

## VOICES FROM THE FIELD

### **Emergency volunteer support for PWDs in China during the COVID-19 pandemic: reflections on the work of an online civil response network**

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People with Disabilities (PWDs), particularly those from low-resource countries, face layers of challenges during disasters and pandemics. It is important to reflect on how PWDs have been treated in the COVID-19 pandemic. In response to the unmet needs of PWDs in China during the COVID-19 pandemic, a volunteer network, consisting of nearly half of PWDs, was formed. Through the network, we provided support to 272 PWDs. In this field reflection, we aim to 1) present the process of forming the network and the services provided, 2) and reflect on lessons learned from organizing and empowering PWDs during this pandemic. We found that what worked well was our efforts to ensure accessibility and our practice of supported decision-making. Although we reached a significant number of people in need within a short amount of time, many PWDs who are illiterate were likely not reached. Our reflections provide first-hand insights into how civil response coalitions can be formed to take actions during disasters and pandemics to meet marginalized group's unmet needs in low-resource countries. Future emergency response coalitions may consider reaching out to the health care and the formal disability service system, to reach more PWDs in need.

**Keywords:** COVID-19; China; Civil Response; Emergency Response.

#### **Introduction**

People with Disabilities (PWDs) are among the most vulnerable groups during the COVID-19 pandemic (National Center for Immunization and Respiratory Diseases, 2020; Zhou et al., 2020). As COVID-19 continues to spread globally, it is important to reflect on how PWDs have been treated. PWDs are often at elevated risk during natural disasters and pandemics (Jonkman et al., 2009; Tate et al., 2016). Having a disability, including chronic health conditions, increases the risk for severe COVID-19 (Chow et al., 2020). A recent report by UK's Office for National Statistics shows that PWDs are at significantly increased risk of death from COVID-19 (2021). Although the exact number of deaths of PWDs affected by COVID-19 globally is

unknown, literature has documented that PWDs experience multiple layers of disadvantages due to the disease itself and the lack of in-person services after the lockdown (Brennan, 2020). China has the largest documented number of PWDs in the world (approximately 85 million) (Zheng et al., 2011). As the original epicenter of COVID-19, China's disabled communities faced layers of challenges during the pandemic. Although China's fast economic development has advanced many people's quality of life, most PWDs still struggle with poverty (Guo et al., 2019). The majority of PWDs reside in under-developed rural areas where accessible infrastructure is limited (Chen et al., 2009). Despite the number of PWDs experiencing barriers and challenges even before the pandemic, there is limited literature documenting how the COVID-19 lockdown impacted their lives and how the civil society responded in support of their unmet needs.

The limited literature on how PWDs fair in disasters in China underscores the lack of action supporting this population during disasters. Fu and colleagues documented the unmet communication needs during the Sichuan earthquake in 2008 for PWDs (Fu et al., 2010). Ten years after the devastating earthquake, PWDs still face more severe consequences from disasters (Xu et al., 2021). During the COVID-19 pandemic, a 17-year-old teenager with cerebral palsy's death related to the lack of access to care stirred media and public reactions worldwide (Yan, 2020). The teen was left without any care even though his disability requires 24/7 assistance after his single father and younger brother with autism were taken away for quarantine. Despite the father's constant effort to arrange a caregiver, the teenager passed away after six days without proper care. The teen's death catalyzed civil society's response to support PWD's unmet needs during the pandemic. An emergency disability volunteer network was formed to reach PWD's in needs during the lockdown in February 2020. As key members of this group, the two authors had a critical conversation about the process and reflected on the process together. The first author asked key questions and documented the main themes of this conversation. In this field reflection, we aim to 1) present the process of forming the emergency response network, 2) and reflect on lessons learned from organizing and empowering PWDs during this pandemic.

## **Forming the emergency disability volunteer network and providing services**

### ***Initiation and expansion of the volunteer network***

Shaken by the news about the death of the teen with cerebral palsy, the second author, an independent journalist covering disability justice issues, promptly reached out to nonprofit organizations serving PWDs and online disability peer support groups to recruit volunteers. Within two days, approximately 180 volunteers joined the online volunteer group, of which approximately half are PWDs. A third of the volunteers are from Hubei province, where the virus had hit the hardest at that time.

Several subgroups formed to serve different needs as follows: 1) the needs assessment subgroup gathered brief needs assessment surveys from PWDs and coordinated follow-up for each case; 2) the accessibility subgroup ensured materials and information related to COVID-19 were accessible to people with various kinds of access needs (see more details in section 4.2.1); 3) the special education subgroup shared tips to parents on how to set up a home-based routine and activities to engage children with special needs; 4) the mental health support subgroup supported people experiencing acute stress and anxiety; and 5) the in-kind support subgroup coordinated the distribution of masks, feminine care packages, and gift cards that can be used to pay telehealth medical appointments. In addition to these direct service subgroups, each subgroup selected one corresponding subgroup leader based on their expertise and availability. The subgroup leaders formed a committee where they discussed the direction of services, referred cases to each other, and problem-solved challenging cases.

### ***How we reached PWDs in need***

Volunteers put together a WeChat<sup>1</sup> site that listed a detailed description of the network's mission and available support. At the end of this blog post, we posted a QR code linked to the needs assessment survey's website. Additionally, a volunteer who is a disabled illustrator made a recruitment flyer (Figure 1). Volunteers then circulated the post and the recruitment flyer to various disability online groups.

The brief needs assessment survey asks for basic demographic information, disability type, and assistance needed. Once someone in need fills out the survey, a volunteer follows up with the individual to find out the nature of their needs and whether the network can meet their needs. Approximately half of the clients were reached this way. The other half of the clients were reached through word of mouth, Weibo (the Chinese counterpart of twitter), and referrals from people who received help. During China's hardest-hit month of February, 2020 the network helped 272 PWDs.

### ***How support was provided***

Various kinds of support were provided to meet clients' needs. The network distributed free telehealth gift cards to over 250 PWDs, feminine care packages to 150 women with disabilities, and provided masks to 19 PWDs. Close to half of the clients served came from Hubei province. Policy wise, the network interviewed visually impaired business owners in Hubei province and drafted letters to advocate for business owners who did not have Wuhan household registration<sup>2</sup> so they could be covered under the local Disabled Persons' Federation's (DPF)<sup>3</sup> rent assistance. To ensure accessibility, the network also produced three Chinese sign language videos (COVID-19



Figure 1: Volunteer Recruitment Flyer: The image shows a united fist in the center. A girl with long hair wearing a mask sitting in a wheelchair is on the right of the big fist holding up her left fist. A boy without visible disabilities wearing a mask sat on the left side of the big fist. The top center writes "Combating the Pandemic-Disability Support Network" in simplified Chinese.

Disability Volunteer Network Apr 28<sup>th</sup> 2020), provided image descriptions for people who are visually impaired, and created a series of visual support tools for people with cognitive disabilities. As the needs for emergency response decreased, our work shifted from emergency case management and mailing masks, to distributing in-kind support and policy advocacy on financial relief. By June of 2020 as China reopened, we wrapped up our COVID-19 related volunteer work. The online volunteer group still serves as a space to share information and resources related to PWDs.

### Reflections on what had worked

#### *Elements and contexts that facilitated the timely response of the network*

In this section, we reflect on how societal contexts influenced the formation and services of the network to PWDs. We aim to provide these contextual factors so that organizations or civil

groups in other low-resource countries can critically analyze if such facilitating factors exist in their own country and whether they can be utilized in mobilizing and organizing in similar situations.

First, the surge of disabled people's organizations and mainstream media exposure of the injustices faced by PWDs have created what we would call the nurturing soil for the formation of our network. After the 2008 Sichuan earthquake, China has witnessed a drastic growth in disability related organizations, as well as disabled people's organizations. Organizations like One Plus One Group for Disability, Minority Voice, and other organizations have been pushing forward agendas on accessibility, equal opportunity to education and employment, and the construction of a dynamic disability community bonded through a shared disability identity (Wang, 2017; Zhang, 2017). What's more, disability justice related issues have been under the media spotlight more and more in recent years. Mainstream media Phoenix TV created a series of documentaries featuring challenges faced by PWDs in China (Phoenix Zone, 2018). This series, centered on the perspectives of the disability community instead of taking the traditional charity model perspective, is unprecedented. In this milieu, many of the volunteers were familiar with the key concepts of universal access and supported decision-making prior to joining the network, which alleviated supplemental training. Subsequently, the volunteers were able to act quickly in response to this public health crisis.

Second, technology played an important role in facilitating efficient communication, especially for cases demanding immediate attention. WeChat was used to enable group communication, sharing resources, and recruiting clients. In addition, we researched and selected an accessible survey platform that could allow people who are blind or visually impaired to fill out the survey. A cloud-based collaborating software similar to google drive was utilized to create shared spreadsheets for case assignment and progress report. Although these web-based tools have distinct functions, a shared characteristic across the tools was their built-in accessibility features.

As society moves forward from the pandemic, discussions on inclusion of PWDs in various online spaces has gained increasing attention. What is missing is the discussion on the possibility and practicality of emergency response organized with and for PWDs utilizing existing technology (Xu et al., 2021). Literature has documented the emerging practices of online citizen-driven organizing after natural disasters (Qu et al., 2009; Sutton et al., 2007). However, existing literature mostly focus on analysis from the perspectives of researchers who were not part of the emergency response. Furthermore, to the best of our knowledge, there is no literature documenting organizing efforts with and for PWDs online. Reflecting from inside, we realized the empowering nature of an online organizing space. PWDs would likely face environmental and attitudinal barriers if they attempt to participate in emergency response organizing in person. For example, in Confucius depiction of an ideal society, PWDs are viewed as those needed to be taken care of (Yu et al., 2011). This cultural view of disability in

turn shapes society's perspectives on whether people with disabilities should fully participate and be in the position to help others. Environmentally, the lack of accessibility of the built environment can also prevent PWDs from fully participate in advocacy. However, an online space allows many disabled volunteers to participate in organizing with the support of accessible tools.

Additionally, compared to governmental responses, one advantage of a self-formed civil coalition is its effectiveness, flexibility, and lack of cumbersome bureaucratic processes in managing and coordinating work. Leaders of the network facilitated a self-directed style of task assignment. China's Disabled Person's Federation (CDPF) serves as the political branch managing formal services provided to PWDs. Although it is designated as a unique government entity to "represent", "serve", and "manage" PWDs, scholars have criticized that it has largely been "managing" instead of "representing" PWDs overlooking voices from the disability community (Chen & Liu, 2015). Furthermore, the CDPF central branch often encounters challenges when enforcing certain policies through local CDPF branches, since local branches primarily report to local government, not the central branch. The lack of centering community voices along with the bureaucratic challenges faced when enforcing policies in local levels made it exceptionally difficult to respond and support PWDs appropriately in a timely manner to address urgent needs in disasters. As a result, although the CDPF released an administrative notice requesting local government to provide care services, medicine delivery approximately two weeks after the teen's death made national news, many PWDs still experienced prolonged distress (Xu et al., 2021).

In contrast, the volunteer network was able to respond immediately without excess management layers and bureaucratic challenges. All volunteers had access to the needs assessment database. During the first few days, the second author and the subgroup leaders were leading the assignment of case follow-ups. As volunteers became familiar with the procedure of case management, a streamlined process organically emerged. For example, when a new survey was received, based on the specified needs, volunteers either assigned themselves to follow up or directed the case to a subgroup that may better serve the needs of the individual. Some of the cases required multiple subgroups to collaborate. By avoiding cumbersome bureaucratic processes in managing, communication among volunteers remained fluid and efficient.

### ***Practices of the network that worked in ensuring accessibility for PWDs***

One of the key elements that facilitated the work of the network is our recognition of accessibility and access needs. Disability advocates have been pushing for an accessible physical environment for many decades. Recent efforts have focused more on the accessibility of internet usage and information for PWDs (Rau et al., 2016). This entails providing image descriptions for people who are visually impaired or blind, having sign language interpreters

for the deaf community, and using simple and accessible language, or pictures, for people with cognitive disabilities. In the beginning, the team made sure the language was simple and accessible. However, as we started collecting surveys, we realized there were very few deaf people who filled out the survey. To ensure accessibility, the team recorded a sign language version of the survey along with information on who would be eligible for the services through the network. After we publicized the sign language version of the survey, we saw an increase in deaf individuals who filled out the survey. To ensure accessibility, we provided image descriptions so that the visually impaired community could access critical health information. One of our volunteers is a talented illustrator. Along with the special education group volunteers, they created an illustrated social story (Figure 2) and a medical communication board.

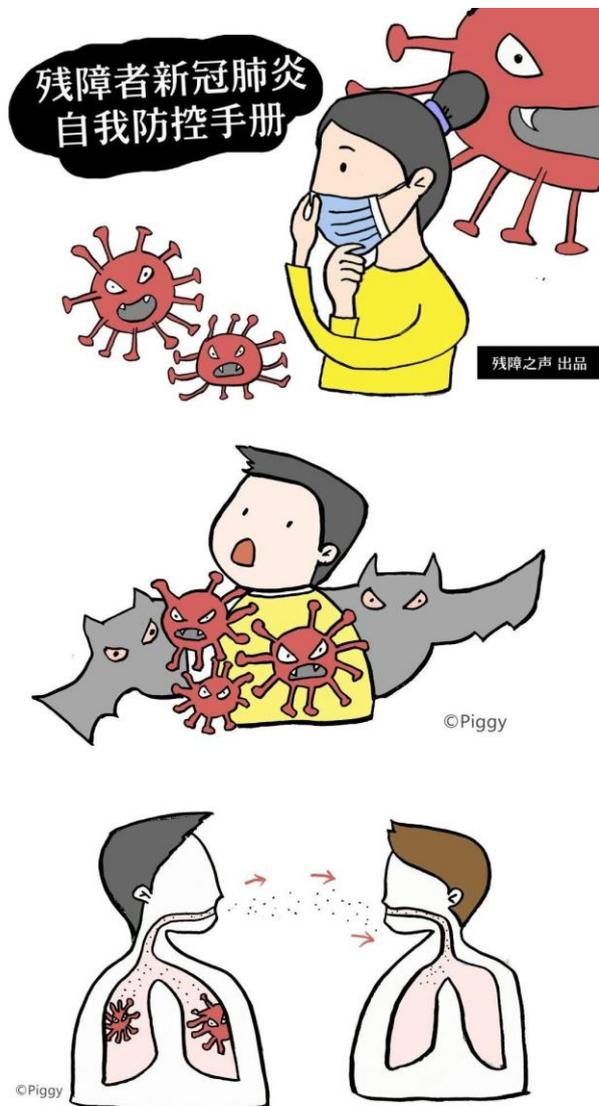


Figure 2: Parts of the Illustrated Social Story: the image shows three panels of a social story. The top panel shows enlarged caricatured COVID-19 virus with a scary face on it. A girl wears a mask facing the virus. In the black thought bubble, the text reads, "Self-protection booklet for people with disabilities during the COVID-19 pandemic" in simplified Chinese. The second panel illustrates a boy infected by the caricatured COVID-19 virus.

*The third panel shows how the virus spreads from one infected person to another person through droplets.*

Although there is lack of information on how to design an accessible survey in Chinese, the team was reflective in who are and who are not filling out the needs assessment survey. This reflective practice enables us to make the response efforts as inclusive as possible given the limited time and information available. Civil responses to support PWDs in low-resource countries may be challenging due to the lack of guidelines, information and experiences in making emergency response inclusive and accessible. Reflecting who are and who are not being rescued or supported can serve as an efficient approach to promote inclusion in emergency response.

The fact that our network stepped in to promote accessibility of critical information reflects the lack of accessibility awareness of public health officials in China. Many of the health promotion campaigns surrounding COVID-19 were publicized in image formats or infographics. However, images without written image descriptions are not accessible to people who are blind or visually impaired. Despite our efforts in reaching out to PWDs in need, there are still a great number of PWDs who could not access critical information during the pandemic due to the lack of sign language interpreting, image description, and information in simple and accessible language.

*Bridging communication to link local resources with PWDs*

In addition to our practice of ensuring information accessibility, our team also facilitated communication between PWDs and local community workers. Social workers and other community workers took a lead in organizing and enforcing the stay-at-home order and coordinating grocery shopping and other essential trips during the lockdown. However, they are often not trained to work with PWDs. For example, one deaf individual needed someone to help bring his mother to the hospital. He reached out to the neighborhood community workers but they did not respond to his request. Noticing that the local community workers may not know how to work with him, our team called the neighborhood workers to advocate for him and provided sign language interpretation to facilitate communication. There are numerous similar cases where our team helped bridge the communication gap between PWDs and local community workers.

Our efforts in bridging communication to link local resources with PWDs exposes another pressing issue of the emergency support system in China. As we discussed earlier, there is a lack of accessibility awareness in public health and emergency response leadership. This lack of awareness extends to first responders and community workers. Future advocacy and intervention efforts should focus not only on the accessibility of information related to disasters, but also on the training of frontline workers on how to support PWDs.

*Supported decision-making and participatory action*

The volunteer network practiced the concept of 'supported decision-making' and maximized the participation of PWDs. In a traditional charity approach, PWDs are often on the receiving end of help with their voices overlooked. Supported decision-making puts PWDs at the center and allows them to decide what kind of help they would like when making decisions about their life receiving support and information from loved ones and those with whom they have developed trust (Dinerstein, 2012). Although this concept has been around in the United States as an alternative to guardianship for people with cognitive disabilities, it is relatively new in China. PWDs often experience overprotection from their families in China (Ho et al., 2008). However, such a style of caregiving could be detrimental to the mental health of PWDs (Sanders, 2006). Therefore, to facilitate participation and decision-making of PWDs, volunteers were actively listening to those in need and providing them with viable options instead of making decisions for them. For example, a blind woman was on the edge of becoming homeless. As we reached out to her, our volunteers found that she had an argument with her husband's family and left their house. She then wanted to travel back to Wuhan where her maternal family resided. But at that time, Wuhan had already resorted to lockdowns. Our volunteers listened to her concerns and connected her with another blind woman online to offer peer support. With information from our volunteers and peer support, she decided to postpone her visit back to Wuhan to reduce the risk of getting COVID-19.

Participatory action with the disabled community emerged as we worked with the blind community in Wuhan. The local DPF issued a relief fund worth three-months' commercial rent for disabled business owners. However, only business owners with a Wuhan household registration were eligible for the fund. Hearing the needs of blind business owners, we helped draft a letter to advocate for including all business owners in the relief fund, regardless of what their household registration stated. The Wuhan DPF later released a relief fund through the local red cross to people with Hubei household registrations. Although business owners in Hubei with household registrations from other provinces are still ineligible for the funds, our advocacy did help expand the coverage to more business owners with disabilities. This letter was later adapted by disabled business owners in other provinces facing similar issues.

Having volunteers with disabilities in the network promoted supported decision-making. Volunteers with disabilities bring into the network their lived experiences of why supported decision-making is key to support PWDs. For example, we asked one of the key volunteers who identifies as someone with severe disabilities what made this volunteer experience unique. She pointed out that being able to work with others who also hold similar values that PWDs can and should make their own decisions is empowering. She did not have to make efforts to explain concepts such as supported decision-making and accessibility. A civil response team consists of PWDs and allies who share these values make communication much more efficient at times of emergencies.

Such approaches promoting inclusion and agency may also lend insight in designing public health interventions. Future emergency response intervention studies targeting vulnerable populations such as PWDs may consider taking a participatory approach. For example, involving PWDs as key researchers in assessing needs, identifying effective elements in designing such interventions can potentially enhance recruitment and effectiveness of such public health interventions. Although participatory action research has emerged as a critical method that aligns well with the fundamental values of disability studies (Goodley & Lawthom, 2010), in reality, PWDs still remain an afterthought when it comes to disaster management and intervention design (Smith et al., 2012; Qi & Hu, 2020). There is urgent need to promote interdisciplinary collaboration between disability studies and public health and center the voices of PWDs in the process of disaster plan, intervention design, and response through participatory approaches.

### **What needs to improve**

#### ***Proactive outreach to the underserved***

Our needs assessment survey did not reach as many PWDs as we anticipated. Although sign language videos were produced for accessibility, many PWDs who are illiterate were not able to access the survey. In 2009, 45% of PWDs who were 15 years and older were illiterate in China (Chen et al., 2009). This is significantly higher than the illiteracy rate of 4.9% in the general population (United Nations Development Programme, 2019). Another factor that may have played a role in our outreach is the fact that we distributed our surveys online. Although within the last decade there is a drastic increase in the number of internet users in China, a significant percentage of the population still does not have an internet connection. In 2019, approximately 40% of China's population did not have an internet connection (China Internet Watch, 2019). On the other hand, the percentage of mobile phone users is almost universal in China (China Internet Watch, 2019). Future efforts in reaching PWDs who are illiterate may consider methods other than online surveying such as phone calls, connecting with key community leaders with disabilities, recording audio or video clips of recruitment materials. Although it may be challenging to place personal phone calls without access to a national registry of PWDs, such databases do exist in local DPFs. Connecting volunteers with local DPFs may enhance the outreach effort.

Another issue with using needs assessment surveys is that many PWDs do not perceive that they have needs. This is especially pronounced when it comes to mental health needs. Although many people experience stress, anxiety, and depressive moods, due to the cultural stigma of mental illness, people tend to avoid reaching out for help. A recent study on cultural stigma against people with mental illness in China revealed that an alarming percentage of their sample were unwilling to develop interpersonal relationships with people with mental illness (Xiong

et al., 2020). Although we made changes to our survey questions so that mental health needs are articulated in a more ambiguous way, a more proactive approach, such as reaching out to PWDs instead of having them fill out online surveys, may help identify those needs.

### ***Lack of collaboration with formal systems***

Due to the urgency presented by the pandemic, our volunteer network did not develop formal collaborations with the healthcare system, nor local disability serving organizations. Although we helped call hospitals in a few cases, we were not able to reach more people that could provide urgent help. A collaboration with the healthcare system, especially emergency health departments, would allow us to provide accessibility support to more PWDs nationwide. A hotline where healthcare workers and local community workers could call for support would benefit more PWDs facing crisis. Another formal system that would help expand support to more PWDs is DPFs and other direct-service agencies serving PWDs in the community. Local DPFs have their own registry of PWDs living in the community. Collaborating with these organizations could facilitate more PWDs in need being reached.

Due to the urgency and the rapidly changing situation, we did not have an established collaboration with the healthcare and disability service systems. Nevertheless, our work could serve as a launching point of collaboration to construct a robust, accessible, and person-centered system bridging the healthcare system and the disability service system. In doing so, we will be much better prepared in reaching out and supporting PWDs during public health emergencies like COVID-19.

### ***Other limitations of the network***

One of the biggest limitations of the network is that we were unable to provide any in-person services due to the lockdown and the fear of the novel coronavirus at the time. During the lockdown, all social services, including personal assistant services, were discontinued. Although we provided communication and accessibility support remotely, much of the urgent needs during the lockdown required in-person support. Another limitation of the volunteer network is that we did not follow up with clients to obtain feedback. This is partially due to the lack of planning prior to the network's formation. Without outside feedback, we may have overlooked certain aspects that need to be improved for future emergency response work. Furthermore, the future path of the network is unclear. Although the online group serves as a hub where people from different organizations share information and resources, there is a limited capacity to continually address issues surrounding emergency planning for PWDs in China. When time is precious, developing the volunteer network and subgroups was a limitation in itself. Forming emergency preparation coalitions similar to our volunteer network prior to emergency situations like the pandemic may help promote the consistency of such work.

## **Conclusion**

The emergency response network within a short amount of time serving PWDs is unprecedented in China. The network is also unique since half of the volunteers come from the disability community rather than professional organizations and social service agencies. Our experiences working with the disabled communities in China during COVID-19 shed light on the lack of emergency preparedness for this vulnerable population. Developing the network and serving PWDs during COVID-19 sets up a basis for how to integrate accessibility and supported decision-making by and for PWDs in emergency planning. Furthermore, the participation of PWDs in the process of policy-making and advocacy not only empowers these individuals but is also key to ensuring the effectiveness of potential solutions addressing the unmet emergency planning needs of the disabled communities. Concrete policy measures connecting the healthcare system, local disability service agencies, the CDPF may help promote the well-being and safety of PWDs during public health crises like the COVID-19 pandemic.

## **Notes**

1. WeChat is a widely used multi-purpose social media app for the Chinese-speaking population.
2. Household registration, or otherwise referred as Hukou system, is a nationwide system that registers an individual's permanent residency. Registration is distinguished based on provinces, cities, and districts. Household registration is often used to determine eligibility of public welfare.
3. China Disabled Persons' Federation (CDPF) is a government-commissioned national organization that aims to protect the rights and interests of PWDs. The CDPF has branches throughout China.

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