the state. The other part of the equation is who gives that help, through their taxes. Taking more money from the man who goes out to work long hours each day so the family next door can go on living a life on benefits without working – is that fair? Fairness means giving people what they deserve – and what people deserve depends on how they behave. If you really cannot work, we'll look after you. But if you can work, but refuse to work, we will not let you live off the hard work of others."

This part of the speech is important. It emphasizes the redrawing of the lines of who is and who is not deserving of disability benefits (Goodley, 2014). It categorizes only those who are in “critical condition” or who “need it most” as in need of resources (Un.org, 2016, p. 11) and as a result, from 2011 to 2013, this redrawing of boundaries between those deserving and undeserving of benefits led to a large increase of benefit sanctioning of those deemed as not seeking work in the appropriate manner, a measure that correlated with a steep increase in those requiring emergency supplies from food banks and the possible harming of people’s health (Loopstra et al., 2018).

The population appeared to be in support of these actions. This change in public attitudes was different from those seen following recessions in the past. Previously, the struggles of friends, neighbors, and others in need influenced people’s attitudes making them more sympathetic towards the needs of others. This was no longer the case. What appears to have backed the change in these expected responses was the role of political parties and their positions on welfare. This is in part because, as stated in the NatCen report, when people trust their party and its viewpoints, they can be expected to adopt and replicate them when asked about their own views (NatCen, 2011). The same report also suspected that, “recent political and media debate about the government's welfare reforms - including claims that large numbers of welfare recipients do not really deserve their payments - will have influenced attitudes, inclining people to be less supportive of benefits and those who receive them.”

While the use of this rhetoric by politicians such as Cameron was harmful, what was equally destructive was their requests for UK citizens to police the validity of the impairments of disabled people. In the same speech discussed previously, Cameron stated that to solve the social problems he identified, and to see positive social changes throughout the nation, citizens should not look to the government for too much help. Instead, he issued a “call to arms” from those who would “seize the opportunity,” who would “step up and own it" and who would become "more powerful people." He wanted them to focus on internalizing the "big society spirit," a portion of which was to go out and identify government waste. Cameron stated that a part of this big society spirit meant, "facing up to this generation's debts, not shirking responsibility" and placing the blame not just on Labour for this occurring but also upon those, "sitting on their sofas waiting for their benefits" (Cameron, 2010). This truly was a call for the populace to: locate those they felt were benefit cheats; to shame them; to shun them; to be prejudicial against them; to stigmatize them.

The Media Carries the UK Governments Disability Stigma to the Masses

> "National governments and their associated executive agencies and arms length bodies are crucial influencers over both the tone and the content of news since they play a dominant role as a prolific source of news and as co-producers of political narratives" (Garland, 2018, p. 334).

The media was quick to latch onto the UK governments' narratives and to expand them. This is supported by research from Briant, Watson and Philo whose research compared and contrasted UK media coverage of disability in 2004-2005 and 2010-2011. Their conclusion was that the way the UK newspapers reported on disability significantly changed between these two periods. They also stated that this coverage "was less sympathetic and there was an increase in articles that focused on disability benefit and fraud, and an increase in the use of pejorative language to describe disabled people. An audience reception study suggests that this coverage is having an impact on the way that people think about disabled people" (Briant, Watson and Philo, 2013, p. 874).

The researcher's data tied these changes back to media coverage that was much more politicized than seen previously and that was highly reflective of the Coalition Government's agenda. This coverage framed disabled people as a burden of the state and whose access to disability benefits was a problem (Briant, Watson and Philo, 2013). For example:

> “The Sun declared ‘war on benefit scroungers’, saying: ‘They cannot be bothered to find a job or they claim to be sick when they are perfectly capable of work because they prefer to sit at home watching wide-screen TVs -paid for by you’ (Sun, 2010). This was followed, a couple of weeks later by the Express warning that ‘scroungers who play the benefits system to milk incapacity benefit’ will be put back on the dole and forced out to work’ (Express, 2010)” (Quarmby, 2013, p. 70).

The Daily Mail ran the headline “State-funded idleness: 1.5m are spending fifth Christmas in a row on sick benefits,” and a story that stated that:

> “The young are becoming accustomed to relying on benefits…the system needs radical overhaul…as evidence that the Coalition is right to demand incapacity claimants undergo a medical assessment to see whether they can work” (Shipman, 2010).

The government and media’s key argument was rooted in a belief that disabled people were getting free money from the government, that disabled people felt benefits were preferable to employment and that “these people” are abusing the system because the benefits are “overly generous” (Lindsay and Houston, 2013, p. 4).

Other media platforms, such as television, latched onto this narrative and launched shows that framed disabled people as “scroungers” and “skivers.” One such show was *Benefits Street.* Launched in 2014, the show was deemed by Jensen (2014) to be a part of an emerging genre of television known as “poverty porn.”

But once again, this was not a naturally occurring media event. It followed the lead from other media forms whose origin was the UK government’s narrative. For instance, the Sun’s “beat the cheat” campaign, which it deemed as a “crusade” that all patriotic Brits should participate in (Dunn, 2012), was launched in 2012. Its campaign, which claimed there were systemic issues of fraud in the benefits system, was launched following the UK government’s launch of its own campaign calling on citizens to “report a benefit thief” (Department for Work and Pensions, 2011).

After the launch of the government's campaign that encouraged people to report those, whom they felt were possibly fraudulently claiming benefits, six large disability charities reported to the UK Parliament that they had seen a large increase in resentful treatment targeting disabled people. They stated that while the media did play an inflammatory role by sharing the narrative that disabled people were ‘scroungers’ and ‘fakers’, it was the government’s focus on alleged fraud by disabled people that was fueling the issue. The charities also warned that these increased hostilities could potentially result in hate crimes against disabled people (Pilkington, 2012) and from 2011 through 2015 the number of recorded hate crimes against disabled people in England and Wales increased from 1,748 to 3,629 (a 107.6% increase) (GOV.UK, 2018).

Despite these increases, the Department for Work and Pensions (DWP) Fraud and Error Service did not end this campaign but rather relaunched it in 2014. The older and newer campaigns both encourage people to, “Report someone you think is committing benefit fraud,” either by using an anonymous form on their website or by calling the National Benefit Fraud Hotline (NBFH) (GOV.UK, 2015). However, the newer campaign dropped the blatant accusation of thievery and added a secondary request aimed at those on benefits. It asked them to report if they have obtained a new job to report it to the DWP. It kept the portion of the campaign which told the public that, “if you know someone claiming benefits who shouldn’t be, call us,” in conjunction with the line, “when you report benefit fraud, we investigate it” (GOV.UK, 2014).

The rhetoric that disabled people represent, “the welfare-dependent individual passively reliant upon social security payments, draining the public coffers, unprepared to do a day’s hard work,” (Goodley, 2014, p. 9) was effective in getting neighbor to report on neighbor and thousands of calls were made. Over the financial years 2015-2016 and 2016-2017, there were 332,850 cases closed that resulted from members of the public who had reported fraud. Of these, 287,950 were shown not to have evidence to validate the claims of fraud they received. These numbers reflect that 87% of those cases reported were invalid (Cowburn, 2018). The number of the remaining 13% that was also determined to be non-fraudulent, after further investigation was conducted, is not known nor is the cost estimate for the monies dedicated to investigating these calls and cases.

Disabled People’s Recognition of the Government’s Role in Spreading Stigma

Interviewees identified that the rhetoric that emerges from the government and through the media points the finger at the “disability cheat,” “the scrounger,” and the “skiver.” They know that they were being presented as people who abuse the welfare state, rob the populace, and harm the country. They also recognized that this framing ignores that their current vulnerabilities (e.g., unemployment, undereducation, and poverty) are a direct result of government discriminatory policies. However, they felt disempowered to challenge these stereotypes, especially when powerful bodies were using stereotypes and fears to imbue disabled peoples’ vulnerabilities with “normative assumptions about deservingness, deviance, and deficit” (Emmel, 2017, p. 456).

In talking with interviewees, their interpretations of the media outlets’ role in spreading negative narratives about disabled people were made clear. They said:

> “If you read The Sun, I won’t even say the newspaper The Sun. The collection of words, The Sun or the Daily Mail, that’s kind of what you get, ‘oh benefit cheats

> this, that and the other thing'... it's almost then straight away, everyone was a benefit cheat." – Alpha
>
> "Media representation is probably a big problem. I think that they can paint a picture that makes it really hard for people to understand life with a disability, to understand what it is to be seeking work, or to be homeless, or any of those things...the Daily Mail says, that 'these people' are getting all this money and they shouldn't be getting it." – Omicron
>
> "The media don't help, the only portrayal of disabled is either 'oh my goodness, aren't they so brave and courageous and sporty' or 'aren't they all spongers taking all our money and asking for so much money? what do they spend this money on? it's for the nice TV'...it's the media and the current government and their whole rhetoric around disability and taking people off benefit, and then where do you put them, and making them feel like crap, and making them feel like they have to justify the fact that they have a disability and it's as bad as they say; it's quite toxic." – Gamma

However, it is not just print media that is cited. Interviewees recognized that television plays a large role in the spread of stigma as well.

> "There was a programme – I was really disgusted with it at the time – It was about a couple who were blind, and they had kids, now the kids were sighted, but the couple basically was just throwing bread on the floor, and then the children were coming in and sort of picking that up and eating that. Now the couple were also alcoholics, and to them obviously, you know their main concern was getting money for the next drink ... To me, that would have greatly set back people's perception of someone that's blind. They just look at that and go, 'well there you

are, that's all that they can do type of thing.'" – Eta

"Did you know that there was a programme called Benefit Street or some shit like that? It was about a street where there was a lot of people on benefits on it and it really just followed them round, and it showed the worst possible side. So, everyone assumes that's what everybody's like." – Alpha

"If they're commenting about somebody in the media, like the TV shows that have all come out about disability – you know Benefits Street and all the rest – you ask them, 'Well who do you know in your life who does that?' and they'll say 'Oh I don't know anybody like that'. You know the person in their family who's receiving disability living allowance or PIP or whatever, now you know they deserve it, but everybody else they don't. I don't know if it's just, are we being made to hate each other for a particular reason or is that just what we do, I've no idea." – Gamma

But, once again, it is not the media alone that is bringing these negative stereotypes and the resulting stigma to fruition. As Gamma stated above, "it's the media *and the current government* (emphasis added) and their whole rhetoric around disability and taking people off benefit." This was acknowledged by Alpha as well who stated, "it doesn't help when you have government officials or shadow government officials coming out and saying things like disabled people should be paid less." It is important to note here that interviewees identify that the government, which has been mandated with ensuring their equality, is identified by this marginalized group as working against their best interests. Walker et al. have reported, that in Britain especially, the shame of poverty, and subsequently, disability was spread through the mass media. They found that "British respondents felt disenfranchised, pilloried by the media as being 'workshy' or 'scroungers' and targeted by politicians, government, by 'them', with welfare cuts and 'beat the benefit cheats' campaigns" (Walker et al., 2013, p. 228). This was supported by interviewees for this project who added that these actions negatively impacted their lives.

The Fallout of Government-Supported Stigma

The sweeping dedication to austerity by the coalition government, and other governments within the UK, since 2010 has had substantial impacts on disabled people by increasing poverty and intensifying social inequality (Mattheys, 2015). There has also been a large increase in hate crimes against disabled people and remains an issue that is continuously underreported (UK Independent Mechanism, 2018).

> "About 2 days ago, I was called a 'spastic,' a 'fucking spastic' for that matter, in that gym back there. And I always think 'aw what a tit,' but that's a hate crime, but it never really registered with me until I kind of had a bit of thought. You kind of go, 'well you know what, he's a fucking arse,' but that's me. What about if he kind of said it to somebody who really had an issue?" – Alpha

Alpha's conveyance of experience supports Hoong-Sin's findings that "disabled people's interpretations of what constitutes a 'hate crime' can lead them to downplay the 'everyday' experiences" through the "wrong 'labelling' of incidents" and that this "can exacerbate the under-reporting [of hate crime] by encouraging the victim to change their behaviour instead of taking action and reporting incidence to police" (Hoong-Sin, 2013 p.156). This provides good insight into how a government's rhetoric, and the resulting social stigma that results from it, can place the impetus of social change, not on the system creating the oppression, but rather within those being oppressed. In cases of social abuse, disabled people may seek safety through social isolation (Gov.uk, 2021). This can mean that the government's efforts to shame disabled people into work to reduce benefits can have a reverse effect by distancing disabled people even further from the labor market and employment.

Instead of seeking employment to remedy the scrounger narrative against them, this hate, created through social narratives produced by the government and administered through the populace, serves only to harm disabled people. This is supported by (1) Brookes' work which shows that, "through the constant feed of aggression which wears the disabled person down" (Brookes, 2013 p.130); (2) by Thomas who found that even when "these acts of hostility against a disabled person may not amount to crime … [they] nevertheless hurt psychologically and emotionally" (Thomas, 2013 p.136); and (3) by Pérez-Garín et al. who found that, "although there are a few studies examining the emotional reactions of people with disabilities to stigma, all of them (qualitative and quantitative) agree that most emotional consequences of feeling stigma include anger" (Pérez-Garín et al., 2018 p.2). None of these reactions has been shown to be productive in encouraging disabled people to seek employment, to get off benefits, or to want to spend more time with others in society.

Instead, what disabled people have reported is that concerns about other people's views have stopped them from seeking education (38%), relaxing (71%), or going outside (62%) at least 'some of the time'. In addition, 51% of disabled people report that concerns about other people's views of them have stopped them from working. However, it is not others' views alone that can stop disabled people's inclusion into society. It is the actions that can stem from these perceptions. For instance, 54% of disabled people and 42% of carers worry about being insulted or harassed while in the street or any other public space at least 'some of the time' (UK Cabinet Office, 2021). This supports that "the attitudes and behaviour of non-disabled people are a major factor in the extent to which disabled people are isolated or integrated into networks or communities" (Shakespeare, 2006, p. 177) and how the non-disabled can perpetuate a stigma against disabled people that involves them being labelled, stereotyped, separated from society and discriminated against because the stigmatizers have access to social, political, and/or economic power (Whittle et al., 2017 p. 182) that disabled people do not possess. This article adds that this can be done in purposeful ways through the use of a discriminatory model of change.

Conclusion

In this article, the actions of the UK government were discussed. The motivations and process it used to lessen government benefits for disabled people were illustrated. The argument was made that the UK Government instituted a new model of oppression called the Personal Tragedy Model. This model was based on the personal theory of disability. This theory postulates that disabled people warrant pity and charity because they have had the misfortune to be born with or acquire a disability. As conveyed the personal tragedy model took this a step further. It removes the pity and charity portion and replaces it with the belief that disabled people deserve little assistance as it is not social barriers but rather a disabled person's own moral failings that lead to their dependency on benefits. The UK's government supported and emphasized this view through the creation of a campaign of consent that used information on public attitudes to create a socially acceptable narrative that would allow the government to implement austerity initiatives that harmed disabled people. This harm was demonstrated through feedback from disabled able people who shared the impact these campaigns have had upon their inclusion into society and the negative treatment they received from fellow citizens following its proliferation. Understanding how powerful bodies' actions can have long-lasting impacts on stigma, social exclusion and abuse should remain at the forefront of sociology and disability studies. Only by understanding how this manipulation is performed can useful models and methods be developed for counteracting them. The personal tragedy model of disability is just one of these models.

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Burrito Texts: Mel Baggs and the Language of Crip Life

Sarah Cavar

University of California, Davis

Author Note

Sarah Cavar https://orcid.org/0000-0001-8819-787X

Abstract

Public scholar, poet, and activist Mel Baggs (sie/hir pronouns) died on April 11, 2020 in the thick of a catastrophic pandemic responsible for spotlighting long-held ableist, eugenic rhetorics that literally and figuratively structure disabled life. Since hir passing, however, Baggs's! emblogged" archive — remains powerfully relevant to anti-ableist discourse in an age of COVID-19, laying bare the invisible institutional contours, material and linguistic, undergirding disabled existence. In this article, I will engage with critical texts from Baggs# online oeuvre, what I call an *emblogged* activist archive, written both from within and in the wake of pre-COVID institutional violence, asking what it means to survive/archive against a medical industry built to hasten disabled death. I will explore the ways in which Baggs reveals the discursive architecture of institutionalization, which follows and constitutes disabled subjects — including and especially Baggs hirself — both within and outside of hospital walls. Reading renewed interest in the euphemistic language of !triage," "quality-of-life," and !congregate care" through what I call hir !Baggsian Experiential Framework," I will argue that Baggs remixes the language of hir oppression, using new and renewed terminology including the "Nice Lady Therapist," "Snake Words," and the "Burrito Test." At the same time, sie remaps the institution as a discursive condition of disabled life rather than only a discrete(/discreet) location in which certain lives are led. Baggs uses emblogged, queercrip digital space to advance a formidable counter-discourse that has saved hir life and now preserves hir legacy.

Keywords: Blogging, social media, ableism, collective memory, activism, eugenics, disability

Burrito Texts: Mel Baggs and the Language of Crip Life

> Memory is important.
>
> But your own personal memory is not necessary.
>
> The best of human memory is fallible, changing, and fickle. And memory can fail. In so many ways they can't be counted.
>
> It can be frightening when memory disappears. In all the ways it can disappear.
>
> Temporarily. Permanently.
>
> Memory is not what defines us.
>
> We are still here even when we can't remember.
>
> And the world remembers for us.
>
> Everything we are, everything we have done, everything we have been part of, everything we have affected. Those things are still there in the world.
>
> Our mind may fade or distort or completely eliminate the events but the events, and we in them, are still there, embedded in the world.
>
> Memory is useful, important, valuable. But our memory is not the only memory.
>
> There's a deeper memory, a longer memory, a memory that doesn't require anything of us.
>
> And in that memory, nothing is forgotten, and nothing and nobody is invisible.
>
> (Baggs, 2018k).

At a 2020 Gala by the Autistic Self-Advocacy Network, executive director and longtime autistic activist Julia Bascom took time to honor late blogger, poet, and multiply-disabled activist Mel Baggs, to whom "we [autistics] owe our movement a North Star…[and] owe a debt we can never repay." (ASAN, 2020) Baggs, whose pronouns, sie (S-I-E, "see") and hir (H-I-R, "hear"), were chosen in order to draw attention to hir unique sensory experience of the world, was an anti-ableist social media activist with several blogs, the latest of which, *Cussin' and Discussin',* I will be focusing on in this article. Baggs died at the age of thirty-nine on April 11, 2020, after a life refusing confinement or simple definition, one in which scholarship, creativity, and life-saving activism necessarily and digitally blended to resist both the rhetorics and physiological barriers posed by institutionalization, abuse, and neglect (and their justifications) by so-called caregivers. Amidst what was at the time of hir death a nascent pandemic, in which ableist narratives of "triage" and the rationing of care came to widespread attention, disabled writers' prescient works gained readers — due, in no small part, to the sudden, COVID-induced destabilization of abled norms — a grim reminder that able-bodiedness is always and already temporary, and that each of us is vulnerable to medico-psychiatric violence.

We disabled people have long acted as "canar[ies] in the coal mine" (Mitchell and Snyder, 38) of neoliberal capitalism, climate crisis, and now COVID-19. The language of *prescience* itself has been roundly criticized by disabled writers and activists, not least via hashtags like #DisabledPeopleToldYou, started by Canadian activist Gabrielle Peters (@mssineomie) and designed to alert abled readers of their willful ignorance of disabled struggles (and a priori delegitimization of disabled knowledge) against systemic ableism, struggles many of those heretofore-abled readers may now share post-COVID (Peters, 2020). Such hashtags occupy an extra-academic space for the theorization of critical disability studies (CDS), the primary framework through which I'll be analyzing Baggs's work, which holds that disability is inherently political and socio-culturally contingent, and that ab/normal bodyminds are not born but *constructed* (Meekosha & Shuttleworth, 2009). Further, and with the Disability Justice (DJ) principles of Leadership of the Most Impacted, Interdependence, and Collective Access in mind, I foreground a necessary critique of the university and governmental co-optation of disability studies, in which only certain individual disabled scholars may produce legitimized knowledge, while others — particularly queer and trans, racialized, poor, fat, and intellectually, developmentally, and psychiatrically disabled people –– are largely excluded from scholarly discourse (Meekosha & Shuttleworth, 2009: 50).

With this in mind, I look to just a handful of Baggs's numerous *emblogged*, or digitally embodied through blogging, interventions. I have chosen these among Baggs's numerous writings because they represent some (not all) key examples of coinage and resignification toward collective crip knowledge; that is, the posts I cite constitute not the conceptual limits of Baggs's oeuvre, but starting points for engagement. These are necessarily divorced from (and frequently hostile to) the institution of academia, and grounded in what Johnson and McRuer (2014) call *cripistemological* conceptual and methodological frameworks, derived from the epistemological "backwoods" rather than traditional channels of knowledge-production (128). These frameworks prioritize emergent knowledges that cannot and will not comply with the demands of an academia shrouded in classist ableism, and instead celebrate and explore the potential of un-gatekept, unruly knowledge. Particularly in the face of the mass death resulting from the COVID-19 pandemic, honoring cripistemic forms of knowledge-production becomes not only a crucial anti-ableist intervention, but a materially life-saving one. Specifically, I engage and cite from and within *crip space* (McRuer, 2006; Erevelles, 2011), both literal and figurative alternatives to spaces whose contours are defined and whose substances are (pre)occupied by able-bodied and -minded norms and relationships with reality itself. In doing so, I *dis*place heretofore "settled" assumptions about the authority of providers over patients and of "scholars" over "subjects," citing in such a way that refuses the boundary between the latter two. Such interventions are not only crucial to anti-ableist scholarship, but also, now, a materially life-saving intervention: “listen[ing] to crips about how to handle this pandemic” is of paramount importance in the face of mass COVID-induced disability (Peters, 2021). Furthermore, it is crucial to inventing a future hospitable to crip freedom and survival.

While not *inherently* digital, cripistemologies find purchase online alongside other forms of disability activist-scholarship. It has been argued elsewhere for the importance of digital, experiential, and identity-based activism for building and strengthening disabled communities, especially those that are also queer and trans (Cavar & Baril, 2021). I follow others who have noted social media as a vital means of activist counter-narration and community building for marginalized populations traditionally gatekept from knowledge production and dissemination (e.g., Jenzen, 2017; Jackson, Bailey, & Foucault, 2018; Kinloch, Penn, & Burkhard, 2020; Ekins, 2021) and denied the rhetorical legibility afforded to “rational” human beings (Price, 2011; Yergeau, 2018). While such work may be dismissed as “armchair-activism,” and thus institutionally devalued, digital activism is a particularly important mode of resistance for disabled activists who are bed- or housebound; in pain; environmentally/chemically-sensitive; immunocompromised; or, as I will explore below, institutionalized by walls or words (Cavar & Baril, 2021). Indeed, Baggs used the blog form as a uniquely effective tool to identify and combat the shared experience of institutional violence often camouflaged as bureaucratic benevolence, not only to educate and (in)form anti-ableist, anti-institutional political movements, but also for self-preservation. With what I call hir *experiential framework*, an interdependent and emblogged approach to activist-scholarship, Baggs used hir status of institutionalization-survivorship to link readers across spacetime, to (re)invent language, and to use blog-based connections as a mode of anti-ableist resistance. Further, the digital medium is itself, literally, life-and-legacy-sustaining for Baggs, thus providing an opening to engage seriously with emblogged texts as legitimate scholar-activism and with social media as an anti-ableist tool.

In this article, I will first examine Baggs's analysis of language as both a technique of institutional violence and a vital means of fighting back. Both coining and adopting terms, including "snake word(s)", the "Nice Lady Therapist" (NLT), and the "'X'ed" unperson — sie fashioned what I refer to in the title of this essay as hir "Burrito Texts": digital texts produced in light of ongoing medical violence and incarceration. Then, I will consider Baggs's 2013 brush with medically-sanctioned murder, and the subsequent deployment of hir own framework toward robust and ultimately life-saving activist effort, as a guidebook for enduring ongoing conditions of crip apocalypse (Piepzna-Samarasinha, 2017), and locate the seeds of anti-normative resistance and movement toward a "new social order" (Robles-Anderson & Appadurai, 2020). Ultimately, I ask: how might Baggs's experiential framework be deployed in scholarship on and against eugenic practices, both in the midst of, and in the ongoing aftermath, of mass murder through resource deprivation, medical neglect, and organized abandonment? And further, how do hir digital and community-based counter-epistemologies aid in producing and preserving hir legacy?

From Agencies, Toward Agency: Cripping/Cribbing Language

Language is not only a descriptive project, but an inventive one. It carries violent, carceral, and material implications, which are particularly evident when considering the impacts of disability diagnosis on personal agency and personhood itself. Such gatekeeping can be described using Miranda Fricker's (2007) term, "epistemic injustice," and particularly, "hermeneutic injustice," which refers to "when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (1) — for example, the hiding of or refusal to give diagnoses. Not only are disabled people routinely hermeneutically wronged; we also experience epistemic injustice in the "testimonial" sphere. That is, due to our status as speakers, our attempts to describe ourselves and our conditions are rendered illegitimate and untrustworthy (Fricker, 2007:1). Examples include anosognosia, or a "lack of insight" said to characterize certain psychiatrically disabled persons, and the attribution of tensions with consensus reality to the "delusions" of psychiatrically disabled people (Gong, 2017). Particularly pronounced and understudied are the impacts of epistemic injustice on cognitively, intellectually, and developmentally disabled people, particularly those who use augmentative and alternative communication (AAC) and facilitated communication (FC), which limits both vocabulary access and access to neurotypical frameworks of rhetorical legitimacy (Denome, 2020; Yergeau, 2018: 91-93). Verbality, so long as the correct verbiage is used, reigns supreme.

The rise of social media and other technologies have enabled a variety of disabled subjects not only to digitally travel, share knowledge, and form community, but also for those heretofore barred from access to legitimate "speech" to communicate textually, albeit largely in forms restricted to the neurotypically legible. For Baggs, the blog form was one technology through which sie could reveal everyday rhetorical violence, oftentimes through translation from hir felt experience to readable text. Crucial to this translation process, in which sie gestured — sometimes literally — toward the gaps left by neurotypical ways of translating, “knowing,” was the coining of new language and the disruptive resignification of existing and often-euphemistic language. Sie did this in order to denormalize and expose the ableist conditions under which sie and others lived. In the following sections, I will look to several of Baggs's terminological interventions into neurotypical (NT) ways of knowing disability, and consider hir digital writings as a radical, emblogged break with and from institutional epistemologies. I argue that hir blog is a (re)birth place for crip resistance to the normative language of “care.” Indeed, while critical care theorists, particularly in the wake of Leah Lakshmi Piepzna-Samarasinha’s (2019) text *Care Work: Dreaming Disability Justice,* have imagined queercripped genres of feminist, horizontal, and interdependent care, Baggs identifies “care”’s grounding in linguistic and material hierarchies and naming paradigmatic practitioners. Sie draws from hir lived experiences of institutionalization, which began in early childhood and continued intermittently until hir death, to use two critical terms with which to unpack the violence of care: the entwined power of the “Nice Lady Therapist,” “snake words,” the “[person-centered] institution,” and the “Burrito Test” whose collective constriction of embodied/enminded freedom implicate not only experiences of disability but race, class, geographic region, and gender. Using hir experiential framework, Baggs wields the above terminologies to challenge both institutions and their theoretical constriction to physical space.

Cultures at War: The Nice Lady Therapist

First and foremost, the Nice Lady Therapist (NLT), according to Baggs, is a force bent on extinguishing human emotion in order to render bodyminds compliant — all, as coiner Rabbi Ruti Regan (2014) of the blog *Real Social Skills* details — with a smile. Examples of this violence, according to Regan, may include inappropriate touching (sexually or otherwise), educational infantilization, coercive identification of ownership (referring to clients as “my kids”), and punishing expressions of pain, fear, and anger (Regan, 2014). The NLT, Regan notes, is usually a woman, and often acting in a formally therapeutic position. Her occupation, gender, and prototypical whiteness preemptively rescue her from accusations of abuse — this holds not only violent consequences while the abuse is occurring, but also may stymy disabled survivors from accessing resources about trauma, given that such resources typically identify men as paradigmatic abusers — this fundamentally transforms disabled peoples’ “relationship to gender” and understanding of patriarchy (Regan, 2014). In Baggs’s case, it also enables a more capacious understanding of institutional power. Following Regan, Baggs identifies NLTs as both a genre of person and a culture oriented toward “looking nice, never directly showing emotion, sounding bland and detached in a certain way, no matter what you#re feeling or thinking or doing” (Baggs, 2018e). Baggs’s critique follows Regan’s not only in identifying demands for compliance at the expense of autonomy as inherently ableist, but also in locating the NLT’s capacity to harm in *her* particular social location. This care-work, set in implicit and explicit opposition to the crip interdependence Baggs both discusses and enacts through hir blog, is “degrading in ways that are hard to pinpoint” and best described by Baggs’s vivid posts. That is, Baggs deploys hir experiential framework to discuss the ableist classism embedded in the NLT, who provides and denies care based on assimilationist logics of respectability and capacity for normative behavior.

The cultural norms which produce the NLT and her demands are embedded in white, middle-class, and abled norms; the white woman assimilated into what Baggs calls an "[disability services] agency-middle-class fear of feelings" is here imbued with the power to police "deviant" expressions of emotion — for instance, embodied, visible anger (Baggs, 2018e). For developmentally disabled people, Baggs writes, it is often more difficult to conceal one's true feelings, communicate with euphemistic tact, or conceptualize immediate feelings abstractly, all trappings of middle-class assimilation presented as "social skills" to disabled youth (Baggs, 2018e). Here, the false language of "care" — specifically, notions of care as always-already benevolent — fuse with paternalistic anxieties about unassimilable or unsightly (disabled) people in order to punish them for non-normative expressions of emotion. As Baggs notes, heretofore class- and region-specific behavioral norms heavily influence the work of the NLT, who exercises her power paternalistically (or maternalistically) to produce conformity, and names conformity as a prerequisite to personhood. Identifying most closely with the classed, regionalized behavior of a "working-class Okie," Baggs writes of anger one can "see…on [hir] body," a genre of "pissed-off […] write into [hir] every movement, a statement which applies to an entire spectrum of emotion" (Baggs, 2018e). As a direct result both of this and hir association with other advocates who tend to "fly off the handle," Baggs faced threats of institutionalization, emotional surveillance, and ultimately being forbidden from discussing hir lived experiences of medical mistreatment (Baggs, 2018e).

Given that "[NLTs] tend to be terrified of anger…[and] emotion in general," their impulse is to psychiatrize middle-class values as markers not only of social superiority but also of *correct* neurotypical perception, pairing abusive behavior with denial of abuse itself. In these spaces, hierarchical power dynamics are collapsed into “friendships,” and “frightening or painful exercise[s]” are transformed into “therapy” (Regan, 2014). As Baggs describes, while the “crude” behavior of the working class/disabled subject disrupts clinical, middle-class norms, the “nice” behavior of the NLT obfuscates discursive and material violence, including, ironically, outright “denials of care” for disabled people (Baggs, 2018e) Caring becomes a form of shaping, chiseling, molding: to “care” is the verb by which disabled, poor bodyminds are brought into the proverbial fold of “carable” community, “rescued” from outcast (and, as we will later discuss, “Xed”) status and from physical institutions.

A combination of experiential grounding and borrowed language render the NLT a sharp tool in Baggs’s hands, not only as a critique of carceral ableism but as a critique of the classed notions of respectability always-already entangled with disability service providers, if one that, given its grounding in Baggs’s white disabled experience, elides a robust critique of race that would have further strengthened the analysis. Here, disability is not inherent to one’s bodymind, but rather, formed with and in relation to already-classed milieus; the same is true for the unequal and violent conveyance of normalizing “care.” Using hir blog to expand the concept of the NLT with a working-class perspective, Baggs makes visible the class politics of institutionalization — and, perhaps, middle-class hegemony as an institution unto itself — as well as the dire need to imagine care Otherwise from the institution, specifically, as we will see later, in the non-hierarchical form of crip friendship.

“Person-Centered”: Snake Words and the Language of Violence

As illustrated by the figure of the NLT, violence is endemic to the architecture and definition of “care” itself, which by definition occurs at the whim of the caregiver. But these violences are not only the province of individual therapists, rather, they are built into a common language shared by a variety of medical/disability service workers, baked into educational curricula and medical and psychiatric programming. Beyond the NLT, a type of *individual* symptomatic of an ableist, classist, and paternalistic care industry, Baggs also revealed the false-sensitivity of so-called "snake words" within disability discourses. These words euphemize the everyday dehumanization experienced by disabled people, especially those in full-time care and those without access to spoken language. Using both blogged and filmed interventions, Baggs reveals the danger of snake words while resisting their underlying logic, which exclusively prioritizes verbal speech over other modes of communication, and honors alternative relationalities instead.

Baggs's blog engaged intimately with the quotidian and largely unacknowledged denials of autonomy central to hir disabled life; from here, sie observed trends in caregivers' (ab)use of language to further these ableist denials. In "Developmental Disability Service Agencies: Can't vs. Won't (2018i) Baggs describes being given hir bedtime medication at progressively earlier times, based on the convenience of a disability services agency. The agency refuses to administer the medication at the appropriate time, but also refuses to send Baggs reminders to take the medication hirself, forcing hir to take the medication at the whim of the attendant and thereby removing hir autonomy. As with the NLT, what at first appears to be care in fact manifests as violation; part of this violence lies in the description itself. The !person" that "person-centered care" centers does not actually exist: rather, they are the promise of a recovered bodymind against which the apparent !brokenness" of the disabled person is measured. Further, in a compounding use of snake words, the very language of brokenness is also euphemized; Baggs elsewhere describes a shift from the widespread use of the r-word, which overtly marks hir as "'less than a thing, something disgusting, [and] something that shouldn't exist'" (Baggs, 2018d), to the language of "*special.*" These shifts constitute a "glamour," a way of "hiding the dystopia" (2018b) under which disability renders one a perpetually-abusable *unperson*.

While both medical and laypersons can and do fall victim to euphemistic language about disability, such language — and subsequent neglect of patients — is also fundamental to their education. Baggs photographs and describes "person-centered" worksheets brought to hir by caregivers from a recent disability support workers' conference, worksheets designed, in spite of their name, for caregivers and not disabled people. These worksheets, Baggs notes, emblematize the divide between the rhetoric of "person-centeredness" and disabled peoples' lived realities. One worksheet, titled "[Mel's] One-Page Description," contains blank bubbles in which Baggs is to write which activities, practices, and persons are "important" and "supportive" to hir (2018c). Such worksheets, which direct users to mark bubbles to answer pre-set questions, allow only a narrow range of self-description. They also pathologize everyday activities and relationships, limiting the ways in which disabled people may "correctly" communicate with caregivers, and thus, document their realities.

If the "person-centered" agency's "person" does not exist, we might look to Baggs's experiential framework as a form of counter-documentation (documentation authored and authorized by Baggs, not by record-keeping medical institutions), wherein hir evidence of self both reveals the fallacy of the "person-centered" ableist agency and thus retrieves "agency" for Baggs hirself. Baggs does this through visual and textual language: in fact, sie initially came to prominence as a digital disability activist through hir viral video, *In My Language*, a resounding critique of the privileging of spoken language and devaluation of non- and semi-verbal modes of communicating, made through the very assistive technologies so often devalued alongside their developmentally and intellectually disabled users (Baggs, 2007). The computer, and specifically the internet, opens new linguistic and relational possibilities such that Baggs can create a counter-discourse to ableist snake words. On and through hir blog, as well as hir YouTube channel, Baggs reimagines the power of untwisted and reclaimed language, using a distinct communication style described by Jellicoe (2021:6) as “careful [and] exploratory.” Jellicoe writes of *In My Language*: “Instead of rushing its point, the film makes us see. It patiently explores the duality of sound and image […] motions are paired: a swimming human, a flag that rises and falls in the wind” (2021:10). With these images, Baggs recenters the ways of seeing, thinking, and moving denied rhetorical legitimacy. In “hir language,” a new definition of “person-centered” may be born:

> ***Person*-centered is supposed to mean that when they decide what support you need from the DD system, everything comes from what you actually need and want out of life and out of the support you’re getting** [emphasis added].
>
> It means that rather than forcing you into a ‘support model’, they look at what you need out of life, what you want out of life, and how you can get it. (Baggs, 2018c)

While linguistic interventions like euphemisms and worksheets both conceal and consolidate structural ableism, normalizing the conditions under which sie hirself is rendered silent, Baggs imagines a respect for linguistic pluralism that sie express in hir blog posts and video. Rather than normalizing tropes of neurodivergent people as “lost in [our] own worlds” (Yergeau, 2018:8) marking those with non normative modes of communication as divorced from Real (neurotypical) Life, and thus from “personhood” in a “person-centered” context, respect for alternative modes of communication — blogs, videos, AAC, and more — is in fact required for a good-faith person-centered approach. Finally, and as we will consider more extensively in the following section, language — especially that which selectively grants and removes personhood — not only snakes and constricts but also *constructs* institutional walls around disabled people, including Baggs. And Baggs's ability to talk back against institutional "head games and word games" (Baggs, 2018m) can make the difference between life and death.

The Institution Yet to Recede: Xing and The Burrito Test

The role of institutional violence in disabled life and death has been widely theorized, perhaps most famously by Liat Ben-Moshe, to whose article, !The Institution Yet to Come," which expands and disables Goffman#s (1968) conception of !the total institution," and Foucault's (1988) critiques of the asylum, I owe the title of this section. For Ben-Moshe, the institution is not a singular, fixed entity where disabled people !end up," but rather, a specter, a continuously-moving target, and a threat haunting disabled people regardless of status: !the ghost of forced confinement haunts us all," particularly those who are multiply-marginalized (Ben-Moshe, 2013: 132). Cognitive disability activist Cal Montgomery, one of Baggs's longtime interlocutors, further describes institutionalization not simply as a specter but as an inheritance, a legacy, a connection across disabled generations, all despite its isolating ethos (Montgomery, 2001). This is an inheritance of collective dehumanization, wherein the dependent person is excluded from the bounds of personhood at all, and is thus not only barred from accessing the means to their autonomous subsistence but also to the capacity to narrate their lives.

In hir experiential analysis of institutionalization, Baggs makes use of hir "explanatory" and layered writing style, "expanding from a core idea" (the lived reality of institutionalization) to a more abstract analysis of the mechanisms of dehumanization. Sie shares hir knowledge of words as tools and as weapons with activists like Dave Hingsburger, whose theory of the !Burrito Test" heavily influences hir own anti-institutional work. The theory, which made its debut in one of Hingsburger#s direct support newsletters (n.d.) asks readers a simple question in order to determine whether a space is or is not an institution: *can you get up in the middle of the night and microwave a burrito?* Such a visceral intervention into the abstract matter of bodily autonomy reflects Baggs#s priorities as a writer and activist, and promotes a more capacious understanding of the institution, not as a building but, especially in a post-deinstitutionalization era, a narrative and relational structure (Mitchell and Snyder, 2018:38-39). Home-based care, which Baggs describes as !independence theater" (2018a) is a form of institutionalization, as are conditions of housing- and food-insecurity. Baggs makes the latter observation in "Why I'd sometimes feel safer dying on a street corner than going to the hospital," (2018j) figuring the hospital, street, and other institutional spaces are figured in parallel as sites of disabled, racialized, classed, and gendered abjection, spaces to offload "disposable" bodyminds. These are spaces which hold what Baggs calls the "Xed," citing the fictional process of soul-erasure Madeline L'Engle details in her novel, *A Wind in the Door* (Baggs, 2017). When one is Xed, they are disappeared from the realm of the cared-for, a nonperson whose existence is without value. As in the case of NLTs and snake words, humanity, here, is selectively ascribed and heavily policed: speech, behavior, and embodiment outside its bounds warrants intentional, organized abandonment. Alongside the Burrito Test model of the institution, Xing — which can be extended not only to the institutionalization of disabled people but to antiblack police murder, to eliminationist anti-trans rhetoric, to the filicide of disabled children, and to mass disabled death during the COVID-19 pandemic — offers a tangible way to map one#s own story onto a larger narrative of dehumanization and disposability. It also critiques the standards by which certain bodyminds are rendered disposable in the first place; this Baggs demonstrates in and through hir blogging.

Given hir own experience of institutionalization, Baggs, in hir opposition to the process of Xing, makes subtle and meaningful moves to connect hir struggles with others'. Sie both brings hitherto "Xed," erased perspectives into disability discourse, and in so doing advocates for intracommunity, cross-disability solidarity, despite longstanding lateral aggression and the marginalization of intellectually disabled people in the disability rights movement. In order to do this, Baggs does not resist Xing by reversing it, by attempting to "prove worthy" those community members marked as worthless. Rather, Baggs places hirself among the dehumanized while asserting a digitally public life. Sie presents images and videos such as *In My Language*, in order to establish concrete linkages not only between hir visibly disabled bodymind and hir online life, but also between hir bodymind and words and those of other disabled people without a public platform. Sie marks hir experiences as emblematic of disabled dehumanization, wielding hir writing as evidence of hir disabled experience rather than proof of the hidden, exceptional intelligence of which mental disability advocates are often accused (Yergeau, 2018:32). Baggs moans, flaps hir hands, and poses in front of a therapeutic garden plot, forcing readers to link the prolific writer whose work they consume with the bodymind diagnosed "abusable" — a "patient who doesn't matter" — by medical doctrine (Baggs, 2018j).

Under Baggs's experiential framework, the Burrito Test to personal interactions, documents, and bureaucratic processes: it is not only the walls of the hospital that confine, but also the humans within. Sie also embodies resistance to the weaponized, ableist text. After a blog post recounting a false accusation of physical assault on a staff member after a disagreement, Baggs describes the transformation of "office gossip" into medical and legal record, and the literal "institutionalization" of ableist lies about patient behavior:

> They can write anything about you […] if someone doesn't like you challenging their power, they have the ability to throw that power around by accusing you of crimes. They don't have to prove you did anything (2018f).

The written word is a weapon of erasure, a means of "disappearing" noncompliant bodyminds. Baggs also enters hir own experiences of institutional violence — particularly through the non-traditional institution of home-based care and services (HCBS), an instance in which the Burrito Test applies outside the four walls of the hospital. Even in the nominally "deinstitutionalized" context of HCBS, "on a deep level involving power and control, not on a cosmetic level where all you've done is slap some new decorations on the walls of the old system" (Baggs, 2018f). Baggs differentiates hir critique of HCBS from others' criticisms of failed-deinstitutionalization, using hir own lived experience as evidence: the services falsely named "community-based" fail not because they are not institutional enough, but because they so explicitly mimic longstanding institutional structures — "the same people at the top all have the same kinds of power" (Baggs, 2018g).

If words are weapons in the hands of ableists, Baggs demonstrates that it can also be a weapon in the hands of disabled people. Writing is the medium through which Baggs deploys hir experiential framework, as well as a demonstration of the humanity — the refusal to be silenced or siloed — of hirself as a speaker. This is the beating heart of Baggs's experiential framework: the awareness that life lives in its telling, and that the telling of the story is in itself a demand for human connection — the connective tissue of what Baggs imagines as a "good agency," grounded in friendship and generosity (2018h). *Our lives depend on it.*

Conclusion: “If I am killed…”

Mel Baggs's life, extended and mediated online, was a continuous push to exercise autonomy, and to create conditions under which hir personhood would go unquestioned. Writing, “I will no longer pretend that I am not trying to scrabble together some kind of meaningful life living on the ragged side of a nightmare,” sie resisted hir aides’ and the public’s impulses to consider hir a mere “pile of medical problems” and linguistically demote hir to the status of “unperson” based on hir real and perceived needs and limitations (2018l). Instead, sie advocated relational transformation through shared narrative, prioritizing interdependent, non-hierarchical models of caregiving and foregrounding cross-disability collaboration within a broader disability community, especially in light of divisions between “mentally” and “physically” disabled groups (Baggs, 2020). Hir blog posts provide a means of speedy and ungatekept communication with others heretofore “Xed” by ableist institutions, while also facilitating the crip friendship that, seven years before the COVID-19 pandemic of 2020, saved hir from death-by-medical-neglect. In this conclusion, I step back from the analysis of specific language and turn to the life-sustaining power of radical crip friendship, friendship which was only facilitated by Baggs’s digital linguistic transformation.

On March 31, 2013, Baggs was hospitalized for complications related to hir gastroparesis. Sie made a post on hir Tumblr blog expressing anxiety over what quickly proved to be medical coercion. According to Lydia X. Z. Brown’s summary: medical providers attempted to deny Baggs access to a feeding tube and thus starve hir to death. When sie resisted, asserting hir desire to live, doctors asked whether or not sie was "at peace" for the decision to remain alive (Drake, 2013b). Sie was only surgically intubated after a flurry of calls from disability activists across the country and around the globe, including the anti-physician-assisted dying organization Not Dead Yet (Brown, 2013). News releases by

Not Dead Yet updated concerned readers as to Baggs's situation, quoting from hir blog post update, titled "Oh also wanted to thank all the ppl I don't even know":

> Who called the hospital on my behalf. The woman from Disability Rights Vermont who, free of charge, sat through all my doctor visits yesterday. All day long. Etc.
>
> You did have an impact. One of my doctors said there's an abrupt change in my charts starting when ppl started calling and stuff. I noticed too because they turned from hostile to conciliatory on a dime.
>
> Just be aware even if my surgery goes perfect there's lots more patients to protect. (quoted in Drake, 2013a).

Mel Baggs was prepared for such a crisis, writing hir experiences of medical neglect as part of a broader pastiche of disabled experiences whose deadliness crossed space and time. In 2006, on an older blog called Ballaexistenz, sie made the post "If I am killed," a confession, warning, and manifesto in which sie details the risk of filicide and caregiver murder disabled people, including Baggs hirself, frequently face. Sie describes the majority of these deaths as "invisible" — entirely unknown, confined to institutions, or otherwise justified by the rhetoric of "burdensomeness." Here, sie solicits readers, friends, and loved ones to remember hir and other Xed individuals actively, prior to their deaths; to remember that sie "lov[ed] life" and was not a mere object, but a *participant* experiencing its richness (Jellicoe 2021:2). Here, Baggs's story does not only foreshadow deadly ableism in an age of COVID-19, but illuminates and powerfully resists erasure. Such texts not only preserve Baggs's memory, but sow solidarity among disabled readers, expanding a digitized crip network of community care, of which Baggs was a critical component. This is not only a cripped reconfiguration of the Harawayan cyborg, in which the technological medium realizes hir inseparability from hir readers and interlocutors, but also a mechanism by which words, quite literally, save lives and make afterlives anew.

The relational connections sie formed as a blogger, scholar, and activist, the robust digital network sie built in pursuit of genuine, active cross-disability solidarity would not have existed to sustain hir had sie not cultivated it via reclaimed anti-institutional language. Baggs reclaimed language and rebuilt relationships, ultimately emblematizing the material power of language-based internet activism, and of grounding political work in personal experiences — including the ongoing personal experience of deadly medical (mis)treatment. In doing so, sie not only preserved hir own life but awakened others to the immediate needs of the disabled body politic: it was through Baggs's blog posts that I myself entered into politicized disability identity, and first gained the language to articulate experiences of medical and psychiatric abuse. Baggs's observations of the institutional violence that unites uniquely across disabled generations and lived experiences, sie curated a space of care and honor in which disabled lives and memories could survive, in which new community members could be welcomed-in, and in which, whether in body, word, or both, sie would not be Xed.

Notes

1. While this is not an autoethnographic article, I choose to explicitly identify myself with the !we" of disability community and deploy the first-person when needed throughout the piece.
2. I use !Post-COVID" throughout this piece to refer to any time after the initial global lockdowns of March, 2020, as a shorthand for !Post-[onset of] COVID." I explicitly do not use Post-COVID to refer to an imagined COVID-free present or a !finished" pandemic.
3. As described by disability performance collective Sins Invalid, available from: https://www.sinsinvalid.org/blog/10-principles-of-disability-justice.
4. While I lack space here to further discuss non-rational and Mad modes of communication, engagement with these forms is ripe for Mad study and critical to what I have elsewhere termed !transMad" digital praxis. (Cavar, 2021).
5. In his novel *Lords and Ladies*, coiner and fantasy author Sir Terry Pratchett describes words whose !meanings can twist just like a snake," noting that, !if you want to find snakes look for them behind words that have changed their meaning." (Quoted in Baggs, 2018b).
6. For further examples, see the Twitter thread started by Esther Leighton (2021, July 22).

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Fetishization of the Disabled War Veterans in Iran through the Ideological Construction of “Living Martyrs”

Sona Kazemi

University of Wisconsin-La Crosse

Abstract

This paper explores the ways in which disability gets fetishized in the global context using the case study of disabled war veterans in Iran who were injured during the Iran-Iraq war. Relying on a Disability Studies' lens, I analyze the ways in which the Iranian state after the Iran-Iraq war has "dealt" with its disabled veteran and civilian population. The paper argues that since the war ended in 1988, the Iranian state has engaged in what I call "fetishizing" the disability of its injured population, both veterans and civilians, in several ideological ways. Throughout this paper I indicate how the state has managed to use the disabled bodies of the injured survivors as a way to guarantee its survival by portraying them as an ideological construct called "living martyrs," as opposed to disabled humans in need of physical and affective care. Additionally, the paper discusses how the injured survivors' disability has too been fetishized in the global context during and after the war, as the world has remained silent in the face of violent chemical attacks on Iran and Iraqi Kurdistan.

Keywords: Middle East, Iran, Iraq, war, transnational, martyrdom

Fetishization of the Disabled War Veterans in Iran through the Ideological Construction of "Living Martyrs"

My research program is located in contradictions among transnational Human and Disability Rights frameworks in the context of global and regional imperialism(s). For the past decade, I have been studying the living conditions of injured survivors of war, incarceration, forced displacement, political torture, acid attacks, and punitive limb amputation in parts of the Middle East such as Iran, Saudi Arabia, and Iraqi Kurdistan. This paper stems from the study[1] of the living conditions of the Iranian veterans and civilians who became injured/disabled during the Iran-Iraq war, in the middle of which I was born. My methodology was archival research and digital study of the disabled veterans' memoirs, eyewitness testimonies, and online comments that they posted on the Iranian state-sponsored News Agencies' websites. This was their only podium to express their discontent[2] with the utterly inadequate care they received. Conducting the project and observing the every-day violence around the globe, I started wondering about the ways in which disability/injury of war survivors become fetishized in both local and global contexts. Growing up in a post-war Iran, I witnessed how the nation-state uses disabled bodies to legitimize its existence and guarantee its survival by portraying them as an ideological construct called "living martyr" as opposed to injured/disabled people in need of care.

On the other hand, I have observed that, in the global context, the disability of disabled people, whether wounded veterans from Iran or other parts of the "global south," are soma-fetishized, meaning their disablement is perceived as the "natural" state of affairs

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[1] I have talked about different social and political aspects of this war and the disabled bodies it has produced elsewhere see Kazemi, 2017, 2018, 2019.

[2] The veterans' narratives expose their post-war experiences, including poverty, unemployment, inadequate medical-care, lack of medication due to the Islamic Republic's regional-imperialist adventure and the resulted U.S.-imposed economic sanctions, as well as the presence of a dysfunctional disability-measurement system employed by the Iranian state (Kazemi, 2019, p. 1).

(Erevelles, 2011; Kazemi, 2018). The fetishization of disabled bodies in the global south, or what I call "soma-fetishization," takes place through political, economic, cultural, and intellectual production sites, such as the mass media and the academies of the global north when violent processes that render those bodyminds[3] disabled, are masked/justified/naturalized[4]. In this paper, I clarify the concept of soma-fetishization through the case study of the Iran-Iraq war, highlighting the Iranian state's role in *disabling* populations and then masking and justifying their injury/disability in order to legitimize its own existence and survival.

Soma-fetishization of the Disabled

Let me explain this further by first defining what commodity-fetishization of the body or soma-fetishization means in both original Marxian as well as Materialist Disability Studies' (DS) terms and present a few examples.

As soon as an object is produced and exchanged, it becomes a commodity (Marx & Engels, 1867). Marx argued that a commodity becomes fetishized when it is viewed without any social and historical context. For example, if a worker builds a product, and we look at that product, but don't see the worker who is oppressed and exploited in the process of building that product, we engage in what Marx calls "commodity-fetishism." A concrete example of commodity fetishization occurs when we look at a table in a furniture store and just "see" the table as a neutral commodity without thinking about the worker who has been oppressed and exploited in the process of making it. Therefore, looking at a product, whether it be cultural, physical, or intellectual, outside the power relations that mediate its production,

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[3] Eli Clare, Margaret Price, William H. Poteat, and Sami Chalk, among others, have contested the dualism of/between body and mind, arguing that the two are inseparable as they actively affect each other.

[4] I have extensively defined what I mean by fetishization elsewhere (Kazemi, 2018).

is fetishizing that product.

Within the capitalist system, there are conditions in which disability is produced including the commodification of human beings for profit. Within this very system, discrimination produces disability by virtue of the fact that labor is purchased for an exchange value. The lesser the exchange value, the higher the profit. Labor power in the capitalist system is purchased for an exchange value, the lesser the exchange value, the higher the profit. Furthermore, race, as Young claims (2009), is an important factor to consider within a political and economic context, because it is exchanged for less. Young (2009) further adds that race is not a commodity, but a “commodity fetish” that has been historically deployed to accumulate more profit for the capitalist system. This has been primarily accomplished by occluding the oppressive historical and social relations behind its production as a deviance and less “valuable”/ “less profitable.”

Erevelles (2011) has argued that the same discrimination has been applied to disabled bodies, because the capitalist economy purchases the labor power of a worker with impairment for less. This *produces* disability among workers in the global context. This can be better understood if we look at different examples around us such as sheltered workshops, subminimum wages, and the financial exploitation of disabled people. Sheltered workshops or sheltered work settings, also known as affirmative industries, training facilities, or rehabilitation centers, are segregated spaces that amass a large number of disabled people to exploit their labor power (The National Disability Rights Network, 2011). These settings often claim that they provide a “transition opportunity” for disabled people to become rehabilitated and prepared for the general, more competitive labor market. However, in the best of these situations, not only do they fail in providing a meaningful experience for workers with disabilities, but also the jobs are often menial, tedious, and repetitive (ibid). The sheltered workshops are isolating and segregated, as they only employ disabled people and pay them below the federal minimum wage, although "legally," through *the Section 14(c) of the Fair Labour Standards Act* (ibid). The National Disability Rights Network conducted a study about isolation and exploitation (i.e., sub-minimum wage compensation) of people with disabilities in the American labor force. "[S]ection 14(c) of the Fair Labour Standards Act allows employers to pay individuals less than the minimum wage if they have a physical or mental disability that impairs their earning or productive capacity" (The National Disability Rights Network, 2011, p. 6). The study reported that:

> Sub-minimum Wage Reinforces a Life of Poverty for People with Disabilities. Labor law exemptions for employers of people with disabilities have created jobs that pay as little as 10% of the minimum wage with most workers earning only 50%. Reports on sheltered workshops often show that workers take home about $175 each month, while those working in traditional jobs take home about $456 each week. Few workers receive health or other employment benefits typical for the average American worker, and since workers do not have a voice, there is little opportunity to improve their conditions. Yet their employers are reaping the benefits of their labors.

These examples clearly indicate that the capitalist system produces disability by exploiting disabled bodies as laborers *for less exchange value* and more profit. Another example of fetishization of race and/or disability is how the global northern countries outsource their mass production and manufacturing. Most large manufacturing corporations outsource their production processes, meaning they prefer to produce in "third world" or global southern countries where the minimum wage is much less than that of their own countries. The residents of the "third world" accept work in sweatshops to survive financially. Thus, corporations (e.g., Nike, GAP, H&M, Apple, etc.) *buy racialized labor for less* and profit greatly by exploiting them much more than white workers in the "first world." Furthermore, many racialized workers in the "third world" become disabled due to injury and unsafe working conditions (Abberly, 1987; Erevelles, 2011; Da Silveira Gorman, 2005, 2016; Meekosha, 2011).

Silent Global and Oppressive Local

One way in which DS, per se, as a field of knowledge and as a discourse, fetishizes disability is by focusing primarily on the contemporary attitudes and barriers that turn impairment into disability, often ignoring the historical, political, and economic conditions that produce disability in the global contexts. However, in the past few years, activists and scholars have begun to go beyond[5] the "rights-based" approach to disability and refused to understand its meaning, unless locating it in a complex matrix of other sociopolitical struggles, axes of oppression, historical discontinuities, and identities.

Erevelles argues that the romanticization of DS, in general, has prevented us from seeing the roots of the ableist tradition in the global context, especially the global south. It seems that understanding disability as a local issue only satisfies the dominant powers in the social relations currently prevailing in the world. She argues, "the very category of disability operates as a commodity fetish that occludes the violence of the socio-economic system" (2011, p. 67). The truth is that we rarely talk about "global southern" residents' disabilities because their misery has become so "naturalized" that we do not even notice it as a

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[5] Those leading this major shift are grassroots disability justice movements, such as the Disability Justice movement (Sins Invalid, 2015), dreamed into being by writers, performers, poets, and activists such as Mia Mingus, Leah Lakshmi Piepzna-Samarasinha, Patricia Berne, Leroy Moore, Eli Clare, and Aurora Levins Morales, among others. Additionally, in the past decade, incredible contributions have been made to the DS field as it intersects with state violence, especially by BIPOC and transnational feminists, such as Nirmala Erevelles, Rachel da Silveira Gorman, Sami Schalk, Julie Avril Minich, Lezlie Frye, Liat Ben-Moshe, Cynthia Wu, Jasbir Puar, Eunjung Kim, Robert McRuer, and Therí Pickens. Postcolonial DS scholars, such Helen Meekosha, Shaun Grech, and Karen Soldatic have also made meaningful contributions to what they have most recently called, "Southern DS[5]".

"disablement" problem rising from poverty and exploitation.

Both Puar (2017) and Da Silveira Gorman (2016), among others, have observed that only in the global north have people been permitted to claim their disabled identity as a "disabled subject," while the disability of the people in the global south appears as a "natural" state of affairs. In an article published at *Somatechnics*, discussing the "naturalization" of injury in the Middle East, Gorman (2016, p. 9) argues:

> Despite the fact that all of these violations [in the Middle East] are about disablement, political claims are [only] made in the context of the UN General Assembly, the International Court of Justice, and the International Criminal Court, *not the UN Convention on the Rights of Persons with Disabilities* [my emphasis].

Now that I have briefly defined fetishization in relation to the state, political economy, and nation, I will present a case study of how disabled bodies became fetishized in the longest war of the twentieth century, the Iran-Iraq war, which, I, myself, survived as a child. My point here is to show that not only disability and race can be fetishized, but also the body itself, which I have come to call soma-fetishization.

Iran-Iraq War and Its "Already-Dead" Living

How can they compare what we did [in the war] to a few numbers/digits [disability percentage]? — Seyyed Hadi Kasaeizadeh, a disabled veteran

The Iran-Iraq war produced hundreds of thousands of disabled veterans. Generally, the Iranian state estimates that about four percent of the population is disabled (Moore & Kornblet, 2011; WHO, 2011), although the most recent report issued by the Human Rights Watch states that the number is likely between 11 and 14 percent of the population, or about 9 to 11 million people (Human Rights Watch, 2018). There are 800,000 disabled Iranian survivors of the war with visible burns, blindness, chronic fatigue, sexual dysfunction, mood disorders, and severe bleeding problems (Ahmadi, et al., 2006; Najafi Mehr, et al., 2012; Wright, 2014) who have received no acknowledgment from the international community whatsoever (Bajoghli, 2015; Wright, 2014).

In Iran, like many other societies, disability is associated with a sense of tragedy and shame. In other words, the disabled person and his/her family are expected by society to experience grief and shame (Goodrich, 2013). In the public's view, having acquired a disability through war is different from other kinds of disability, such as congenital or acquired through natural causes or accidents. This is largely due to ideological perceptions that people uphold, such as "patriotism" or "martyrdom," concerning the justness of the fight in which disablement occurred. Therefore, veterans receive a certain amount of respect that non-veteran disabled people rarely do. Kashani-Sabet (2010) points out that the relationship between disability and the state can vary drastically based on possible causes of disability. This is definitely the case in Iran. However, this does not mean that veterans necessarily receive special attention from the state.

In fact most Iranian veterans live with poverty and inadequate care and are often institutionalized in psychiatric wards and nursing homes. Iranian veterans in particular, and Iranian people with a disability in general, complain about inaccessible buildings, streets, curbs, and pavements (Hallajarani, 2014). They cannot go outside their homes because they cannot get around due to inaccessible buildings and the lack of ramps[6]. If there is a ramp, they often lead to a body of water without a bridge (Goodrich, 2013). Unfortunately, many disabled war veterans are afraid to voice their discontent with the economic and social

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[6] Negin Goodrich (2013) reveals that in Iran, there is legislation in place to protect the rights of people with disability, such as *The Comprehensive Law to Protect Disability Right,* which was ratified by the Iranian parliament in 2004. Such legislation is supposed to benefit both the population with disabilities in general, and disabled war veterans, in particular. However, these regulations are often not enforceable because there is no proper system in place for their execution as planned on paper (Goodrich, 2013). There is a gap between legislation and the everyday experiences of disabled people. The veterans' requests are legitimate and have been predicted in the law, but most of those laws are never enforced. And no person or organ is ever punished for violating them.

conditions that they are forced to endure, because the Iranian state immediately silences them by cutting their minimum social welfare benefits and often imprisoning them even before they voice their complaints publicly. There have even been veterans who have committed suicide as a result of extreme poverty (see e.g., Fashnew, 2016; Ir.voa.com, 2017; Namehnews.ir, 2013; Nasr, 2014; Soleiman nia, 2012).

Furthermore, after analyzing veteran accounts, testimonies, online political commentary and blogs, I discovered that they are usually struggling to raise their designated "disability percentage[7]" in order to obtain more or better care. For instance, the veterans whose disability percentage has been determined by the Disabled Veterans and Martyrs Foundation (DVMF), as less than 25%, usually complain, because few of their needs are ever met. A percentage below 25% qualifies a veteran only for basic medical insurance (Alef.ir, 2010). According to the veterans' own words, veterans whose disability percentage is 49% or below can use the university entrance quota only once for their children, but children of veterans with a percentage of 50% or above can use the quota as many times as they want with no restrictions. 50% and above can also qualify to receive a car (Fashnews, 2016; Kaleme.com, 2016; Mehrnews, 2014).

Many veterans believe that the "percentage system," or what I call "soma-technologies of disability measurement," is a discriminatory one because it divides them into groups with drastically different benefits (see their own words in Alef.ir, 2010). I call them "soma-technologies" because they measure the veterans' disabilities by numerous biomedical tests, bureaucratic policies and rules ratified by the state. The medical commissions at the DVMF assign a "disability percentage" to the injured veterans based on those technologies, mediated by political and ideological bureaucracies. One veteran, Ali Kordlou, wrote in a

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[7] I have extensively discussed this dysfunctional measurement system based on percentage elsewhere. See Kazemi, 2019.

digital comment (cited in Fashnews, 2016):

> Are right and left hands related to each other or not? Last week, I went to the [DVMF or the foundation's] medical commission, and I explained to the doctors that I have serious problem in both hands and can't move any of them any longer. My neck also has serious arthritis. They told me that my problems have nothing to do with the war, and therefore, I shall receive no disability percentage for these issues. I told them that since I have lost my right hand in the war, I have put all the pressure on my left hand and my neck. Now, I have arthritis in my neck and my left hand. How can you say that this is irrelevant to the war?

An anonymous group of mentally disabled veterans with brain injuries who are institutionalized, along with the on-site psychologist, talk about their living conditions in a video footage that was uploaded to YouTube (see Soleiman nia, 2012). The institutionalized veterans tell the cameraman that the feeling of worthlessness hurts them. They say, "We are useless, and everyone has forgotten us." They say that their addresses change very frequently, or they go homeless, because their landlords kick them out of their homes. Their stress makes them very irritable, and they accelerate swiftly to the point of screaming and swearing for no apparent reason. The on-site psychologist states that if people were only aware of their condition, then they wouldn't take it personally and would try to understand the veterans' trauma and stress and act accordingly (Soleiman nia, 2012).

A veteran, Seyyed Hadi Kasaeizadeh (2015), wrote in an online comment: "For those who deny us, I will give you three addresses to attend and witness our pain with your own eyes: Nesar Dire [town], Sardsht [town], Zarde [village], and Sasan Hospital in Tehran." He tells us that another veteran's father died in a lineup in a pharmacy while waiting to receive his medication. Kasaeizadeh adds:

> I think the medical staff at the foundation work like robots who have been brainwashed and just manage to make us feel worse. I myself never go to the hospital as long as I am conscious, unless I faint or have a seizure, then my children take me. How can they compare what we did [in the war] to a few numbers/digits [disability percentage]? I have given up on them in this life, but in the afterlife, I will make sure that justice is served.

Another (anonymous) veteran writes:

> I've been belittled and humiliated by the foundation so much that I cannot even begin to describe the things I've been told by the authorities. During the war, my best friend died in my arms. Today, I'm very traumatized. I keep bursting into tears. I've witnessed so many scenes that I can never talk about them to others who haven't been there. The foundation doesn't recognize me as a veteran, even though I went to them after 30 years when I really needed help (cited Kasaiezadeh, 2016).

An anonymous (5% veteran) with a direct bullet injury in the right ankle and post-traumatic stress states:

> I have had a series of hospitalizations in psychiatric institutions. Am I a mentally disabled veteran or not? The foundation says you don't have a proof for your injury in the war; you need to show us a proof of treatment right after injury in a war zone field hospital or clinic (*soorat-e-saneheye-hamzaman*) [simultaneous accident memo]. This is absurd, because I couldn't possibly have had someone taking my photo, as I got injured in the frontline (cited in shohadayeiran.ir, 2015).

It is evident in the veterans' own words, the disability percentage system or the "soma-technologies of Disability Measurement" is problematic, because it is not geared towards rehabilitation and healing wounds; Instead, it incentivizes the exacerbation of veterans' health issues (Soleiman nia, 2012). The material reality under this system is that those who are given higher percentages, receive slightly more services from the state, although the social welfare system for veterans is extremely corrupt and dysfunctional. As such, the system pushes veterans to believe that the worse they become, the higher percentage they are granted and the better care they can obtain.

Often, the idea of rehabilitation (or "cure") after trauma is about helping the person feel better and getting them closer to their state before the trauma (e.g., natural disaster, war, car accidents, etc.). However, the percentage system acts as a counter-rehabilitation mechanism, "pushing veterans to never become rehabilitated or feel better. If they do, they risk losing the percentage they have already been given, which means losing already inadequate benefits" (Kazemi, 2019, p. 10).

Somatechnics of "Cure" and the "Sacred" State

Discourses about rehabilitation or cure inspire uncomfortable conversations within Mad Studies and DS. Eunjung Kim (2017) makes the polemical claim that cure is a form of violence. "Curative Violence," according to Kim, "is when cure is what actually frames the presence of disability as a problem and ends up destroying the subject in the curative process . . . [becoming] at once remedy and poison" (14). In her foundational work, *Curative Violence,* Kim does the important theoretical work of introducing us to the complications of cure. It argues against the dominant narrative of cure as a final journey with a clear destination. Kim conceptualizes cure as a "transaction" or "negotiation" of potential risks, benefits, and harms taken on by bodies seeking transformation (10). The Iranian society, both within and outside its geographical borders, very much holds ableist attitudes toward disability, perceives it as "lack", and craves cure at all costs. Since working with the Iranian survivors of violence (e.g., survivors of war, genocide, displacement, political torture, and punitive limb amputation, and acid attacks), I have stretched myself between their needs and my discipline's politics. This has not been an easy task. I have often asked myself whether I can avoid apologizing for "cure seeking," while narrating its violent excesses.

In her analysis of the tensions pertaining to cure, Eunjung Kim (2017) enables us to imagine possibilities for disabled lives free from violence with cure seen "as a negotiation rather than a necessity" (back cover). On a personal level, I have lived most of my adult life in Canada, where universal healthcare, although with low quality with the "first world" standards, is available. My research, however, is situated in Iran where healthcare is expensive and access to it is not available to all, accompanied by an ableist and curative culture prevailing both inside the nation and Iranian diaspora. Kim (2017) argues for reimagining "cure" as "a set of political, moral, economic, emotional and ambivalent transactions that occur in social relations" (p. 41). This observation is accurate in many contexts including Iran. If the survivors lived in a society that didn't demand what McRuer (2010) calls, "compulsory able-bodiedness," they would not suffer as much as they do, encountering the ableist violence that doesn't "approve" of their injuries, such as blindness, mental disability, or disfigurement.

At first glance, the rationale behind the dysfunctional and counter-rehabilitative technologies of measurement deployed by the Islamic Republic of Iran, may appear reminiscent of Puar's (2017) argument in *The Right to Maim,* that the Israeli Defense Forces (IDF) do not shoot the Palestinians to kill them but rather, to maim them. Their logic, as Puar (2017) argues is "will not let die." There is certainly a similarity between 'the IDF's logic to keep Palestinians alive, but let them live', and the Iranian state's logic to 'keep the disabled veterans alive by often providing a minimum, to keep them alive, but not to let them get better'. However, the IDF's logic is more comprehensible coming from a settler-colonial state perspective with the intention to sustain itself at any cost, similar to other settler -colonial states, such as the United States, Australia, and Canada.

Similarly, as Salih Can Açiksöz (2019), demonstrates in *Sacrificial Limbs*, the Turkish state acts a settler-colonial state towards Turkey's Kurdish population and uses the Turkish soldiers' bodies in its internal conflicts with the Kurds to suppress and annihilate the Kurdish autonomous movement. Açiksöz demonstrates how the Turkish veterans' experiences of war and disability leads them ultimately to the embrace of ultranationalist right-wing politics, which fosters the state's colonial aggression. In turn, this fascist tendency then perpetrates more disabled bodies on both sides of the conflict in order to continue its colonial rule of Kurdistan and to crush Kurdish resistance.

Contrastingly, the Iranian state is not a settler-colonial state by definition, although it commits the same number of atrocities that the Turkish and Israeli states commit, if not more, by indiscriminately oppressing its own people. Some examples of this oppressions include imprisoning journalists and activists, public executions, torturing political dissidents, punitive limb amputation for petty theft, running a gender apartheid, and turning Iran into a huge prison for women, members of the LGBTTQI, and religious minorities like Baha'is, not to mention sustaining a corrupt economy which fosters extreme inequality between the social classes.

How do we explain this level of atrocity from a "legal" state? Usually, states need their masses to rule over them, to reign over their lives and properties, and to control them. Therefore, states usually need the masses to be there and be alive, although not necessarily living a quality life, but be there physically, so their labor can be tapped, and their taxes can be collected. However, with ideological/theocratic states things could be different, in the sense that the state could even benefit from its citizen's death, if it fits with their ideological agenda, and if they could frame it as "martyrdom" in order to guarantee their own survival as a "legitimate" power.

The ideological state needs to cultivate the culture of "sacrificing" for the divine state, as a way to justify its legitimacy. It is in this context that veterans' deaths become as valuable as their lives, if not more, because the state can take advantage of their dead bodies on the front line, or after the war, to show its enemies that the masses are ready to die for the survival of the state. Once someone goes to "jihad" to fight for God against the "Sacred State's Enemies," whether or not the person comes back alive or with/out injury, the state has gained its profit, since there is an extra soldier fighting the enemy. As such, the person's life or death is immaterial to the state, which can be interpreted as the ultimate act of indifference. It is in this set of circumstances that the veterans' life and death should be read against the ideological state's tendency to soma-fetishize the veterans' bodies, because the state will survive as long as someone goes to war for it. In other words, the veteran's life and death are a mark against the ideological state's tendency to soma-fetishize the veterans' bodies.

Somatechnics of Remaining Disabled: The "Living Martyrdom"

During and after every war, states are left with the crucial job of narrating and remembering violence in a such a way that the ideological legitimacy of state and the now-concluded war are not questioned. The Iranian state has been selling an "official public narrative of the war" since it started (Haghgou, 2014), and disabled survivors are a major part of it. Haghgou argues that the Iranian state has been involved in the project of "cultural nationalism" since the war started, in order to legitimize the war and the state's necessary existence according to Shi'a ideology (2014). This project of cultural-nationalism is anchored in the process of "memorizing" and "remembering" the war, using it as a powerful tool in legitimizing the theocratic regime's rule through its ideological cultural constructs, such as the notion of the *jānbāz* /"Living Martyr," a euphemism for a disabled veteran. In Farsi/Persian, *jānbāz* (literally, the one willing to sacrifice his/her life) is a disabled veteran who has come home after fighting for his faith (Ghamari-Tabrizi, 2009). This word did not exist in the Persian vocabulary until the Iranian state strategically invented it in accordance with its ideologies of "jihad" and "martyrdom."

After the signing of the ceasefire, the war did not end for either the state or the people who had fought it. After 32 years, the state still uses "memorialization" or "commemoration of the war" in creating a culture of imaginary "struggle" against an invisible "enemy."[8] The Iranian state has strategically deployed the concept of "resisting" against "forgetting" the eight years of "sacred defense" in order to sustain its dominance and control over the nation. Hahghgou (2014) argues that the Iranian state keeps the memory of the war alive "as a mechanism for 'modeling' of the past in the present moment" (p. 75).

Hahghgou (2014) reveals that the Iranian state's project of cultural nationalism is carried out through texts, memoirs, photography, museums, street art, memorial sites, cinema, theatre, and commemoration events. Oddly, to this long list of cultural production sites, I add both martyrs' cemeteries, which the Iranian state calls the Rose Garden of Martyrs,[9] as well as the nursing homes for disabled veterans, which the state calls Ā*sāyeshg*ā*h*[10]. This seems like a bizarre addition, but if we think about why my school staff would take us for mandatory visits to these sites, we start to see the same project in effect here. Schools were

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[8] This happens in the midst of a strategic public amnesia which has been forced upon the nation. Nobody is allowed to ask a question or even talk about the political prisoners, who have been executed and buried in anonymous mass graves in the outskirts of Tehran and other cities (Abrahamian, 2008). As such, the state has used "forgetting" certain things and "remembering" others as a tactic to (re)establish itself in the past 43 years after the revolution.

[9] See Katouzian (2009).

[10] آسایشگاه

not supposed to take us to nursing homes and cemeteries to make the veterans feel cared-for and loved. I argue that this was also part of the cultural nationalism project to prepare the next generation for the same “sacrifice” and “defense” against internal and external “enemies”, both present and future. The main agenda is the regime’s survival at any cost.

Bannerji (2005) argues that it is a mistake to think that cultural production sites, such as religion, text, art, or language, can exist in isolation from power relations embedded in the social. In fact, considering them as independent categories that can function outside the relations of power is an ideological construct itself. Therefore, it is important to take a holistic approach when thinking about cultural production, in relation with the material world, mediated by social relations. In other words, perceiving culture, theocracy, or religion as neutral and harmless *ideas,* conceals the oppression and exploitation that could be happening within them as routine *practices*. Along with Haghgou (2014), I contend that the Iranian state’s survival, achieved partially through the project of cultural nationalism, occurs at the price of silencing a myriad of war stories. This concealing of truth and concrete evidence once again reminds us that we are dealing with an ideological regime.

The state accounts and narratives of the war are deeply shadowed by invalidities and untruths, based on manufactured, ideological knowledge. Inspired by Haghgou’s work on the construction of “Muslim Women,” we can say that the proliferation of state-sponsored content on disabled veterans and the Iran-Iraq War, “is a well engrained component of the same ideological machinery in ‘protecting’ the status and sanctity of the [1979] revolution” (p. 35). The construction of “living martyrs” as a social category is not the only ideological category within the Iranian state’s cultural production projects. Haghgou reveals that the same project has been in effect since the war with Iraq to construct the category of “Muslim Women,” as opposed to just “women” or “Iranian Women”. This construct, she claims, is a necessary part of the cultural nationalism project. The future generations matter tremendously to the state, not as human beings with free will, but only as pawns to be managed and ruled over. Educating the future generations with ideological, and therefore fragmented, knowledge is an insurance policy for the state to sustain itself without having to worry about potential dissidents.

According to Marx, ideology and ideological knowledge production operate as a process that separates the individual from material reality (Marx, 1845/1976). This is precisely why the Iranian state uses ideological knowledge, as its public war story, to indoctrinate the new generation of Iranians. If the younger generation ever has the opportunity to discover the real experiences of those who fought in the war and have come back, they might start questioning its legitimacy. Behrooz Ghamari-Tabrizi, the contemporary historian, argues that the Iran—Iraq war “transformed into a vehicle for the consolidation of the Islamic Republic’s power,” and the Iranian state managed to “exploit it as a state-building tool” (2009, p. 107). The war’s legitimacy is the foundation upon which the Iranian state has established itself. The state cannot afford any questioning; any kind of query invariably means questioning the legitimacy of the state.

Let us, in this context, consider this parallel example from India. India’s Hindu Nationalism, according to Bannerji, is a political and cultural project that equates “national” with Hindu, aiming at homogenizing the entire Indian polity. Hindu nationalism is a Hindu-nation building project carried out through mobilization of discourses such as essentialized Hinduism (*Hindutva*) and proliferation of ideological cultural productions such as state-run TV shows. Bannerji (2005) demonstrates that the process of cultivating “Hindu Nationalism” with a significant increase in Hindu right-wing movement in India is partly carried out via reference to manufactured evidence from imaginary glory days of the nation, a romanticized past, authenticity, and “true” Hinduism.

The same logic applies to the Iranian state as it fights to legitimize itself every day, as it has done since the 1979 revolution (Katouzian, 2009). This is an ongoing process in which the Islamic state struggles to cultivate its national narrative, deeply rooted in the manufactured glory days of the nation at the dawn of Shi’ism some 1,400 years ago (Haghgou, 2014). For instance, the ubiquitous referral and comparison of disabled veterans to a prominent historical Shi'a figure, Imam Hussein's brother, Abolfazl, who was mutilated during the highly-grieved, yet celebrated, incident of Ashura,[11] is framed in a way to indicate that the Iran-Iraq war resembles previous wars fought in defense of and for the integrity of Shi’a Islam.

The cultural nationalism project is not easy to carry out, though, because it needs a constant struggle on behalf of the state to exploit the nation and oppress people’s individual and social liberties through a sophisticated and corrupt judiciary system (Haghgou, 2014). To make the process easier, the state manufactures the truth, in order to decrease the space between consent and coercion. Manufacturing the truth usually involves a missing link between what has actually taken place in the material world and what is being narrated in the here and now (Bannerji, 2005; Shahidian, 2002). Finally, this ideological concealment between material reality and ideology facilitates the soma-fetishization process. The concept of “living martyr” becomes an ideological construction that produces disability as a fetishized category of body, meaning, and being. This also involves the fetishization of social, political and economic relations, as well as the fetishization of ways of being, such as disablement (being disabled).

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[11] The day that the battle of Karbala happened, and Imam Hussein was killed.

Free Labor of Dying

Given the elaborate lengths the state goes to in its construction and maintenance of the memory of the war, it is ironic that it does not actually care about the *real/material* remnants of the war, the disabled bodies of the wounded, both soldiers and civilians. What the state considers as a remnant is a "memory," which it has been manipulating since the war ended. The Iranian state has assigned a special role (i.e., a form of free labor) to disabled veterans who have survived the war. The idea of "living martyrs" is an assignment or a form of free labor that the disabled veterans are supposed to perform/fulfill. This construction has been propagated through popular culture, poems, films, museums, and a myriad of events. This works as a form of soma-fetishizing that masks the reality of disablement in wounded soldiers. In fact, the state has managed to hide the inadequacy of care for the veterans' disabled bodies under the concept of the "living martyr," who is supposed to live and act like a Shia "saint," and not like a disabled human being. The Islamic Republic of Iran is an amalgamation of class society, kleptocracy, carceral statehood, and Shia militarism, which uses disabled and dead bodies as a resource for cheap labor. This is what I mean by soma-fetishization, the fetishization of the dead and disabled bodies as sacrificial commodities for the state. The disabled bodies of "living martyrs" are used to ensure the survival of the state by performing crucial, free, and ideological labor for the state, while *remaining* disabled in the meantime.

The "living martyrs" (read disabled veterans) and the way the state deploys their bodies is an interesting fusion of the social and medical approaches to disability. They have medical conditions that allow society to understand them as disabled. Furthermore, the state uses medical institutions and a lack of care to keep them unwell. This proves that the state has a political stake in keeping them unwell, to ensure that they can perform their ideological role/function. This is another layer of soma-fetishization that the state adds to their multilayered processes of producing and maintaining disabled bodies, as part of their capitalist-theocratic approach in which bodies of the masses are human shields during war and ideological objects in the aftermath of war.

The “living martyr” essentially exists as the “living dead,” fulfilling the obligatory, ideological role of the state, but not existing as a living, disabled human who wishes to live with adequate care and support. This contradiction is a traumatic experience, an extra layer of psychological pressure on the disabled veterans who are expected to occupy an impossible position of being and not being at the same time. Muhyi al- Din Ibn ʿArabi (d. AH 638/1240 CE) had defined *barzakh* as “an imaginal border that joins by separating, such as an isthmus or a bridge, and that is the site of a passage for bodies and spirits; a partition, a screen, between two modalities of being, spiritual and corporeal, widening and delimiting, this world and the other; the site where the impossible can manifest itself in concrete form” (cited in Pandolfo, 2018, p.156). In this context, this *barzakh* is a space, an image, the eclipse of human presence, a purgatory that a “living martyr” is expected to occupy. This framed “image” is an imaginary status that rests at once in the material world of the experience of injury, trauma, and “almost dying’” in its historical reality, and on the autonomous ontological status of the “images” itself as the state views it. This soma-fetishization process produces a “living dead” with no effect but ideology, and a “dead living” whose disability is stigmatized, glorified, and erased all at once.

This contradiction, once internalized by the veteran, becomes a commodity fetish, a part of reality concealing all of reality. Once the commodity fetish takes over the real person who is behind it, the exploitation process begins, and it sustains itself if the veteran doesn’t resist it. In other words, the soma-fetishization process relies on the veteran’s silence to suppress his human agency behind the ideological role of a “living dead” to survive and receive the bare minimum services to scarcely live, or to remain living. Therefore, the theocratic-capitalist state produces disability as a problem in need of erasure (read solution), by suppressing the veterans’ humanity and agency as disabled persons, discriminating against them, and commodifying their scars. Furthermore, the “living martyr” is part of a bigger official state narrative, an ideological narrative, that is supposed to help the next generation understand history.

“Museumization” of Disablement as a Form of Soma-Fetishization

The instrumentality of commemoration sites, museums[12], holidays, texts, movies, and other art and cultural portrayals of the Iran-Iraq war, becomes significant once it is placed within the social, cultural, and political contexts of the Iranian state. Narges Bajoghli, an Iranian-American scholar reports her observations after visiting the Peace Museum in Iran. She ties her observations and interviews of the disabled veterans to the Iran Nuclear Deal. She reveals that disabled veterans were very influential in pressing the Iranian state to sign a deal with the Six World Powers.[13] Bajoghli quotes a disabled veteran and peace activist, Ahmad, stating, “War is horrible. War is the most horrible thing in the world.” When asked if he would let his own son go to war, if Iran is ever attacked, he stated: “I hope there isn’t an attack. But I never want them to go through what I went through. That’s why we have to stop a war before it even starts” (Bajoghli, 2015). Bajoghli reveals that Iran has the largest population of disabled war veterans in the world. She states:

> In addition to veterans who suffer from collapsing lungs, blinded eyes, and melted skin from those chemical bombs, tens of thousands of veterans have been confined to

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[12] Sacred Defense Museum and Tehran Peace Museum

[13] United States, Russia, China, United Kingdom, France, and Germany

> wheelchairs since the war, legs blown off by bombs, limbs mangled by land mines, and spines crushed under tons of concrete.

Bajoghli informs us that, not long after the war, a group of veterans decided to launch a non-governmental organization (NGO) called The Society for Chemical Weapons Victims Support. Their objective was to promote a culture of peace and raise consciousness about the horrifying effects of chemical weapons. They also focused on the survivors' needs, especially the needs that are never met by the Iranian state. Bajoghi claims that they gradually organized themselves into a group capable of giving the world a message different from that of the Iranian state. After getting in touch and learning from several peace organizations across the globe, this group was given a space and funding by the state to launch a museum, called Peace Museum, in 2011. This place is an NGO, and it receives funding from the state, specifically from Tehran's former infamous corrupt head of the Islamic parliament, Mohammadbagher Ghalibaf, who the head of the Islamic parliament in Iran.

Bajoghli depicts the Tehran Peace Museum as "a stark reminder of the destruction of war. Its walls are covered with the horrors of armed conflicts around the world and the grave suffering that soldiers and civilians have endured for political means" (Bajoghli, 2015). She reveals that during her visit with veterans at the museum, they showed her pictures of their fellow soldiers who had been injured in the battlefield during the Iran-Iraq war. In her conversations with the veterans, she recounts that they all agreed war is the most terrifying phenomenon that anybody could ever experience and that every nation should avoid armed conflict. Bajoghli informs us that there are a small number of veterans who hold high political offices within the Iranian state, while many others do not even receive minimum care in nursing homes and hospitals. The veterans in the museum tell Bajoghli that their intention is to promote a culture of peace and to avoid armed conflict at all costs. Some of these veterans in the Peace Museum engage in lobbying for peace with their fellow former soldiers who now hold high political posts. They try to remind them of the horrors of what they all went through not very long ago. One of the veterans tells her: “Those who champion war think it’s like sitting behind their television screens as they play video games. There is nothing glorious about war. Our population suffered enough in the 1980s. It doesn’t need to suffer again.” Bajoghli argues that the only group of people who can advocate for peace and get away with it are the disabled veterans. In my personal experience with the Iranian state and the regime’s 43-year report card, any non-veteran members of the society, openly condemning any future wars, can be accused of “acting against national security” and face a possible political prison sentence.

However, it would be naïve to simply view this museum as a commemoration site. This museum serves a significant political purpose. Sharon Macdonald, in her important book, *Politics of Display,* argues that historically, exhibitions and museums have not been neutral; instead, they have always been mediated by politics and social relations (Macdonald, 1998). Currently, she points out, the structure of museums and exhibitions is changing as they are becoming more reflexive and interactive with their audience. In the case of the Peace Museum in Tehran, we see disabled human beings as part of the display. This is a highly political exhibition. Here, the people’s pain and suffering are being displayed in order to provoke a feeling of hatred for chemical weapons, Saddam Hussein, and those who supported him, such as the American and Soviet governments. This museum is not a display to condemn war, because the latter is destructive, but rather, it exists to condemn, especially, the West, for arming Saddam. This site is not intended to give voice to disabled veterans’ experiences but is instead a propaganda site that uses disablement to convey its manufactured political message. This is another example of the fetishization of disability.

Additionally, according to the actual words of the disabled veterans, during the war, the state sent the wounded bodies hit by chemical and biological weapons to European countries such as Spain, Austria, and Germany for treatment. Even the veterans themselves suspected that perhaps this trip was just to "showcase their bodies" to the world to convince the world of the Iranian claim that Iraq was using unconventional weapons (Mohammadian, 2002). In his memoir, *Unfamiliar Odor*, Hossein Mohammadian (2002), a disabled veteran, reveals that, while he was in Spain in a military hospital for treatment, the Iranian embassy personnel closely monitored all aspects of his life. For example, they did not allow the Iranian patients in the European hospitals to watch TV while under treatment. Their rationale was protecting the veterans from the danger of what they called "cultural invasion" (2002, p. 203). They also exerted enormous control over the possibility of disabled veterans refusing to go back to Iran and seeking asylum in Europe (Mohammadian, 2002, p. 210). The problem of "museumization," along with the lack of economic and medical attention, are certainly among the reasons that have perpetuated the disability of the survivors over the course of these many years.

In Their Own Words

In the following section, I review some of the veterans' own words that they posted online in the form of digital comments.

Mohammad, a chemically injured 15%-disabled veteran in Shishdar region, states:

> I got shell-shocked [acquired a brain injury] trying to rescue my fellow solder. On the same day, they took me to Shahid Salimi combat field hospital and after a while I felt troubled mentally. I went under treatment for mental disability. I went to the Ilam province's revolutionary guard's station. Now, they say we have no record for the

> Salimi hospital. When I go to the medical commission, they tell me that I have been injured in my lungs. Since you don't have your mental disability/injury incident memo (soorat-e-saanehe ye aasab)/[memo of a mental disability causing accident], you don't get more than 3% disability percentage (Afkarnews, 2013).

A veteran's brother said that his brother committed suicide, due to not being able to work, economic pressure, and the stress caused by unemployment. He attempted to obtain a disability percentage. Even though the application was complete, the foundation refused to acknowledge his disability. The veteran (Akbar Ghaeini) burnt himself alive before the eyes of the staff of the foundation in Qom city. The veteran killed himself because of the foundation's irresponsible and apathetic response to his needs. Mehdi Ghaeini, the veteran's older brother told everyone that his brother attended the war, just as a sign of his faith. He never applied for his disability support percentage as long as he could work, in spite of his serious chemical injuries. He applied for his disability support after he realized that being shell-shocked would prevent him from working. The lack of response from the foundation, along with his traumatized state, finally led to his suicide by burning himself alive (Tabnak.ir, 2009).

Another veteran, who was working as a blue-collar worker, burnt[14] himself alive before the municipality building. There was a rumor that he couldn't afford to buy a proper dowry for his daughters. He was a 25%-disabled veteran who had purchased a cubical/table in the local farmers' market from the municipality. After four years, he was told to empty the table because they did not intend to renew his permit. He fought his right to keep the table for

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[14] Please note that self-immolation is not (just) a suicide attempt to end one's life; rather, it is a form of protest to resist the social, economic, cultural, and/or political relations exercised on the bodymind of the person. In other words, setting oneself on fire is weaponizing one's life as well as one's body to resist the unequal power exerting on the body from outside the body (Bargu, 2016). The source of this power could be the state or any other powerful actor.

a long time by going back and forth with the authorities, but they never paid any attention to his request. He even asked for a loan, which was also denied. After becoming completely hopeless, he burnt himself alive before the municipality building. After the news circulated, different organizations passed the ball without any accepting the responsibility for the veteran's problem – a veteran who just wanted a table in the local farmers' market (kaleme.com, 2016).

A veteran named Ahad commented on a news agency's website stating: "We are only important during *The Week of Holy Defense*[15] and the global day of fighting chemical weapons. Why can't the authorities care about us during the rest of the year?" (Alef.ir, 2010). This comment demonstrates Ahad's political consciousness and his awareness that the cleric-fascist regime (Kalantari, 2016) of Islamic Republic only showcases/promotes certain (disabled) bodies like his to earn legitimacy while actively eliminating that of others, such as the regime's dissidents. Furthermore, it is not a secret that the regime has executed more than 38,00 political prisoners who had already served their sentences in the summer of 1988 – the same year that Ruhollah Khomeini had to accept the ceasefire with Iraq (Akhavan, 2017). This is how fascism operates, showcasing certain bodies under the guise of patriotism, religion, and nationalism, while actively eliminating their "Others" or "enemies" (Kalantari, 2007). Providing for Ahad as well as other disabled war victims is of no concern to the state with the exemption of two occasions, The Week of Holy Defense and the Global Day of Fighting Chemical Weapons, which are both necessary for the state's survival as a "victim."

Towards Non-Ideological Forms of Knowledge

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[15] The rhetoric that the Iranian state uses to refer to the Iran-Iraq war is ideological. For example, the Iran-Iraq war is referred to as "the imposed war" or "eight years of holy defense." The Week of the Holy Defense is a week in the national Iranian calendar that commemorates the Iran-Iraq war. During the holy defense week, the national media talk about the Iran-Iraq war and broadcast movies about the war.

Growing up in Iran, my classmates and I were taught that the war was about defending our nation, Islam, and the revolution against Saddam Hussein and the West. The Islamic Republic of Iran claims that it was defending its borders with Iraq for the entire eight years of the war, and even calls the war the "sacred defense." This has been challenged by numerous scholars and historians, demonstrating through historical evidence that the state was only defending its borders for three years (1980-1983) and was on the offensive for the following five years until 1988 (Abrahamin, 2008; Ghamari-Tabrizi, 2009; Katouzian, 2009). Commanders ordered veterans to run in front of the enemy tanks and form a "human shield."[16] However, the official state narrative completely denies this, with many surviving veterans claiming otherwise. The reality is that the Iranian state has only fought one actual war, but it is always in the process of "defense and resistance" against imaginary wars waged upon its "revolutionary values". The state calls this process "promoting the culture of martyrdom," because it argues that the "enemy" is attacking us on every possible front. Therefore, the whole society is in need of protection.

Therefore, if veterans, researchers, historians, and scholars, who have studied the war, had the space and security to tell us what actually happened, the public will have access to what I call the "non-ideological" knowledge of the war, a knowledge that is based on truth and not manufactured narratives. We know that, if people have access to the truth their view of the state changes, which ultimately poses a threat to the state that rules by justifying its existence based on manufactured narratives of the war. This non-ideological knowledge and consciousness may also lead people to oppose the state in the form of protests, demonstrations, and possibly resulting in an overthrow of the authoritarian state.

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[16] See (Bastani, 2020) and (Bastani, 2019).

Haghgou (2014, p. 14) argues that the Iranian state through an orchestrated effort includes “Muslim” women’s experiences within its official war story to “curb the actual potentials of these experiences.” In other words, the Iranian state co-opts women’s experiences of the war, which by extension “severely impacts the history of women’s resistances, and as well presents a limited framework under which women can be active during times of conflict” (65). The Iranian State encourages women’s participation in society insofar as it is curtailed within the framework of the regime’s ideological apparatus committed to militarized antagonism towards the West, liberal democracy, feminism, gender equality, and secularism. Correspondingly, Iranian women’s representation in the cultural production of the war is framed within the imposed identity of “Muslim women” who “serve” the nation (read her husband, father, brother, son) and the *Ummah* (Islamic community), so they can fight the “sacred” war with the state’s enemies (Shahidian, 2002; Haghgou, 2014).

On similar grounds, the state is never interested in the real memories of those who have actually fought the war and have come back wounded/disabled, because it realizes the real potential of those stories. These stories, unlike the official public war story, are not ideological. This means that, neither do they mask the entire reality, nor are they fragmented. Instead, they could connect the dots and tell the next generation “why the war was fought and how”.

Haghgou (2014, p. 72) reveals that the official public war story is used “as an educational repository, where the experiences of those men and women are to be used as models for the current and future of state building”. Therefore, all this effort, on behalf of the state, is for producing ideological knowledge around the war as a process of “culturalization.” The archival materials of the Iranian state consist of several sources, such as the *Foundation for the Preservation and Publication of Values of the Sacred Defense* (Sāzmān hifẓ āsār nashr arzeshhai defā' moqaddas), the *Foundation of Martyrs and Veterans Affairs* (Bonyād shahīd va omūr īsārgarān, Tehran Peace Museum, etc. In these sources, produced by the state, the category of "living martyr" is not limited to what it means literally, but what it means in relation to the "sacred" state's futurity.

The Iranian state sustains itself by funding and empowering organizations like the Veterans' Foundation that overlook the production of cultural content on the Iran-Iraq war and uses disability as a token, tool, or a propaganda technology, to construct that content.

Disabled veterans, or "living martyrs," are constructed as part of the state ideology, in the forms of *embodied cultural icons*, rather than disabled persons in need of care. What is reflected in the cultural materials produced by different institutions is in fact a direct implementation and concretization of how "living martyrs" should be and behave[17]. This is an indirect way of ensuring how they make sense of their disability and injury, or how they behave as being more than ordinary human beings. "Living martyrs" are constructed as extremely gracious and patient people who are supposed to be "content", if not euphoric, with what has happened to them. Note that "content", in this instance, means apolitical, because claiming a disability identity inevitably constitutes a political relationship between the individual and the state, in which the state is expected to provide support, access, and accommodation for the disabled. The disabled veterans, however, are expected to perceive their disability as a blessing from Allah, who has been kind enough to have given them an opportunity to "give" something for their faith, country, and revolution. Sadly, we rarely hear

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[17] See myriad movies in this genre that the state calls the "sacred defense:" *The Scent of Joseph's Shirt* by Ebrahim Hatamikia (1995), *From Karkheh to Rhein* by Ebrahim Hatamikia (1993), *In the Name of the Father* by Ebrahim Hatamikia (2006), *The Glass Agency* by Ebrahim Hatamikia (1998), *The Marriage of the Blessed* by Mohsen Makhmalbaf (1989), *The Third Day* by Mohammad Hossein Latifi (2007), *M for Mother* by Rasoul Mollagholipour (2006), *The Red Ribbon* by Ebrahim Hatamikia (1999), and *Chronicles of Victory* series (aired on national television) by Morteza Avini.

their actual voices.

Wounded veterans, who have come back from the war, have a particular form of consciousness arising from their concrete experience, which should serve as an entry-point to produce a non-ideological form of knowledge. I say non-ideological because it does not conceal the connection between the individual subjects and the material world. One example includes memoirs, or any other cultural production, written/produced by veterans. However, the veterans must be allowed the freedom of expression to narrate what actually happened in the battlefield and not repeat what the state wants them to. The state's official narrative of the war has been challenged by several historians such as Abrahamian (2008) and Behrooz Ghamari-Tabrizi (2009) as well as veterans themselves. Although a veteran challenging the state's official narrative, while inside Iran, could face arrest, torture, imprisonment, and deprivation of their small monthly disability support wage, some may subtly challenge the official version of events and get away with it. for instance, when Bajoghli (2014) had attempted to interview them, one of them had said to her: '"Miss, do you want the official version that we have to tell the television crews every year?"' (Bajoghli, 2014, p. 42)

Defetishizing the Body

Bannerji defines cultural nationalism as a nation building project often rooted in tensions and conflicts propagated by sexism, racism, castism, ethnicity, religion, imagined "enemies" of the nation, and an historical prototype (i.e., gool old days of the nation). Through the project of cultural nationalism, Bannerji argues, the state is in a constant oscillation between consent and coercion. One way to manage this steady struggle is the invention of ideological categories such as "woman", "the glorious past", "and "culture". To this list, I add the category of "living martyr". These categories are disconnected from the historicaland material context in which they exist. When we look at the “Living Martyr” category within the official war story of the Iranian state and analyze it through Bannerji’s (2005) cultural nationalism lens, we can start to defetishize this concept.

The process of defetishization is necessary if we aim at seeing a real person with a disability behind the ideological construct of the “living dead.” Haghgou (2014) points out that the ideological content of the constructed categories can tell us a lot about those who created them and why they did so. As such, if we can carry out a thorough analysis of these categories, we will be able to unveil the social relations behind them. This unveiling process is equivalent to a defetishizing process, which has the revolutionary capacity to produce non-ideological knowledge and praxis.

One way in which the process of defetishization can take place is by listening to what the veterans have to say about the war and by refusing to believe the official narrative that the nation-states impose on us and on those who die and become disabled through wars. If we aim at producing a form of knowledge based on the material reality under which disabled people live, we need to shift our analysis and pave the way for a revolutionary understanding of disability and its relationship with the nation state, capitalism economy, and class society, contextualized within transnational political consciousness and activism. It’s as important to organize ourselves as disability-rights activists as it is to organize ourselves against disabling wars, and resist becoming, what Bannerji calls (2000, p. 42), “cultural sel[ves], floating non-relationally in a socio-historical vacuum.” Therefore, we need a new conceptualization of disability that can become a transnational form of collective political consciousness, a revolutionary response, stemming from lived-experiences of violence.

Helen Meekosha, Robert McRuer, Karen Soldatic, Shaun Grech, and other DS scholars have indicated that a process of intellectual de-colonization must take place if millions of disabled war survivors, who reside in or escape from the global south and their forms of consciousness, are to be included in scholarly thinking, "official" DS knowledge, theoretical developments, and peace projects. As a disabled disability-rights activist and a war-survivor, I believe in the possibility of achieving feminist, non-ideological, and anti-racist revolutionary peace praxis through a new conceptualization of disability. This new conceptualization should be capable of unveiling the social relations behind disablement caused by many different transnational issues on a global scale. A decolonized and anti-imperialist conceptualization of disability should be geographically, historically, and economically sensitive. These features can help us to further understand disability as a raced, gendered, and classed power relation, rather than as a tragedy.

While conducting my doctoral research, I became acquainted with several disabled war-survivors, who are now actively involved in anti-war efforts and activism. Research suggests that an excellent example of a grassroots movement and organized effort toward peace is the involvement of disabled people in conflict resolution and peace-building efforts (World Institute on Disability, 2014). My research indicated that disabled survivors of war, wounded veterans and civilians, emerge from war with a particular form of consciousness (which I call revolutionary peace pedagogy), arising from their concrete experiences. I found that their political consciousness, having arisen from embodied experiences can result and have resulted in political action. My research also found that documenting the first-hand experiences of disabled/traumatized war survivors can become a point of departure that provides a powerful locale for expanding the notion of experience, within the field of DS, toward connecting disabled people's resistances and struggles globally as an oppressed group.

As an extension of this study, I hope that future DS scholarship will engage more deeply in deconstructing the economic, social, and political relations of power, especially in the invisible parts of the world that are rarely showcased in the media or academia. I also hope that future studies like this will awaken a desire in DS scholars to go to places that we never see on the news – so that they render visible the bodies and disabilities that have remained hidden.

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Staying Indoors Due to COVID-19:

How People Who Are Not Disabled May Learn About Mobility and Reasonable Accommodations and Become Allies of Those With Disabilities

Aravinda Bhat

Department of Languages, Manipal Academy of Higher Education

Author Note

Aravinda Bhat is an assistant professor and holds a PhD in English literature from the English and Foreign Languages University in Hyderabad, India, and works at the Department of Languages, Manipal Academy of Higher Education. He teaches European literature in translation, intellectual history of Europe, critical thinking, creative writing and German. His research interests include literature by blind and visually impaired authors, disability studies, philosophy, and the novel. Through his work, he indulges his love of books.

Aravinda Bhat ORCID ID: 0000-0003-3312-1020

Abstract

This essay argues that lockdowns imposed by governments in 2020 and 2021 due to the COVID-19 pandemic starkly foreground the perennial problems of mobility and accessibility faced by individuals with disabilities. Since non-disabled people have experienced what it means to be prevented from moving out of doors freely, they should, at long last, be able to comprehend the negative impact that inaccessible roads, buildings, offices, recreational facilities, and attitudinal barriers in employment have on the lives of persons with disabilities. Thus, living through the pandemic may assist those who are not disabled to become allies of such persons. I draw on a number of sources to make my case: three memoirs on life as a blind person by Stephen Kuusisto, an American poet and memoirist with a visual disability; news articles from India; scholarly articles on the pandemic and employment of disabled people; and the latest data provided by the World Health Organisation (WHO). In the course of the argument, the essay calls for greater respect and reasonable accommodation for individuals with disabilities in our societies.

Keywords: COVID-19 lockdown, attitudinal barriers, accessible infrastructure, reasonable accommodations

Staying Indoors Due to COVID-19:

How People who are not Disabled May Learn about Mobility and Reasonable Accommodations and Become Allies of Those with Disabilities

With the start of the COVID-19 pandemic in the early months of 2020, countries around the globe declared lockdowns one after another. This extraordinary move plunged most citizens into a remarkable situation, that is, of staying in quarantine for extended periods of time. This isolating experience made it possible for people who are not disabled to comprehend, in a way unlike any other, how physical and attitudinal barriers exclude those with disabilities from participating in essential human activities on a day-to-day basis (Sins Invalid, 2020; Piepzna-Samarasinha, 2022). Thus, the experience of being in the pandemic carries the potential of making non-disabled people allies of those with disabilities. It might motivate the former to support the policies and practices needed to provide the latter with reasonable accommodations (Schur et al., 2020).

This essay, then, sets out to reflect on the implications of the COVID-19 lockdowns for disability inclusion. I adopt an autoethnographic method to probe my experience of the lockdowns as a person with a visual disability and to connect the understanding I have gained to broader socio-economic concerns as represented in creative nonfiction, scholarly articles, and journalistic texts that deal with the mobility of disabled persons. In a politico-ethical spirit, I note, unsurprisingly, that while the pandemic has likely brought the reality of disability exclusion to the notice of non-disabled people, increased awareness does not necessarily lead to the promotion of disability justice (Wong et al., 2022).

Grappling with mobility issues

Beginning on Wednesday, March 25, 2020, my mother and I walked religiously every evening for around 35 minutes. From March to May, we measured the 19 meters from one end of our front yard to the other and back again. This exercise was sparked by the lockdown declared on the night of 24 March 2020 by the Prime Minister of India, Narendra Modi. Marching to the sound of a modified sprinkler spraying water on plants in the garden, we heard an eerie silence from the main road nearby. No one was abroad. One day early in that strange period, I remarked to my mother that the stay-at-home decree was really not alien to me as a blind person. This understanding had suddenly surfaced as my mind forged a connection between something I had read in a memoir of blindness (Kuusisto, 1998) with lockdown experience during the pandemic, which had abruptly brought the lives of humans around the world to a grinding halt.

In this context of enforced isolation, the American poet and memoirist Stephen Kuusisto's words (1998) – in the opening page of *Planet of the Blind: A Memoir* – acquire greater meaning: "None of the turmoil or anxiety of being lost will reach us because moving is holy, the very motion is a breeze from Jerusalem" (p. 1). The author goes on to explain in the prologue how he, a blind man, and his guide dog, a yellow Labrador named Corky, were moving through New York's Grand Central Station "in a different tempo" "like two sea lions." Kuusisto's (2018) latest memoir, *Have Dog, Will Travel*, conveys the elegant poise of the author and Corky through the expressive phrase, "'man-dog'" (pp. 58, 81, 86). This compound noun paradoxically connotes an action figure by suggesting the vitality of a verb.

So, moving is holy (Kuusisto, 1998). This realisation dawned on humans in the time of the novel Coronavirus as most of us spent long periods of time cooped up inside our houses, in lockdown. On Monday, 6 April 2020 (the thirteenth day of the first lockdown in India), a media report on public mobility appeared in a national newspaper, namely The Hindu. Yuthika Bhargava (2020) states that the movement of people in places meant for retail and recreation was significantly less between 16 February and 29 March, 2020, as compared to the period from 3 January to 6 February in the same year. Based on Google's research into anonymized data about phone locations, this report implies that free mobility of people was, until February 2020, considered normal. Further, it presages, by means of statistical data, what most of us went on to experience day in and day out for nearly two years.

Millions of people suffered from a profound sense of suffocation during the prolonged confinement because of the stringent restrictions placed by governments on stepping out of doors. Many more persons than had previously been recognized faced psychological issues (Bates et al., 2021). Their distress stemmed not only from social isolation, but also from the fear of infection. As per the grim data presented by the World Health Organisation (WHO) on 25 January 2023, in the course of three years, more than six hundred and sixty-four million people fell sick with the disease. The official death toll is over six and a half million persons globally.

The exclusion of the disabled from public spaces and employment

Having undergone the isolating experience of the pandemic, it may have become possible for non-disabled people to pause midstride, as it were, and reflect on how 'lockdown' is an everyday reality for millions of persons who are blind, have other disabilities, or are elderly. David Bolt makes the provocation that the coronavirus might have seemed to herald "the end of disability history," meaning "the triumph of equality over the dominance of normative positivisms (i.e., indifference to disability [. . .] displaced in favour of appreciation)" (Bolt, 2021; cf. Piepzna-Samarasinha, 2022). During "the first peak of the pandemic" in the United Kingdom, disabled people witnessed an increased interest in their "personal narratives of isolation and social limitations" (Bolt, 2021). With the disruption of 'normal' life, non-disabled people seemed to realize that persons with disabilities may have important lessons to share about coping with isolation and uncertainty. However, with perceived improvement in the pandemic situation, this interest waned (Bolt, 2021; Piepzna-Samarasinha, 2022).

With the restoration of 'normalcy' in what is termed "the new normal" (Bolt, 2021), societies which subscribe to normative values about the body hold disabled persons' physical conditions alone as limiting factors. It is seldom recognized that these persons have to grapple daily with the challenge of moving out on roads and non-existent footpaths to schools, colleges, workplaces, or places of retail and recreation, if at all they have access to them. This itself is a rarity in many economically underdeveloped countries (Das et al., 2021). Because individuals with disabilities experience what Kuusisto aptly describes (2018) as "the intimidating quality of unseeable spaces" (p. 81), they often hesitate to venture outdoors. On some occasions, I have been derided by sundry busybodies for seeming to be unsure of myself. If persons with disabilities feel walled in, rolling out blithely on wheelchairs or walking out with white canes and engaging in recreational activities is not an option: our surroundings, roads, footpaths, and buildings are inaccessible and pose real danger to life. This is a comment of sadness and rage on the repeated failure of governments, policymakers, and contractors to incorporate accessibility in their development plans.

To extend this critique, consider a crucial point raised by Tony Kurian in an article published on 1 May 2020 on Scroll.in. It pertains to the livelihoods and economic independence of persons with disabilities. It needs to be said that this matter too constitutes an issue of reasonable accommodation. Right from the time the first lockdown was declared, people who have disabilities remarked how companies moved their operations online in a hurry. However, earlier the same employers refused to consider requests from workers with disabilities to be permitted to work from home and perform their duties online on the grounds that they were unreasonable demands. Kurian calls out Indian companies on such discriminatory practices in his trenchant article (Mampatta, 2022; Piepzna-Samarasinha, 2022).

Barriers to Disability Inclusion

On November 30, 2016, I was reminded, in a serious way, of what it means to face a physical barrier. That afternoon, I walked out of the building housing the department where I taught and started tapping down a dirt path leading to the main road in order to meet my father. He was going to pick me up in his car. I was looking forward to welcoming home my sister and her family from Germany. In my excitement, the end of my white cane slipped and I sat down by the side of the path with my feet in the ditch. Surgery had to be performed on my broken left ankle, and I had to spend four painful months convalescing.

Perhaps not coincidentally, just after my accident that day, I also encountered a stubborn attitudinal barrier in the form of a few thoughtless words uttered by a professor working in a different department. When my father drove up, the man in question asked him sharply, “Why do you let him come out alone?” Granted, he was pained to see my fractured leg, but is this not how disabled persons are generally viewed by most able-bodied people, i.e., as being incapable of looking after ourselves? Poorly constructed roads and buildings are evidently not the real problem; the disabled are to blame for their suffering. A contentious relative once said to me, “people like you have to be made normal.” She failed to realize that her mulish adherence to oppressive norms about the human body is what actually does great harm. Disabled persons no longer need to be “made normal”; structural and attitudinal barriers have to be dismantled and everybody included in the common life of the world.

Circling back to the COVID-19 pandemic, we are confronted by a forceful paradox. Although the expression is cliched, we cannot help but acknowledge that a virus, a creature so tiny that it cannot be seen by the naked eye, succeeded in thoroughly disrupting ‘normal’ life across the world. In this regard, I wish to call the reader’s attention to coping strategies used by racialized people caught in various forms of incarceration in the U.S. Bates et al. (2021) present “stories of formerly incarcerated people who teach us what they learned in prison that can now help us all adjust to life during the pandemic” (p. 64). Artaysia Malisham shares her wisdom on “self-care.” She says, “So during my experience being locked up, I learned how to do my own hair, how to do my own makeup, and to take care of myself to make me feel confident” (p. 65). Then, Romando Valeroso recalls how he used Islamic prayers during a lockdown imposed in prison “in the late 1970s due to a TB epidemic” to build “structure” into his life of incarceration. He says, “ ... it gave me like a regimen, a structure in my life, something that I could do every day—something that I had to look forward to every day, to deal with the lockdown” (p. 67). Finally, Juan Juan Willis speaks performatively about how “venting,” that is to say, “put[ting] whole songs together” (p. 70) on paper, or writing songs about his experiences helped him to “cope with [his] twelve years” (p. 69) of imprisonment. As noted by Patrick Bates, these lessons hold significance for both the present, post-pandemic situation and even our future (Bates et al., 2021). Further, they possess relevance not only during lockdowns, but also for the everyday lives of persons with disabilities. The strategies used by the former prisoners are similar to how Kuusisto deals with isolation as a blind child and adult.

In the collection of essays (2006) entitled *Eavesdropping: A Life by Ear*, several lyrical prose compositions center on the activities of Kuusisto in his boyhood, when he struggled with social isolation arising from the ableist rejection of his blind self. For example, in the piece “Ice” appearing in Part one of the book (“Sweet Longings”), the author narrates how as a small boy he made “instantaneous” (pp. 13-14) music by walking and rolling on the ice forming “between the trees behind [his] house” (p. 13); by plucking the wire of a rusted, frozen “fence in the woods”; shaking shards of ice from birch trees; and “tapping” on metal drums “with [his] fingers” (p. 14). These acts of creative play kept the lonely blind boy engaged at a time in which the world at large was unwilling to accept those with disabilities.

To further explore the matter, in an essay from Part one of *Eavesdropping* called “Birds” (pp. 10-12), and in the late composition “The Twa Corbies” (147-154) appearing in Part two (“Walking by Ear”), the essayist goes independently as a young boy and an adult, respectively, into the woods in search of avian fellow creatures. Similarly, in a late essay entitled “Skull Flowers” (155-156), he sits still in the open, listening to the denizens of the natural world, like a purple martin diving to catch “an errant hornet” (p. 155). These experiences of isolation, which prisoners and the disabled alike share, may give rise to art (Villoro, 2020), and provide models for coping with loneliness during lockdowns. They may also cause people who are not disabled to view reasonable accommodations for those with disabilities as just that, reasonable, and as something that could benefit society as a whole. However, as Shenaz Patel reminds us (2020), creative responses to the pandemic should not ignore the despair of people who lost their loved ones to the Coronavirus, or whose survival became precarious in the difficult economic circumstances during the pandemic. Leah Lakshmi Piepzna-Samarasinha goes further in an article published October 1, 2022 on Truthout and severely criticizes the U.S. establishment for trying to suppress the memory of COVID; she calls on abled-bodied leftists to never forget the disabled and the millions who died from the disease and urges that both abled and disabled people join in solidarity to achieve the revolutionary possibilities in disability accommodation that the pandemic made evident.

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“The Only Disability in Life Is a Bad Attitude”:

So-Called “Inspirational” Media in The Age of Trump

Eve Bohakel Lee[1], Amy Lein[2], Kyle S. Barnett[3], and Moira O’Keeffe[4]

[1]Bellarmine University
[2]School of Education, Bellarmine University
[3]Department of Communication, Bellarmine University
[4]Department of Communication, Bellarmine University

Author Note

Eve Bohakel Lee is a 2021 graduate of the Master of Arts in Communication program at Bellarmine University. Amy Lein is an assistant professor of special education in the School of Education at Bellarmine University. Kyle S. Barnett is an associate professor of media studies in the Department of Communication at Bellarmine University. Moira O’Keeffe is an associate professor of communication in the Department of Communication at Bellarmine University.

Abstract

This study explores the reactions of ideologically divergent social media users to so-called "inspiration porn." The objective of this study is to describe an observed association between the popularity of inspiration Porn and the political, religious, educational, and disability-related social identities of those adults who consume it. The article takes a quantitative approach to analyze which religious, and socio-economical groups of people support and share inspirational porn of people with disabilities. It should be understood that these forms of media harm people with disabilities and neglect to help them in their true integration to society as a whole.

Keywords: inspiration porn, politics, Facebook

“The Only Disability in Life Is a Bad Attitude”: So-Called “Inspirational” Media in The Age of Trump

This study explores the divergence between American conservatives and liberals surrounding the social media consumption of what disability activist Stella Young called “inspiration porn”: depictions of people with physical disabilities doing unexpected things—unexpected in that many nondisabled or bodily typical people underestimate their abilities to live independently, raise a family, pursue hobbies, or partake in athletic activities (Young, 2014). One example is a picture of an elite athlete who happens to be an amputee, and often accompanied by a quote such as one made famous by Olympic figure skater Scott Hamilton: “The only disability in life is a bad attitude” (The Associated Press, 1997, p. B18).

As a matter of self-identification, liberals traditionally support social programs to remove barriers that promote inequality and are known for being more broad-minded regarding gender roles and philosophies. Alternatively, conservatives are more identified with laws and customs promoting adherence to traditional gender roles, Judeo-Christian morality, patriotism and nationalism, and limited government intervention. This extends to the saving of federal monies by cutting into health and social services spending, including Supplemental Security Income for disabled Americans (Rappeport and Haberman, 2020). The hypothesis is that, with these differences in mind, conservatives are more likely than liberals to positively respond due to this internalized ableism. This prediction is based on Nario-Redmond’s “A, B, C’s of ableism: affective emotions or attitudinal reactions; behavioral actions/practices; and cognitive beliefs/stereotypes that go beyond general negativity” (Nario-Redmond, 2020, p. 6). Similarly, these three attributes contribute to what makes an image of a disabled or nontypical person become inspiration porn.

There is also the question of the concomitant characteristics of education and religion on this interaction—that Donald Trump's base of less educated, evangelical Christian conservatives (Tyson, 2018) are fonder of inspiration porn as seen on Facebook than their more liberal, more educated, and nonevangelical counterparts. The prediction is that those most liable to interact with the media fit the profile of a Trump supporter—even when Trump himself hardly is a traditional conservative. This is because of the base's tendency to espouse a religious belief in extra-scientific phenomena (Packer & Oden, 2004); favor limited government and self-reliance (The Heritage Foundation, n.d.); and fit the traditional image of workers taking pride in challenging physical labor as a means to improve one's circumstances, as opposed to a job that may involve less physical exertion but require higher levels of formal education (Express Employment Professionals, 2018).

Stigma and Supercrips

Stigma lies at both the root and as a manifestation of the social model of disability. Goffman (1963) described the difference between the *virtual social identity* (what one might assume another person to be like) and the *actual social identity* (the person's actual attributes). He then discredited the use of attributes to describe a person—congruent with what Young spoke of when she cited the medical model, which puts the responsibility on disabled individuals to adapt to mainstream society—in favor of relationships, à la the social model, which compels society to accommodate everybody regardless of ability (Young, 2014). However, he acknowledged, despite social conventions dictating benevolence toward disabled persons, the belief remains that they are less than human. Rationalization ensues: "We tend to impute a wide range of imperfections on the basis of the original one, and at the same time to impute some desirable but undesired attributes, often of a supernatural cast" (Goffman, 1963, p. 5). The resulting archetype is the "supercrip"—a disabled person who is "inspiring to others because they have achieved success against all odds (or above what most expect from them)" (Nario-Redmond, 2020, p. 103). These images, particularly when coupled with a pithy caption, communicate the fallacy that an extra bit of effort and a positive attitude can vanquish any challenge that people with disabilities face in life based on their given disability.

These mediated triumphs do not mean that the stigma is gone. Societies, particularly during times of strong nationalistic sentiment, have flirted with eugenics, championing a body politic comprised of physically robust citizens; weak bodies, after all, beget a weak regime (Davis, 1995). Stigma, in the form of fear, stereotyping, and social control, motivates societies to marginalize their weakest members (Coleman-Brown, 1986). Interestingly, political conservatives are more likely to champion the ideal of physical superiority (Nario-Redmond, 2020), seeking to limit the physical and social mobility of disabled persons.

Sincerity and Performance in Conservative Action

While Trump uses disparaging rhetoric on social media and at rallies directed at, among others, disabled persons, his supporters do not appear to mind, justifying his malevolence as "un-P.C." or "telling it like it is" (*USA Today*, 2016). However, many of those same supporters, when faced with the image of a disabled person "overcoming" a challenge, will not insult the person on social media but "like," share, or leave a comment intended to convey a positive, heartfelt, and life-affirming recognition of shared humanity. In doing this, they rationalize that they are not following Trump's example of stigmatizing other humans to make themselves feel better about themselves. Alternately, inspiration porn consumers can be engaging in "slacktivism"—performative displays of support or awareness through nominal effort, such as simply "liking" a post.

Inspiration porn is designed to be seen and shared. If somebody "likes," shares, or comments on a post, it is possible that that person's Facebook friends will see it on their own feeds; they almost certainly will if they visit that person's page. Often accompanied by platitudes drawing attention to the novelty of the subjects' actions or perceived attitudes, they become spectacle for the nondisabled or typical viewer, evoking emotions such as wonder, pity, gratitude, or self-reproach that moves some social media users to interact with these image-caption combinations, ensuring the propagation of the media far and wide among the users' networks.

A peculiarity of the Trump-era Republican Party is its inflammatory rhetoric fueling suspicion of outsiders, dissolution of aid for disabled and underclass Americans, and allegiance to a Christian identity. Three-quarters of the white evangelical vote—20% of the overall electorate—voted for Trump in the 2016 presidential election (Pew Research Center, 2018), allowing the real-life media phenomenon the power to spread his message far and wide as well. More than half of American adults get at least some of their news from social media (Shearer & Grieco, 2019)—but those who rely on social media *primarily* for news are more likely to be exposed to content not necessarily based in fact (Mitchell et al., 2020). This polarized media landscape mirrors a polarized America.

Dissonance, Framing, and Resonance

While the Americans with Disabilities Act of 1990 prohibits disability-based discrimination in sectors ranging from employment to transportation to commercial facilities to education (U.S. Department of Justice, 2020), in practice the enforcement of this law "creates the impression that individuals who receive accommodations are recipients of special treatment or welfare" (Bogart & Dunn, 2019, p. 658). This impression exists among many bodily typical people who, when faced with a disabled person in public, paper over their annoyance—even resentment—with a smile, as opposed to true acceptance.

The incongruity between American conservatives' personal reactions to disabled bodies in media and their Christian charity (in a shared humanity sense if not a financial or even religious one) has not yet been explored. To do so would complement the formidable body of work documenting this unprecedented time in American history, adding color to the narrative of Trump-era communication—even if the communication originates as an electronic transmission from thousands of miles away, subsequently translating into interpersonal discourse and even policy formation when citizens vote (or abstain from voting).

An event that effects a change in how humans perceive, categorize, and interpret the world around them is what Goffman called the "astounding complex" (1974, p. 28). Something amazing happens, and—similar to Festinger's concept of cognitive dissonance (1957)—to fit everything into the tidy frame they have created, people expect resolution. In the inspiration porn narrative, the crowd-pleasing happy ending shows the person depicted "overcoming" their disability, and the specter of ableism is pushed out of the audience's mind because there is no disability here—as disability does not fit into this frame of "normal."

Complicating this personal frame design is the concomitant existence of social frameworks (Goffman, 1974), which are subject to manipulation by others, forcing humans to adapt their frames as they recognize and are recognized by others in their social circle—in this case, those who share a common political ideology. Giorgi (2017) broke down this mutual recognition into cognitive resonance and emotional resonance—alignment that is perceived vs. alignment that is felt. However, she posited that challenges can exist in the form of a person's life experiences or how the situation sits between the framer and the frame. All of these disturbed resonances, accordingly, result in dissonance; although cognitive dissonance—the head—is more familiarly cited, it is emotion—the heart—that moves people to impulsively "like," comment, and share on social media. While not impossible, is harder to plug a hole in emotional resonance with cognition than with more emotion. It is this path of least resistance that Trump uses to his advantage.

Method

With political affiliation hypothesized to be the most important predictor of interaction with online inspiration porn, participants were recruited based on their partiality to conservative or liberal ideologies. Along with this overarching category, the primary interests of investigation were those most associated with the political divide: religious (or belief) worldview, and educational level. Disability status was also included; although socially and politically agnostic, it can affect a person's attitude regarding disability in others.

The main author chose this topic—based on an original graduate thesis—due to interest in disability studies, communication studies, and social media. The coauthors, members of the thesis committee, were chosen for their expertise in communications, as well as with research design and analysis.

Participants

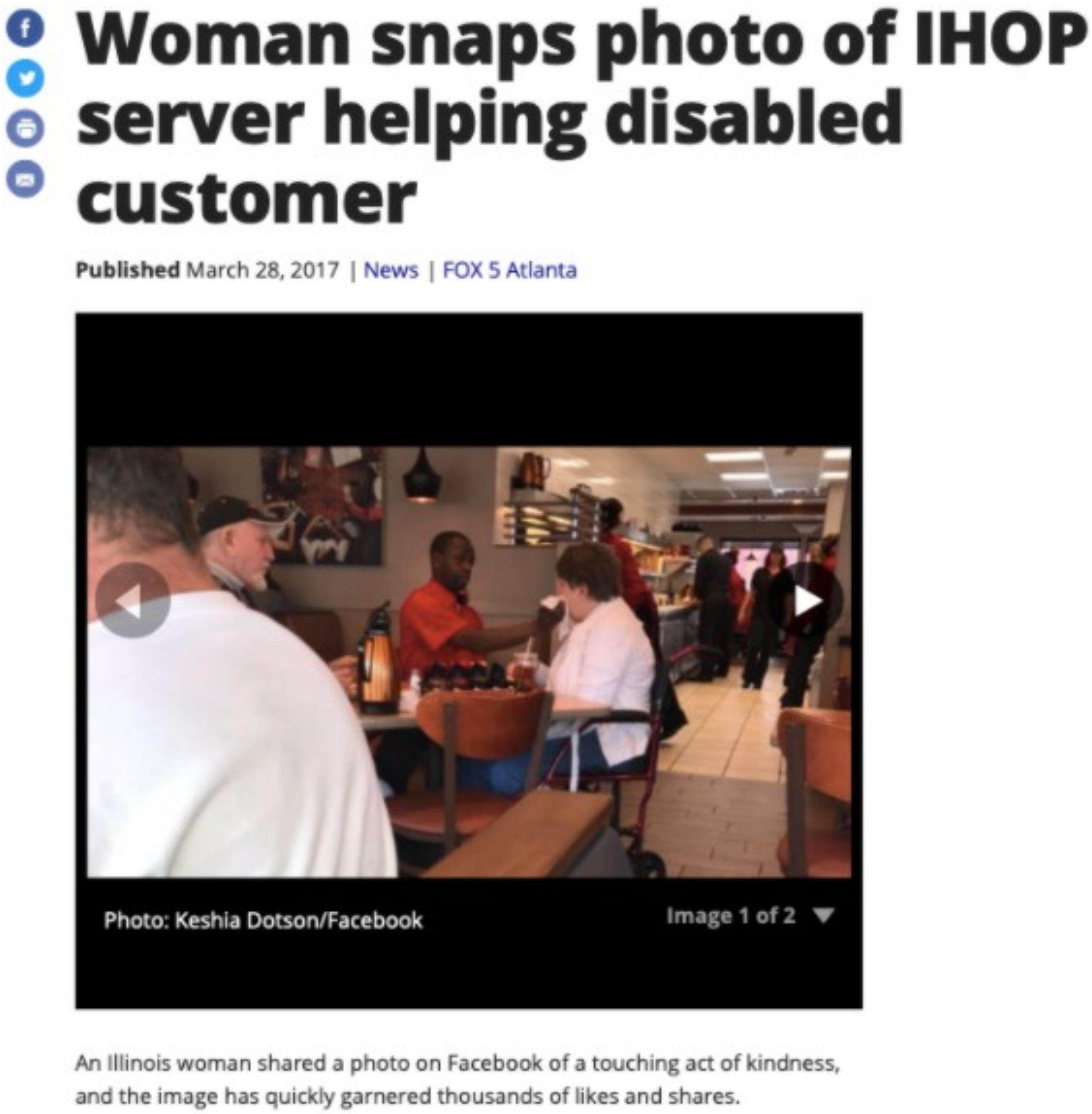
A total of 800 workers recruited through the Mechanical Turk (MTurk) data collection platform—400 conservatives and 400 liberals, all Facebook account users living in the United States—completed the study, which took place in mid-2020. Exactly 400 members of each political affiliation were permitted, screened ahead of time through their own self-identification to MTurk.

Procedure

Survey respondents were provided with three real image-caption "posts" as seen on Facebook (Figures 1–3) and, using a five-point Likert scale (Not at all, A little, Somewhat, Quite a bit, A lot), rated their potential for engagement and their emotional reactions. Engagement actions included "'Like,'" "Share," "Leave a positive comment," and "Leave a negative comment"; possible emotions included feeling "Inspired," "Irritated," "Lucky," and "Manipulated." Finally, participants reported their sex or gender identity, age bracket, race or ethnicity, religious or faith tradition, highest educational level completed, and disability status (including that of themselves and of family members—defined as a parent, spouse or partner, child, sibling, grandparent, grandchild, aunt, uncle, niece, or nephew—or close friends). Results were collected via the MTurk platform and nonidentifying user codes cross-checked against those provided by the participants at the end of the survey to ensure fidelity.

Figure 1

FOX 5 Atlanta (2017)



Woman snaps photo of IHOP server helping disabled customer

Published March 28, 2017 | News | FOX 5 Atlanta

Photo: Keshia Dotson/Facebook

Image 1 of 2

An Illinois woman shared a photo on Facebook of a touching act of kindness, and the image has quickly garnered thousands of likes and shares.

Figure 2

Spags (2015)

High School QB Keeping A Fourth Grade Promise To Take A Girl With Downs Syndrome To Prom Is Just An Awesome Dude

Chris Spags
5/13/2015 5:25 PM

Figure 3

Brainfuel Solutions (2020)

Results

The following sections examine response patterns within salient demographic categories (e.g., political affiliation, religious or faith tradition, education, and disability status). In reviewing the data, categories of “Not at all” and “A little” were collapsed into the category of “Unlikely.” Responses of “Quite a bit” and “A lot” were collapsed into “Probably.” The “Somewhat” answer was treated as a neutral response.

Participants

Along gender lines, the overall sample was 52.6% female (52.7% conservative, 47.3% liberal), 46.5% male (47.6% conservative, 52.4% liberal), and 0.9% who identified as other/nonbinary (14.3% conservative, 85.7% liberal). Younger adults (18 to 39 years old) represented 53.9% of the sample (42.9% conservative, 57.1% liberal), and adults 40 and older made up 46.1% (58.3% conservative, 41.7% liberal).

Most respondents reported their race or ethnicity as white (79.1%, including 52.6% conservative and 47.4% liberal), 6.8% Black or African American (31.5% conservative, 68.5% liberal), 5.9% Asian (including South Asian) (38.3% conservative, 61.7% liberal), 3.1% Hispanic/Latinx (28.0% conservative, 72.0% liberal), 3.0% multiracial (50.0% conservative, 50.0% liberal), 2.0% Native American or Alaska native (81.3% conservative, 18.8% liberal), and 0.1% declining to answer (0.0% conservative, 100.0% liberal).

Concerning belief systems, 29.4% reported being agnostic or atheist (19.1% conservative, 80.9% liberal), 20.6% Catholic (66.1% conservative, 33.9% liberal), 19.5% nonevangelical Protestant (66.0% conservative, 34.0% liberal), 14.2% evangelical Christian (85.1% conservative, 14.9% liberal), 8.8% spiritual but not religious (40.0% conservative, 60.0% liberal), 1.4% non-Orthodox Jewish (9.1% conservative, 90.9% liberal), 0.9% Mormon/LDS (85.7% conservative, 14.3% liberal), 0.6% Muslim (20.0% conservative, 80.0% liberal), 0.3% Orthodox Jewish (0.0% conservative, 100.0% liberal), and 4.4% other or declining to answer (28.6% conservative, 71.4% liberal).

Regarding the highest educational level reached, 41.4% of respondents reported having a bachelor's degree (50.2% conservative, 49.8% liberal), 18.1% a master's degree (45.5% conservative, 54.5% liberal), 15.6% some college but no degree (48.0% conservative, 52.0% liberal), 12.6% an associate degree (46.5% conservative, 53.5% liberal), 8.3% a high school education or less (66.7% conservative, 33.3% liberal), 2.1% a doctoral degree (47.1% conservative, 52.9% liberal), 1.8% a professional or vocational certificate (64.3% conservative, 35.7% liberal), and 0.1% other or declining to answer (0.0% conservative, 100.0% liberal).

One final demographic question centered on personal experience with disability, either firsthand, with a close personal contact (defined as a parent, spouse or partner, child, sibling, grandparent, grandchild, aunt, uncle, niece, nephew, or close friend), or both. Nearly two-thirds, or 62.6%, reported having no close contacts living with a disability (46.7% conservative, 53.3% liberal); 24.3% reported at least one family member or close friend but not themselves (57.7% conservative, 42.3% liberal), 6.1% reported themselves only (51.0% conservative, 49.0% liberal), 5.6% reported themselves and at least one personal contact (53.3% conservative, 46.7% liberal), and 1.4% declined to answer (45.5% conservative, 54.5% liberal).

Respondents largely felt strongly about their preference to react positively, but very few reported a likelihood to leave a negative comment, feel irritated, or feel manipulated: Those responses represented less than 4% in each category.

Political Affiliation

Overall, out of the 800 respondents, 44.6% (59.1% conservative, 40.9% liberal) reported they would probably “like” the media presented, 21.3% (62.9% conservative, 37.1% liberal) probably would share it, 28.9% (60.2% conservative, 39.8% liberal) probably would leave a positive comment, 43.8% (60.6% conservative, 38.4% liberal) probably would feel inspired, and 15.4% (66.7% conservative, 33.3% liberal) probably would feel lucky.

Religious or Faith Tradition

Categories included agnostic or atheist, Catholic, evangelical Christian, Jewish (Orthodox), Jewish (other), Mormon/LDS, Muslim, Protestant (other), spiritual but not religious, and other/prefer not to answer. Those religious traditions with fewer than 5.0% of respondents represented were collapsed along with other/prefer not to answer, adding up to 7.5% of all respondents; 8.8% of respondents identified as spiritual but not religious. Conservatives and liberals were broadly represented among Catholics (20.6% of all respondents) and mainstream/nonevangelical Protestants (19.5% of the total); however, the groups with agnostics and atheists (29.4%) and evangelicals (14.3%) were notable in that the former group was largely liberal and the latter group largely conservative.

Like

Evangelical Christians reported at a rate of 56.1% (64 out of 114 with that faith) that they probably would “like” the media presented, the highest of all the belief groups. Although evangelical Christians comprised 14.3% of all respondents (114 out of 800), including 24.3% of conservatives, among those 64 respondents who reported that they probably would “like” the media, 56—or 87.5%—were conservatives. This was a larger proportion of conservatives than seen in any other denomination, including Catholics (69.7% of conservatives vs. 30.3% of liberals in the “like” group, or 53.9% of all Catholic respondents) or nonevangelical

Protestants (66.7% conservatives vs. 33.3% liberals, with 50.0% of all nonevangelical respondents probably "liking" the media). Agnostics and atheists, while accounting for 29.4% of the total and the largest liberal bloc in the sample, said they probably would "like" the media presented at a rate of 29.8%—the lowest rate among all respondents surveyed. About one in eight (12.3%) evangelical Christians explicitly reported that they were unlikely to "like" the media presented; at the other end of the spectrum, about one in three (35.3%) agnostics and atheists reported the same sentiment.

Share

Evangelical Christians most favored sharing the media (33.3%), second only to Catholics (35.8%); among those denominations' members who said they probably would share, most were conservative (almost nine out of 10 evangelicals and a little more than seven out of 10 Catholics identified as conservative). Agnostics and atheists were the least likely to report that they probably would share (8.1%). Of those who specifically reported being unlikely to share, agnostics and atheists had the highest numbers (76.2%), and 43.0% of evangelical Christians explicitly reported that they were unlikely to share the media presented—more than the Catholics' response in that area (35.8%), but fewer than among the other denominations.

Positive comment

Compared with other religious affiliations, evangelical Christians were less likely to report that they probably would leave a positive comment: 37.7%, vs. 41.8% of Catholics and 40.0% of combined other religions. Among the 37.7% of evangelical respondents who said they probably would leave a positive comment, 83.7% identified as conservative. The opposite tendency was similarly reflected: 34.2% of evangelical respondents—82.1% of them conservative—stated they were unlikely to leave a positive comment. (The remaining 28.1%

were neutral.) All other groups reported at rates above 38.3% that they would not leave a positive comment, with the exception of the Catholic respondents (28.5%).

Inspiration

On the whole, 57.0% of Protestants—58.8% of evangelicals (86.6% conservative) and 55.8% of other Protestants (69.0% conservative)—reported that they probably would feel inspired by the media presented, making them the most likely to respond in this way. Agnostics and atheists were the least likely to feel inspired by the media (26.8% overall). About one out of 10 (9.6% overall) evangelicals specifically reported being unlikely to feel inspired, compared with 20.5% of all respondents across all denominations.

Lucky

Among conservatives, the likelihood of feeling lucky when observing the media presented was most salient in those respondents who identified as evangelical Protestants, at 17.5% (85.0% conservative), Catholics at 26.1% (79.1% conservative), and nonevangelical Protestants at 18.6% (62.1% conservative). More than half of those surveyed, or 53.6%, did not anticipate feeling lucky, ranging from Catholics (37.6%) and evangelicals (45.6%), to agnostics and atheists (70.6%).

Educational Level

The categories included high school education or less, professional or vocational certification, some college but no degree, associate degree, bachelor’s degree, master’s degree, doctoral degree, and other/prefer not to answer. The 66 with a high school education or less accounted for 8.3% of the total respondents; the associate, bachelor’s, master’s, and some college categories were collapsed into one (college educated), which represents 702, or 87.8%, of respondents; and doctoral degree holders and those with certifications were collapsed into a non majority category on account of their low numbers overall (17 and 14, respectively, or 2.1% and 1.8%). One person declined to self-identify. Politically, all groups were closely split between conservatives and liberals, with the exception of the high-school-or-less; this sector consisted of exactly twice as many conservatives as liberals—44 to 22.

Like

Respondents who reported having a high school education or less were the most likely to "like" the media (56.1%), and 75.7% of those who said they would probably "like" it were conservative. In the non majority education group, 37.5% were likely to say they would "like" the posts, with seven of the 12 respondents (58.3%) in the conservative group. Across all educational levels, relatively few of those with a high school education or less reported explicitly that they probably would not "like" the media (16.7%), with college-educated respondents at 26.2%.

Share

The percentage of respondents with a high school education or less who said they would probably share the media was 27.3%, and 72.2% of them were conservative. Across all educational levels, more conservatives than liberals were likely to share it. From that same high school demographic, 47.0% specifically said they were unlikely to share the media, contrasted with 62.5% in the education group consisting of those with doctoral degrees, technical or vocational certification, and other/decline to answer.

Positive comment

The respondents most likely to leave a positive comment were those with a high school education or less (36.7%, with 70.8% of them conservative); while the respondents least likely to leave a positive response were those with doctoral degrees, technical or vocational certificate, and other/decline to answer (21.9%, with five out of the seven respondents being conservative). Of those who expressly reported a lack of interest in leaving a positive comment, 59.4% of members of the non majority education group reported that they were unlikely to comment positively, as opposed to 46.0% of bachelor's degree holders.

Inspiration

Across all educational levels, more conservatives than liberals said they probably would feel inspired. More than half (59.1%) of respondents with a high school education or less reported that they probably would feel inspired, with three out of four (74.4%) of them identifying as conservative. In the other two educational groups, less than half of respondents reported that they would probably feel inspired; of those who reported they would feel inspired, 58.8% were conservative. Of respondents with high school educations or less, only 12.1% said they were unlikely to feel inspired, while 21.4% of those with college educations reported this unlikelihood.

Lucky

Slightly more than 15% of all respondents (123 out of 800) reported that the media presented probably would make them feel lucky. Across all educational levels, twice as many conservatives as liberals were likely to report that they would feel lucky. A quarter of respondents with a high school education or less reported they probably would feel lucky (25.8%), nearly eight out of nine them conservative, while a smaller amount (14.7%) of those with a college education reported the same feeling. More than half the respondents (53.6%) specifically reported that they would be unlikely to feel lucky; these respondents were relatively evenly distributed across both political affiliations and educational levels.

Disability Status

There were four categories regarding disability status: None (neither oneself nor a family member or close friend living with a disability), Yes (oneself only), Yes (a family member or close friend, but not oneself), and Yes (both oneself and a family member or close friend). Because of important differences among the Yes categories, they were not collapsed.

Out of the 800 people surveyed, 501 (62.6%) said they neither had a disability nor had a close family member or friend with a disability. One hundred ninety-four (24.3%) reported having a family member or close friend with a disability but not themselves, 49 (6.1%) reported themselves only as having a disability, 45 (5.6%) reported both themselves and someone close to them as having a disability, and 11 (1.4%) declined to identify their status.

Like

Of people without experience of disability in their personal lives, whether in their own existence or that of a family member or close friend, 39.7% (199 out of 501) reported that they probably would “like” the media presented, with 58.3% of those identifying as politically conservative. Of those with a close contact living with a disability, 55.2% answered that they probably would “like” the media; 63.6% of those were conservative). Over half (55.2%) of those who reported having a disability themselves probably would “like” it and 48.1% of those respondents were conservative. Under half (42.2%) of those with a disability themselves and someone close to them also with a disability reported that they probably would “like” the media; of those respondents, 63.2% were conservative. Respondents who were the only persons in their circle living with a disability doubted the most that they would “like” it (10.2%), and those without a close experience were nearly three times as likely to avoid hitting the “like” button (29.1%).

Share

Of the 170 respondents who said they probably would share the media on Facebook, percentages ranged from 16.4% (64.6% conservative) who did not have a personal experience of disability, to 38.8% (63.2% conservative) who had a disability but no similar close contact.

Respondents living with a disability but without also affected close contacts doubted the least that they would share (24.5%), vs. 63.3% among those without personal disability experience.

Positive comment

Those who reported that they probably would leave a positive comment ranged from 23.4% among those with no personal disability experience up to 49.0% from those having a disability themselves (54.2% conservative), but with no one else in their immediate group having a disability. The only group where liberals outnumbered conservatives was the one composed of respondents who declined to note their disability status, and that group numbered only three respondents. Regarding the unlikelihood of leaving a positive comment, those reporting no disability experience had the highest numbers (54.1%), as opposed to persons living with disabilities without anyone else close to them, declined to leave a positive comment (20.4%).

Inspiration

The only discrete group (that is, of those who supplied an answer) that saw more than half (51.0%) probably feeling inspired was of those individuals living with a disability themselves but lacking friends or family members who do; respondents in this group were split nearly evenly between conservatives and liberals (48.0% to 52.0%, respectively). On the other end of the spectrum, 38.9% of those who reported that neither they nor anyone close to them was living with a disability said that they probably would feel inspired when viewing the media presented; 60.5% were conservative, congruent with the overall political slant of those who felt that way. Those who reported having a family member or close friend with a disability—either separately or in conjunction with their own personal experience—and 58.7% of those who answered affirmatively were conservative. More than one in five respondents said they would be unlikely to feel inspired when viewing the media presented, ranging from 13.9% of those who both experienced disability firsthand and had a disabled person in their lives, to 24.0% of those without any of that experience. (More than a third who answered as such declined to identify their status; however, that group consisted of only 11 individuals.)

Lucky

Among those who reported that they probably would feel lucky looking at the media presented, the distribution of disability identity and political ideology was similar to those who said they probably would feel inspired. Percentages of respondents who specifically reported that they were unlikely to feel lucky upon viewing the media presented ranged from 40.0% of those living with a disability along with a family member or close friend with a disability, to 58.3% of those with no one disabled in their personal network.

Discussion

A Note on Labels

Although “conservative” does not always equal “Republican” and “liberal” does not always equal “Democrat,” the alignment of the two tend to parallel each other ideologically in American politics. With that in mind, comparisons of this study’s data with external survey data will assume ideological alignment.

Characteristics of Inspiration Porn Consumers in this Study

As predicted in the hypothesis, reactions to the media varied between conservative and liberal participants, with conservative evangelical Christians without a college education reacting most positively. Without individual interviews or more extensive questioning, it is impossible to fully know the motivations of those who predicted they might “like,” share, or leave a positive comment, or why they felt a particular way. This part of the discussion will focus on the characteristics of religious tradition, education, and disability status most salient in conservative respondents.

The scarcity of published work on this specific topic of inspiration porn and persons representing these particular social demographics makes it ripe for investigation. Many people who voted for Donald Trump, as an article of faith, consider themselves Christians, with 77% of white evangelicals (20% of the overall electorate) casting their ballots for him in 2016 (Pew Research Center, 2018). Along with social media playing such a significant role in powering the Trump juggernaut, it also has served to facilitate the sharing of stories (true and false) and images (still and video).

The AARP cited research suggesting the growth of the social media site Facebook among Americans 55 and over (Schaffel, 2018); Trump, similarly, was more popular than Democrat Hillary Clinton in both the 50-to-64 and 65-and-over demographics (Pew Research Center, 2018). This potential overlap of older Americans, Facebook users, conservative voters, and white evangelicals suggests that people who identify with at least one of these groups are more likely to share inspiration porn images and videos than people who hold liberal or nonevangelical ideologies (or both).

Prominent Characteristics of the Most Likely Inspiration Porn Consumers

The most salient characteristics of those participants with the greatest likelihood of positively interacting with the inspiration porn—that is, “liking,” sharing, leaving a positive comment, or a combination of these three—were conservative political affiliation; evangelical Christianity; an education limited to high school; and a close personal experience with disability. This section will explore these prominent characteristics and pose questions based on those identities, calling to account those participants' inspiration porn consumption.

Evangelical Christianity. Evangelical Christianity appears to be a dominant identity among politically conservative Americans (as seen with 24.3% of conservative participants) when compared with political liberals (4.3% of liberal participants). Conservative religious communities are known for a strong sense of tradition, family, and faith—in God, in leaders, and often an inextricable mixture of the two. This ethos can manifest in an acceptance of their situation here on earth and the anticipation of a rewarding afterlife; trust in paternalistic government leadership; and resistance to change, particularly regarding social issues. Further, there is a belief in extra-scientific cures as a very present and plausible article of their faith, which is rooted in the evangelical belief in Christ's power at work.

Even more prevalent among liberal Americans is a profession of agnosticism or atheism. Although these participants appear on the surface to be the ideological opposite of evangelical Christians, nearly three out of 10 (29.8%) agnostics and atheists overall did report a likelihood of "liking" the media presented—and more than one out of four (26.8%) reported at least a probable twinge of inspiration. Clearly, the absence of a religious identity or belief does not preclude feeling cheered—even inspired—when witnessing the triumphs of one's fellow human.

Limited Formal Education. Self-reliance is another tenet of political conservatism, as opposed to the so-called "social safety net" embodied in American liberal society by laws benefiting those affected by poverty, disabilities, job loss, and so on—but also working parents, retirees, and those seeking affordable health insurance or assistance with college tuition. While conservatives also avail themselves of these options, a culture of individual independence runs deep in the conservative psyche.

The proud American tradition of hard work is seen across the nation, but areas dominated by blue-collar industry in particular tend to run conservative. A poll from staffing company Express Employment Professionals (2018) found that both skilled and unskilled laborers, regardless of political affiliation, tend to regard the Republican Party as better for business and blue-collar Americans than the Democratic Party. Blue-collar occupations often involve on-the-job training that does not require postsecondary education. Thus, when industry trends change, many such workers are hesitant to change their profession because of a limited skill set.

Conversely, it stands to reason that the more education one has, the more likely that person will be to live in an area with greater opportunities for positive social and economic mobility, be more aware of myriad concerns that may not visibly affect more insular communities, and exercise agility when those opportunities and concerns demand adaptation.

Despite the achievement of a college education among both conservatives in liberals in this study, the specific achievements varied widely: While liberals were almost 20% more likely than conservatives to hold a master’s degree, they were also 8% more likely than to have attended some college but not earned a degree. It is notable that exactly twice as many conservatives than liberals surveyed for this study reported having a high school diploma or less (11% vs. 5.5%). While it is reasonable to expect this educational level among very young adults (all participants were 18 and older), the distribution of participants with a maximum educational level of high school is rather constant once the mid-20s are reached.

Elevated Incidence of Disability. Continuing the association between low education and blue-collar work, the higher percentage of conservatives with disability experience among those surveyed overall was not unexpected. Not only do certain professions—

particularly in conservative areas, or those professions which require noncollege training—have a higher incidence of worker injury, but there also is an overlap between areas where such factors are prevalent and citizens' health is failing. Rates of smoking, obesity, heart disease, and diabetes are greater in the typically conservative-leaning Southern states than in the rest of the country (United Health Foundation, 2019). Areas with higher rates of Social Security disability benefit payments are marked by a population that is less educated and likelier to go into physically demanding blue-collar industry—and older and prone to age-related conditions—than the rest of the country (Ruffing, 2015).

Among disabled social media users, the interaction with inspiration porn might be regarded as more inspiring and less pornographic—a genuinely uplifting, nonpatronizing action. For them, perhaps "The only disability in life is a bad attitude" is a healthy mindset to have, but realistically there is more to it than outlook . . . and yet, perhaps, they feel buoyed by these media.

More than a third of the overall sample reported themselves or a close family member or friend as living with a disability. Conservatives were more likely to disclose the presence of disability of themselves only, a close family member or friend, or both. Although liberals were less likely to positively interact with the media presented, the incidence of positive interaction was higher among those with a personal experience with disability overall.

Theoretical Frameworks and Contradictions in Inspiration Porn Consumption

Framing Theory

In understanding the appeal of inspiration porn, it is helpful to revisit framing theory and its role in consumer perceptions. Because humans naturally tend to associate with others with similar values and tastes, the mere existence of a particular social media artifact on a contact's Facebook page may serve as an endorsement, a recommendation, or even an urgent call to action.

Cognitive Dissonance

The contradictions or competing situations that create a feeling of emotional disagreement or disequilibrium result in what Festinger (1957) described as "cognitive dissonance" that demands resolution. This is done by denying the appeal of at least one of the discomforting factors and then making every effort to avoid that discomfort in the future.

This is where the real contradiction of conservative Trump voters and inspiration porn comes in. The concept of rugged individualism always has been paramount in the American story, and the appeal of inspiration porn can be explained through that lens—that grit can propel one over most any obstacle, including physical disability—regardless of political affiliation. For many, Trump offends on a personal level with his denigrative remarks about Christian practices, such as when he referred to communion as "my little cracker" (CNN, 2015a, 2:30); with his predatory "Trump University" that swindled some 5,000 customers in search of a better life out of nearly $1,500 each (Tuttle, 2016); and with his mockery of those with disabilities, notoriously when he caricatured disabled reporter Serge Kovaleski (CNN, 2015b) at a 2015 rally. Paradoxically, instead of alienating his base—with many religious, undereducated, and disability payment-receiving Americans at its bedrock—Trump made them feel they belonged. Instead of holding up a mirror for them to see themselves as the target of his mockery, he held up a frame—their frame—through which they saw him in the same picture with them, together deserving of the power he had finally seized for them.

Limitations

Education. The Pew Research Center (2020) reported that among voters with a high school education or less, 48% identified as Republican and 44% as Democrat. This represented a more even split than in this survey, which had 66.7% of those at that educational level being conservative and 33.3% as liberal. Further, those without college experience represented 33% of registered voters at the national level, and 8.25% in this study. This gap reveals a limitation in the participant recruitment; approximately seven out of eight reported having some college or other training, compared with two out of three at the national level.

Disability. Other demographic information differed between the survey participants and Americans nationally. Although 61.4 million American adults (25.7%) live with a disability (Centers for Disease Control and Prevention, 2018), this survey's participants reported 6.1% for themselves. Those who reported that they did not have a disability—including those with a close contact who did—amounted to 86.9% of the survey participants. The variation may be at least partially explained by the fact that more than half of the participants were age 39 or younger; although disability can happen at any age, many people face disability for the first time later in life. This also aligns with the educational attainment differences between this study's participants and the general public; as more undereducated people are likely to work in physically risky fields, the more likely they are to become physically disabled on the job.

Age. The favoring of younger participants (53.9% were 39 and younger) appears to be approximately consistent with the makeup of the United States population, with 60.6% under the age of 45 as of the 2010 census (Howden & Meyer, 2011).

Other Limitations. Study limitations stem mainly from the opt-in nature of the survey. Although the purposively sampled group of 800 participants is not random but instead composed of individuals who elected to join the study, Clifford et al. (2015) suggested that from a political and psychological disposition standpoint, there is great congruence between MTurk workers and the general population as measured by samples from American National Election Studies benchmark data.

Three key demographic groups were underrepresented in the current study as compared to national demographic data. Specifically, only 3.1% of survey participants identified as Hispanic/Latinx as compared to 18.5% nationally; and only 6.8% of participants identified as Black or African American compared to the national average of 13.4%. Lastly, evangelical Christians were underrepresented in the survey compared with the general population (14.2% vs. 25.4%), according to the United States Census Bureau (n.d.). This underrepresentation must be taken into consideration when attempting to generalize results of this study to the larger population.

We identified two interesting overrepresentations regarding ethnic breakdowns along party lines: three times as many conservative Black or African-American participants (31.5%) as compared to the national average (10%), and twice as many conservative Asian-identified participants (38.3%) as compared to the national average (17%). Therefore, it may be difficult to make comparisons to national data without first considering the participants' race/ethnic background.

Conclusion

These findings raise questions about the incongruity of those who consume inspiration porn the most with their personal convictions. Certainly, conservatives and likely Trump voters have their reasons. It is easy to compartmentalize, to separate a person's words and actions from what one believes that person to be like deep down. When one of his supporters shares a video of a teenager with Down syndrome doing ordinary things and appends a phrase about how inspirational it is, chances are the now-former president has no place in that compartment. And, when Trump uses ableist rhetoric to put down an opponent—attacking the other person's energy level, mental faculties, or sanity—it is possible for some people to get swept up in the moment, perhaps smile, agree that he is saying what everyone is thinking . . . and give silent thanks for not being as bad off as his rival.

It is important to point out that this survey represents a snapshot in time marked by three major global events with American epicenters—widespread unrest regarding the violent treatment of Black Americans by law enforcement, the COVID-19 pandemic, and economic recession—that continue to polarize the nation along political lines. As the new administration seeks to mend these formidable divisions in the American social fabric (including COVID-induced chronic illness and disability issues) (Biden, 2021), future replication of this study should remain of interest—albeit with potential for differing outcomes.

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Dissertation & Abstracts v18i4 & v19i1

Raphael Raphael

University of Hawaiʻi at Mānoa

Abstract

The following provides a listing of select recent citations of dissertations and theses relevant to disability studies.

Keywords: disability, disability studies, dissertations

Kryger, K. (2023). *Challenging Neuronormativity: A Disability Studies Framework for Communal Justice in Writing Assessment* (Order No. 30485955). [Dissertation: The University of Arizona]. ProQuest Dissertations & Theses Global. (2829333459).

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Conference Announcement: 39th Annual Pacific Rim International Conference on Disability & Diversity, February 27 and February 28, 2024

Sandra Oshiro

Center on Disability Studies, University of Hawaiʻi at Mānoa

Abstract

This article announces the 39th Annual Pacific Rim International Conference on Disability and Diversity organized by the Center on Disability Studies, College of Education, University of Hawaiʻi at Mānoa.

Keywords: conference, disability, diversity

Conference Announcement: 39th Annual Pacific Rim International Conference on Disability & Diversity, February 27 and February 28, 2024

The 39th Annual Pacific Rim International Conference on Disability and Diversity runs from February 27 to February 28, 2024 (HST) at the Hawaiʻi Convention Center in Honolulu, Hawaiʻi. Organized by the Center on Disability Studies, College of Education, University of Hawaiʻi at Mānoa, the conference offers participants both in-person and virtual options and provides opportunities for deep and lively exchanges of ideas and practices to further global disability rights and support.

This year's theme, "Beyond Access: Building a Culture of Belonging," recognizes the progress achieved thus far as well as the ongoing challenge in developing communities that fully encourage inclusion and actively expand opportunities for all.

Several pre-conference and post-conference events are planned, among them a virtual international forum, "Conversations on Disability Studies," set for February 26, 2024, 9 a.m. to 3 p.m. (HST), and the 2nd Annual Summit on Employment First scheduled on February 29, 2024, 8:30 a.m. to 4 p.m. (HST).

Join our gathering of people with disabilities, advocates, policymakers, global scholars, practitioners, educators, students, family members, and businesses as we collectively define and help to create a culture of belonging in our schools, universities, workplaces, healthcare systems, and communities.

To register and learn more about the conference, please visit the Pacific Rim website.

The *Review of Disability Studies: An International Journal* will be publishing the conference proceedings in coming months.