



From State Humanitarianism to Equal Citizens

The Making of Disability Subjects in China

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This essay traces the formation and evolution of the sector of Chinese civil society engaged with issues related to disability from 1988 to today. It argues that, due to both domestic and transnational forces of sociopolitical change, the associational life of people with disabilities over the past three decades in China can be divided into three historical phases: in the first (1988–2007), disabled people were treated as objects of socialist humanitarianism; in the second (2008–14), disability rights advocacy took centre stage; in the third (2015 to today), the main role is played by social service organisations and community networks.

Blind activist Li Jinsheng, who in 2013 convinced the authorities to reconsider his application to take the national college admission exam after they initially rejected him citing his condition, setting an important precedent. PC: sina.com.

On 23 January 2020, the city of Wuhan, the epicentre of the coronavirus outbreak in China, went into lockdown. That day changed the lives of tens of thousands of citizens in China—and the world thereafter—including those of a family with two children with disability. On that day, Yan Xiaowen, the father of two boys with severe disability, was taken to a mandatory quarantine centre in Huanggang City, Hubei Province, along with his younger autistic son. His elder son, Yan Cheng, a 16-year-old with severe cerebral palsy who needed round-the-clock personal care,

was left to fend for himself at home. Six days later, Yan Cheng died alone in the house in the freezing winter, without food or care.

The tragic death of Yan Cheng exemplifies the systematic inequalities faced by people with disability in China. Thirty years after the passing of the Law of the People's Republic of China on the Protection of Disabled Persons, in 1990, people with disability and their family members often still lack access to economic security, health care, employment, education, and many other aspects of social life. In the case described above, Yan Xiaowen engaged in intensive labour to provide care to his children before the pandemic; as a single father, he sacrificed his work and life to take care of his two disabled sons, who were refused enrolment in public schools. The family lived in the office of a parents' self-help organisation called Home of Snail (蜗牛之家) in Wuhan, and relied on the minimum livelihood allowance provided by the local government and on public donations to survive. When the pandemic hit the country and Yan Cheng's father and caregiver was placed in quarantine, no individuals or public institutions stepped in to fill the care vacuum.

The tragedy also tells a story about the increasingly dynamic forces of community organising and advocacy *for* and *by* people with disability and their families. Local and national self-help organisations such as the Home of Snail played an important role in navigating care arrangements for Yan Cheng's family before, during, and after the pandemic. On the tragic death of the teenager, the disability community and parents' self-help organisations across the country rapidly formed collective care networks such as the Disability Volunteer Network (残障义工网络) and the Family Aid Network (特殊需求困难家庭疫情期间紧急救助网络) to provide all sorts of emergency relief services to families with disabled members. According to the most recent official population census data, there are 83 million people with some form of disability in China, which means that one in every five households has at least one member with a disability (NBS 2007). With a social policy that emphasises the family as the primary welfare provider proving inadequate to address the needs of what has been called China's 'largest minority group' (Shang and

Fisher 2014; WHO 2020), it has been the rapid development of nongovernmental organisations (NGOs), self-help groups, and individual rights advocates that has filled the vacuum since the 1990s.

In this essay, I trace the emergence and development of the civil society sector surrounding the broadly defined issues of disability rights since the late 1980s. I pay particular attention to the development of civic associations *of* and *for* people with disability, as well as the formation and negotiation of the collective consciousness and political subjectivity of people with disability in the process. In many ways, civil society is a highly contested and even problematic conception. As a concept derived from Western historical experience and theorised, at least initially, by Western thinkers, civil society is generally seen as 'an arena in society, distinct from the state, market and usually the family, where collective action in associations and through other forms of engagement takes place or, more rigidly, as the sector composed of voluntary non-profit organizations' (Heinrich 2005: 213). This liberal notion of civil society as voluntary, autonomous, and independent from the state is particularly problematic in the Chinese context, where the Party-State plays a crucial role in defining the political boundaries of where civic associations can survive (or not), strategise, and operate (Fu and Distelhorst 2018; Salmenkari 2013).

In this essay, I use the concept of civil society to refer to the associational life surrounding disability. I see the civic associations *of* and *for* people with disability, rather than being independent and autonomous from the state, as constituted by the authoritarian state's formation of disability (残疾) policy (Fjeld and Sagli 2011), on the one hand, and the transformations of the political rules that regulate the associational life on the other. Moreover, the manifestation of disability associations has developed hand in hand with the influence of the transnational flows of cultural and institutional forces of disability rights as a rising agenda in international development. I unpack the formation and development of the civic associations surrounding disability into three historical periods: the first, between 1988 and 2007, when those with disability were seen as objects

for socialist humanitarianism; a second period, between 2008 and 2014, which witnessed the blossoming of disability rights advocacy; and the third period, from 2015 to today, in which social service organisations and community networks have taken centre-stage.

In the following sections, I illustrate each of these periods in greater detail. In so doing, I am aware that any divisions of historical periods are in essence arbitrary and risk losing the nuances and contingencies of the complex historical processes. However, my attempt here at a tentative chronology is valuable in that it provides a glimpse into the key features of the associational life of the disability sector, as well as the major political and social forces underpinning them over the past three decades.

Sowing the Seeds (1988–2007)

While scholars of Chinese civil society generally refer to the Fourth World Conference on Women held in 1995 in Beijing as a turning point for Chinese NGOs (Kaufman 2012; Howell 2019; Yang 2007), I trace the formation of disability associations and the political subjectivity of people with disability from 1988, the year the China Disabled Persons' Federation (CDPF, 中国残疾人联合会) was founded. From 1988 to 2007, disability gradually became a target of state policy under the ideology of socialist humanitarianism, which paved the way for a shared (although still loose in many ways) collective consciousness of disability. International organisations also launched chapters and projects in China with an emphasis on rehabilitation. Disability assistance organisations (助残组织) and civic associations emerging from the ideal of socialist humanitarianism, and which looked at people with disability as subjects for charity and help, proliferated in those years, along with social service organisations (社会服务组织) established mostly by family members of people with disability to meet their everyday care needs.

Before the late 1980s, people with disability had never been a homogeneous social group and

disability had not been part of any unified policy put forward by the Chinese authorities. The making of the state's disability policy was a co-construction of the Party-State's modernisation efforts and the involvement of international institutions in the reform era. After the end of the Cultural Revolution, the Party-State adopted a developmental orientation and was eager to promote the economic and social modernisation of the country to catch up with the West. At that time, disability rights were gradually becoming an international development agenda for transnational institutions such as the United Nations (UN) and the World Health Organization (WHO), especially with the growing momentum of the international disability rights movement since the 1970s. The United Nations declared 1981 the International Year of Disabled Persons and, later, launched the Decade of Disabled Persons campaign, from 1983 to 1992. In light of all this, humanitarianism towards the most disadvantaged group in society, people with disability, came to be seen as a symbol of national development by China's Party-State. Under this array of domestic and international forces, a series of institutions, laws, and policies on disability has been introduced in China since the 1980s (Dauncey 2013; Kohrman 2003).

In 1988, Deng Pufang, the son of Deng Xiaoping who was left paralysed from the chest down after a suicide attempt during the Cultural Revolution, founded the CFDP. After the Cultural Revolution, Deng had spent several months in Canada to receive orthopaedic surgery. There, he was 'treated with medical care unavailable anywhere in China and exposed to discourses about disability that then were being championed by a growing number of international organizations' (Kohrman 2003: 12). On returning to China, he became a strong advocate of disability assistance, which at that time hardly existed in the policy agenda of the Party-State (Kohrman 2005). Only in 1987, one year before the founding of the CDPF, did China conduct its first National Sample Survey of Disabled Persons, which used an internationally recognised and biomechanically based questionnaire. For the first time in Chinese history, people with disability were categorised as a homogeneous group, comprising five subcategories: hearing disability

(听力残疾), intellectual disability (智力残疾), visual disability (视力残疾), physical disability (肢体残疾), and mental disability (精神残疾). Two more subcategories were added in 2011: verbal disability (言语残疾) and multi-disability (多重残疾).

With a target group now defined, the CDPF was founded as a vice-ministry that combined the functions of a representative organisation for disabled persons, a social welfare group, and an administrative organisation. In 1990, the Chinese Government passed the first comprehensive national legislation on disability, the Law of the People's Republic of China on the Protection of Disabled Persons, which had been drafted by the CDPF. The law adopted a medical definition of disability and declared:

[A] disabled person refers to one who suffers from abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and who has lost wholly or in part the ability to engage in activities in a normal way. (NATLEX Database 1990)

Even though it defined disability as a form of medical abnormality, the law empowered people with disability by granting them equal rights to rehabilitation, education, employment, cultural life, and personal and environmental welfare. It also stipulated that the third Sunday of every May would be the National Day of Assisting Disabled People, rooted in the idea that 'the whole society should uphold the socialist humanitarian spirit, understand, respect, care, and assist disabled people and develop the work of disability'.

With the state's policy turn to addressing disability, the way in which people with disability as a social group were defined, understood, and managed in China drastically changed. A new Western biomedical paradigm of disability was adopted that focuses on rehabilitation, prevention, and integration (Dauncey 2013). Moreover, under the mandate of socialist humanitarianism, the state considered people with disability as a 'vulnerable group' (弱势群体) and focused heavily on 'assisting' (帮扶) them. As Patricia Thornton (2017) has pointed out, evolving from China's longstanding 'mass work' practices, this public

discourse about 'vulnerable groups' reinforces, reproduces, and extends the state's penetration, policing, and patronising of the underclass. As such, people with disability were seen as pure objects for biomedical intervention and socialist humanitarianism.

As mentioned above, three types of disability associations stood out during this period: international organisations focused on disability rehabilitation, the so-called disability assistance organisations, and disability social service organisations. International organisations with a disability focus arrived in China at the inception of the economic reforms, as disability was becoming increasingly important in the international development agenda. One of the most influential organisations was Handicap International (now called Humanity and Inclusion, or HI), a Nobel Peace Prize-winning humanitarian organisation founded in France. HI came to China in 1998 and its work was initially focused mainly on providing rehabilitation services to people with disability, especially in rural areas in underdeveloped provinces/regions such as Guangxi, Yunnan, and Tibet. The early work of HI included providing prostheses and rehabilitation programs, as well as disability prevention, which boosted the view of disability as merely a biomedical problem that needed to be fixed or cured.

Under the influence of the state's socialist humanitarianism, disability assistance organisations were founded throughout the country to assist people with disability as a vulnerable group. Taking various forms, from informal social groups to registered formal organisations, these groups held volunteering activities such as home visits, outings to tourist sites, and the collection of donations. For example, a disability assistance organisation called Tongren Zhucan Volunteer Service Centre (同人助残志愿者服务中心, or Tongren) was founded in 1989 by 13 people with disability to 'serve the people with a full heart' after the example of Lei Feng. The organisation attained registration in 2005 and has since conducted a variety of activities, such as training disability assistance volunteers, visiting the homes of disabled people before the Lunar New Year, one-to-one volunteer programs that match a person with disability



Zhang Haidi, a Chinese writer, translator, inspirational speaker, and chairwoman of China Administration of Sports for Persons with Disabilities (the national paralympic committee of China).. PC: Wang Jing (Sohu.com).

with a non-disabled volunteer, and fundraising campaigns for disabled children in the countryside (China Wenming Net 2016).

While organisations such as Tongren were established to assist people with disability, their volunteering activities were not enough to serve the everyday needs of people with disability and their families. Social service organisations—very often established by people with disability and their family members—thus started to emerge in this period. This trend was especially salient among parents of people with intellectual and developmental disability, who struggled to find stable care and intervention services to meet their children's everyday needs in the absence of publicly subsidised services. For example, Tian Huiping, the mother of an autistic boy, initiated the first intervention institution for children with autism in

China, the Beijing Xingxingyu Education Initiative (北京星星雨教育研究所, or Xingxingyu). At that time, autism was not categorised as a disability by the CDPF, yet children with autism and other disabilities were (and are still) regularly refused enrolment in public schools, leaving families in a desperate situation. Parents from urban areas with better access to resources and information, such as Tian Huiping, thus initiated service organisations to meet the care needs of their children. As with many of the civic associations serving marginalised groups at the time, these disability service organisations could not gain registration under the dual administration system that required NGOs to seek approval from both a professional supervisory unit and the Ministry of Civil Affairs (Yang et al. 2016). Xingxingyu instead mobilised resources by establishing collaborations with the media, inter-

national funders such as the German and Canadian embassies, and international scholars and practitioners with experience of autism intervention (Zhao 2017).

Nothing about Us without Us (2008-14)

While the state's policy agenda on disability has long been focused on assisting people with disability as a vulnerable group under the vision of socialist humanitarianism, in the mid-2000s, the discussions surrounding a new international human rights convention, the UN Convention on the Rights of Persons with Disabilities (CRPD), as well as the rapid (yet in retrospect short-lived) development of the civil society sector in China, pushed civic organising around disability to the next stage.

After a drafting process that involved five years of negotiation between more than 40 countries, the CRPD was approved by the UN General Assembly in 2006 and opened for signature in 2007. The convention adopts a human rights approach that sees disability as a social and human rights issue instead of merely a biomedical one, and emphasises removing environmental and attitudinal barriers instead of individual impairments. The CRPD entails strong civil society participation, as seen in its slogan of 'Nothing about us without us'. Not only did the process of negotiating and drafting the convention involve the highest level of civil society participation, but also the convention put strong emphasis on the role of civil society in monitoring and participating in achieving the rights of people with disability (Kayess and French 2008). The passing of the CRPD has therefore spurred a new wave of global grant-making to adopt this human rights framework and fund local projects on disability rights.

The Chinese Government's ratification of the CRPD in 2008 opened up spaces for Chinese disability rights activists to frame their experiences using a set of international rights-based discourses. Since the introduction of the CRPD, a significant number of international donors and UN devel-

opment organisations have initiated and funded programs in partnership with local civil society groups in China using the rights-based model of disability services (Huang 2020). International disability organisations that were already active in China, such as HI, changed their focus from rehabilitation to civil society empowerment. Other international organisations, such as the European Union, the Ford Foundation, and the Open Society Institute, also adopted this new human rights framework to initiate and fund programs on disability rights that mirror the international mandates in China.

The civil society sector continued to grow and blossom after 2008 (see Kang's essay in the present issue). Shieh and Deng (2011: 194) noted that the 2008 Sichuan earthquake triggered an unprecedented burgeoning of a nascent civil society in China, as signified by the 'display of public-spiritedness, charitable giving, volunteering and networking' in the wake of the disaster. According to estimates by Guosheng Deng (2010), in 2010, there were one to 1.5 million unregistered NGOs and more than 1,000 foreign NGOs in China. Deng found that the Chinese authorities were adopting a 'three nos' attitude towards this vast number of unregistered and foreign NGOs: no recognition, no banning, no intervention. As such, civic associations were able to operate with a certain level of autonomy, with some even turning into social movement-oriented NGOs that mobilised around sensitive issues such as labour rights and feminist activism (Fu and Distelhorst 2018; see also Howell's essay in the present issue).

These changing opportunity structures at the global and domestic levels played an important role in shaping the politics of disability organising in China. A nascent disability rights movement that used rights discourses and approaches to influence domestic policy and legislation emerged (Huang 2019). A new generation of disability rights activists with and without disability who had been exposed to and motivated by the CRPD's human rights framework found themselves fed up with the state's discourses and policies, which saw people with disability as a vulnerable group in need of assistance. Instead, they turned to the approach of rights advocacy (权利倡导) to claim equal rights



President Xi Jinping meets with representatives attending a ceremony commending role models with disabilities and people who have made outstanding contributions in helping the disabled in Beijing in 2019. PC: Xinhua.

for disabled people in education, employment, environmental accessibility, and other aspects of social life through legislation and cultural change (Huang 2020).

One salient rights advocacy campaign from this period strived to get people with disability equal access to higher education. Throughout Chinese history, people with disability rarely had access to university education, with one of the most important reasons for this being the lack of means to accommodate disability—for instance, with braille exam paper. The deprivation of educational opportunities made people with disability particularly vulnerable, both economically and socially. In the 2010s, disability activists such as blind masseur Li Jinsheng spent years advocating through various strategies—including petitions to representatives of the National People's Congress and the Chinese Political Consultative Conference,

and performance art aimed at attracting media attention—for the CRPD's ideas of reasonable accommodation to be introduced to the university entrance exam to grant students with disability equal access to higher education. In 2015, this series of civic actions finally led to a national policy from the Education Ministry and the CDPF that provided reasonable accommodation of people with different types of disability in the exam.

This wave of disability rights organising, along with other 'boundary pushers in civil society' (Fu and Distelhorst 2018: 106), was shut down abruptly under the Xi Jinping administration. However short-lived it was, the upsurge of disability rights advocacy of the late 2000s and early 2010s has left a significant legacy that sees the political subjectivity of people with disability in China being renegotiated and reshaped. As rights discourses were disseminated through advocacy campaigns in the

public sphere, and even adopted in national and local legislation and policies, people with disability increasingly have appeared in public discourse as equal citizens who demand equal participation in social life, instead of subjects of socialist humanitarianism passively waiting for help.

The Great Transformation (2015 to Today)

A short period of rights advocacy in disability associations faded out gradually under the Xi Jinping administration, especially after several disability rights-oriented NGOs, including the Yirenping Centre (益仁平中心; see Lu Jun's essay in the present issue) and the Enabled Disability Studies Institute (亦能亦行身心障碍研究所), were shut down in 2014 and 2015. Since these shutdowns, disability associations have endeavoured to make strategic transformations by focusing on providing social services instead of rights advocacy. Meanwhile, vibrant online community networks have started to grow among the new generation of people with disability, paving the way for a collective disability consciousness-building from the grassroots community.

Since Xi Jinping gained power in 2012, the previous approach to social governance has been replaced with initiatives that seek to restructure Chinese civil society. The Xi administration has set clear political boundaries for the sector by penalising NGOs' contentious participation, on the one hand, and by incorporating the formerly unregistered and thus unfettered organisations through the opening of new institutional channels for participation on the other (Fu and Distelhorst 2018; Teets and Hsu 2016; Teets and Almen 2018). Central to these civil society restructuring initiatives is a series of legislative and regulatory processes. The Charity Law that came into effect in September 2016 is a significant attempt by the Party-State to regulate NGOs and their activities, including placing restrictions on their sources of funding, internal governance, information disclo-

sure, scope of activity, and so on. The Law on Administration of Activities of Overseas NGOs in Mainland China (also known as the Foreign NGO Management Law) that came into force in the same year furthered this trend of institutionalising the sector by regulating foreign NGOs and their activities in mainland China. The law not only stipulates that foreign NGOs must seek double registration from the public security department and supervisory organisations, but also, and more importantly, forbids domestic organisations and individuals from cooperating with or receiving funding from unregistered foreign NGOs. Along with these processes is the promotion of what Jude Howell (2015) calls a model of 'welfarist incorporation'—that is, the governmental purchasing of social services from selected civic organisations as a political and economic arrangement. Under this 'new normal', disability organisations have to make strategic transformations by cutting off sources of funding from abroad and curtailing their contentious activities to seek legitimacy and support from the Party-State.

One strategy to which disability associations have resorted as they seek to adapt to the changed circumstances is to shift their focus from rights advocacy to providing social services. As illustrated by the example of Yan Cheng at the beginning of this essay, the existing social policies and services are far from being enough to meet the everyday needs of people with disability and their families. Moreover, the previous international grant-making and local rights advocacy initiatives predominantly focused on the broader picture of the political and civil rights of people with disability, even though people with disability were still experiencing practical social and economic challenges such as poverty and lack of access to services (Huang 2020). Even though the Party-State's civil society restructuring initiatives have now cut off the channels for contentious participation, disability NGOs still find plenty of opportunities to manoeuvre and serve the needs of the community through the provision of social services. Moreover, the emergence and rise of private philanthropy have made the civil society sector increasingly diverse through engagement in foundations, corporate social responsibility initiatives, social enterprises,

and, more recently, internet public fundraising information platforms (互联网公开募捐信息平台)—that is, online platforms authorised by the Ministry of Civil Affairs, such as Tencent Gongyi (腾讯公益) and Taobao Gongyi (淘宝公益), where NGOs and individuals can conduct fundraising activities. Private philanthropy has provided alternative channels for disability NGOs to gain funding and public influence, although small-scale organisations and those with a rights-advocacy orientation are systematically marginalised, if not excluded, in the process.

One example of this transformation can be found in the China-Dolls Centre for Rare Disorders (CDCRD, 瓷娃娃罕见病关爱中心), which was formed in 2008. While previously adopting the rights-based approach of the CRPD and conducting activities mainly in the field of policy advocacy and community empowerment, the CDCRD has undertaken a rather successful transformation since 2014. Rooted in the emergent needs of the community, the organisation has shifted its focus to the accessibility of medicine through public education and policy advocacy of medical insurance coverage through institutional channels. In 2014, it also launched its own foundation, the Illness Challenge Foundation (ICF, 北京病痛挑战公益基金会), to provide cash relief to patients with rare diseases after initiating a successful ‘Ice Bucket Challenge’ online fundraising campaign (CDCRD 2020). The founder of the organisation, Wang Yi’ou, herself a woman with disability, pursued an Executive Master of Business Administration degree from the famous Cheung Kong Graduate School of Business to learn about introducing a business model to the civil society sector. This series of transformations has allowed the organisation to gain a level of resources, attention, and policy influence that was previously impossible for grassroots NGOs.

Besides these formal organisations, new generations of people with disability more conscious of their rights are gradually connecting through internet platforms, forming a number of online networks. One of them is ‘The Minority’ (少数派), an online community initially formed in 2016 on the Zhihu (知乎) platform by a group of university students living both in China and abroad (Guo 2017). Xu Ye, the founder of the network, is a

PhD student researching disability issues in the United States and she started the platform to facilitate discussion among the disability community about their own experiences of discrimination and exclusion, as well as to introduce concepts of disability studies from the West to reframe these experiences. The Zhihu group soon grew and evolved into several WeChat groups with a membership of hundreds of people with disability. As they discussed their everyday experiences, these community members decided to form a WeChat official account to raise public awareness of disability, hold offline community-building activities, and conduct participatory research to unravel the community’s experiences.

Even without the apparatus of a professional organisation, community networks such as The Minority continue to evolve from the grassroots, defining their agenda, and articulating their conceptions of equality and inclusion. From these processes, the political subjectivity and the collective consciousness of people with disability continue to grow. People with disability are now connected through shared experiences of oppression and exclusion more than ever (Linton 1998). Similarly, this new generation of well-educated people with disability is neither satisfied with being the subjects of socialist humanitarianism nor bounded by the narrow vision of policy and legislative change. They are now bringing the rights model of disability to their everyday existence: the road they pass every day in their wheelchair, the discriminatory attitudes they face daily, the inaccessible website they must use to purchase train tickets, the bullying they encounter in school. Each is now an active agent to initiate change in their individual, community, and public lives—with the backup of a community of shared experience.

Towards the Future

In this essay, I traced the formation and evolution of the disability civil society sector in China from 1988 to today. I have argued that the associational life of people with disability in the past three decades in China can be divided into three histor-

ical phases defined by both domestic and transnational forces of sociopolitical change. Evolving from the mandate of socialist humanitarianism, disability moved on to the state's policy agenda and disability associations started to emerge and develop in the 1980s. The coming of the CRPD in 2008 marked a new period of disability organising by introducing a new human rights model through rights-based discourses, a rights advocacy-oriented approach, and international funding. While this short period of rights advocacy ended abruptly under the Xi administration, disability associations continue to seek organisational survival and development by transforming into service provision organisations. More diverse ways of community organising also emerged in the form of online networks.

During these historical processes, the political subjectivity and collective consciousness of people with disability have developed. In the 1980s, people with disability were defined as a homogeneous social group under the Western biomedical benchmark for the first time in Chinese history. With the introduction of the international rights discourses in the 2000s, people with disability continued to negotiate their social identity as equal citizens entitled to a set of human rights. Finally, with the blossoming of community networking, people with disability are increasingly seeing themselves as a minority social group that shares similar experiences of oppression and exclusion—a collective consciousness that might potentially transform into the driver of change.

It is impossible to predict the future as the development of the civil society sector (in China as elsewhere) is full of contingencies, and dependent on the transformation of domestic and international opportunity structures. One certainty, however, is that these disability rights entrepreneurs with a growing sense of political subjectivity and collective consciousness will continue to seek change for a more inclusive, equal, and diverse future for their community. ■

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