

Family Care of People with Intellectual Disability in Rural China: A Magnified Responsibility

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Background Welfare for the disabled is becoming an important issue in China and care for people with intellectual disability is challenging because of the inadequacies in formal support and the social service system.

Material and Method Based on ethnographic research in two villages in North China, this paper analyses the dilemmas of family care for people with intellectual disability. The essential data is the ethnographic record of three cases.

Results Rural families strive to provide care through a set of arrangements and bear tremendous stress in the process.

Conclusion Family care for people with intellectual disability in rural China has been increasingly challenged by the forces of labour migration, demographic changes and the ever-growing processes of commoditization. The role of the state has to be strengthened in welfare provision to balance the weakened family care ethos in transforming societies.

Keywords: family care, intellectual disability, rural China, social transition, social welfare

Introduction

The fact that family is the primary caregiver in the life of people with intellectual disability is true in societies with various cultural and socio-economic contexts. The vast majority of research work has been devoted to this unique subgroup of family caregivers, articulating the potential stress they face in these exceptional circumstances (Taylor 1980; Waisbren 1980; Friedrich & Friedrich 1981; Moroney 1983; Turnbull *et al.* 1986; Seltzer *et al.* 1991; Olsson & Hwang 2003; Haley & Perkins 2004; Heller *et al.* 2007), particularly at the interface of a retreating welfare state and overarching social trends (Heller *et al.* 2007). However, both policy debates on deinstitutionalization and community service as well as academic arguments on

family care have been mainly going on in Western, English-speaking countries, primarily Scandinavia, the USA, Canada, the UK and Australia (Mansell & Beadle-Brown 2010). Lately there has been a growing interest in cultural differences within countries, yet there is a relative paucity of research in Asian and less developed countries (Blacher & Mink 2004). This is especially the case in China, where family care, as a traditional and predominant form of welfare provision, is being drastically strained in filling the gap in formal social welfare for people with intellectual disability.

Disability is increasingly becoming an important issue in China as the population with disabilities has soared to 82.96 million in the 2006 national survey, among which 5.54 million have an intellectual disability.¹ In

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¹China publishing the communiqué on the data of the Second National Survey on the Disability. Chinanews, 2007-05-28. Available at: <http://www.chinanews.com/gn/news/2007/05-28/945274.shtml> (accessed on 23 October 2010).

contrast to the welfare demands of the population, China underwent a slow and winding evolution in legislation. It was not until 1990 that the first special law for the disabled, the Law of the PR China on the Protection of the Disabled, was issued. It is undeniable that remarkable progress has been achieved in China in terms of social security and services for the disabled since the 1990s. By 2007, for example, there were 1667 special education schools nationwide with 580 000 students enrolled and approximately 6.39 million disabled people had benefited from the system of subsistence allowance. It is more important to note, however, that the development of social welfare and services can hardly catch up with the distressed situation of the population. The living arrangement of disabled people in the countryside is especially problematic, given the urban-biased development of China. The two primary social security policies for the disabled in rural areas, namely the Five-Guarantees program (*wubao*)² and the basic subsistence allowance system, cannot serve all the disabled people in need because of the low level of relief. Taking Hebei Province, an economically less developed province near Beijing, for instance, the subsidy standard is 325 RMB *yuan*³ each quarter under the Five-Guarantees program and 126 RMB *yuan* each quarter for basic subsistence allowance. Currently more than 75% of disabled people in China are rural residents and among them only 5.5% are covered by the basic subsistence allowance system (Li *et al.* 2008). Nearly 87.8% of the impoverished households of disabled people are concentrated in the countryside (Zhou 2006) and 20.91% of families of rural disabled people are living with an annual income per capita of less than 944 RMB *yuan* (Xu *et al.* 2006). Most disabled people are barely supported by their family as the social security system has not been effectively institutionalized to respond to their hardship (Cheng 2006).

As far as the daily welfare of the disabled is concerned, the life of people with intellectual disability in rural China deserves special attention. Apart from their biological disadvantage, people with intellectual disability in the countryside face severe social stigma. Such people are prone to be associated with magic and devil power. According to interpretations of Buddhist

doctrines, human beings often suffer disability for sins committed in a previous life. Intellectual disability is often considered to be a punishment for parental disobedience of Confucian teachings (Cheng & Tang 1997), as a result of which, parents feel inferior in social interaction (Zhou 2000) and are condemned by society to pay the price (Tang *et al.* 2000). Comparative studies of culture also distinguish the attitude of Eastern society towards intellectual disability as a moralist, collectivist and fatalist viewpoint; hence both a disabled individual and his or her family are highly stigmatized (Westbrook *et al.* 1993). In spite of their social marginalization, people with intellectual disability are not favourably treated in policy-making and welfare provision. There is no special legislation for people with intellectual disability. Plus, the government-sponsored social service for the group is so lagging that, by 2007, there were about 1000 care centers nationwide accommodating only 18 000 people with intellectual disability and mental disabilities.⁴ Non-governmental organizations are comparatively more active in the field, although most of them are oriented to urban areas and are facing challenges with financial solvency and institutional legitimacy (Liu 2006).

The debate on institutional and community services has not been prominent in developing countries because most people with intellectual disability live with their families and services to support them institutionally are undeveloped (Mansell & Beadle-Brown 2010). Community services in rural China are challenged by the shortage of public finance. Meanwhile, market-oriented care services are either too expensive for rural families or geographically inaccessible for them. People with intellectual disability in the countryside consequently can rely only on their family for support. Families, however, cannot always be counted on as natural caregivers, and the village 'community' is equally failing with increasing modernization in Chinese society. The structure, function and intergenerational relations of rural families in China are rapidly being reshaped by the forces of institutional transitions and social transformation. The traditional autarchy of household economy in the countryside is giving way to a market economy. The accelerated process of urbanization since 2000 has triggered the exodus of

²The programme outlines the government responsibility in providing food, clothing, housing, medical care and funeral services to elderly, widowed, orphaned and disabled people.

³Chinese currency, 1 RMB *yuan* = 0.15 USD.

⁴Statistical Communique of China Social Service Development for Disabled People in 2007. Available at: http://www.china.com.cn/aboutchina/zhuanti/cjr/2008-09/04/content_16390133_3.htm (accessed on 20 September 2010).

rural labour, typically adult male labour migration from less-developed rural areas in mid-west China. The emergence of a vast number of split families is characterized as a weakened and even damaged family structure and function (Yang 2009). Considering these changes, the efficacy of family care has been endangered by the intrusion of materialized relationships into the traditional intergenerational equilibrium (Guo 2001).

One might characterize the family care of people with intellectual disability in rural China as unsustainable and problematic in terms of substantial stress, insufficient formal support and the fading away of traditional family ethics. The central aim then emerges in understanding the mechanisms of such family care: what are the daily forms of caregiving in families of people with intellectual disability in rural China, and how do those families cope with their responsibilities? This paper is designed to address these questions within the context of a transforming countryside in rural China.

Materials and Methods

This paper is based on a study of three families of people with intellectual disability in two villages. The two research communities, Liu village and Li village, are located in the mountainous area of Hebei province in North China. Hebei province is a less well-developed province in North China that surrounds Beijing. According to the sixth national census in China in 2010, the population of Hebei province is 71.85 million, among which the disabled population is 5.195 million and the population with intellectual disability is 404 000, accounting for 7.78% of the total disabled population.⁵ The average annual income per capita in Yixian County, the county where the two villages are located is only 1200 RMB *yuan* and many households are still struggling with substantial hardship. The scarcity of natural resources in such mountainous areas constrains the development of agricultural production; hence labour migration and multiple job holding becomes critical for income sources. Responsibility for support of disadvantaged people lies at the village level and without a solid collective economy, such villages

are too weak financially to provide public services for vulnerable people, including people with intellectual disability. Intellectual disability is not an unusual phenomenon in the two, adjacent villages. On average, in a 200-household village, there would be five or six people with intellectual disability. The causes of intellectual disability in this area are mainly attributed to chromosome disorder, brain trauma and hereditary factors, which reflect the inaccessible medical information and underdeveloped medical care in China's rural areas. While the huge regional socio-economic differences in China are fully acknowledged, the two research communities can be viewed as an epitome of the vast less-developed countryside in mid-west China in terms of economic growth, societal structure and public service provision.

The authors entered into the research communities for the first time in 2004 as practitioners and researchers for a community-based development project. In the processes of community development, the group of people with intellectual disability and their families gradually caught the attention of the researchers. The research on people with intellectual disability and their families was initially proposed in 2007 and the field work was mainly conducted in September 2008 and August 2009. In the first step of the field work, we obtained village profiles with the help of village cadres and some key informants so as to grasp the overall demographic situation and identify people with intellectual disability in the two communities. Research objectives were further confirmed after interviews with villagers.

The three families were purposively chosen as cases. The authors meant to interview all the seven people with intellectual disability – as identified by the key informants – and their families in the two research communities, but some of them were either unwilling to be interviewed or mentally unable to finish the interview. Hence these three cases were eventually chosen due to their accessibility and representativeness. The three families are typical for understanding the scenario of family care for people with intellectual disability in China, as they reflect the most common dilemmas faced by other Chinese families. As the research shows, Chinese families of people with intellectual disability are characterized by: heavy mental, economic and physical stress for caregivers; difficulty in employment, social interaction and marriage for people with intellectual disability; and above all a dramatic burden for families (Beijing Disabled Persons' Federation 2002; Zhang 2006). The

⁵Number of disabled people and population with different disabilities in 2010. Hebei Disabled Persons' Federation, 2013-07-24. Available at: <http://www.hebcl.gov.cn/tongjiread.asp?id=9244> (accessed on 5 January 2014).

three cases reveal the many typical situations with which other tens of thousands of rural families of people with intellectual disability are struggling. In addition, there are varying challenges in providing family care for handicapped people with different characteristics, for example sex, age, marital situation, level of disability and family type, that are highlighted in the three cases, and this allows for a substantial recognition of the multiple dilemmas in family care for people with intellectual disability. The three cases are representative and significant for understanding the life of all the people with intellectual disability in rural areas if we take into consideration that more than 75% of disabled people in China are rural residents (Li *et al.* 2008), nearly 87.8% of the impoverished households of disabled people are concentrated in the countryside (Zhou 2006) and 20.91% of families of rural disabled people are living with an annual income per capita of <944 RMB *yuan* (Xu *et al.* 2006). In the vast rural areas in China, especially the mid-west where social services for disabled people are nearly a vacuum and rural people strive hard for subsistence under commoditized modernity, people with intellectual disability are generally experiencing care hardship and, as media report, even ignorance and abandonment. In this sense, the three cases could be seen as a drop in the bucket of a larger group of people with intellectual disability and their families in the countryside.

After the identification of case families, the research relies on ethnographic techniques for data collection. Non-participatory observation and interviews were mainly conducted in September 2008 and August 2009. During these two periods, the authors lived in rural households, visited case families every day and joined their agrarian, household and leisure activities. Our integration in everyday life was a trust-building process and also a great opportunity for in-depth observation of the lives of those families. In each case family, a structured interview was carried out with the primary caregiver, including the parents, partner, siblings and children, to explore the following points: family arrangement in housing, economic activity, labour division and everyday life of caregiving; skills and capability of people with intellectual disability and the assistance they demand for basic life needs; interaction and communication between family members; the perceived stress and difficulties of the caregiver and their attitudes and plans towards people with intellectual disability; and the social network, social support and coping strategies of the family. On average the authors carried out ten interviews in each family

and each interview lasted for 1-2 h. Even More visits were paid to each family beforehand for trust building and socializing. For people with intellectual disability, due to their communicative handicap, the authors joined in their everyday life so as to observe their daily activities and the way they were treated by family and community members. In the two communities, a total number of about 60 people were interviewed to investigate their perception and attitudes towards people with intellectual disability and their opinion on the caregiving responsibility for those people. The average age of the respondents was 50 years and 60% of them were male. Older villagers tended to be more sympathetic to people with intellectual disability. As the information from authors' observations and different narrations were compiled, the caregiving dilemma of each case family gradually stood out and became significant in comparison with the normal daily life cycle in the village. What remains central in the analysis of research results is to place and understand the case family within a macro and changing social setting.

Last but not least, in the preparation of this research with human subjects, was the consideration of research ethics. According to the convention of the Chinese academy, this research is not subject to human research ethics inspection. However, the conduct of the research did follow a set of guiding ethical principles, i.e. consent, respect and beneficence. Information about the purpose and demands of the research was provided to guardians to obtain their consent for researchers to approach and associate with people with intellectual disability. All the research participants were respected with regard to their rights, beliefs, perceptions, customs and autonomy. People with intellectual disability were treated in ways that fully respect their dignity, despite their intellectual inadequacy. This research as well as researchers' actions during the field work aimed at promoting the benefit and well-being of people with intellectual disability and their families and the risks of harm were minimized as much as possible. The principle of beneficence or harm-avoidance was practised with the consideration of local culture and custom. For example, field research on other demographic issues proceeded simultaneously in the two communities to avoid stigmatization of case families due to over- visitation by the researchers. No institution was responsible for the supervision of research conduct. Instead, informal supervision by local community and villagers played a major role. Long-term cooperation has been maintained between researchers and the two rural communities since 2004,

and academic morality and ethics have always been considered necessary to sustain good relationships.

The three cases of family care for people with intellectual disability

In terms of intellectual disability, local people tend to seek an explanation beyond medical science and attribute intellectual disability to mystery power and *fengshui*.⁶ Because intellectual disability is seen partly as a punishment for ancestral misbehaviour, the family is deemed by the community to be the legitimate caregiver. This common assumption has predetermined the keynote of family care for people with intellectual disability such that all through their lives, parents and other family members would be involved strategically in caregiving in various ways. They would also have to cope with tremendous stress with limited formal support. In the story-telling of three families of people with intellectual disability, a general image of stressed families has been depicted at the interface of underdeveloped social welfare and rural society in transition.

Jianjun's family

Jianjun is 60 years old. He suffered from mental trauma as an infant and now he cannot speak, work or behave as an ordinary person. Jianjun lives with his 91-year-old father and younger brother Jianguo, a 48-year-old widower. The authors visited and talked with Jianjun's father and brother during the field work, and Jianjun's sister, who occasionally came over to help with housework, was interviewed as well. In Jianguo's words, "People with intellectual disability do not think in our way, they only live in their own world." Jianjun does not wash himself. He likes to put on all his clothes at the same time such that villagers usually see him wearing many shirts in summer or winter. He does not follow any routine for eating or sleeping. Sometimes Jianjun is awake all night and goes to bed at 7 am. When his mother was alive, she used to talk to Jianjun and teach him. Since her death several years ago, Jianjun's father and brother lost the patience to train him.

This family is one of the most impoverished households in the village. Jianguo used to drive a

tractor to transport mineral stones before the impact of the globalized economic recession in the mining industry reached the village. The family now can only maintain subsistence through farming. Jianguo plants 4 mu⁷ of peanuts for sale and maize for self-consumption. The biggest expenditure is the college tuition for Jianguo's son, for which the family still has a debt of more than 30 000 RMB *yuan*. To save money, they never buy fresh vegetables at the market; they cook only with potatoes or sweet potatoes that they have planted. As the only breadwinner in the family, Jianguo farms by himself. "My brother (Jianjun) cannot help, rather he creates trouble. Whenever I brought him to the field, he would spend hours in the toilet or worked on other people's land." The distance between their farming plot and the village is 1500 meters. Jianguo has to carry all the harvest on his back to the village since vehicles cannot pass on the mud road. Despite being cash-starved, Jianguo cannot go to the city for job-hunting,⁸ leaving his brother unattended at home. "We need money but there must be someone at home to look after Jianjun. My father is too old to take care of him", Jianguo explained. To alleviate their economic difficulty, Jianguo's son has been doing a part-time job in the college and also working in Beijing on each summer holiday.

In addition, Jianguo has safety issues regarding Jianjun. He is afraid that Jianjun would feed the pig with pesticide-contaminated grass. He is afraid that Jianjun would set fire in the field, especially in winter and spring. Each time Jianguo meets villagers in the street, he would ask them to stop Jianjun when he is setting a fire. The staff of the township government asked Jianguo to sign a contract to guarantee that Jianjun would not set the forest on fire and, if he does, Jianguo must take all the responsibility for the outcome. "I am very annoyed. It is unfair. I have been suffering too much for him. Why should I take such responsibility?" Jianguo questioned.

Jianguo often feels tired and depressed and needs company.

My wife passed away several years ago. Nobody would like to marry me because of my idiot

⁷1 ha = 15 mu.

⁸As a result of low profits in farming, it is common for the adult labour force in the countryside nationwide to head to the city for work as a migrant labour, whereby livelihood maintenance in the home village is better secured.

⁶The location of ancestral grave or the conduct of an ancestor is believed to have an influence on the fortune of his offspring.

brother. Anyway, we are siblings and I cannot leave him alone. That is my fate. However, who else would like to marry me and share the burden? Nobody,

Jianguo said.

Now I am worrying more about my son. He is in college now and going to have his own life in the city. My brother and I have to rely upon my son for the old-age care. Will he accommodate us in the city? Will he ever get married with such a heavy burden? I am unable to prepare for our future because it only makes me more depressed. All we can do now is drift along in life.

Jianjun and Jianguo have an older brother living in the same village and a younger brother living in the countryside, who rarely lend a helping hand due to their own livelihood difficulties. Only one of their three sisters visits them every 2 weeks to help with the cleaning. Jianguo seldom appears at the village fair or in public to socialize with villagers. "I do not like to bother others for help. Village society values mutual help. Since I cannot give much in return, I'd better not receive any," Jianguo explained.

Li Hui's family

Twenty-year-old Li Hui's intellectual disability is thought to be associated with his mother's high-risk pregnancy. Yuan Jinxia was more than 35 years old when she conceived Li Hui. Li Hui had a stroke several days after his birth and was taken to the township hospital. Though he revived a couple of days later, he could never speak thereafter. The parents gave up their attempts of further treatment due to economic difficulties at that time. "We could merely maintain minimal living through farming in the early 1980s. Moreover, my first son was going to marry, thus the priority was saving money for his wedding." Yuan Jinxia still feels guilt for Li Hui's disability. "He would be able to speak if we took him to the doctor in Beijing or to a provincial hospital."

Li Hui's father still does labour work in cities even though he is 60 years old. Fortunately, the father was at home to help with the maize harvest when the authors visited the family. Li Hui's brother and parents were interviewed in this case. The father has worked as a migrant labourer since Li Hui was diagnosed with a disability. He works for more than 6 months each year in the city while his wife attends the family at home.

She raises a pig and plants maize, sweet potatoes and vegetables and tends fruit trees. Yuan Jinxia is very thrifty. She saves as much money as she can for their long-term livelihood. She never buys meat or vegetables and goes to the fair only to buy fruits and snacks for Li Hui. She never buys health products for herself in spite of her severe arthritis. "My husband works so hard in the city to earn money. I need to save more money for Li Hui before we are too old to work," she said.

Li Hui needs his mother's help for washing, eating and dressing. "Li Hui needs assistance in every step. For instance, he has to be told when to go to bed or when and how to eat. I need to take him along wherever I go." Not until his fourteenth birthday did Li Hui not need his mother's assistance to go to the toilet. As well as supplying consistent personal care, Yuan has to endure the bad temper of her son. Every time Li Hui is in a bad mood, he yells and shouts at his mother and even beats her. Yuan is too weak to escape her son's outbursts, so she can only hide in the corner of the wall. Yuan Jinxia is so busy every day that she is only at home for meals and sleep. She has arthritis and her fingers hurt badly in winter. However, only at the end of the winter, when the farm work is not too demanding, does she have the time to sew new shoes for the family. She envies all the other women in the village. "How I wish I could enjoy my life as other women do. They don't have such heavy workloads and can do needle work in the summer. I am so tired," she said.

Li Wei, the first son of Yuan Jinxia, lives in the same yard with them. Li Wei is 33 years old, married and has his own family. Since he separated his household registration from his parents, Li Wei has not given much help to reduce the burden of his parents. No matter how late she comes back from the field, Yuan Jinxia has to cook by herself or even eat the cold food that was left the day before. Li Wei never asks his mother to come over for dinner or sends food except for one time when Yuan Jinxia was badly ill. Yuan has serious arthritis and sometimes she sobs because of the pain. The daughter-in-law has never helped Yuan Jinxia with any housework. However, Yuan shows great consideration for her first son.

They have their own difficulties. My daughter-in-law is babysitting their little son and does not involve herself in any labour work. My granddaughter will go to middle school in a few years. They need money. We do not expect Li Wei to support us right now. We expect him to look

after Li Hui when we are dead. We would better not bother him as long as we can work,

Yuan Jinxia said.

Actually we are not sure whether Li Wei will treat his brother well. He is a burden for everyone. It would be perfect if there was a nursing home or other caring institutions in the township. We would spend all the money we have to ensure Li Hui's life,

Yuan said.

Yuan Jinxia always looks down upon herself because of her son's abnormality. "I feel inferior to other people. I can tell that people look at me with different sight, although they will not speak out," Yuan Jinxia said. She seldom complains to other people about her trouble. "I can only complain to myself. It is my fate and guilt. How can I talk to other people? I owe it to my son and have to pay the debt with all my life," Yuan said. The village committee applied for a subsistence allowance for Li Hui considering his serious disability, from which he gets 100 RMB *yuan* each month. Yuan feels guilty for receiving this subsidy. "It is my fault to have an idiot son. I have never counted on the government to alleviate my burden. I do not deserve it," Yuan said.

Shuhua's family

Shuhua is 54 years old. She came from another village 36 years ago and married her husband in Liu village, who was 20 years older than she and too poor to find a wife at that time. She has two sons, Shaowen and Shaowu, the youngest son having an intellectual disability, the result of inheritance. After her husband passed away years ago and after separating with her first son in the household registration process, Shuhua now lives with her second son in an abode not far away from Shaowen. Their room looks dark and dirty with only one brick bed and cooking stove inside. Shuhua and Shaowu cook by themselves and the rice and flour is provided by Shaowen. The clothes they wear are mostly given to them by the villagers and sometimes do not fit them well. Shuhua is only capable of basic cooking and she usually cooks a pot of porridge and eats it for days. She rarely takes a bath and her hair is so smelly that villagers who pass by her often frown. Being busy with their own livelihoods, her son and daughter-in-law do not have time to assist Shuhua with housework or personal care.

The authors first interviewed Shuhua's daughter-in-law Wang Qiaoyan because the oldest son Shaowen went out as a migrant labourer. When the authors went to the village for the second time, Shaowen had stopped his migration and accepted the interview. Shaowen and his wife Qiaoyan plant 3 mu⁹ of maize and sweet potato and then exchange the crops for rice and flour on the rural market for family consumption. "My mother-in-law and brother eat much more than Shaowen and me," Qiaoyan said.

The food we reaped from the field can by no means meet their needs. We have to spend another 700 RMB *yuan* each year to buy rice and flour for them. Shaowu smokes and drinks, therefore each month we spend about 80 RMB *yuan* to buy cigarettes and alcohol for him. Otherwise he would yell and cry.

Qiaoyan always wants to work as a migrant labourer in the city. Her son is studying at the boarding school in the county which costs 4000 RMB *yuan* each year for the tuition and accommodation. Her little daughter is going to primary school in 2 years, implying more expenditure for this family. However, there has to be someone staying at home to watch Shuhua and Shaowu. "Although they (Shuhua and Shaowu) can take care of themselves in daily life, they are not normal persons anyway. You never know when they will burn the house during cooking." Shaowen used to work on the construction site in Beijing as a migrant labourer. He earned a moderate salary of 2000 RMB *yuan* each month but had to commute to his hometown from time to time to help with the farm work. In order to look after his family, Shaowen decided in 2009 not to work in the city, even though the decision would reduce their family income. The couple now runs a small convenience shop in the village and the monthly profit is only 500 RMB *yuan*. Qiaoyan's family is in Sichuan province in Southern China and she has not visited her parents for 5 years because of money constraints. Shaowen and his wife have not received moderate kinship support in spite of their intensive family duty. Shaowen does not have any relatives on the paternal side. He has two uncles on his mother's side living in a village about four miles away from Liu village, yet they have not sent a word to Shuhua for decades.

At the moment the marriage of her son is emerging as a top concern for Qiaoyan. Shaowu is in his middle age

⁹1 ha = 15 mu.

and unmarried. Qiaoyan worries more about the future life of Shaowu than her mother-in-law.

We can take care of our mom until her death. For the old-age life of Shaowu, it is my son who should take care of him. My poor son needs to sustain three old people, i.e. his parents and uncle, which makes it very difficult for him to find a wife.

Findings

Identifying the dilemma of family care for people with intellectual disability in rural China

Prolonged parenting and interrupted intergenerational relationships. Parents, especially the mother, are usually the caregiver for people with intellectual disability. In rural communities, there are chances that parental care for females with intellectual disability is replaced by partner care through their marriage. For example, in the case of Shuhua and several other women with intellectual disability, they do get married and the caring responsibility has been transferred from their parents to their husbands, and to their children later on. For males with intellectual disability, for whom it is difficult to get married, however, their parents have to prolong the duty until they are physically unable to manage it any longer. This kind of parenting is different from the normal model in the Chinese family, where the purpose of parenting is precisely to end this task and thus the family is a temporary social group in this sense (Fei 1998, 38). In the family of people with intellectual disability, the termination of parenting does not depend on whether a child with intellectual disability can live independently, but on the parents' capacity to give care. As we can see in Jianjun's family, his father was 91 years old and only stopped doing the caring when he was too weak to continue his duty. Although relatively younger, Li Hui's parents have decided to dedicate their whole life to caring for their son and have been struggling with practical difficulties by so doing. Traditional intergenerational relationships in China are characterized as mutual, meaning that parents need to raise their own children and adult children need to support their aging parents in return. In the families of people with intellectual disability, the intergenerational relationship has been interrupted such that disabled children cannot fulfil the responsibility of supporting their parents in later life.

Prolonged parenting of people with intellectual disability is a common phenomenon among families in the West as well, where caregiving for a child with intellectual disability can last for 60 years or more and become a lifelong responsibility for a vast majority of family caregivers (Haley & Perkins 2004). In the Chinese family, the prolonged parenting of adult children with intellectual disability has been especially strengthened by ethical principles. Children are usually taken as a part of the parents in Chinese culture; thus the biological connection expands parents' perception of ego and generates intimacy (Fei 1998, 202, 268), which comprises the emotional connection between parents and their children. Yet, however important the biological and emotional connection between parents and their kids is, the responsibility of parenting is essentially guaranteed by social forces. Liang (2005) defines Chinese society as an ethics-oriented society where obligations are bonded with different kinds of ethical relations. Responsibility and obligations are the first principles in a family relationship, whereby family members need to perform their responsibilities to each other and not expect equal rewards. Those who refuse to fulfil this duty would be placed under moral accusation (Yang 2004, 104). In Taiwan, for instance, more than 90 percent of people with intellectual disability are living with their family (Chang & McConkey 2008). Families attach great importance to their reputation with respect to caring for family, and failing to support a disabled family member would destroy that (Holroyd 2003). All kinds of family relationships are determined by fate and are inescapable, however unfavorable they may be (Yang 2004, 101). This maintaining mechanism of caregiving is well represented and verified in the case families. As a rural folk saying goes, "children are parents' debt in their previous life," Parents such as Li Hui's mother and Jianjun's father tend to conclude that their austerity is paying the debt to their disabled children, especially when they feel frustrated after prolonged caregiving. It is especially the case if the intelligence problem of the offspring is biologically associated with parents. Li Hui's mother has tolerated all the bitterness in her caregiving not primarily because of her deep affection for her son, but because of her feelings of guilt and the inescapable duty bound up in her role. Trapped into the fatalism of guilt, parents take their children's disability as a personal issue and feel ashamed to ask for formal support. Parents can consequently endure tremendous pressures, both materially and mentally, in their lifelong career of caregiving.

Multifold stress. Families of people with intellectual disability face their own difficulties in maintaining normal family functions while coping with the special caring demands of a disabled family member. For families of people with intellectual disability in rural China, the extent that caregiving could be perceived as a stressor depends greatly on the socio-economic condition of the family and the specific life events along the family cycle. Their stress usually arises from issues which might endanger the function of the family rather than ensuring the survival of a person with intellectual disability, the most prominent one of which is the shortage of labour and the barrier to migration as a result of persistent care demands at home.

Regardless of the extent of the disability, people with intellectual disability do not qualify as competent livelihood contributors; instead they generate heavy labour burdens on other family members, often distracting them from livelihood pursuits. Caregivers also need to supervise people with intellectual disability constantly in order to prevent trouble and self-harm. In rural China, most peasants have to maintain their livelihood by depending on agriculture and labour migration as an integrated system for managing risk. However, families of people with intellectual disability can hardly make efficient arrangements in balancing farming and labour migration in spite of the importance of income from pluriactivity. Initiated by the economic reform in late 1970s, the large movement of rural labourers to cities in China is commensurate with accelerated industrialization as well as underdevelopment in rural areas. According to national statistics in 2005, the temporary worker population nationwide amounted to 0.147 billion (Chen 2007). According to data released in the Chinese Statistic Yearbook in Rural Areas in 2008, salary income from labour migration accounted for 40% of the average income per capita in rural areas. Given persistent caregiving demands and an insufficient labour force, rural families of people with intellectual disability either rely solely upon agrarian production and get trapped in a vicious circle of poverty or realize migration through stressful labour divisions within the family (typically men go to the city for labour work and woman stay behind for family care and farm work). In the case of Jianjun and Shuhua, their families have to stay in, or return to the village for the daily care of their intellectual disability family members and thus lose the opportunities of labour migration and economic improvement. This clearly explains why rural

households of people with intellectual disability are typically classified as the poorest in the community by wealth ranking. In Li Hui's family, the household labour division was also made at a price. In order to keep a balance between earning income and caregiving, the father has to choose long-term circular migration while leaving the mother under enormous pressures, both physically and mentally. In the latter case, generative issues of left-behind women and feminization of agriculture are emerging. The reason why women are frequently left behind in the countryside is closely associated with their perceived gender advantages in attending to housework and caregiving (Gao 1994; Ye & Wu 2008; He *et al.* 2010). The feminization of agriculture is becoming increasingly prominent in male-dominated labour migration (Bossen 2002). The female in the family of people with intellectual disability, usually the mother, is most often the immediate bearer of the stress generated by livelihood maintenance and care.

Other types of stress arise from the caregiving process itself, including mental stress, and difficulty in marriage are unique stressors for the family of people with intellectual disability in rural China. Male villagers who do not have a decent economic standing face difficulty in getting married. This marriage stress may be extended to other male members in the family. Male family members on the paternal side of people with intellectual disability, such as a son, brother or nephew, might also face such difficulties as they are the default caregiver in a patriarchal system. In the case of Jianjun, the caregiving role is currently taken up by his brother, who will be 1 day be succeeded by his nephew. The issue of caregiving has become a real impediment in his brother's remarriage and a potential block in his nephew's mate selection. In Shuhua's family, the daughter-in-law has been plagued by a similar anxiety since her little son may be expected to take up the entire care responsibility in the future.

The economic, marital and mental stress for families of people with intellectual disability is indicative of their common dilemma, which is the scarcity of family care in the context of the nuclearization and miniaturization of the rural family in China. Since the nationwide implementation of the One-Child Policy¹⁰ in 1970, there are more than 30 million one-child households in the countryside and the number is increasing by 3.5 million

¹⁰In the countryside, couples are allowed to have another child if the first-born is a girl and they will be rewarded if they choose to stop at the only girl.

each year (Meng 2009). With the emergence of the 4-2-1 family in the countryside, meaning that an only child needs to support his parents and four grandparents, there is no doubt that stress for the offspring to sustain dependent family members will be aggravated.

As well as the trend of fewer children and shrinking family size, population ageing is another challenge influencing family care for both people with intellectual disability and their family members. Asian societies have long traditions of filial piety that constitute family care for the elderly (Ng *et al.* 2002). Given the decrease in family size, increase in female employment and adult children's migration, some Asian countries are adapting more positively to these changes, for example, in Thailand, Hong Kong, Malaysia, the Republic of Korea, Singapore, Taiwan and Thailand, whereas in China the family care system is breaking down (Chan 2005). Due to insufficient formal social service and low levels of support in the rural pension system in China, the family is still the irreplaceable source of caregiving for the rural elderly (Zhou 2013). Population ageing in rural areas is overlapped with the wave of urbanization and rural labour migration. Adult children tend to work and move to the city and provide only financial support to the elderly. As a result, the elderly may lack family members committed to providing instrumental support when they are too infirm to care for themselves (Zhou 2013). It has been estimated that in 2012 there were 23.6 million floating population¹¹ and nearly 50 million left-behind elderly living in rural areas while their adult children worked elsewhere.¹² Caught in survival stress, adult children in rural families can hardly fulfil their filial obligations and improve their livelihoods simultaneously. Economic, social, cultural and familial changes have made it increasingly difficult for older Chinese to receive support from adult children (Cheung & Kwan 2009; Chu *et al.* 2011). Adult children's migration and the form of the split family raise the prospect that the rural elderly are at great risk of falling into poverty (Zheng *et al.* 2012) and have come to rely primarily on their own labour income or savings for

support (Giles *et al.* 2010; Zheng *et al.* 2012). We can conclude that both for older people with intellectual disability and their ageing family caregivers, the intertwined trends of population ageing, family miniaturization, labour migration and urbanization will exacerbate the multiple stresses of family care in rural China.

Weakening of family ethics. Common sense would suggest that the multifold stress for families of people with intellectual disability could be relieved through the application of various coping strategies and informal support, especially from kin. Indeed the family is deemed as an active agent across various cultures in meeting changing demands for caregiving. In Latino families, for example, the extended family is mobilized to share the burden in taking care of people with intellectual disability (Meisgeier 1966) or making care arrangements for children who are left behind by their migrant parents (Mummert 2007). In Mediterranean countries such as Italy and Greece, supports from extended family are of heightened importance under the 'familism' model, given the very limited state-funded social care services (Blackman 2000). However, the cases in the rural communities concerned here point to a different situation. Certain family members would take the major duty of caregiving in different life periods of people with intellectual disability rather than mobilize all the kinship members into some form of collaboration. When parents relinquish care, the succession of the next caregiver is arranged according to the kinship hierarchy; the partner, children and siblings are successors by default. In the case of Jianjun, it is his brother who became the major caregiver after the father. Currently living with his parents, Li Hui will be taken care of by his brother in the long run. Shuhua also experienced different caregivers sequentially, from parents, husband to children. Normally the duty of caregiving is only circulated among family members who live with people with intellectual disability in the same nuclear family or trunk family instead of extended family.

Unlike many cases of social support reported in the literature (Hall & Wellman 1995; He 2001), the size of the family network and number of kinship relations for families of people with intellectual disability does not have a positive correlation with the quantity of perceived support. The three family cases presented here demonstrate that relatives merely keep loose contact through courtesy interactions at festivals, but provide little substantial support. In spite of their broad

¹¹National Health and Family Planning Commission of the People's Republic of China publication, the *Development Report of Floating Population in China 2013*, 2013-09-10, Available at: http://legal.china.com.cn/2013-09/10/content_29983200.htm (accessed on 15 January 2014).

¹²Nearly 50 million Left-behind Elderly in Rural China facing Prominent Problems of Disability and carelessness. China News, 2013-09-20. Available at: <http://www.chinanews.com/gn/2013/09-20/5302461.shtml> (accessed on 15 January 2014).

kinship and family ties, the case families have rarely received moderate support from their family network, with the exception of Jianjun's sister who still kept up a periodic visit. Kinship network members fail to engage in caregiving for people with intellectual disability for various reasons. First, some relatives are incapable of providing support because of their own livelihood difficulties. Secondly, the social ties between relatives who live at a distance because of marriage or migration might be disrupted. Moreover, kinship networks would be eroded rather than strengthened according to the constant support demands from families of people with intellectual disability in the long run. Therefore, the burden of caregiving for people with intellectual disability usually falls on the back of a single person in spite of his or her kinship network.

Changes in the rural family have an essential bearing on the succession and arrangement of family care for people with intellectual disability, as mentioned earlier in this paper. Traditional forms of extended family and co-residence of family networks have been vanishing in the wave of nuclearized rural families as intimate cooperation in production is no longer necessary for many rural households (Wang 2007). Corresponding to family nuclearization is the weakening of family ties and ethics. The intensity of kinship relationships has been impaired along with the modernization of rural society, where economic interests have become the dominating principle in family ties (Wang 1987). The intimacy of kinship relations beyond the nuclear family increasingly depends upon their cooperation in businesses and the maintenance of reciprocity. Even the parent-child relationship has been altered by rational calculations under market conditions (He 2007). As a result, many old people with intellectual disability in the countryside are living a miserable life with minimal subsistence support from their children. Similarly, those ageing parents of people with intellectual disability have to be self-reliant to maintain family care and their livelihoods as long as their physical condition allows.

Discussion

Caregiving: family or the state?

Historically, there has been a differentiation of welfare regimes in developed countries with regard to the role of the state in caregiving. In Esping-Andersen's (1990) typology of welfare state regimes, three models of liberal welfare states, conservative welfare states and social democratic states characterize the welfare regime

in European countries. The liberal welfare states have rather moderate social security systems and a low level of benefits. The provision of care is oriented towards the market system and demand for intra-family solidarity. In conservative welfare states, influenced by Catholic doctrines, family resources have to be largely exhausted before the intervention of the social security system. Social democratic welfare states aim to achieve equality at the highest level and social services are provided to all citizens (Mai *et al.* 2008). In China, as in many other East Asian countries, a different Confucian-patterned welfare regime can be identified (Jones 1993; Goodman & Peng 1996), under which the welfare state is operating through the household economy or via traditional, Confucian and extended families means (Jones 1993). Confucianism has become an institutional preference for countries of East Asia to cope with risks, in that they would transfer the responsibility of welfare to community, enterprises and family. A strong sense of family and self-reliance is underlying this approach (Walker & Wong 2005). In traditional Chinese culture, the family tends to rely upon itself and fulfil its caregiving responsibility within the family rather than seeking formal social support (Lam & Mackenzie 2002; Chiu 2004). The focus of Confucianism is on social stability and ethics and it is an obligation for a person to maintain and nurture his family ties through submitting to and respecting family ethics (Slote & De Vos 1998). In modern Chinese society, the privatized responsibility of welfare provision has been preferred as a political and development strategy when the state is in the initial stages of industrial development. As a combination of a residual and low-level welfare model, the Chinese government has built a moderate payment system to guarantee the subsistence of vulnerable people, whereas a more extensive system of social service for all the people in need remains a dim vision. With the economic reform since the late 1970s and welfare reform since the 1990s, social welfare in China has been characterized as 'contracted government and enlarged individual responsibility', and fiscal budgets for housing, medical care, public education and other social services for vulnerable people is in huge deficiency (Wong 2001).

In China, indeed, the care demands of disabled people and other dependent populations have for a long time been satisfied within the family. Family care remains a traditional feature in the welfare arrangement for disabled people in China, except for the people's commune period (1956–1978) when caregiving was undertaken by the collective. Since the late 1970s, the

caregiving for disabled and dependent people again fell back into the family domain. Although the mechanism of welfare homes in the countryside, e.g. old people's homes, were built in 1958 and maintained till now to accommodate and take care of the elderly, widowed, orphaned and disabled people, there are now only 600 000 disabled people that have received institutional care services.¹³ It is worth noting that, in contrast to the traditional extended-family-based caregiving before 1980, the capacity and forms of family care in current Chinese society have been severely challenged by the growing tendency of modernization in the countryside. Family structure in the countryside tends to be nuclearized and miniaturized as the result of social and institutional transformation in terms of birth-control policy and urbanization-led rural labour migration. Individualism and consumerism gradually outweigh filial piety and family collectivism under the penetration of the market economy. Rural labour migration particularly weakened the social regulation and intergenerational relationships among traditional family members, so that young people's mobility reduces their willingness and capacity to support their parents (Wilensky 2002, 891). Rural families are going to be split in the rural-urban segregated development path such that the dependent members are staying in the countryside, striving hard for a basic life, while the competent ones are floating in the city and only maintain a loose contact with the family. Family care for people with intellectual disability, although it is still arduously maintained at the expense of exhausted families, will face additional risks and uncertainties in the general context of the split family.

The fact is that families are the primary caregivers for dependent populations and are found in societies across various cultural and socio-economic contexts. In European countries, such family roles were jointly reconstructed by neo-liberalism and deinstitutionalization since the 1970s, after which the welfare state retreated from social provision and individual responsibility was highlighted in the market-based society. While deinstitutionalization links closely to the development of social service and underlines community-based social care on the one hand, the role of informal care has been strengthened on the

other. The provision of welfare and care for people with intellectual disability is usually privatized and contributed by families, particularly women (Gilbert *et al.* 2003). Despite the different models of family responsibility in providing care for dependent people in the West (van Hoof *et al.* 2009), the role of family caregiving has been endowed with strong responsibility, morality and anticipation and is becoming increasingly important in the recent global context of state financial containment (Le Bihan & Martin 2012). In the USA, for example, informal and unpaid caregivers in the third sector supply most long-term care and provide an increasingly critical link in the continuum of care of older Americans (Rubin & White-Means 2009). As a result, family caregivers have been enduring tremendous and multidimensional burdens, including impacts on well-being, health, functioning, and worries or feelings of being overwhelmed (Caserta *et al.* 1996; Gupta 1999; Navaie-Waliser *et al.* 2002).

Along with population ageing and the greater longevity of people with intellectual disability, family caregivers are facing the increasing burden of long-term care. States are strongly required to meet the escalating care demands of a dependent population. Demographic ageing in China is occurring at a rate unprecedented for any world region; the proportion of Chinese aged 65 and over will increase from 4% in 2000 to 14% by 2025, amounting to 200 million older people.¹⁴ An effective long-term care policy for disabled people in China is becoming especially pressing, for which the European experiences have provided a good reference. Change in policies towards the long-term care of senior citizens has been a main element in the reforms of European welfare states during the last two decades. On the one hand, the sector of social care has been strengthened with the performance of expanded financial support and public provision and the formalization of long-term care programmes (Pfau-Effinger 2012). On the other hand, the caring role of the family has also been consolidated by state programmes such as 'cash-for-care' systems ((Le Bihan & Martin 2012). A 'semi-formalization' of care is emerging as formal agreements have partly entered informal care work (Geissler & Pfau-Effinger 2005). In Britain, there are three basic forms of long-term care: informal care, formal home and community-based care

¹³Press conference: Career development of people with disability in China. The Official Website of the Beijing 2008 Paralympic Games, 2008-09-08. Available at : <http://en.paralympic.beijing2008.cn/news/pressconference/livewebcast/n214591555.shtml> (accessed on 27 June 2011).

¹⁴The International Institute for Applied Systems Analysis: China's Population by Age and Sex, 1950–2050. Available at : http://www.iiasa.ac.at/collections/IIASA_Research/SRD/ChinaFood/data/anim/pop_ani.htm (accessed on 05 November 2012).

(including home health care), and institutional care (nursing and residential care homes) (Davey & Patsios 1999). The provision of care is mainly statutorily regulated and delivered by a mix of statutory, private for-profit and non-profit organizations (Le Bihan & Martin 2012). Now it has been taken away from local authority providers and given to the private and third sectors (Netten *et al.* 2007; Cangiano & Shutes 2010) and the great majority of services are run by private or profit-making businesses, with costs met by a mixture of public and personal funds (Hussein *et al.* 2012).

The 'balance of responsibility' between state, individual and family continues to be central to policy debate regarding care (Government 2009). The policy arrangements on care in all countries are dynamic and located among this welfare triad and emerge as different combinations of those factors. While informal caregiving by the family will remain crucial for dependent populations, formal care should be reinforced in tandem with caring demands. In China, however, the well-being of people with intellectual disability is becoming problematic due to inadequate formal care and declining availability of family care in a transformative society. Lacking sufficient state support and the opportunity to avail themselves of paid services, people with intellectual disability have been deprived of chances for social rehabilitation and their families have to be highly self-reliant to maintain a minimal level of caregiving. Many families can hardly fulfil the responsibility of caring all by themselves; thus effective involvement of the state is becoming more pressing than ever. The problem at the moment is that the ground of family care has been reshaped by modern forces while the state-subsidized social care system is too frail to fill the gap. Borrowing the experiences of the UK and other European countries, the mutual complement of family care and social care should be a way out for people with intellectual disability and their stress-stricken families. Formal care would hardly be a substitute, but rather a complement for informal care. Strengthening the role of the state in welfare provision and keeping the balance of state-family is the utmost imperative for the well-being of disabled people. Stress on the family caregiver for people with intellectual disability would be largely relieved by diversified provision of social care services through the private sector and subsidized informal care work. Meanwhile, in the reframing of the welfare regime in China, it is equally important to defend humanity in a market-oriented era and rebuild the caring ethics of family. The

solidarity of the family is above all the most fundamental for the well-being of all dependent people.

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