

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

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### **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 23<sup>rd</sup> 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 disproportionately 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 (%)
<b>Gender</b>	
Male	12 (54.5)

Female	10 (45.5)
<b>Age</b>	
18-29	8 (36.4)
30-54	4 (18.2)
55-70	10 (45.5)
<b>Disability Type</b>	
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)

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### *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 23<sup>rd</sup> 2020 on LingXi360.com, a Chinese questionnaire management platform. We concluded this phase of data collection on October 3<sup>rd</sup> 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	<ol style="list-style-type: none"> <li>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.</li> <li>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.</li> </ol>
Community Living	<ol style="list-style-type: none"> <li>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.</li> <li>2. Train community workers on accessibility, disability rights, and knowledge of basic emergency responses to support vulnerable people with disabilities and seniors during evacuation.</li> </ol>

	<ol style="list-style-type: none"> <li>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.</li> <li>4. Enact a flexible policy to ensure independent living for people with disabilities, including allowing personal assistant services to continue with clear guidelines.</li> <li>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.</li> </ol>
<p>Employment and Financial Impact</p>	<ol style="list-style-type: none"> <li>1. Issue an emergency relief fund for people with disabilities.</li> <li>2. Add information about employers' accessibility infrastructure to job-listing websites.</li> <li>3. Offer stable stalls for street vendors with disabilities; expand philanthropy or disability service job opportunities for people with disabilities.</li> <li>4. Ensure reasonable accommodation for both online and offline employment.</li> <li>5. Mandate employers to plan and practice emergency evacuation for employers with disabilities.</li> </ol>

**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 1<sup>st</sup>, 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%)

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