

## Introduction

### Understanding Disability and Citizenship in China

---

There are those who call me a disabled person and those who call me a cripple. I always correct them. I say that I am a disabled person, not a cripple. I am ‘disabled but not useless’. Without that spirit, I wouldn’t be where I am now.

Yang Xingdong

Perhaps one of the most important things we have learned over the past fifty or so years of developing disability discourses is that words matter. In fact, they matter a lot. As long as we have had a history, words have been used to stereotype and stigmatise (Goffman, 1963); but we also know that words have been used, particularly in more recent times, to empower and enable (Oliver, 1990). What we are also beginning to understand is that the way disability is understood, articulated and experienced is not constant or uniform across cultures. The notion of a ‘global disability culture’, however tempting to imagine, is now being challenged by academics and activists, organisations and individuals from around the world. While the forces of globalisation are working to create greater connections and forge common goals, particularly in the area of disability rights, it is clear that historical traditions and cultural expressions, group and individual experiences, and the languages used to describe and disseminate these understandings differ widely across the globe. Not only that, we are beginning to see more clearly how these differences are not just limited to national boundaries; they may also differ based on ethnicity, gender, religion, age and a whole host of other complex factors that interact to create more local and personal responses to disability. Understanding the ways in which such knowledge about disability is produced, disseminated and received in a specific cultural context is, therefore, key to revealing new or hitherto overlooked discourses and cultures of disability and, ultimately, the complexity and heterogeneousness of disability in the world today.

As the opening epigraph from Yang Xingdong 杨兴东 (b. 1957) – a calligrapher who lost both arms to the shoulder in an industrial accident in the central Chinese city of Wuhan 武汉 in 1996 – suggests, the

2 Introduction

language of disability in China can be both stigmatising *and* enabling. For Yang Xingdong, *canjiren* (残疾人), which was adopted as the term of preference by the Chinese state in the early 1980s and is generally translated as ‘disabled person’, is infinitely preferably to *canfeiren* (残废人), the Chinese equivalent of ‘cripple’ or ‘invalid’, which was the more common term prior to then. While he may be ‘disabled’ because he no longer has his arms, he certainly does not feel ‘useless’ on account of his acquired impairment; he is ‘disabled but not useless’ (*can er bu fei* 残而不废). As a *canjiren* rather than *canfeiren*, we are told, he avoids the stigma of being a ‘cripple’ and appears able to draw strength and optimism from this more positive disabled identity (‘Yang Xingdong’, 2012). While the Chinese term *canjiren* itself should not be considered unproblematic – it is, after all, formed from the combination of two negative characters, *can* ‘incomplete/defective/damaged’ and *ji* ‘sick/ill/diseased’ – there are clearly sufficient positive messages circulating about the term that Yang Xingdong feels more than comfortable in describing himself as such. By contrast, the *fei* character of the former term *canfeiren*, with its explicit sense of uselessness and ineffectiveness, is seen as a stigmatising appellation that appears to deny him any possibility of a life of value and worth.

This book sets out to explore how Yang Xingdong, and other people like him, are negotiating their identities as disabled people in China today. Through the examination of the construction of disabled identities and citizenship from the perspective of Chinese cultural epistemologies, my research here reveals multiple understandings of what it has meant to live with impairment in China since the establishment of the People’s Republic (hereafter PRC) in 1949 by the Chinese Communist Party (hereafter CCP), but particularly since the end of the Cultural Revolution (1966–1976). It looks to establish the standards against which disabled people have been held across this period as the state itself has grappled with the expectations of the ‘ideal’ Chinese citizen. Yet, it also reveals how these standards have sometimes changed and morphed to accommodate those who did not easily fit the normative expectations for full socialist and subsequent post-socialist citizenship. The book explores how these often fluid and complex narratives of disability and disabled citizenship have been created and employed by the state, but also how they have been both embraced and challenged by disabled people and others. It reveals how culture offers a potent site where the ideals and norms of disabled citizenship are negotiated, a dynamic space where collective social, political and cultural understandings of what it means to live a disabled life are both imbued and contested. As such, it seeks out those places and situations beyond the obvious, beyond the formal, that work to define disability in China, both for those tasked with

defining disability for the state and its purposes, but also for those upon whom the burden of ‘being disabled’ falls once those definitions have been determined. Indeed, I argue that it is particularly important in a country like China to look beyond civil society organisations, where the challenge to official discourse is often fomented (Hallett, 2015), to other influential areas such as culture, which might offer an alternative space for the potential reimagining of disability in the future.

Through this study of disability in China, and particularly the culture of disability in China, I propose that the current theoretical conceptions of disability and citizenship which, for the most part, posit disabled people as less-than-full citizens, sometimes overlook the instability of impairment, the agency of disabled people, the dynamism of citizenship norms and ideals, as well as the highly affective nature of particular discourses of belonging. By contrast, the term ‘para-citizenship’ I propose here has, I would argue, a greater capacity to capture the various ways in which disabled people can be isolated and marginalised, viewed as different and not ‘normal’, and considered ancillary to the ‘mainstream’. It also has the added advantage that it can reflect a sense of equality and inclusion, parallel, side-by-side, in the same way we might talk of para-sport, for example. Employing a term that denies neither structure nor agency enables us to recognise the precarious and unstable nature of citizenship *for* disabled people, as well as the reflexive choices that *they* themselves might make about the engagement with their communities and the emancipatory feelings that they have about their own experiences, even though they may not always chime with approaches looking to address structural barriers and sources of oppression. It also helps to avoid envisioning top-down conceptions of citizenship as wholly static or wholly negative, and opens up the potential for nuance and change as when, for example, rights-based approaches to policy making are introduced and take effect.

Further to this theoretical contribution, the cultural focus of this study means that it is also, in effect, the first comprehensive empirical study of changing representations of disability in China across the modern period.<sup>1</sup> As I argued in my first research article on disability in China, now well over a decade ago (Dauncey, 2007), the evolution of disability representation and the development of disabled identities in the post-Mao era have been some of the most dramatic, but also most overlooked, features of recent Chinese history. By the end of the Cultural Revolution, disabled people had become largely absent from film, documentary,

<sup>1</sup> A single book cannot hope to cover everything from 1912 and the end of the imperial period onwards, hence the focus on this particular period.

4 Introduction

fiction and life writing, as socialist views of the body focusing on active and useful function had effectively whitewashed images of disability from most forms of literature and culture. The only exceptions here were if the disabled body could be shown to match or, better still, exceed the ‘performance’ of the non-disabled body in the service of the communist revolution and other political imperatives of the time. By contrast, the years following 1976 saw many changes, including the formation in 1988 of the highly influential China Disabled Persons’ Federation (*Zhongguo canjiren lianhehui* 中国残疾人联合会; hereafter CDPF), which have permitted and even actively promoted the representation of disability. Moving forward to the second decade of the twenty-first century, we have numerous literary, cinematic and other cultural works representing an increasingly diverse range of disabled lives and with an equally wide range of impairments that have drawn on changing conceptions of disability over the past six decades or so and, in turn, contributed to the reimagining of disabled identities and disabled citizenship.

Despite this, there is relatively little work on disability, culture and identity in China in either English or Chinese, and there are no studies as yet that look at his issue from a citizenship perspective. This forms a stark contrast to the wealth of research on such aspects of disability in Europe, North America and Australia, areas that are now often referred to as the ‘global North’. This work is, therefore, highly timely because we are at a juncture where there is an urgent need to address the fundamental problem caused by applying theories – which may be founded in sociological, cultural studies or disability studies traditions – that have been developed in these Western or Anglophone contexts directly to China or other societies. As my own research and that of others has already shown, such theory is often based on specific socio-political contexts and often foregrounds contemporary (and again highly contextualised) ideals to challenge actual circumstances in those very specific socio-political contexts. As a result, the findings will inevitably show the non-global North context in an *even more* negative light than would be found for the global North context (Dauncey, 2013a). But the problem may be even deeper than this because, as Helen Meekosha argues, disability studies ‘coming out of the north assumes the south’:

With a few exemptions scholarly work is not located in terms of geography. The metropole is not named. The issues matter: education, employment, care, the theory matters: normalization, social model/medical model, postmodernism, but the *where* does not matter. Only those positioned outside the metropole need to make their geopolitical position clear. (Meekosha, 2008: 2)

While this is understandably frustrating for those of us working outside ‘the metropole’ as we must continually clarify our geographical focus

when others have no such need to do so, such an assumption can be highly problematic in several ways – not only does it continue to perpetuate the now thoroughly debunked myth of universality, it also means that nuances, and even glaring differences, in other contexts are overlooked or, even worse, explained away as exceptionalism. It fails to recognise the sometimes violent processes of colonialism, neo-colonialism and post-colonialism (from war, labour exploitation and pollution, to policy making and ideology) that are the cause of many impairments or disabling attitudes more broadly in these colonised and other contexts (see, for example, Barker and Murray, 2010; Meekosha, 2011; Chataika, 2012).<sup>2</sup>

Disability may well be a global phenomenon – in so far as there are known to be hundreds of millions of people around the world living with physical and mental impairment – but this certainly does not mean that there is a uniformity to the way in which disability is understood or experienced on a global scale. Disability studies in the United Kingdom (hereafter UK) has been dominated by the social model and its notion of a ‘disabling society’.<sup>3</sup> Rebecca Mallett and Katherine Runswick-Cole go further to suggest that British disability studies ‘often seems to demand an unquestioning adherence to the social model of disability’ (2014: 18). In the United States (hereafter USA), by contrast, the minority model, which is positioned in relation to debates on wider minority politics, takes a central role in revealing the ways in which an ‘ableist society’, its cultural ‘norms’ and concomitant assumptions of the ‘normal’, work to create exclusion and prejudice (Davis, 1995). But even these concepts and theories that have been so useful in helping us to understand disability in what is usually described as the ‘global North’ may not necessarily

<sup>2</sup> Researchers working in different contexts often focus on different impairments, too, and for good reason argue Whyte and Ingstad (2007). In regions with recent histories of conflict, for example, a particular focus might be on physical impairments caused by armed violence of land mines; in states with weak healthcare infrastructures, the focus might be on bodily disorders caused by communicable diseases such as polio or leprosy. In other circumstances, a bodily condition that is considered desirable in some cultures (female genital mutilation being a prime example) would be classified as disabling once the individual moved outside that culture; and even within the same culture, a particular condition might be viewed very differently depending upon age, gender, religion, status, class or other intersecting factors. These considerations are important, particularly when it comes to defining ‘disability’ or understanding what diagnoses or prognoses are considered by individuals, groups and societies as ‘disabling’. For wide-ranging explorations of some of these different global contexts, see the numerous valuable contributions in Ingstad and Whyte (1995, 2007), as well as the more recent volume by Grech and Soldatic (2016).

<sup>3</sup> For a highly informative analysis of the origins and development of the various medical and so-called ‘social-contextual’ models of disability that have shaped political understandings of disability and impairment to this day, both in the UK and globally, see Shakespeare (2006: 9–28).

6 Introduction

be the dominant understanding of those working in regions there. Even countries that fall firmly within said global North reveal sometimes quite different interpretations and explanations (Mallett and Runswick-Cole, 2014: 19–25). How much more glaring the discrepancy, then, if we attempt to take these ‘minority world accounts’ (Priestley, 2001) and apply them to the rest of the world where, according to the ‘World Report on Disability’, 80 per cent of disabled people live (World Health Organization and World Bank, 2011)?

Of course, we cannot ignore the effects of globalisation and the ways in which new forms of media, communication and policy making have begun to transform understandings of disability around the world, and the cultures that surround and frame them. We have to remember that these changes are relatively recent phenomena and that certain societies have been quicker to adopt and embrace them than others. Traditional or local understandings may be more resistant to change, depending upon a society’s ‘openness’ (political, social or cultural) to such changes and innovations. One of the most far-reaching and fundamental attempts to change global attitudes and approaches to disabled people is the United Nations Convention on the Rights of Persons with Disabilities (A/RES/61/106) (hereafter CRPD), which was adopted on 13 December 2006 and entered into force on 3 May 2008. It takes an intentionally broad categorisation of disabled people in order to ensure that people with all types of impairments are able to enjoy fundamental freedoms and all human rights:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (United Nations, 2008)

In doing so, it attempts to move global understandings towards viewing disabled people as ‘subjects’ with rights, ‘who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society’, and away from the view that they should be viewed as ‘objects’ of medical treatment, social protection and charity (United Nations, 2008).

The sheer ubiquity of the CRPD in political, academic and institutional discourses of disability these days, however, means that it is almost *too easy* to assume that there is a common, global vision of disability and of disability rights. Yet, while activists and policy makers from both the global North and South are in increasing conversation about promoting social, cultural and legislative change in line with the aims and objectives of the CRPD – and China is included here, having signed up in 2008 –

these contacts are also revealing continuing wide gaps in assumptions about what this might actually mean in practice. As Benedicte Ingstad (2001) has argued, the realities of daily life for disabled people in particular contexts need to be taken into account if imagined interventions are to be effective. Environments that are resource-poor or communities that have different conceptions of personhood or impairment may struggle to implement, or even comprehend, the definitions, policies and processes introduced to (or possibly even foisted upon) them. Shaun Grech (2009), similarly argues that for many disabled people outside the global North, individual rights may be subservient to family or community (local, regional or even national) rights; and basic ‘survival’ itself might even be the key issue regardless of what rights may or may not be understood or granted in their particular society.

And, so, while we now see China as very much a global player with a rapidly developing economy, we must remember that its engagement with the outside world in the contemporary period is relatively recent. It is still, effectively, a one-party socialist state with a strong tradition of socio-cultural control and welfare systems that are still struggling to catch up with its rapid pace of development, as well as the challenge of a growing disabled population. According to China’s Second National Sample Survey of Disabilities (*Di er ci quanguo canjiren chouyang diaocha* 第二次全国残疾人抽样调查) of 2006, 6.34 per cent of the Chinese population, an estimated 82.96 million people, were categorised as ‘disabled’. Broken down into officially recognised categories, this amounted to 12.33 million people with a ‘visual disability’, 20.04 million with a ‘hearing disability’, 1.27 million with a ‘speech disability’, 24.12 million with a ‘physical disability’, 5.54 million with a ‘learning disability’, 6.14 million with a ‘mental disability’, and 13.52 million with ‘multiple disabilities’ (*Di er ci quanguo canjiren chouyang diaocha bangongshi*, 2006).<sup>4</sup> As a result, many disabled people in the country are known to live isolated and impoverished lives, where accessing essential basics, such as medical and welfare services, can be tremendously difficult, never mind education and employment opportunities (see, for example, Campbell and Uren, 2011; Fjeld and Saggi, 2011; Loyalka et al., 2014; Carillo, Hood and Kadetz, 2017; Fisher, Shang and Blaxland, 2017). These political and socio-economic factors have affected the degree to

<sup>4</sup> There has yet to be a follow-up census, so the numbers are likely to be much higher in 2019 based on China’s general population growth alone. But these figures are also unlikely to include the ‘hidden’ population – people who are physically hidden away or those people not counted because they do not fall into one of the categories of disability defined by the state.

8 Introduction

which external pressures and developments shape the environment for disabled people in the country, even though it has been actively engaging with the CRPD and other international disability rights initiatives since the early 1980s.<sup>5</sup> And other societies, and cultures within those societies, will have their own peculiarities that require closer examination too.

What we need to address this complexity, therefore, are more ‘culturally specific’ examinations of disability and impairment (Sherry, 2007). Starting, as Susan Reynolds Whyte and Benedicte Ingstad encourage us to do, with ‘where people live, with their concerns and resources and the particular political ecology in which they are interacting’ (2007: 3), might enable us to avoid automatic assumptions about the relevance of, for example, disability rights, identity politics or other policy-related expectations common to the global North, to better document the detailed ways in which disabled people experience themselves and their world. It is only once these subjectivities, power relationships and communication flows at the local level are understood that we can begin to see ‘the ways in which links are made (or not) to powerful broader visions and possibilities that might produce effects in the local world of social practice’ (Whyte and Ingstad, 2007: 2–3). Unravelling the fluidity and complexity of disabled identities through an understanding of the political, social and cultural narratives of disability that frame them, and which may be both local and global, both immediate and imagined, offers a methodology for addressing disability representation in non-global North contexts. With this detail, we find ourselves in a much better position to develop more robust frameworks for undertaking necessary cross-cultural comparison, but also we will be able to be in a much better position to question and possibly even challenge those ‘overriding’ epistemologies from the global North that have for so long ‘bypassed, ignored or rejected’ studies situated outside its immediate sphere of influence (Chataika, 2012: 253).

### **Imagining Disability in and through Chinese Culture**

So, how might such an objective be achieved for China? The research here applies a fresh approach to what is, to all intents and purposes, a developing field of study. Building on a recent trend that focuses on ‘situated reading practices’ to ‘highlight how particular disability experiences can shape cultural histories and are written into artistic and representational practices’ (Barker and Murray, 2010), the project’s

<sup>5</sup> For a report on China’s progress in meeting its CRPD obligations to date, see United Nations Committee on the Rights of Persons with Disabilities (2012).



methodology integrates literary and cultural analysis with social history, disability studies understandings and the sociology of cultural citizenship. This approach resonates with Stephen Greenblatt's (1989) concept of a 'poetics of culture', which allows us to view cultural production as not only reflective and constitutive of a specific socio-historical context, but also as a mechanism that informs the construction of identities and behaviours therein. Close readings of the Chinese literary and cultural sources (some of which will be familiar to scholars in Chinese studies or related disciplines and some of which will be new to even these specialist audiences), as well as other Chinese language materials related to the socio-historical context, determine what specific terms, analogies and locations of disability might signify to the community (disabled and non-disabled) and how these function within a particular piece or genre and within the broader cultural logic. Following the circulation of terms and images through the various media, identifying areas of formation, adoption, consolidation, negotiation, contestation and rupture, offers a better understanding of how images are refracted between media and lived experiences. In doing so, the book aims to stimulate new reflections on personal and collective responses to representation, not only from a historical perspective, but also with an eye on how disabled identities and disabled citizenship – what I describe here as 'para-citizenship' – might be reimagined in the future.

For activist scholars, like Paul Longmore, a more rigorous cultural history of disabled people is, in fact, crucial for the development of 'positive and sustainable disabled identities in future':

The scholarly task is to uncover the hidden history of disabled people and to raise to awareness the unconscious attitudes and values embedded in media images. The political task is to liberate disabled people from the paternalistic prejudice expressed in those images and to forge a new social identity. The two are inseparable. (Longmore, 2003: 146)

The broader field of disability studies is already served by an extensive range of academic books on culture and identity that have begun to dissect and deconstruct those disabling images that have consciously and unconsciously informed social and political attitudes towards disabled people. From Alan Gartner and Tom Joe's edited volume, *Images of the Disabled, Disabling Images* (1987), which examines the relationship between various forms of disability representation and public policy, through Rosemarie Garland-Thomson's provocative reframing of disability as a minority discourse in American literature and culture in *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997); from G. Thomas Couser's explorations into the

10 Introduction

relationship between '(auto)somatography' and disability consciousness in *Signifying Bodies: Disability in Contemporary Life Writing* (2009) to David T. Mitchell and Sharon L. Snyder's narrative theory of the pervasive use of disability as a device of characterisation in literature and film in *Narrative Prosthesis: Disability and the Dependencies of Discourse* (2000), there are few impairments or genres that have not been the focus of expanding critical attention. All of these, and more, contribute a range of theoretical understandings against which my analysis of disability representation in China here is tested.

When we come to such research on China itself, however, it is a very different story. While there is a striking paucity of published monographs or edited volumes in English or Chinese (more on this in a moment), there is a small but growing body of excellent, predominantly film-focused research articles. Deidre Sabina Knight (2006) explores the moral dialogues on mental and physical anguish as revealed in two 1990s docu-dramas – *Sons* (*Erzi* 儿子, 1996, dir. Zhang Yuan 张元) and *The Common People* (alt. *Stories about Love, Guanyu ai de gushi* 关于爱的故事, 1998, dir. Zhou Xiaowen 周晓文). Steven L. Riep's (2008) 'A War of Wounds' examines disability and disfigurement in retrospective mainland and Taiwanese portrayals of the War of Resistance against Japan. Tina Mai Chen's (2004) study offers a fascinating look at the way in which Russian fictional hero Pavel Korchagin and his disabled body introduced alternative bodily forms to Maoist discourse through film; and this is complemented by her later (2012) work on 'The Human-Machine Continuum', which demonstrates how the uniting of disabled and non-disabled bodies with tools was seen as central to the socialist transformation in the Mao era. And *Silent River* (*Wu sheng de he* 无声的河, 2000, dir. Ning Jingwu 宁敬武) has received particular attention from both Zhang Jin (2010) in the context of Western Deaf film culture, where she contrasts it directly with Nicolas Philibert's documentary *In the Land of the Deaf* (*Au Pays des Sourds*, 1992) to highlight the deficiencies of the film when examined from a disability studies perspective, as well as in my own study (Dauncey, 2013a), where I contrast it with *Breaking the Silence* (alt. *Beautiful Mother, Piaoliang mama* 漂亮妈妈, 2000, dir. Sun Zhou 孙周) to reveal perceptions of the educational experiences of young deaf people in the 1990s that both embrace and challenge Western and Chinese stereotypes of deafness. The research undertaken on works by disabled people themselves is still very much in its infancy, but the potential for further development is clear. My own explorations of the semi-autobiographical work of Zhang Haidi 张海迪 (b. 1955), a former model citizen and current president of the CDPF who is also the subject of Chapter 2 (Dauncey, 2013b), as well as the young entrepreneur and