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When Sexuality Meets Disability: Experiences, Attitudes and Practices from China

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In China, there are more than 83 million people with disabilities. Approximately, 41 million of them are women and girls, and 8 million are aged between 10 and 19 (Leading Group on the Second China National Sample Survey on Disability & National Bureau of Statistics of the People's Republic of China, 2006). In 2008, China was one of the first countries to sign, ratify, and start translating into laws the Convention on the Rights of Persons with Disabilities (UNCRPD). It is a binding international convention which was adopted by the United Nations (UN) General Assembly in 2006 (United Nations, 2006) and ratified by more than 175 countries by the end of 2017 (United Nations Enable, 2018). To date, some of the Chinese laws are still not in line with the UNCRPD principles and weaknesses in their

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M. Mac-Seing University of Montreal, Montreal, Canada e-mail: muriel.k.f.mac-seing@umontreal.ca implementation are visible. The most prominent example is the Law on the Protection of People with Disabilities (People's Republic of China, 1990, 2008), one of the most important Chinese pieces of national legislation pertaining to disability, which defines a person with disabilities as someone "who suffers from abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and has lost wholly or in part the ability to perform an activity in the way considered normal" (Article 2).

This chapter is aligned with Article 1 of the UNCRPD that defines people with disabilities as "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, 2006). In other words, people with impairments become disabled when confronted with attitudinal, environmental and structural barriers which prevent them from social participation. As emphasised by the Concluding Observation Report of the UNCRPD (2013), China's medical focus on "normality" contrasts with the basic principles of participation and inclusion enshrined in Article 1 of the UNCRPD. Chinese disability-related policies continue to maintain the medical model of disability which promotes primarily medical/rehabilitation and special services "to restore normal functioning" (Bill, 2004, p. 2) and assumes that the "reparation" of individuals with impairments alone is sufficient for them to participate in society.

The UNCRPD includes several articles closely related to the sphere of sexuality, such as Article 16 on freedom from exploitation, violence and abuse, Article 23, on respect for home and the family, and Article 25 on health. These articles, which remain largely unimplemented in China as in many other countries around the world (Equality and Human Rights Commission, 2014; European Commission, 2014), describe that States Parties shall take all the appropriate measures to protect people with disabilities, eliminate discrimination in all matters relating to marriage, parenthood and relationships, and provide people with disabilities with the same range, quality and standard of free or affordable access to sexual and reproductive health (SRH) information and services.

China's policy and legal framework makes no specific reference to the SRH needs and rights of young people and adults with disabilities (Zheng & He, 2014). Furthermore, a disability perspective is not included in the current Chinese SRH policies and programmes, and China's first Anti-Domestic Violence Law (People's Republic of China, 2015), which directly targets physical and psychological violence against people with disabilities, does not discuss sexual violence. In terms of the access to and needs for SRH information and services of people with disabilities, there is a paucity of information in China. This could be attributed to the fact that people with disabilities are often perceived as not fully capable of being in a relationship, and when it comes to sexual contacts, they are mainly perceived as potential victims of violence and abuse rather than sexual subjects entitled to rights. People with disabilities are erroneously considered asexual, with no sexual desires and needs, and when these are openly expressed, they may create uncomfortable feelings, be perceived as wrong and inappropriate and, therefore, open to criticism and punishment (Zheng & He, 2014). It has also been reported that people with disabilities who are same-sex desiring experience double discrimination due to dominant assumptions of heterosexuality which are embedded in Chinese policies; only recently the effects of these assumptions have started to be explored (Zheng & He, 2014).

Among national scholars and professionals, the use of rights-based approaches to discuss sexuality and disability is still limited. The disability and sexual rights movements, in China, as in many other countries around the world, have no significant history of collaboration (Goblet, 2011) and sexual rights of people with disabilities are described as "newly emerging rights" (Liao, Xiong, & Ju, 2013). Limited awareness about SRH needs and rights of people with disabilities among the general population, service providers, as well as people with disabilities themselves, inevitably represents a barrier for people with disabilities to fully enjoy their sexual rights and access information and services pertaining to SRH which end up being mostly inappropriate and inaccessible (UNFPA, 2009). This not only implies a violation of people with disabilities' rights, but may also expose them to higher risks of contracting HIV and other sexually transmitted infections, unwanted pregnancies, violence and abuse (Ortoleva & Lewis, 2012).

In the last few years, a small number of Chinese non-governmental organisations (NGO) have increasingly expressed the need to promote a better access to SRH information and services for people with disabilities. The international NGO Humanity & Inclusion, working in China since 1998 under the name "Handicap International", has brought its relevant experience in promoting accessible HIV and SRH information and services throughout the world (Mac-Seing, 2012, 2014) into play. In 2013, the organisation took the initiative to address this need and launch the first comprehensive intervention on Disability, Gender and Sexuality in China. The project's two main components include: (1) An advocacy pilot project promoting the implementation of Article 25 of the UNCRPD, conducted in partnership with local NGOs; (2) A study of the knowledge, attitudes and practices around SRH and access to SRH information and services among young Chinese people with disabilities, conducted in partnership with the United Nations Organisation for Education, Science and Culture (UNESCO).

After providing a general glimpse on sexuality, disability and rights, and analysing some of the key aspects of the Chinese modernising discourse related to sexuality and disability, this chapter discusses experiences, attitudes and perspectives on sexuality and disability in China, in accordance with the findings of the first phase of the Disability, Gender and Sexuality advocacy pilot project (2013–2016). Final results of the research conducted in partnership with UNESCO will be included in the forthcoming report "Seeing the invisible: Sexuality-related knowledge, attitudes and bahavior of young people with disabilities in China", which will be available at www.unesco.org/openaccess and www.hi-us.org/publications.

Sexuality, Disability and Rights: A Global Overview

In 2011, the disability community, development practitioners, researchers and decision-makers witnessed the release of the first World Report on Disability. In this report, people with disabilities are estimated

to constitute 15% of the world's population, and one woman in five (19.5%) lives with some form of disability (World Health Organization & The World Bank, 2011). Moreover, 80% of people with disabilities are reported to live in low and middle income countries (United Nations Enable, 2014). As a result of a multi-year endeavour, the report constitutes a breakthrough, as until then, no new world disability statistics have been generated since the 1970s. The report further provides invaluable data pertaining to a population that has long been invisible and, in combination with the UNCRPD, it provides professionals in the field of disability as well as decision-makers an unprecedented reference to definitions, community-based rehabilitation initiatives and examples of good practices worldwide. More recently, the adoption of the Sustainable Development Goals (SDGs) have clearly emphasised the importance of inclusion, accountability and data disaggregation, and included disability in the post Millennium Development Goals definition (United Nations General Assembly, 2015). More than ever, countries and development partners will need to seriously revisit their international cooperation and aid agenda towards promoting disability inclusion and revise national plans to achieve the ambitious goal of leaving "no one behind". Despite these unequivocal States' obligations and many countries voting for the promotion and protection of the rights of people with disabilities at national level, the SRH rights of people with disabilities mainly go unaddressed. According to "Forgotten sisters", a report on violence against women with disabilities, their sexual rights continue to be violated due to deep-rooted discriminatory attitudes and practices, and lack of law and policy enforcement (Ortoleva & Lewis, 2012). It was further reported that forced sterilisation and contraception, gender-based violence, denial of maternal, parenting and parental rights, denial of legal capacity and decision-making, lack of access to SRH information and services, and a lack of access to justice are among the key rights violations women with disabilities face on a regular basis (Frohmader & Ortoleva, 2014).

There are several reasons attributed to these grim observations. In 2004, a global survey looked at the intersection between HIV and disability and reported that people with disabilities were often believed

by their communities as being asexual and not in need of SRH information and services. As a result, women and men with disabilities were often excluded from HIV-related awareness-raising campaigns and services (Groce, 2004). In 2010, the World Health Organisation (WHO) and the United Nations Population Fund (UNFPA) also reported that the SRH needs of people with disabilities had not been recognised. People with disabilities have been denied the freedom of choice in building an intimate relationship or a family of their own. They have been at a heightened risk of sexual violence, and have often been deprived of access to basic healthcare services (World Health Organization & United Nations Population Fund, 2010). According to a study in South Africa, young people with disabilities have little or no access to sex education (Rohleder, 2010). In Nigeria, a lack of sex education is further exacerbated by the limited availability of disability-friendly teaching material (Aderemi, Pillay, & Esterhuizen, 2013). Based on studies that measured the needs and practices of educators, designing culturally appropriate tools for special schools' educators and providing the technical support needed for teaching sex education to young people with disabilities is a key to success (Hanass-Hancock, Henken, Pretorius, de Reus, & van Brakel, 2014; Rohleder, 2010). In the early 2000s, Humanity & Inclusion undertook one of the few multi-year initiatives that addressed the issue of access to sex education for people with disabilities for a period of eight years (Handicap International, 2007). The project focussed on supporting people with disabilities, their families and professional caregivers to feel more comfortable talking about and experiencing sexuality. This has progressively broken parental denial of the "discovery" of their adult children's sexuality and helped addressing the embarrassment displayed by professionals in institutions and in health facilities where people with disabilities would live in and/or visit.

A participatory research study conducted among Zulu-speaking youth with physical and visual impairments in South Africa (Chappell, 2014) showed that young people with disabilities did not differ from their non-disabled peers when it pertains to the construction of their

sexual identities. Contrary to common beliefs, they were much more similar in their ideas of love, intimacy and relationship building than expected. Their sexual identity seemed to be more influenced by gender identities and roles than by their impairments (Chappell, 2014). Moreover, based on a methodological content review of literature on culture and disability in sexuality, it was further reported that the cultural aspect and ethnicity have been overlooked when examining the intersection between disability and sexuality. Authors concluded that more research is needed to better understand the various related levels of intersectionality (Greenwell & Sigmund, 2008). In the context of China, where the medical model of disability is still widespread (Kohrman, 2005), and where the conceptual link between sex, reproduction, population quality, eugenics and education characterises China's modernising discourse since the early 1920s (Aresu, 2006; Dikötter, 1995), the pilot advocacy project conducted by Humanity & Inclusion builds on experiences in sub-Saharan Africa to further explore the intersections between sexuality and disability. It will contribute to shedding more light on a topic which remains largely overlooked to date.

Sexuality, Disability and Modernisation in China

In the early 1920s, Chinese modernising elites constructed unprecedented conceptual links between modernisation, understood as the process through which China could become a strong and prosperous nation, and the topics of sex, reproduction, population quality, education and eugenics (Dikötter, 1995). National and population weaknesses were seen as firmly interlinked and the improvement of population's health and hygiene, and regulation of sexual desire and human reproduction were considered to be the requirements for increasing the population's quality (Aresu, 2009). Eugenic criteria targeted premarital and extramarital sex, as well as conjugal couples' sexual life. Intercourses practiced not more often than once weekly were regarded, for example, as a condition for improving the quality of the offspring, while excesses in sexual life were considered responsible in making their children weak, unhealthy and unintelligent (Zhang, 1967). A lack of SRH knowledge was pinpointed in the discourses as the main causes of diseases, low-quality offspring, disordered sexual lives and overpopulation (Wang, 2006). For the modernising elites of the early 1920s, popularising scientific sexual knowledge through education was a key step towards regulating sexual desire and human reproduction, thereby strengthening the population's quality, the race and the nation (Liang, 2000).

Although the circulation of these discursive formations remained limited within the intellectual elites, they laid the foundations of discussions that were all taken up by the communist leadership in the late 1940s with the only exception of the eugenic elements. These were reintroduced only in the late 1970s after the inauguration of a new chapter in China's modernising project, internally characterised by a progressive marketisation of the economy, and the launch of the One Child Policy (Aresu, 2009). In the 1980s, the One Child Policy brought the quality of births and eugenics back into the Chinese government's agenda (Dikötter, 1998; Sharping, 2003; White, 2006). A Policy of Prevention of Impairments was also implemented as a key component of the One Child Policy by forbidding people with hereditary genetic conditions to reproduce. The Policy allowed married couples to have a second child if the first one was a child born with an impairment. Unavoidably, this attached negative connotations to disability within the public discourse (Fjield & Sagli, 2011) and limited people with disabilities in the fulfilment of their basic and reproductive rights.

Demographic and eugenic concerns in the early 1980s official discourse provided the stimulus for sex education to enter into schools through classes on family planning (Aresu, 2009). China formally introduced sex education into the secondary school system in 1988 and, since then, implemented sex education programmes in mainstream schools in a slow and unsystematic manner (Liu & Su, 2013). Through the provision of a set of "truths" defining normative standards of moral and responsible social and sexual behaviour, and the use of "disciplinary and normalising techniques" (Foucault, 1977, 1984), sex education aimed to shape young people as manageable and malleable bodies, and as healthy and moral subjects able to contribute to the requirements of a modernising society (Aresu, 2006). Young people with disabilities, however, defined by their impairments, had a hard time in contributing to China's modernising project. It is only since the late 1990s, with the introduction of China's first Protection and Rehabilitation Policy aiming to support people with disabilities in becoming "able" to contribute to modernisation (Fjield & Sagli, 2011), that disability in China "has been intertwined with the government's complex management of China's modernisation" (Kohrman, 2005, p. 17).

Throughout the years, the policies on Prevention of Impairments, Protection, and Rehabilitation have been one of the main concerns of the China Disabled Persons' Federation (CDPF), a semi-governmental organisation that reports directly to the deputy prime minister of the State Council. CDPF is responsible for representing the common interests of people with disabilities, protecting their rights, and providing services. However, since its establishment in 1988, sexuality has not been identified as a priority within CDPF's agenda, which focusses primarily on health, education, employment, poverty alleviation and rehabilitation. As a result, special education schools have been excluded from the implementation of China's national sex education programme, and the SRH needs of boys and girls with disabilities have largely remained neglected.

The first debates on sex education for children with disabilities started to emerge in the mid-1990s, in conjunction with national scholars' increasing attention to female survivors of sexual violence (Huo, 1995; Xie, Zheng, & Huang, 1998; Zhang & Yao, 1995) and the need to improve self-protection skills of women and girls with disabilities (Chen & N, 1995; Tang & Lee, 1999). Several other studies also started focussing on sex education for children with hearing impairments (Chen, 2012; He, 2005; Zan & Liu, 2005) and children with intellectual disabilities (Liu, 2011; Zhou, 1999). The discussion on the need to strengthen the provision of information on SRH and self-protection also targeted parents and teachers dealing with practices that are generally perceived as inappropriate and typical of children with intellectual disabilities, such as masturbation in public or searching for physical contact with strangers. Studies conducted with parents describe them as

mostly unprepared to deal with these behaviours and unaware of their children's needs (Sun et al., 2007; Wang & Zhang, 2003). The lack of teaching materials, and teachers trained on sexuality education able to support children with intellectual disabilities in their sexual development was also highlighted (Wang & Wang, 2005; Xiong & Zhang, 2004).

Although, the provision of sex education to children with disabilities has been reported to be extremely limited (Wang, 2013; Xiong, 2013), these emerging debates have stimulated and inspired the launch of the first pilot projects aiming to facilitate the access to sex education for children with disabilities in China. Since 2009, the local NGO Nurturing Relations has been mobilising resources in the area of Guangzhou (Guangdong Province) to comprehensively address the sex education needs of boys and girls with disabilities, both at home and at school. This resulted in China's first curriculum on sexuality for people with disabilities (Quint, 2010), and the launch of an education programme to train teachers, professionals and parents about sex education for people with disabilities. This localised experience has hence informed the first pilot advocacy project promoted by Humanity & Inclusion in 2013, in partnership with the local organisations One plus One Disabled Persons' Culture Development Centre (One plus one), the Enable Disability Studies Institute, and You and Me Community. The project focusses on awareness raising of the needs of people with sensory, intellectual and physical impairments, while promoting their access to quality SRH information and services and advocating for their sexual rights.

Considering the lack of Chinese scholars and professionals with a relevant experience on both sexuality and disability, as well as the scarce collaboration among the gender, sexuality and disability fields, the initial phase of the project focussed on establishing a sexuality and disability network. This network aimed to facilitate collaboration among specialists with different backgrounds committed to supporting the implementation of the project. The project involved 300 people with disabilities, 40 family members, 160 social workers and staff from rehabilitation institutions and government departments, 40 gender, sexuality and SRH specialists/service providers, and 2000 members of the general public. Peer group sharing, training and seminars occurred in Beijing Municipality, and Jiangsu, Hunan and Sichuan Provinces, where the implementing partners had existing networks and trustworthy relationships with local communities, parents' organisations, rehabilitation institutions, care centres and social workers.

As a result of the first project phase, the communication and working relations established between some disability and sexuality organisations/specialists have become increasingly more substantial. In addition, the project team including Alessandra Aresu, was able to collect sexuality related information on the needs and experiences of people with disabilities, their families, and caregivers by participating in and observing the project activities, and through personal communications and in-depth interviews conducted in May-June 2015. The interviewees included a selected number of Chinese sexuality specialists and leaders of the Chinese disability movement. Among them, Mr. Cai Cong and Ms. Jin Ling, both with visual impairments, and from the local NGO One Plus One, and Ms. Wang Xuehong, project officer at Humanity & Inclusion with a physical impairment, were selected for their significant contribution in designing and implementing the project. Based on this information, the following sections discuss perceptions, understandings and attitudes of people with disabilities and their families on different sexuality related issues, such as dating and relationships, marriage, familv and sex education.

Sexuality and Disability: Experiences, Perceptions and Attitudes

On Dating and Relationships

The expectation for young people to get married and have children remains widespread in China. It is reinforced by the heteronormativedominant discourse that permeates policies and regulations, sex education, family and peer-groups conversations. Young people's search for a partner is deeply influenced by mainstream standards of health, beauty and strength, all important characteristics within their representation of the ideal partner able to provide support, take care of the elderly and ensure descendants. The characteristics of health, beauty and strength are rarely associated with people with disabilities, who are usually represented as weak, dependent and sick (Shakespeare, 1996), and seen as such by people without disabilities and their families searching for the ideal partner for their only child. "As a result, non-disabled young people and their families rarely consider a person with disability as their first choice. This is due to the fact that society looks at us as people of a lower status and this inevitably influences the way our peers and their families look at us" explains Mr. Cai Cong.

Mr. Cai Cong and Ms. Jin Ling recall their experience as teenage students in mainstream schools and shared that their classmates without disabilities always dismissed them as a possible boyfriend or girlfriend, as if people with disabilities simply did not exist on the dating radar of young people without disabilities. Moreover, Cai Cong explains the "lack of self-confidence, communication and social skills remains a barrier for boys and girls with disabilities when it comes to socialising and looking for a partner". Thus, many young people with disabilities attending mainstream schools end up having little or no experience of dating and intimate relationships. This is also reinforced by the fact that parents are extremely protective of their children with disabilities and tend to control them very closely, leaving little space for dating. According to Cai's personal experience, the situation is quite different for young people attending special schools, and especially those attending boarding schools, where children are surrounded by other children with disabilities who experience similar difficulties and opportunities. "The fear of being rejected is reduced when dating another person with disability", concludes Cai.

Sometimes, the behaviours and attitudes of people with disabilities may unintentionally reinforce the idea that they belong to a lower status. For example, Ms. Wang Xuehong shared that many girls with disabilities are particularly inclined to idealise relationships with a partner without a disability and to sacrifice everything for him/her. Other girls, continues Wang, end up dating someone with disabilities thinking that this is the only choice they are left with. Therefore, "having our voices represented in the ongoing sexuality debate would be a very important step to strengthen the self-confidence of many girls with disabilities; however, this still rarely happens in China. Even in the Chinese version of theatre plays coming from abroad like the Vagina Monologues, women with disabilities have no space to express themselves and communicate about their sexuality", concludes Wang. Humanity & Inclusion's advocacy pilot project hence has contributed to create safe and comfortable environments by organising peer-group led activities where youth with disabilities are invited and supported to express, communicate, and be heard regarding their sexuality, as well as to exchange experiences and concerns. In addition to this, starting from 2013 the project has organised several awareness raising events on sexuality and disability for the general public. These initiatives created the opportunity for people with and without disabilities to openly share and discuss experiences and ideas on gender, love, sex, pleasure, protection, family, reproduction and marriage (One Plus One, 2013, 2014, 2015).

When Marriage Comes Along

Recent studies have highlighted an increase in marriages between individuals with and without disabilities, with men succeeding more than women in marrying a non-disabled partner. However, the majority of people with disabilities still marry a partner with disabilities (China Disabled Persons' Federation, 2010; Hao, Xin, Zhao, & Guo, 2013) and believe that this is for them the best solution, explains Mr. Cai Cong. Parents of children with disabilities, on the contrary, rarely see a happy future for disabled couples, and try to persuade their children with disabilities to find a partner without disabilities. At the same time, they have to deal with the fact that many parents of children without disabilities would never accept their children to marry someone with a disability, shares Ms. Jin Ling. In the countryside, where many men struggle to find a bride due to their low socio-economic status and the unbalanced gender ratio (118 males for 100 females) that characterises China's population (UNICEF, National Working Committee on Children and Women, & Statistics, 2014), an increase in men without disabilities marrying women with intellectual disabilities has been observed. Parents of women with intellectual disabilities see this as an opportunity for their daughters

to be economically supported and looked after throughout their lives, but they often underestimate the risk of their daughters being abused by their husbands and in-laws (Pan, 2010).

Marrying a man without disabilities from the countryside is often considered an option also by many low-income families of girls with disabilities living in cities. These men are reported as often "inclined to accept a girl with a disability rather than remaining without a wife and offspring", shares Jin, while a groom's parents see a woman with disability as "a tool to give birth", a way to ensure descendants for their family. Parents of children with disabilities, on the other hand, believe that their lower status as a "family of a child with disability" and the lower status of a poor and/or rural family will end up being "somehow equal" and that this balance can prevent their children with disabilities from being bullied or becoming a victim of violence after marriage, concludes Jin.

The topic of domestic violence against people with disabilities remains overlooked in China, and comprehensive data are still missing. However, China's Anti-Domestic Violence Law (2015) and several reports addressing this theme point out that women with disabilities are particularly vulnerable to different forms of domestic violence as a result of the difficulties they may face in meeting their husband and in-law's family's expectations in relation to sex, procreation and housework, while prevention, protection and punishment of domestic violence remains largely insufficient (Hao et al., 2013; UN WOMEN, 2014). Stereotypes, mainstream standards and family pressure seem to dominate the Chinese discourse on youth, sexuality and disability, leaving little space for young people's voices, desires and preferences to be acknowledged. A deep ignorance of parents related to the desires, needs and rights of their children with disabilities still prevails.

Parents: From Barriers to Facilitators?

The first phase of the Disability, Gender and Sexuality advocacy pilot project represented a unique opportunity to collect first-hand information on parents' knowledge, attitudes and behaviour on disability and sexuality and, for many parents, to discuss their role as sex educators with

peers and professionals. Project activities focussed primarily on parents of children with intellectual disabilities, and included awareness raising activities, as well as specific training sessions aiming to stimulate parents' awareness of gender and sexuality related issues, and to increase their understanding of children's sexual rights and needs. Echoing the Chinesedominant discourse, parents of children with disabilities involved in the project identified early intervention, rehabilitation, education and employment as top priorities for their children. They ignored or denied desire, needs and interest for sex, intimacy, affection, dating and love of young people with disabilities and tended to speak for their children rather than focussing on understanding what they feel, want and desire. Parents were reluctant to talk about their children's sexuality, described their children's sexual development as problematic and genuinely shared their lack of skills to talk about SRH and to positively acknowledge their children's desires for sexual pleasure, affection, physical contacts, love and intimacy. When it comes to sexual abuse, the project shows that most parents choose to limit their children's contact with others rather than educate them on how to be social and safe at the same time, contributing in this way to their children's social isolation and exclusion.

In sum, parents of children with disabilities often seem to represent a barrier to their children's access to sexuality-related information. Considering that children's perceptions of their sexuality are highly influenced by parents' attitudes, future interventions on sexuality and disability must target parents to ensure that they too can promote, rather than neglect, their children's sexual rights. Parents' feedback and participation in these small-scale activities highlighted the need to train parents' leaders and further involve them as the key actors in project design and implementation, as well as in raising the awareness of other parents of children with disabilities on gender- and sexualityrelated issues. A similar conclusion resulted from a study undertaken among South African youth with physical and visual impairments, which recommends the importance of helping parents and caregivers in this lifelong journey of learning and communicating about sexuality between children with disabilities and their families (Chappell, 2015). Much more work on improving parents' understanding of their children as sexual rights holders is needed to ensure they can go beyond

the widespread approach, which prioritises protection and control over children's sexual rights and needs. They can play a more supportive role, and positively transform themselves from constituting a barrier to being facilitators in promoting the rights of their children with disabilities.

Conclusion

The collaboration between the fields of sexuality and disability, and the increasing knowledge acquired by sexuality and disability specialists throughout the project, has allowed an unprecedented level of discussion and analysis regarding the intersections between sexuality and disability in the Chinese context. By the end of the first project phase in 2016, professionals from both fields increasingly recognised the importance of mainstreaming disability and including sexuality into their work and agreed on the fact that discrimination and exclusion are the main barriers that prevent people with disabilities from fully enjoying their sexual rights. The project also confirmed the facilitative and connective role that organisations of persons with disabilities can play in linking services for people with disabilities and their families and acting as bridges between the sexuality field and people with disabilities, their parents and communities. However, a lack of people with disabilities engaged at a professional level in the field of sexuality and equipped with the necessary skills to act as a sex educator, sexual therapist or sexual counsellor has been observed. These limitations need to be further addressed in future discussions on the access of people with disabilities to SRH information and services, while continuing promoting the collaboration between organisations of persons with disabilities and specialists from the sexuality field building on the network already established by the pilot project.

From the perspective of people with disabilities, the project confirmed that even in big cities such as Shanghai and Beijing, people with disabilities have a very limited access to information and services related to gender and sexuality and often feel fear, confusion and shame when the topic of sexuality emerges in their life. They usually do not know with whom they can talk to about these issues. The available

data are too limited to argue which elements have a greater influence on the knowledge and experience related to sexuality of people with disabilities, but this reminds us about the importance of designing tailored interventions based on different local contexts and cultures within which people with disabilities are living. More ethnographic and in-depth qualitative studies should be implemented to better understand the intersectionality between these various factors (Hankivsky, 2012). The forthcoming report by UNESCO and Humanity & Inclusion will provide further insights. Finally, by raising the awareness of scholars, professionals, teachers, people with and without disabilities and their family members of the need to promote equal access to SRH information and services for people with disabilities, this project has been contributing to challenge beliefs, prejudices and stereotypes which historically have characterised the discourse on sexuality, disability, modernisation, education and population quality in China. The findings of the first project phase have informed the second phase of the Disability, Gender and Sexuality advocacy pilot project (2016-2018). The overall project findings will be shared with the major governmental and non-governmental stakeholders both in China and elsewhere to raise their awareness and obtain their support for future interventions which promote social inclusion of people with disabilities and their access to disability inclusive information and services.

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