

Rights and responsibilities

Intellectual Disability in China:
Family, governmental and non-governmental care

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Introduction

When Huiling¹ was established in Guangzhou in 1985, it was the first organisation in China offering services explicitly for people with intellectual disabilities. Its service consisted of rather basic care, the founder of Huiling, Meng Weina, recounts: “We thought that if we let them eat and sleep well, that was how to provide good service for people with intellectual disabilities.”² When two decades later the organisation’s general ideal is summarised, it reads: “Persons with intellectual disabilities should have the same rights as others.”³

Huiling, a name that can be translated as “Intelligent Soul,” is a Chinese non-governmental and non-profit grassroots organisation. The preparation for and founding of Huiling took place at a time when China experienced a massive transition, both economically and politically. After Mao Zedong died in 1976, Deng Xiaoping was chosen to be the country’s new leader. With Deng in power, China was to open up to foreign countries and people, and develop a more liberal market economy. The Chinese were increasingly given more opportunities to choose their own ways of making money and many small businesses were started up. Meng Weina chose not to start a small business, but an organisation for people with intellectual disabilities. When asked in an interview what inspired her, she points to two newspaper articles. One was about Mother Theresa, who in 1979 won the Nobel Peace Prize

¹ The first name of the organisation was *Zhiling*. I am not aware of the difference between *Zhiling* and *Huiling*, but since 1990 the name was changed to Huiling. I choose to only use the name Huiling in this thesis, but wish with this to note that there may be a difference that I am not aware of. Also to be noted is that there are several other people who have been involved and central in the founding and organisation of Huiling. One of these is Mr. Fernando Cagnini, who now is working in Guangzhou Huiling, but who also played a major role in the founding of Beijing Huiling, in 1999/2000. When I in this thesis focuses on certain persons, and events, and omit others, it is done due to my uncertainty on the facts. The entire complexity of the history is left to be described, but I hope I have managed to collect that which is among the most essential, and I am humble in front of the work each of the people involved in the work of Huiling do.

² Interview with Meng Weina. (Interview conducted in Chinese, translated to English by me.) For reasons of anonymity I will as a general rule from now on refer to the interviewees only with singular letters (e.g. “Interview A”), with the list corresponding to names being in my possession only. Only those informants who have given me consent to use their names will be referred to with their proper names.

³ This is from the English version of Huiling’s main web page, Guangzhou Huiling. In the Chinese version of the same page, it reads rather differently: “*huiji canzhang qidi xinling*,” which can be translated as: “intelligent and disabled, spiritual enlightenment”. See Guangzhou Huiling. Available online at:

http://www.gzhl.org/gzhl_website/language/chinese_s/guangzhou/home/index.html (Accessed 07.05.09)

In the web page of Beijing Huiling, the vision of Huiling is described as: “Equal participation of people with intellectual disabilities in community-building, sharing the results of social civilization.” (Chinese: *zhizhangrenshi pingdeng canyu shequ jianshe, gongxiang shehui wenming chengguo*). See Beijing Huiling. Available online at: <http://huiling.org.cn/Html/Article/huiling/HLintro/794868123132.html> (Accessed 01.03.09)

for her work with the sick and the poor in India. The other was an article about Deng Pufang, the son of Deng Xiaoping, who was to establish an organisation that would offer rehabilitation to China's disabled people. The latter is the organisation that in 1987 was to be known as China Disabled Persons Federation (CDPF), (*Zhongguo canjiren lianhehui*). Meng Weina knew that she wanted to help "someone in need", and decided after having met the child of a colleague, who had severe intellectual disabilities, that these were the ones.⁴ Huiling was founded only months later, in the autumn of 1985. Today the organisation is established in twelve cities in China and has developed a relatively extensive service for people with intellectual disabilities of all ages.⁵

The background for writing about intellectual disabilities in China is a stay I had in Huiling's Beijing department. Over an eight months period (September 2007-May 2008) I worked full time as 'international volunteer',⁶ and returned one month (October 2008) to gain more information. During my stays I also visited four of Huiling's departments situated in various cities throughout China; Guangzhou, Xian, Tianjin and Xining; a Catholic monastery in Hebei-province running an orphanage for children and youth with intellectual disabilities, and Stars and Rain (*Xingxingyu*) a non-governmental organisation outside Beijing working with autistic children. In addition to these privately established services, I also visited three governmental services; a provincial rehabilitation centre primarily serving deaf children and people who had lost one or both legs; a sheltered workshop for disabled people in Beijing; and China Rehabilitation and Research Centre, the largest of its kind in China. All these were run by CDPF.

The information gathered throughout my stay in Huiling represents the main foundation for this study, but I have found it necessary to also study, include, and discuss other relevant factors in the Chinese society. The reason for this is that Huiling arguably has had relate to, and possibly develop parallel or responding to these. Of the topics that will be included, is a discussion on the Chinese family planning policies, as it is reflected in relevant laws. It does also include a discussion on whom in the Chinese society that is regarded, normatively and legally, as responsible for the wellbeing of people with intellectual disabilities. And it

⁴ Interview with Meng Weina. (Interview conducted in Chinese, translated to English by me).

⁵ Huiling is per February 2009 established in the following cities: Guangzhou, Beijing, Xian, Xining, Tianjin, Lanzhou, Qingyuan, Chongqing, Changsha, Hong Kong, Shanghai and Inner Mongolia. Available online at: http://www.gzhl.org/gzhl_website/language/english/all_HL/huilingInChinaEN.htm (Accessed 07.05.09).

⁶ The internship was an arrangement I had got through the international student organisation AIESEC and their Make A Difference project that was financed by FK (former Fredskorpset).

includes a discussion on the Chinese government's main institution in charge of disability-affairs: China Disabled Persons Federation. Finally, I have included a brief introduction to disability-issues in Japan, in order to see whether I can identify an East Asian perspective on disability, and in order to see if there are parallels between how intellectual disability is regarded and treated in the two countries. The main questions I attempt to answer to in this thesis are the following two:

- 1. Who has responsibility for the welfare of people with intellectual disabilities in China?*
- 2. What are the general and more specific strategies Huiling is pursuing in the organisation's work with and for people with intellectual disabilities?*

I. Intellectual disability

Approximately two percent of the human population has a form of intellectual disability.⁷ This often perceived "abnormality" is actually a normal variation. A certain proportion of citizens in every country around the world are living with this disability. The People's Republic of China is no exception, but according to the latest statistics, the prevalence of intellectual disabilities is considerably lower there than what is normal in other countries. A national disability-survey undertaken in 2005⁸ showed that China at that time had 5.54 million people with intellectual disabilities.⁹ This number signifies approximately 0.4 percent of the entire population. According to the Leading Group of the Second China National Sample Survey on Disability, who were in charge of the survey, the identification criteria used in the survey was "quite stringent,"¹⁰ which to some extent explains why the prevalence of intellectual disabilities appear to be lower in China than in other countries. The founder of Huiling, Meng Weina, who by the time the survey was made public had been working with intellectual disability for two decades, commented ironically on the result: "Finally a proof

⁷ The statistical number varies, but this number, 2 percent, is the most commonly referred to. Here from Inclusion International (2006: 7). The disability scholar Michael Ashley Stein (2007: 121) refers to a discussion about this statistical number, and notes that it is normally reckoned to be between 1 and 3 percent.

⁸ The Second China National Sample Survey on Disability, 2005/2006. China Disabled Persons Federation. Available online at: http://www.cdpf.org.cn/english/contactus/content/2008-04/14/content_84989.htm (Accessed 07.05.09).

⁹ In the English version of the report the two terms mental disability and mental retardation are used. There are no further elaboration on which disabilities they are referring to, but as the term "mental disorder" was used in the 1987-survey and are not included there now, I assume that mental disabilities refers to this, and mental retardation to intellectual disabilities.

¹⁰ CDPF, "Communiqué On Major Statistics Of the Second China National Sample Survey on Disability." Available online at: http://www.cdpf.org.cn/english/contactus/content/2008-04/14/content_84989.htm. (Accessed 07.05.09).

that we Chinese are more intelligent than the rest of the world.”¹¹ There are other explanations that may be identified, one of them related to measures connected to family planning policies, which may have had an influence on the statistical number.¹² This will be further discussed in Chapter 3. For now it suffice to conclude that whether the number of individuals with intellectual disabilities in China is 5.54 million as the survey showed, or about 26 million, which the two-percent calculation would have suggested, the number is significant.

Theresia Degener, a German law professor and disability-right scholar, claims that people with intellectual disabilities are one of the most “politically marginalised, economically impoverished and least visible members of society.”¹³ Harold Hongju Koh and Lawrence O. Gostin, who have done research on human rights and intellectual disabilities, further states: “[...] the vast majority of the world’s intellectually disabled still live in horrifying conditions.”¹⁴ The former United Nations High Commissioner for Human Rights, Mary Robinson puts it like this:

“We know that persons with disabilities frequently live in deplorable conditions, and face physical and social barriers, which prevent their integration and full participation in the community. As a result, millions of adults and children, throughout the world are segregated, deprived of virtually all their rights, and sometimes lead wretched and marginalised lives...”¹⁵

People with intellectual disabilities have over all had few, if any, opportunities and possibilities to engage in self-advocacy and self-determination processes.¹⁶ They have been defined by others, valued by others, and have had others deciding what is for their (and/or the larger society’s) own good. They depend to a large degree on non-disabled people advocating their cause, in securing and ensuring their rights and possibilities in society.

For these reasons, it is essential to understand how intellectual disabilities are defined and regarded in a given society, as this to a large extent influences, even determines, how people with intellectual disabilities are treated and which possibilities and rights they are given. Intellectual disabilities do not disappear, whether a person receives training and support or not.

¹¹ Conversation, autumn 2007

¹² Xie *et al*, 2008

¹³ Degener, 2003: 154

¹⁴ Koh and Gostin, 2003: 3

¹⁵ Mary Robinson, quoted in Herr, Gostin and Koh, 2003: 3

¹⁶ Nussbaum, 2006: 15

It is not curable, as if it was a sickness. Still, the consequences for the person with an intellectual disability, for the family and the wider society, can vary, according to what kind of training, support and opportunities the person is given.

II. Defining intellectual disabilities

The words used to describe intellectual disabilities in many languages have strong, negative connotations. In addition to describing what is identified as “intellectual disabilities,” these words have been used as invectives to describe and evaluate people whose behaviour we do not like or approve of, or whom at certain moments reveal what appears to be a low intellectual capacity. In the English and Chinese language, the terms used to describe what in English now is referred to as “intellectual disability” have undergone changes, and most probably will continue to do so.

In the English language earlier commonly used denominations have been “backwardness,” “mental retardation,” “mental disability,” “developmental disability” and “learning disability.” People with such traits have been described as “stupid,” “retards,” “cretins,” “morons,” “imbeciles” and “feeble-minded,” to name some. The changes in terminology have been many. The most “politically correct”¹⁷ term used now is “intellectual disability”.¹⁸ When talking about a disability, there is one further distinction; talking about a disabled person or a person with a disability. This issue was raised in the mid-1970s disability movements in USA, by what is called “People First activists,”¹⁹ arguing that by changing the way the language is used, it will be possible to change attitudes to and understandings of people with disabilities. It appears to be a consensus now, among large organisations such as the United Nations and the World Health Organisation that the emphasis should be on the person, not the disability.²⁰ With regard to intellectual disability, these organisations do now consequently use the term “a person with an intellectual disability”, and not the term “an intellectually disabled person”.²¹

¹⁷ This is according to Martin Partridge, a British disability researcher from the Norah Fry Research Centre whom I met in Beijing, October 2008.

¹⁸ Mittler, 2003: 27. For further discussion, see AAIDD, American Association for Intellectual and Developmental Disabilities, (‘American Association on Mental Retardation’ until 2006). Available online at: [http://aidd.allenpress.com/aamronline/?request=get-document&doi=10.1352%2F1934-9556\(2008\)46%5B311:TIDCAI%5D2.0.CO%3B2](http://aidd.allenpress.com/aamronline/?request=get-document&doi=10.1352%2F1934-9556(2008)46%5B311:TIDCAI%5D2.0.CO%3B2) (Accessed 07.05.09)

¹⁹ Heyer, 2000: 117

²⁰ See UN ENABLE. Available online at: <http://www.un.org/disabilities/default.asp?id=109> (Accessed 07.05.09) and World Health Organisation. Available online at: <http://www.who.int/disabilities/en/> (Accessed 07.05.09).

²¹ Mittler, 2003: 27

In China, the federation founded by Deng Pufang; China Disabled Persons' Federation, has been campaigning for a change in the Chinese terms used to depict disabilities.²² The result is that the before commonly used and all-inclusive term *canfei*,²³ now to a large extent has been substituted with the more neutral term *canji*.²⁴ *Canfei* is in the dictionary translated as “a maimed person; cripple.”²⁵ When the two characters the term consists of are translated separately, we see that the first, *can*, is translated as “incomplete; deficient; maimed; cripple”, and *fei* is translated as “waste; useless; disused.” The two characters in the new term, *canji*, are more neutral. *Can* is the same as in *canfei*, but *fei* is replaced with *ji*, which is translated as “deformity; disease; sickness; illness, suffering; pain; difficulty.” With the character for “person,” *ren*, being attached, *canjiren* is translated as “a disabled (or handicapped) person”.

When it comes to the terms used to refer to people with intellectual disabilities in China, some of the most commonly used terms before (and by some people still) is “fool” (*shazi*), and “idiot” (*daizi*), and even the word for “child” (*haizi*), reflecting a common perception that people with intellectual disabilities are like children their whole life. The term, which now is used officially, can be translated as “intellectually obstructed person”, *zhili zhang'aizhe*.²⁶

Despite the CDPF's efforts to change the terms used to refer to people with intellectual disabilities in China, I experienced that the term, “*zhili zhang'aizhe*”, and the aberration for it, “*zhi zhang*,” were not easily recognised or commonly used by people who were not working or otherwise being involved in this field. One example is from an experience I had in Beijing, when returning to Huiling in October 2008. I had to take the bus somewhere, and was assisted by a young man with intellectual disabilities from Huiling, as he knew the city's bus system well. He had an air of self-confidence and pride as we walked towards the bus stop. When we reached it, two women in the mid-50s were standing there, waiting. The man took his task seriously, and asked them if they could help me to get off at the right stop. They nodded, and

²² Blanck and Schartz, 2003: 371

²³The word *canfei* is, according to Kohrman (2005: 62), found in a document dating as long back as to the Wei dynasty (220-265 A.D.).

²⁴The word *canji* is also not a new one, but has, according to Kohrman (2005: 62) been found in documents from the Tang dynasty (618-906 A.D.).

²⁵ *Concise English-Chinese, Chinese-English Dictionary* (New Edition), The Commercial Press, Oxford University Press, 1999.

²⁶ I cannot find a Chinese term specifically used for “intellectual disability” in the Concise English-Chinese, Chinese-English dictionary. What I do find is the word “retarded”, translated as *zhili chidun de*. *Zhili* has here the same meaning as above: “intelligence.” The second part, *chidun*, is translated as “slow-witted,” composed of the words *chi* meaning “late; slow” and *dun* translated as “blunt; dull; stupid.”

asked which work unit we were from, a commonly asked question when strangers meet in China. He explained that we came from Huiling, “a place serving intellectual obstructed persons.” One of the women had not heard about the term “intellectual obstructed” (*zhili zhang’aizhe*) before, and asked what it was. The other woman started to explain, and said it was the same as what a famous Chinese athlete who had participated in Paralympics had. The man from Huiling objected, and said that those kinds of *physical* disabilities did not count as intellectual disabilities. The woman then asked if the term was for people with psychiatric problems. The trainee objected again, and tried to explain to her, by mentioning “autism” (*guduzheng* – literary meaning “the loneliness disease”) as an example. Nor this term was a familiar one. The women did not get it, and started instead to ask where the man was from, his accent being a little strange. The man, who was born in the city and had lived there his whole life, answered slightly offended that he was a local from Beijing. The bus came and the two women and I entered. After some minutes, one of them contacted me again and asked; “That man who did not speak so good Beijing-dialect, he wasn’t an ‘intellectually obstructed person,’ was he?” I told her that he was. The women then nodded to each other and said: “Ah, now I understand!”

This small anecdote can illustrate some of the implications categorisation of people can have. I found the disability-categories in China to be, on the one hand quite determining categories, as there appeared to be strong stigma attached to them. On the other hand, I found there to be a low public awareness and knowledge about intellectual disability as a category. One possible explanation can be that people with intellectual disabilities seldom are seen in public, being either at home or inside closed institutions.²⁷ For this reason, there might be little awareness of and knowledge about intellectual disabilities, at least the more severe types.

Another explanation can be that the categorisation of intellectual disabilities is a relatively new one, introduced first during the national survey related to the founding of CDPF in 1987.²⁸ The methods used for categorising, as outlined under, and the nuances of categories, may not be known for the broad public. This appears to be true, also when we look again at the term *canfei*, which until 1987 was the term used for all disabilities, and where there were no specific and “scientific” term for intellectual disabilities.²⁹ If the ladies at the bus stop had

²⁷ Interview G, I. (Both interviews conducted in Chinese, translated to English by me.)

²⁸ Xu, 2005: 747

²⁹ Interview I. (Interview conducted in Chinese, translated to English by me.)

not been made aware of the term ‘intellectual obstructed’ (*zhili zhang’aizhe*) while we were standing there, the observation of the man “not speaking pure Beijing-dialect” would not have been attached to the fact that he was “intellectual obstructed”, but only to the question of whether he was telling the truth being from Beijing, or if he lied, and in reality came from another place in the country.

Inside Huiling, the employees and the trainees appear to be conscious of the terminology that ought to be used on intellectual disability. They use the most neutral categories, and do not accept anyone referring to people with intellectual disabilities by other words, nor the people with intellectual disabilities referring to themselves by any of the more dishonouring terms. When people were visiting Huiling’s workshop where people with “mild to moderate intellectual disabilities” were working, many were confused about who were employees and who were people with intellectual disabilities. When asked about this, one of the social workers in Huiling said that this was part of their strategy. For the moment, she said, people coming there would be confused about who were in what category; staff or user of the service, but the ultimate goal was that people coming to Huiling should not look for this at all; “just see the people.”³⁰

By establishing a service for people with intellectual disabilities specifically, Huiling has given people who have “intellectual disability” as common trait, a room to demand special rights and stipulate their special needs, on the ground that they share this trait. Simultaneously, or rather gradually, as the short citation above can indicate, there appears to be a stress in Huiling on this trait not being regarded as the individual’s most significant and determining trait. Leaving the discussion there, I will for reasons of clarification, proceed with a description on how intellectual disabilities in general can be identified - and classified.

Intellectual disability is characterised by limitations in intellectual functioning, also called intelligence, and in limited functions in the person’s “adaptive behaviour”³¹. In order to measure a person’s intelligence, the most commonly known tool is Intelligence Quotient tests, commonly referred to as IQ-tests. According to standards set by the American Association on

³⁰ Conversation, Beijing, spring 2008.

³¹ American Association on Intellectual and Developmental Disabilities (AAIDD). Available online at: http://www.aamr.org/content_104.cfm (Accessed 07.05.09).

Intellectual and Developmental Disabilities (AAIDD),³² people who score 70-79 are considered to have a limitation in their intellectual ability. An IQ-score below 70 indicates a mild intellectual disability, below 50 moderate intellectual disabilities, below 35 severe, and below 20 profound intellectual disabilities. In addition to IQ-tests, there are also standard tests aimed at determining a person's adaptive behaviour, and possible limitations in it. Adaptive behaviour is defined by AAIDD, as consisting of three types of skills: conceptual skills (using indicators such as communication and literacy skills); social skills (using indicators such as interpersonal skills, social responsibility and self-esteem); and practical skills (using indicators such as mastering of day-life activities, occupational skills and travel/transportation skills). According to the standards set by AAIDD, a person must fulfil three criteria in order to be characterised as having intellectual disability. First, two or more of the skills outlined above must be significantly limited, second, the person must score under 70 on the IQ-test, and third, this condition must be onset before the age of 18.³³ These standards, which to a large extent have been developed by AAIDD and the World Health Organisation, have also been used by China, like in the nation-wide survey on disability in 1987.³⁴

In China those who are identified as fulfilling the criteria for intellectual disability (and other disabilities) set out by the CDPF, receives a *canji*-card, an identification paper stating that the person is officially recognised as having an intellectual disability. Holding this card can at least in urban areas give certain material benefits, such as reduction in prices on public transportation, and tax reduction.³⁵ Only in cases where the child is diagnosed as severely intellectually disabled, the Chinese government provides some direct financial aid to the parents.³⁶ A story that may be illustrative in this respect is that of a father of a child with intellectual disability I met in Beijing in 2007. In order to get the disability-certificate, they needed to see a doctor to have the child classified. When his son took the IQ-test at the doctor's office, he was diagnosed as having a moderate intellectual disability, with an IQ-score of 45. The doctor and the father discussed the issue, and the doctor agreed to write that the patient had an IQ-score of 35 instead of 45, which signified a severe intellectual disability,

³² AAIDD has revised its definition of 'mental retardation' ten times between 1908 and 2002. The criteria I am referring to appear to be established between 1959 and 1961. Available online at: http://www.aamr.org/content_104.cfm (Accessed 07.05.09).

³³ See AAIDD. Available online at: http://www.aaid.org/content_100.cfm?navID=21 (Accessed 07.05.09).

³⁴ Kahrman 2005: 247

³⁵ Law of the People's Republic of China on the Protection of Disabled Persons, 1990, Article 33. Available online at: http://www.npc.cn/englishnpc/Law/2007-12/12/content_1383889.htm (Accessed 07.05.09).

³⁶ I cannot say if this is a common procedure all over China, or if it was the case in one specific city. In the specific case, the sum was 300 Yuan per month.

not a moderate, and also the right to receive financial aid. What impact categorisation, whether based upon popular perceptions or scientific methods may have on people with intellectual disabilities, will be further discussed throughout the thesis.

My claim is that Huiling's methods can be understood as counter measures to amongst others attitudes towards people with intellectual disabilities that are based on generalised and stereotype understandings of people with intellectual disabilities as a group, not as individuals. In order to understand Huiling and its working methods, I have in this thesis chosen to look at the broader context in which the organisation is established and organised. In the following section I will give a short summary on how I have chosen to divide the thesis, and into which parts.

III. Thesis Overview

In *Chapter 1*, I will introduce the methodology, and the ethical challenges I have met throughout my study. This chapter is divided into four main parts; first, an introduction to Huiling, representing my case in this study; second, participant observation as a method; third, interviews and choice of interviewees and fourth, ethical dilemmas and considerations. In *Chapter 2*, I will focus on two influential models on disability, the medical and the social model on (intellectual) disability. These perspectives have been significant for how people with intellectual disabilities have been regarded and treated the last century, primarily in the West, but also I will argue, in China. *Chapter 3*, is about China and intellectual disability. In the first part I will look at two preventive measures, both aimed at reducing intellectual disability and both of significance in China. Second, I will examine some specific Chinese laws potentially relevant for the lives of people with intellectual disabilities, that is: laws regulating marriage, responsibilities for care taking and family planning. Third, I will discuss the roles and duties of the family and the state in securing the wellbeing of people with intellectual disabilities in China. Fourth, I will introduce the governmental department responsible for the population with disabilities in China, China Disabled Persons Federation (CDPF). Finally, I will briefly discuss the relationship between the government and non-governmental actors working with welfare in the society. In *Chapter 4*, I will present an overview of the general situation for people with (intellectual) disabilities in Japan. When knowing that staff from Huiling has been studying how neighbouring countries work with intellectual disabilities, I hope with this chapter to reveal which issues China and Japan shares,

and which they do not. In *Chapter 5*, I will present Huiling's structure and some of its strategies, related to economy, urban locations and learning. In the final chapter, *Chapter 6*, I will analyse the influence Huiling's methods are observed to have, primarily on the people with intellectual disabilities using the services provided in the organisation, but also on the people around them, including their families.

Finally, although the Huiling represents my main case and source of information, and I refer to Huiling extensively throughout, only two chapters are in their entirety devoted to Huiling. The reason for this is that I have wanted to understand the context of the organisation, and have consequently used much space on factors in the Chinese society that I believe Huiling, in its work with and for people with intellectual disabilities, have had to relate to, indirectly or directly.

Chapter 1

Methodology and Ethical Considerations

The aim of this chapter is to inform the reader on how I have collected my data, and to discuss some of the dilemmas I have encountered throughout the study; before, during and after my fieldwork in China. The collection of first hand data has taken place in two stages, the first when working as a volunteer in Huiling from September 2007 till May 2008, and the second when returning to Beijing for a month in October 2008.

The chapter is divided into four parts. In the first, I will introduce the organisation that serves as my case, Huiling. I will briefly comment on some reasons for why I think this is an interesting case, and on possible generalisations that can be derived from it. In the second part, I will discuss my dual role as a participant in the organisation, and as an observer. In the third part, I will discuss my choice of informants, interview techniques and challenges I met in that regard. Ethical dilemmas I have encountered and tried to deal with during and after my fieldwork are discussed in the fourth part of the chapter.

1.1 Case study: A short introduction to Huiling

A case study is a detailed study of a single case, or a comparison of relatively few cases of similar type. According to Sigmund Grønmo, a case study normally has one of two purposes: One is to develop a deeper understanding of the case that is studied. The other purpose with case studies is to develop more general theories and hypothesis. The case that is studied is then regarded as a typical case in a bigger universe of cases.³⁷ Harrison C. White describes a case study in similar terms, but notes in addition the importance “representativeness of the cases”³⁸ often has in qualitative studies. If the numbers of cases is few, the representativeness of the cases may make a generalisation deriving from the findings of the study more scientifically valuable. I believe that my case is interesting in itself, but I do also aim at including it in a broader universe of similar cases. When trying to identify Huiling as a case of

³⁷ Grønmo, 2004: 90

³⁸ White, 1994, 85-86

something, as any case is to various degrees,³⁹ I would say that it first, represents a non-governmental organisation in China, a country where non-governmental organisations still are few,⁴⁰ but have been increasing in number since the mid-1980s.⁴¹ Secondly it represents a group in the Chinese society offering welfare services to people with intellectual disabilities. With regard to this type of services, the tendency can be said to be the same as for non-governmental organisations; they are still few, but the number of organisations engaged; private, community-based and governmental, have been increasing.

Relative to the situation in China, Huiling has a long history of working with intellectual disability. When founded in 1985, there were no other services for this group of people in the country.⁴² There have been significant changes since then, both inside the organisation, and in the society at large. Studying this organisation can illustrate these changes; factors and dynamics behind them, and possible interaction between societal change and organisational change. A second reason why studying Huiling may be interesting is that as a non-governmental organisation, this organisation can give us some knowledge about the situation for such organisations in China more generally, and about the relationship between non-governmental actors in the society and the government. A third reason relates to some extent to the second, that the government does not support Huiling economically. Although I will not go into depth about this, I will give a brief discussion on the financial strategies of Huiling. This, I believe can give us some information about the dynamics between fundraising, innovation and awareness building. My preliminary expectation is that when a non-governmental organisation, like Huiling, do not receive financial support from the government, it has to develop a service that differs from the services existing elsewhere, in order to attract people's interest and financial support, and in order to attract parents to let their children use its service. A fourth reason why Huiling is interesting as a case is that the organisation has been established, with the same organisational structure and service model in twelve cities throughout China. This, in a country where the regulations set up for certain non-governmental organisations⁴³ appear to be aimed at preventing these from establishing sub-branches, to ensure that they are more easily controllable by the government. Studying

³⁹ White, 1994: 102

⁴⁰ Fisher and Li, 2008

⁴¹ Wong, 1998: 132

⁴² Lu, 2004: 3

⁴³ *Regulations for registration and management of Social Organisations*, Published by the State Council at the 8th ordinary session on September 25th 1998. Translation by China Development Brief, <http://www.chinadevelopmentbrief.com/page.asp?sec=2&sub=1&pg=3> (Accessed 15.06.09)

Huiling may say something about how it is possible to uphold a common identity, purpose and cooperation between the branches of non-governmental organisation in China.

For these reasons a study of Huiling can be a potentially fruitful one, when aiming at reaching a deeper understanding not only about its work and methods, but also indicating more general dynamics and developments in the Chinese society today; on the relationship between the government and the people, and on the general situation for people with intellectual disabilities.

1.2 Participant observation

The internship I had at Huiling was arranged through the international student organisation AIESEC. One of the projects of AIESEC, called Make A Difference, is for the Norwegian participants financed by FK (Norwegian “Peace Corps”)⁴⁴, and offers students internships in private companies and organisations around the world. In 2007, we were five students getting internships in China, Ghana and Bangladesh. The internship I got in Beijing was an arrangement between AIESEC at Peking University and Beijing Huiling. I was working as a volunteer, but Huiling provided me with accommodation in the apartment where most of the staff lived, all of them from China.⁴⁵ Only after four weeks, when I met and talked with the leader of Huiling for the first time, I told her that I had planned to write a thesis on intellectual disabilities in China and on what I would learn during my internship in Huiling. She replied by inviting me to visit other cities where Huiling is established, to get a better understanding of the organisation.

Observations and informal conversations have been of great importance for my study. By staying in Huiling over a long period of time, I was given the opportunity to talk with a large amount of people being involved in the work for people with intellectual disability in China. In the period of my fieldwork I have written about sixty pages with observations and notes. This has helped me to clarify and systematise my observations, both during and after my fieldwork. As my memory may fade with time, these notes have proven useful. They have been written immediately, and are descriptions made before I started to work on the thesis, and therefore “neutral” as such.

⁴⁴ FK Norway (former Fredskorpset) is a public body with special powers, answering to the Foreign Ministry.

⁴⁵ I lived there for almost two months, before moving into a privately arranged place to live.

My main contact was with those working in Huiling and the people with intellectual disabilities using its service, in Huiling referred to as ‘trainees’ (*xueyuan*).⁴⁶ Of importance to note here, is that my everyday work was at the workshop, where trainees who were referred to as having “mild to moderate intellectual disability” were working. Staying in that particular department has influenced my study of Huiling, but I try to discuss the organisation as a whole.

I was invited to participate in all meetings, excursions and gatherings that took place and I experienced the employees to be open and ready to answer my questions underway. In addition to the staff I also had frequent contact with the relatives of the trainees, with neighbours of Huiling, with a large number of volunteers assisting in the work of Huiling, with parents of people with intellectual disabilities who used other services or none at all, with Chinese social work students doing their practise period at Huiling, with researchers from China and abroad; with other people working in the same field, both in the governmental CDPF and other non-governmental organisations, and finally with foreign tourists, coming to Huiling through *Intrepid*, an Australian-based travel agency who has been cooperating with Huiling for several years, weekly inviting their tour-groups to lunch and music performances at Huiling.⁴⁷

One of the organisation’s strategies for integrating people with intellectual disabilities into the society is to actively use the public space, arranging activities outside the organisation several times a week. Consequently I was not only given the chance to observe how the staff worked inside the organisation, but also how people *outside* reacted when the trainees were using various public places like buses, karaoke bars, restaurants, parks, museums and so forth. Altogether this provided me with valuable information and insights that I believe I could not have obtained in any other way.

⁴⁶ *Xueyuan*, meaning trainee or student, is most often used of a person attending a college or training course. When I hereafter refer to *trainees*, it is a reference to those people with intellectual disabilities using the service of Huiling.

⁴⁷ Huiling has regular visits from foreign tourists, both in Xian and Beijing. I talked with a woman from Yinchuan (South of Inner Mongolia), who had helped a foreign delegation to visit a home for children with intellectual disabilities there. An elderly woman had seen it, and yelled to her: “*How can you bring the foreigners to see these idiots?*” Although both Xian and Beijing can be said to be more modern cities than Yinchuan, the arrangement Huiling has with Intrepid can be seen as radical, and efficient in affecting attitudes. The continuation of the project, and the fact that the foreign tourists are willing to pay money to visit Huiling and eat lunch there, proves important, for the trainees, their families, neighbours, and possibly the government, who knows about this happening.

In their book about inquiring-methods, Gretel H. Pelto and Pertti J. Pelto note that a field project “usually consists of the interplay between participant observation and the other modes of data collection.”⁴⁸ For my own study, the experiences and knowledge I gathered both as participant and observer proved to be valuable when I later was to conduct the interviews. Despite the benefits, a problem I encountered was the issue of how to balance the role as a colleague and a “researcher”. Pelto and Pelto warn about the risk when the interviewer and the interviewee have had close contact over a longer period, as they “inevitably create a style of interaction and a shared set of attitudes and tendencies that may significantly colour the information given by the informant.”⁴⁹ This is something I became aware of, in the settings where I knew the informants well, but also on the opposite side, in situations where I did not know the informants, and they not me. I return to dilemmas this pose, at the end of the chapter.

1.3 Interviews and choice of informants

I conducted all together sixteen interviews in China. Of these, three were with people working for the government; one a director of a CDPF-centre at the provincial level, one a director of a CDPF-centre at the community level, and two people (in the same interview) working in China Research and Rehabilitation Centre (CRRC), a department under CDPF. One of these was in charge of the CRRC service to people with intellectual disability, the other with disability research. In addition to these, I conducted one interview with a Belgian PhD-student who does her research on autism in China, and who has volunteered in several non-governmental organisations working with intellectual disabilities in China, Huiling included. The remaining interviews, twelve in total (one person interviewed twice) was with people working in Huiling, in five of the twelve cities where the organisation is established (see map).

⁴⁸ Pelto and Pelto, 1978: 69

⁴⁹ Pelto and Pelto, 1978: 74



A map over the cities where Huiling is established (by February 2009): Guangzhou, Beijing, Xian, Xining, Tianjin, Lanzhou, Qingyuan, Chongqing, Changsha, Hong Kong, Shanghai, Inner Mongolia. (The two latter are not included on the map). The text above can be translated as “People come first, we will respect the elderly and the sick, work accurate and reliable, and give a loving heart.”

The first Huiling organisation was as already mentioned founded in Guangzhou. The second city where Huiling opened up, was in Beijing, in 1999/2000. The other ten have opened up, all over China, since 2000. According to information found on the home page of Huiling, these have been registered with the government in the following ways:

“In the capital, Huiling has had no choice but to remain registered as a business with the local Bureau of Industry and Commerce, but other branches have all registered with local Civil Affairs authorities as “people-run non-enterprise units” (*minban feiqiye danwei*).”⁵⁰

I was early on invited by the leader of Huiling to visit the Huiling departments in other Chinese cities. In this way, I was given the chance to see and compare how the organisation was functioning, its organisational structure and the methods used in various cities in China. I also got to see the organisation at different developmental stages, both in size and age; from that in Guangzhou where Huiling has existed for more than two decades, and where there now is a well-developed and extensive service, to Xining in Qinghai province where Huiling has existed for merely five years, and represents the only service for people with intellectual disabilities in the city. In each of the five cities I visited several of the Huiling subunits; that

⁵⁰ Beijing Huiling, <http://www.huiling.org.cn/en/Html/Home/HuilingNews/533758705060.html> (Accessed 08.06.09)

are Family Homes; day centres; schools; workshops, and training centres. All of them had been informed that I was coming, and they had been told that I was going to collect information for my study.

All of the people I interviewed from Huiling have been working over a long period in the organisation, eight of them since the founding of Huiling in the respective city where they were working. Two of the interviewees were both working at Huiling and themselves parents of children with intellectual disabilities. The interviews were undertaken during two different time periods. Eleven of the interviews were done during my internship period in the organisation. Five of them were done when I returned five months later.

The interviews lasted between thirty minutes and two hours, with an average of about seventy minutes. As part of the preparation, I wrote down about ten general questions I wanted answers to, in addition to some standard questions more specific to the work-responsibilities or experience of the informant I was meeting. An advantage using this semi-structured interview method was that it allowed me ample room for follow-up questions, and to elaborate on issues I had not envisioned. All of these interviews, with only one exception, were recorded on a voice recorder, and with the permission of the informants. The recorder was placed visibly on the table between us. This was a choice I made, despite the chance that the recorder's presence could make the interviewees talk less freely. I had, before I conducted the first of the interviews, observed how three journalists, from Sweden, Germany and France worked when they made interviews with staff at Huiling. They all used voice recorders and it did not appear to influence the flow of the interviews. Secondly, it was useful with regard to my language skill. Although I speak and understand Chinese quite well, by using the recorder, I could concentrate in a different manner than I would have had to if depending on notes and memory. A problematic aspect of using the recorder is that all the information is stored in the device. I did not use any names in the interviews, and kept the device properly stored at home. During the interviews, I first informed about the general topics I wanted to talk about, and then started the interview. The questions I had brought served as structure for the interview. There were in addition two simple techniques I found useful. One was, as described, to ask a question, listen to the response, and then to use some of that response to ask follow-up questions. The other was to crosscheck, or test arguments. I used a statement that one person had provided, and asked the next person questions like: *"I have been told: "... " What is your opinion about that?"* In this way statements I had got, but were uncertain of whether were

correct, and of relevance or not, could get tested, and I could get a more nuanced understanding.

Prior to my stay in Beijing Huiling, I had been studying Chinese for several years and had been living in China for two years. I therefore felt confident enough to conduct the interviews without an assistant or translator. Most of the interviews were conducted in Chinese. Two of the interviews were conducted entirely in English; one partly in English and partly in Chinese, and one of the informants had asked a person to translate, the questions being asked in English and the answers in Chinese. After the interviews, I translated and transcribed them from Chinese into English. A few short segments I have not been able to understand and translate, due to my inability, the informants' use of special words, dialect, or poor sound quality on the recorder.

The information I have gathered through interviews, primarily come from two sources. One is from people working in or otherwise being familiar with Huiling, some of whom I had developed a close contact with. The other is from people working in governmental institutions serving people with disabilities. It can prove useful to divide the interviews into these two groups and see, first, if there are any significant differences between these two, and second, what challenges my own role in them may pose.

The information gathered in the first group is more open and detailed than the information I gathered from the second. The main reasons for this, I believe, is that there was an established trust between me and the informants in the first group, as I spent much time in their organisation. The interviews I had with people from the second group, on the other hand, were all arranged through 'weak acquaintances'; the informants did not know me, and may not have trusted or understood my intentions for interviewing them. The other significant difference between the two groups is that the people I interviewed in CDPF and its subdivisions were all working directly under and with the government, while Huiling is non-governmental. The hierarchical structures in these two groups differ, and when conducting the interviews, I was not familiar with the extent to which the people under the government could talk freely, for example on challenges they faced in their work with disability.

The researcher Steinar Kvale notes that as a basic prerequisite for conducting interviews "The

interviewer should have knowledge about the issues that are discussed, but also about social relations.”⁵¹ When transferred to China, this, I argue, is of particular importance for a non-Chinese researcher, where social and political norms and rules may be difficult to understand, and the potential “traps” many.

1.4 Ethical dilemmas and considerations

Living and studying in China, one has to find a sound balance between paranoia and naivety. During previous periods, when living in China as a student, I have through other foreigners been exposed to innumerable accounts of what the secret police, the surveillance bureau, the spies, and so forth, are (capable of) doing. In order to live normally in a society where such stories are flourishing, but the everyday-evidences almost absent, I have tried to act knowing that what I have heard may be real, but not to such an extent that I have restrained my everyday life or become overly suspicious of people.

What made this period different from my stay as a language student in China can be summarised in two points. The first is the awareness of my acts and words not only representing me, but also the organisation where I had the internship and did my fieldwork. I had to keep in mind potential consequences of my actions, of what I said and wrote down. The other is that by spending much time with the people working in and using the services of Huiling, I got the chance to better understand how it is to live and work in China of today. By taking their accounts and opinions seriously and at face value, not searching for traces of the government’s propaganda to be found in between their words, it opened up for interesting information and insights, though it at times proved challenging. When observing and participating in the daily activities and discussions with the staff at Huiling, it appeared that they were enjoying the right to think, speak, write, organise and act in any way they wanted. That is not to say that there were no restrictions from the government, or surveillance of the activities at Huiling. But I observed that the staff related to this not with anger or uneasiness, but in a manner indicating a thorough understanding of the limits of which their actions and words had to be within, sometimes apparently acting on the fine line between what was accepted and not.

⁵¹ Kvale, 1997 sited in Thagaard, 2002: 86

1.4.1 Cultural challenges

The interview that worked out “worst”, may be regarded as valuable in the sense that it led me to reflect on my own role, both as a foreigner doing research on intellectual disabilities in China, and on the difference between those interviews where I knew the informant personally and those where I did not. During a visit I had in a local CDPF, I asked the director of the centre for an interview. He accepted, and a little later I was showed to a lobby area, where also a woman in a wheel chair, working as an English teacher for the disabled employees was waiting for us. I had after instructions from the Norwegian Social Science Data Services, the Privacy Ombudsman for Norwegian universities⁵², brought a paper where the purposes for the interview, the research plans, the interviewees’ rights and so forth were outlined. This paper the director had to read before the interview, and he had to sign it. He read it, but did not sign. Unsure how to interpret this, if I should proceed or not, I chose a middle way; I did not note down any answers, and did not start the voice recorder. I had prepared about ten general questions as I had done before the other interviews, but while the other interviewees had given me lengthy answers, the director replied most of the time with “Yes”, “No” and other short answers giving me no threads to follow, and revealing no reflections on the various issues. The interview came to an end after half an hour.

Another story from a meeting with an environmentalist organisation in China can further illustrate this point. At a conference I attended we were handed out catalogues by a Beijing-based organisation.⁵³ The catalogue was divided into three parts. The first contained pictures of problems: areas devastated by pollution and other man-caused disasters. The second contained pictures of people in the Chinese government, speeches and plans to protect the environment. The third contained “the results”, pictures of beautiful landscapes in China. While the third section had names written under the pictures, on the places they were taken, the first part had no names that could indicate where in the country these disasters were. I asked the representative from the organisation about this, and he replied that they omitted them in the first part of the book because: “We do not want foreign journalists to visit the places and exaggerate the problems.”⁵⁴

⁵² Norwegian Social Science Data Services (NSD). Available online at: <http://www.nsd.uib.no/nsd/english/index.html> (Accessed 07.05.09). I did not use this paper on my first trip, but informed the informants on my study orally.

⁵³ I am not sure whether they were a non-governmental or a governmental organisation.

⁵⁴ Conversation (in English) Yinchuan, March 2008.

This corresponds to the problematic issues that may follow when a (non-Chinese) researcher is doing research about sensitive issues that may reveal weaknesses in the Chinese society. One of the senior staff at Huiling, who has been working there since its' founding in Beijing, commented like this in an interview:

“If you are to talk with people from the government... Let's say that I was some leader, or Deng Pufang. I would have said “*Good*”, “*Very good*”, “*Our country China is very good.*” I would not say anything about what is not good. They fear that when you go home you will tell people that China is no good. But China has a lot of things that are not good. If you were to talk with them, maybe you could have asked three questions, and they would pick the question where they could give the most positive answer.”⁵⁵

It could have been useful for me to interview people working under governmental agencies, such as CDPF, *after* having established a form for trust. This question of trust introduces the second challenge I had, with information collected from people working in Huiling. I will proceed with a discussion of this.

1.4.2 Self-censorship

The participant observation, the interviews and the interview experience combined have provided me with a broad level of information on these two organisations, Huiling and CDPF, and on how intellectual disability is regarded and treated in China; in the organisations, and in general. The experiences I had when interviewing people from Huiling, differed from the other interviews, as described above. I experienced a general openness and did not encounter the feeling of having asked the wrong question or having touched on too sensitive topics – despite the interviews no doubt touching on many that could be understood as such. This openness characterised the entire experience in Huiling, not only in interview-settings, but also when participating in the everyday work. It was also characteristic of the interviews I conducted in the four additional cities I visited, despite the interviewees at the respective Huiling departments not knowing me other than by reputation only.

The close relationship I have had to the informants in Huiling, poses more serious dilemmas than what I encountered when interviewing people from the government. As noted, I believe the information I have been able to gather, both the amount of it and the character of it, could not have been gathered without there being a close contact between me and the informants.

⁵⁵ Interview G. (Interview conducted in Chinese, translated to English by me.)

The boldness and self-reflection I experienced are aspects in the interviews that I believe I could not have gained otherwise. But here the dilemmas become apparent. How to take advantage of this information, and at the same time ensure an objective usage of it? And what is more: how to take advantage of my informants' boldness and, at the same time, ensure their protection as informants? This has been a great concern, throughout the fieldwork, and afterwards when writing the thesis. It is often difficult to know which issues that are understood as sensitive, and it has been difficult to know what kind of actions or statements that may pose any threat to any of the informants in China. Additionally, what has made this challenging is that I have been drawn between the imperatives of some of the people working in Huiling, who require openness, also on the weakness of both Huiling and China generally, and my own uncertainty about how much I can say or write, without anyone in any way being harmed.

One informant from Huiling said it like this: "To tell the truth may hurt us in the short run, but we can not think in the short run. We must think in the long perspective for things to improve."⁵⁶ All of the informants do not share this boldness, though. I choose to relate to these issues with carefulness. All names of people, with the exception of those who expressed and with conviction have agreed not to. I have also censored some of the information I have got, sometimes with a heavy heart, by not using it, in cases where I have been uncertain of the contents' sensitivity. Finally, I have chosen to exclude some topics, for the same reason. The solution may be criticised, but I choose to follow what Tove Thagaard calls the basic guiding rule for a researcher; to protect those who have served as informants: "[...] the informant shall not be damaged by participating in the research project."⁵⁷ As I still have not found my place between the extremities of paranoia and naivety, I have chosen to lean somewhat towards the former.

⁵⁶ Interview H. (Interview conducted in Chinese, translated to English by me.)

⁵⁷ Thagaard, 2002: 106

Chapter 2

Models on disability

There are certain issues we can identify as being of particular relevance for how people with intellectual disabilities can live their lives in any given society. As noted in the Introduction, people with intellectual disabilities have traditionally, and still are, to a great extent excluded from self-advocacy and self-determining processes.⁵⁸ One may presume then, that the various perspectives non-disabled people have on intellectual disability strongly influence the lives of the intellectually disabled. There are several studies on how people with various psychiatric and intellectual disabilities have been regarded and treated throughout modern history in Europe, and elsewhere. *Madness and civilization: a history of insanity in the age of reasons*,⁵⁹ by Michael Foucault is one example. Through this book, it becomes apparent that the perspectives on and methods for treatment of the intellectually disabled historically have gone through many changes, and most probably will continue to do so.

In this chapter I will introduce two models or perspectives on (intellectual) disabilities that have been particularly influential on how people with intellectual disabilities have been treated. The two models are known as the medical and the social model on disability. The basic difference between the two is linked to where disability is regarded as situated, in the disabled person's body or in society at large that through various obstacles disables the person. The perspectives reflected in these models on disability have grown out of a Western medical and political context.⁶⁰ The question is if they also have more general relevance and can be used to make sense of the situation for intellectually disabled even in East Asia, and China in particular.

2.1 The medical model of disability

To start with, it must be noted that the medical model appears to a large extent to be defined and described by those challenging it, primarily those advocating the social model on

⁵⁸ See Nussbaum, 2006: 15

⁵⁹ Foucault, 1961

⁶⁰ Alison Dundes Renteln (2003: 62) argues that there are few studies to be found on cross-cultural analyses on disability.

disability, and thus the literature about the first appears to be coloured by advocates of the latter.

The medical model goes under several names. Some of them are; the medicine model, the clinical model, the institutional model and the individual model. The model has its roots in medical science and history. The disability is regarded as a medical condition, an illness, and “a condition inhering in the individual.”⁶¹ The adequate measures to be taken according to this view are mostly medical, with a double aim. First, to rehabilitate or cure the person concerned: The medical model reflects a strong value on the healthy, “whole” person, being the norm on which rehabilitation is aimed at achieving for the disabled.⁶² The second aim is to prevent further disabilities.

This perspective came to be the dominant in the West after the Second World War, and had a great impact on how disabilities and disabled people were regarded and how states and organisations structured their services for people with various forms of disabilities. It appears to still have significant influence on how people with intellectual disabilities are cared for and treated around the world, in the West and, I will argue, in China.

An example of the reasoning behind and justification for the medical model of disability is to be found in the article “Sociological perspectives on mild mental retardation” written in 1970 by the disability scholar Jane R. Mercer. In the article she illustrates how and why the medical model-perspective has been so influential, regarding it as a necessary and important shift from former stigma and categorisation of intellectual disabilities. By categorising and identifying it as a medical concern, it became explainable in a scientific manner. This could prevent “metaphysical” speculation on why the disabled is disabled, and it concentrates the focus on the disabled person, not on external factors. When the disability becomes explainable and “naturalised” as a result of it being a medical condition, it can also prevent certain stigmatisation of the disabled person. Her article further illustrates the notion of a normative progress from earlier ways of regarding disability:

“The clinical tradition, which most of us share, conceptualizes mental retardation within a clinical perspective. The clinical perspective is essentially a pathological model, borrowed from medicine. This medical or “disease” model has been a very

⁶¹ Renteln, 2003: 62

⁶² Mittler, 2003: 33

powerful intellectual tool in directing research and treatment of conditions resulting from disease process and biological damage. [...] The mentally retarded are examples of categories of persons who are now defined as “sick” rather than depraved, immoral or “possessed of devils” as they were in earlier ages. Defining such persons as “ill” changes their status in society, the roles they are expected to play, the social institutions, which will treat them, and the professional person who will be responsible for their care. [...]”⁶³

Although this is a description rooted in the Western medical history, Mercer does raise an interesting, and more general point as already indicated: How people with intellectual disabilities live and are treated, is to a large extent in accordance with how their disability, ability and needs are understood and regarded by non-disabled people. For example, we can assume that where people with intellectual disabilities are perceived to be “like children”, the chances for their voices to be heard and taken into consideration in decision-making, are low. Where they are regarded as “sick”, the chances for them being regarded primarily “in need of care and treatment” are big. As a consequence of their identification as “sick” in the medical model, the adequate place for them to be cared and treated for is in medical institutions. The people who ought to deal with them are those with medical expertise:

“With the rise of the medical perspective in the field of mental retardation, many institutions for the care of mentally retarded are now designated as “hospitals” rather than homes, colonies or schools; and are staffed by nurses, medical doctors and psychiatric technicians, rather than by house mothers, matrons and other persons playing surrogate parent roles.”⁶⁴

This shift from “homes, colonies and schools” to institutions and “special designated hospitals”, can be understood in terms of scientific optimism, medical efficiency and of enhancing the possibilities of people with disabilities to be rehabilitated. Another argument is that because the society is not suited for disabled people, it is for their own good to be in closed and special-designed institutions – suiting their abilities and needs. With the idea that disabilities can be reduced or cured if treated by staff with adequate medical training, the former “homes, colonies and schools” will be regarded as insufficient, as they merely replace a normal home, with at best a caring person satisfying those needs primarily being satisfied in a home: a place to sleep and a place to eat and a place to be cared for. These would not be progressive enough, in terms of reaching the two goals of rehabilitation and prevention.

⁶³ Mercer, 1970: 379

⁶⁴ Mercer, 1973: 379

Institutionalisation can be seen as having further advantages: First, it can be regarded as assisting the parents, relieving them from a burden that otherwise would prevent them from functioning as normal (and productive) citizens. This was the for example the argument when the Japanese government in the 1970s for the first time opened up institutions for people with intellectual disabilities: relieving the families from the heavy burdens as care takers.⁶⁵

Second, institutionalisation of people with intellectual disabilities can be regarded as a security for the society, either in the form of securing the society against a potential danger, or by making the society function better; by separating the disabled from the able the mainstream society can be more harmonious and easier to manage. With Japan as an example again, the Mental Hygiene Law (*Seishin Eisei-ho*) from 1950 would, as Yoda Hiroe, in an article about disability and welfare in Japan, notes prohibit “the confinements of psychiatric patients in private houses”⁶⁶, and prescribed instead that they be treated in medical institutions. In China, this appears to be a significant argument as well. According to the US scholar Matthew Kohrman the China Disabled Person’s Federation has to a large extent excluded people with intellectual and psychiatric disabilities, as late as in the 1990s. The responsibility for them was instead confined to the Public Security Ministry, which “historically has been the disciplinary arm for mental health provision in the People’s Republic of China.”⁶⁷

Thirdly, it can be argued that institutionalisation protects the disabled individuals themselves, as the society is not equipped to give them the security and services needed. Finally, the institutions may be regarded as providing people with intellectual disabilities an increased opportunity to meet people in similar situations as themselves.

In spite of this, the challenges following institutionalisation of people with intellectual disabilities, in line with the medical model, may be seen as more severe than the advantages. First, institutionalisation and the consequent segregation, excludes people with intellectual disabilities from social opportunities and participation in the wider society. Institutionalisation may be regarded as a pacified life form, consequently depriving people from possibility to perform active roles as citizens, with the rights and responsibilities that follow.

⁶⁵ Hiroe, 2002: 8

⁶⁶ Hiroe, 2002: 6-7

⁶⁷ Kohrman, 2005: 129

Second, a problematic issue with the stress on medical rehabilitation is that certain if not most disabilities are difficult to cure. Most certainly that is the case for intellectual disability. People with intellectual disabilities cannot be rehabilitated *from* intellectual disability. This, one can reckon, can have consequences for how much priority they as a group are given, for example from governments allocating funds to the rehabilitation centres and institutions. Yoda Hiroe notes that the medical perspective on disability still to a large extent dominates Japan's social policies and laws dealing with people with disabilities. The ideal of medical rehabilitation, she argues, has created a separation between those identified as curable and those identified as incurable, leaving people in the latter group to be confined to the welfare sector, which is "incapable of providing sufficient services [...]"⁶⁸ This appears also to be a tendency in China.⁶⁹

A third problematic consequence of institutionalisation, is that it can lead to homogenisation of the society, leaving people in general less used to and less accepting of people with some sort of perceived deficiency, and the society less fit for the natural diversity of people. Institutionalisation of people with intellectual disabilities can be regarded as limiting these peoples' possibilities for choosing how their lives best should be lived. It further makes a potential integration process more challenging, and it gives few incentives for changes in the society, which could have improve the situation.

Fourth, a concern is how to ensure that unworthy, unacceptable or harming treatment of the disabled can be challenged and prevented if people with intellectual disabilities are not visible in society, and if there is little or no interaction between these and non-disabled people. At a more general level, one may ask with what right society can decide, and how it can justify the exclusion of certain people from participating in it.

2.2 The social model of disability

The social model on disability has its roots in the disability-right movements, first introduced in Great Britain the mid-1970s, by the Union of the Physically Impaired Against Segregation (UPIAS).⁷⁰ It has later been given academic credibility, with the British disability scholar

⁶⁸ Hiroe, 2002: 6, Oliver, 1990, 1996

⁶⁹ Kohnman, 2005: 107

⁷⁰ Shakespeare, 2001: 3; Oliver, 1990

Mike Oliver, the first scholar to coin the term ‘social model,’⁷¹ as one of the central voices.⁷² While writing about what I have referred to as the medical model, however, Oliver uses the term ‘individual model.’ The reason for this, he argues, is that it entails a strong focus on the individual’s personal tragedy, with a theory “that disability is some terrible chance event which occurs at random to unfortunate individuals.”⁷³

While the focus in the medical model is concentrated on the individuals with disability, the social model focuses on the society as a whole. Instead of focusing on the medical and physical limitations of particular individuals, the social model focuses on, as described by Oliver: “the way the physical and social environment imposes limitations on certain groups or categories of people”⁷⁴ and on what Theresia Degener in an article, described as a “lack of consideration of human differences.”⁷⁵

In the article “Disability in a Cross-Cultural Perspective: Rethinking Disability”, Nora Ellen Groce further notices that “[...] the lives of individuals with disability around the world are usually far more limited by prevailing social, cultural, and economic constraints than by specific physical, sensory, psychological, or intellectual impairments.”⁷⁶ What follows this idea is that if these barriers are removed, the persons with disabilities can live fulfilling and independent lives. This in its turn leaves us, she argues, with a moral imperative, demanding the various sectors of the society to change, and to offer more specialised offers, not only to the ones categorised as non-disabled or “normal”, but to the grand variation of people. Even in the wealthiest of societies, this broad ideal of a “barrier free society” is far from being reached, which for example Norway is an example of.⁷⁷ The construction and implementation of barrier-free societies requires significant investments and changes. Simultaneously it also involves a strong norm, in the sense that when first uttered, is hard to ignore or neglect.

If we take a short look again at Mercer’s article, we can observe two points. One is that the

⁷¹ Boxal, 2000: 209

⁷² Shakespeare, 2001: 9-10

⁷³ Oliver, 1990: 3. Campbell and Oliver, 1996

⁷⁴ See Oliver, 1983: 23, sited in Barnes, 1999: 4

⁷⁵ Degener, 2003: 151

⁷⁶ Groce, 1999: 354

⁷⁷ In June 2008 a new law was introduced in Norway, aiming at a universally inclusive society, the ‘Law on prohibition against discrimination because of reduced functional ability’ (my translation). (*LOV 2008-06-20 nr 42: Lov om forbud mot diskriminering på grunn av nedsatt funksjonsevne (diskriminerings- og tilgjengelighetsloven)*).

social model appears to share one of the ideas of what can be identified as the “pre-medical-model” namely the structures with “homes, colonies and schools” instead of hospitals and closed institutions. The other is that the responsibility for the wellbeing and rights of those with intellectual disabilities differs: from medical experts, to every member and sector of the society. Twenty-five years after Mercer’s article about the advantages that followed from regarding intellectual disabilities in a medical perspective, the US disability scholar Stanley Herr wrote:

“Contingent social conditions rather than inherent biological limitations constrain individuals’ abilities and create a disability category. The socially engineered environment and the attitudes reflected in its construction play a central role in creating “disability”. Collectively mandated decisions determine what conditions comprise the bodily norm in any given society. Factors extended to disabled persons limitations are really what determine that individuals’ ability to function. The social model underscores the manner in which disability is culturally constructed.”⁷⁸

In the social model every unit of the society is seen to play a role, both in constructing and in upholding barriers hindering people from participating in the society, and ultimately as having a responsibility in removing these. This is a demand that has been neglected in many countries, when other problems are higher on the agenda and considered more urgent. One of these countries is China, De Clerck argues:

“I was visiting families with disabled children together with a large organisation here in China. The people from the organisation were telling these families “*Please take care of your disabled child.*” But these people didn’t have water in the village, and their biggest hope was to get food for tomorrow. You have to take care of the disabled people, but it’s so hard to say that the disabled children should be in school, when the regular children are not in school.”⁷⁹

In the research on disability in China by Fisher and Li, Chinese officials were asked whether disability-issues were a policy priority: “They responded that other social priorities, such as poverty and inequality, ageing, unemployment and internal migration are more urgent.”⁸⁰

Arguably, there are things that can be done for the disabled that does not cost much, in economic terms. Access to and acceptance of everyone’s equal right to use the public space is one of these, in cases where exclusion has had its roots not in physical barriers, but in

⁷⁸ Stein, “Disability Human Rights,” 2007: 85

⁷⁹ Interview J. (Interview conducted in English.)

⁸⁰ Fisher and Li, 2008: 174

people's attitudes. In the article 'Beyond Disability Civil Right', written by Michael A. Stein, he introduces the concept of "participatory justice,"⁸¹ meaning the ability of a person to have meaningful contact with the society at large. This, he claims, is a concept closely related to the social model of disability. The prerequisite for this is, as Anita Silvers also notes, the idea that "individuals need to interact with other people in some sort of collective activity in order to flourish and develop."⁸² This includes individuals with intellectual disabilities. Stein further argues that individuals' equal right and possibility to participate in the society is a moral imperative: "[...] in a just society everyone should have the ability, if they so choose, to interact with and take part in general culture."⁸³

2.3 Conclusion

From this chapter's discussion on the medical and the social models on disability, it becomes apparent that disabilities in general and intellectual disabilities in particular have been regarded differently at different times and in different places. How it is regarded have consequences for how it is treated, and which status people with disabilities are given in the society. The medical and the social model have strong potential to influence, both how institutions for people with disabilities are organised, and by whom.

⁸¹ Stein, "Beyond disability civil rights," 2007: 1219

⁸² Silvers, 2003: 300, 318

⁸³ Stein, "Beyond disability civil rights," 2007: 1219

Chapter 3

Intellectual disabilities in China

In this chapter, I will examine the allocation of responsibility for people with intellectual disabilities in China. I have chosen primarily to look at the roles of the family, the state, and the society, in ensuring the wellbeing and rights of those with intellectual disabilities. The chapter will be divided into four main parts. First, I will introduce and discuss two preventive measures popular in China that can be understood as aiming to reduce the number of people born with intellectual disabilities. Secondly, I will discuss the roles and responsibilities of both the Chinese family and state in providing for the wellbeing of people with intellectual disabilities. For this purpose, I will introduce and argue the significance of two laws: The Marriage Law of the People's Republic of China,⁸⁴ and the Law of the People's Republic of China on Maternal and Infant Health.⁸⁵ These laws are significant as they establish the family as the main unit for securing a person's wellbeing. Likewise, by establishing categories of people considered unfit for marrying and having children, they raise - however indirectly - a fundamental question of how to define a "wanted human being". In the third part, I will introduce the China Disabled Persons Federation (CDPF), the Chinese State's main organisation in charge of disability-affairs. The CDPF is the largest organisation for disabled people in the world, representing 80 million disabled people. Their task no doubt is enormous. Further, the Law of the People's Republic of China on the Protection of Persons with Disabilities,⁸⁶ which entered into force the 1st of July 2008, marks a change from the family and the CDPF being the main parties responsible for people with intellectual and other disabilities, by including a third party referred to as 'the society'. In 11 of the law's 68 articles, 'the society' is mentioned as being in charge of various responsibilities regarding the wellbeing of disabled people. In the fourth part, I will explore this "society" both in terms of

⁸⁴ *The Marriage Law of the People's Republic of China*, 1980/2001. Official English version available online at the webpage of the National Working Committee on Children and Women under the State Council: <http://www.nwccw.gov.cn/html/41/n-140641.html> (Accessed 07.05.09)

⁸⁵ *The Law of the People's Republic of China on Maternal and Infant Health Care*, 1995. Available at the webpage of United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP). Available online at: http://www.unescap.org/esid/psis/population/database/poplaws/law_china/ch_record006.htm (Accessed 07.05.09)

⁸⁶ *Law of the People's Republic of China on the Protection of Persons with Disabilities*, 2008. Available online at: http://www.cdpf.org.cn/english/lawsdoc/content/2008-04/10/content_25056081.htm (Accessed 07.05.09)

identity and responsibility, with specific interest in its relationship with the CDPF, and with the use of Huiling, as an example of a case representing ‘the society’.

3.1 Preventing intellectual disabilities

Intellectual disabilities arise from many factors, some of which are preventable. There are measures that can be taken to reduce the prevalence of people with intellectual disabilities. What we now see a growing tendency of, is arguably the most drastic one: abortion of foetuses where there are detected or being strong suspicion of intellectual disabilities. In Norway, statistics from 2005 reveal that 84.6 percent of those who got to know that a foetus had Down's Syndrome chose to end the pregnancy.⁸⁷ A 1999 study from USA found that as many as 91–93 percent of the women there did the same.⁸⁸ China has, as I will discuss later, a unique birth control policy that leaves the country with a higher rate of abortion than that seen in many other countries, with 31.5 percent of all reported pregnancies in 2006 being legally aborted.⁸⁹ One of the leaders in Huiling commented on the situation: “Nowadays, if people can avoid giving birth to people like these [people with intellectual disabilities], they do it. All around the world it’s like this. Here a little bit more.”⁹⁰

There are also less controversial measures that can and ought to be taken to reduce the prevalence of intellectual disabilities, including preventive steps that ensure a diet rich in iodine – particularly since its absence has been noted as a significant cause of such disabilities.⁹¹ Iodine is a natural mineral most commonly found in seawater. In inland areas where people have little access to seafood, iodine deficiency disorders (IDD) can be a serious problem. Iodine is essential in the development of the brain, and lack of it causes various degrees of intellectual disabilities in infants and children, and mental and physical fatigue in adults. A report from the World Bank in 2001, explains: “Iodine deficiency disorders (IDD) [...] include cretinism, goiter, mental defects, miscarriages, neonatal and thyroid deficiency,

⁸⁷ Folkehelseinstituttet (The Norwegian Institute of Public Health). Available online at: <http://www.fhi.no/> (Accessed 07.05.09)

⁸⁸ Mansfield, *et al*, 1999

⁸⁹ Great Britain had in 2004 a ratio of 22.6 percent, Norway 1996-2004, 19.2 percent, Mongolia 16.7 percent in 2004, Japan 20.2 percent in 2006. Available online at: <http://www.johnstonsarchive.net/policy/abortion/ab-prchina.html> (Accessed 07.05.09)

⁹⁰ Interview C. (Interview conducted in English.)

⁹¹ See for example World Bank Group 2001: v and the International Council for the Control of Iodine Deficiency Disorders (ICCIDD). Available online at: <http://www.iccid.org/pages/iodine-deficiency.php> (Accessed 07.05.09)

spastic weakness, stillbirths, and lesser physical and mental malfunctions.”⁹² There are simple and cost-efficient measures that can be taken in order to reduce and even remove the problem, the most common of which has been adding iodine to salt, has given good results.⁹³

The World Health Organisation estimated in 1996 that of the 1.6 billion cases worldwide of iodine deficiency, nearly a third, or 500 million, were in China.⁹⁴ Field studies prior to this, in the 1980’s, found that up to 25 percent of schoolchildren in areas suffering from severe iodine deficiency had mild intellectual disabilities, with IQ’s of 50 to 69.⁹⁵ In 1995 newborn infants in every Chinese provincial capital were surveyed. The survey showed iodine deficiencies in 35 to 65 percent of those tested. China’s Vice Minister of Health, Yin Dakui, said the same year that based on testing of schoolchildren, most of China’s population were at risk. The Chinese government had in 1993 launched a National IDD Elimination Campaign, aiming at eradicating the problem of IDD by the year 2010.⁹⁶ The government made it compulsory to iodize salt, a measure that, much due to the fact that China’s edible salt industry was centrally controlled, proved efficient, but “has not yet been fully successfully.”⁹⁷ Five years after its launch, in 1999, 93.9 percent of the Chinese population had access to iodized salt. It was stated that children who had received iodized salt before birth via their mothers, were born with a higher IQ than those whose mothers did not have access to iodine. There was also a registered reduction of child mortality among the first group.⁹⁸ Those particularly vulnerable to IDD: “pregnant women, newly married couples, children 0–2 years old, and the entire population in areas with an incidence of cretinism [a condition that includes severe intellectual disability and various other defects] of at least 2 percent”, were given iodized oil capsules for free by the government.⁹⁹

When intellectual disability can be prevented, it ought to be, as the distress that may result can be profound not only for the individual, but also for the family and society. With regard to

⁹² World Bank Group, 2001: 5-6

⁹³ Xie *et al.*, 2008: 1036

⁹⁴ Patrick E. Tyler, “China Confronts Retardation Of Millions Deficient in Iodine”, New York Times, 04.06.1996. Available online at: <http://query.nytimes.com/gst/fullpage.html?res=9A0DEEDB1F39F937A35755C0A960958260&sec=&spon=&pagewanted=all> (Accessed 07.05.09)

⁹⁵ *Ibid.*

⁹⁶ World Bank Group, 2001:10

⁹⁷ Asch, Gostin and Johnson, 2003: 336

⁹⁸ Shriver, K., E., “In Rural China, Iodine Holds Key to Health,” New York Times, 15.11.1996. Available online at: <http://query.nytimes.com/gst/fullpage.html?res=9502E0DE163AF936A25752C1A960958260> (Accessed 07.05.09)

⁹⁹ World Bank Group, 2001: 6-7

IDD the Chinese government has argued that measures ought to be taken, and that they must be taken universally. There may still be other causes for disabilities, however, that can and ought to be dealt with as persistently as IDD. It should be noted here, however, that there are no immediate normative correlations between the urge to prevent *preventable* intellectual disabilities and the prevention of intellectual disabilities per se.

As mentioned above, in the year 2006 a nationwide survey of intellectual disabilities in children throughout China took place. It found that 0.96 percent of those children surveyed, aged 0-6 years had some form of intellectual disability. The authors of the article listing those findings, all of them from well renowned medical institutes in China,¹⁰⁰ conclude that intellectual disabilities are “still prevalent”¹⁰¹. The choice of wording indicates a strong belief in the scientific possibility to at least reduce and, at best, to eliminate intellectual disabilities. The findings further indicate a significant decrease in the prevalence since the first survey conducted in 1987. In 1987 there were identified 1.21 percent of children as having intellectual disabilities. The authors indicate the following reasons behind this reduction:

First, “the increased importance given to the prevention of intellectual disabilities by the government.” Second, “the new measures adopted nationwide [...]” including “premarital care, neonatal screening.” Third, “the nationwide popularization of qualified iodized salt and iodine supplement.” Fourth, “a rapid development in the economy and in the fields of science, culture and economy.” Fifth; “improvement in the level of material and cultural life of urban and rural residents.” Sixth, “improvement of healthcare conditions.” And finally, a general “awareness of disability prevention.”¹⁰²

There are two points to be made here. The first is the authors’ mentioning “culture” and cultural development as factors influencing the prevalence of intellectual disabilities. The survey in question referred to a list of the “causes of intellectual disabilities judged by the paediatric psychiatrists based on the children’s medical history.”¹⁰³ The three most common

¹⁰⁰ The nine authors are all from well renowned medical institutes in China, such as China Disabled Persons Federation, Peking Union Medical College, Academy of Military Medical Science, Peking University, The First Hospital and China Rehabilitation and Research Centre.

¹⁰¹ Xie *et al*, 2008: 1029

¹⁰² Xie *et al*, 2008: 1029

¹⁰³ None of the identified causes relates to external factors, although there most probably would be. One example of this I observed during a fieldtrip to the Yinchuan province in 2008, where we visited a village. The mayor told us that “many of the children had low intelligence due to naturally poisonous ground water” (Fieldtrip arranged by Fredskorpset (FK) and Yinchuan University, March 20th. 2008).

identified causes are lack of oxygen at birth (12.5 percent), premature birth (8.57 percent) and lack of oxygen in the womb (6.43 percent). The fourth most common cause, according to the article, is categorised as “backward in social culture” (5.54 percent).¹⁰⁴ There are no further references to how the psychiatrists identified this, and as it stands, I will argue that this is a strongly stigmatising way of explaining the occurrence of intellectual disabilities. It may have serious implications on how people being born with intellectual disabilities and their parents are regarded in the Chinese society, and to which extent there will be arranged for services and adjustments in the society for this group of people.

The survey further find that there is a difference in the prevalence of intellectual disabilities in children in the urban and the rural areas, with 0.83 percent in urban areas and 1.03 percent in rural. The most significant difference, according to the survey, though, involves level of income. The survey shows that families with an annual income of more than 9000 Yuan¹⁰⁵ have the lowest prevalence of children with intellectual disabilities, at only 0.28 percent, a number far lower than the average statistics. Among the poorest families, those with an annual income of less than 1000 Yuan, the prevalence is almost ten times higher, at 2.62 percent.¹⁰⁶ There may be several reasons for this major difference. One may be related to unequal access, both physically and financially, to screening devices and other medical tests that can identify disabilities at the foetus. With regard to the discussion above, about culture and “backwardness”, it seems plausible to assume that those who can avoid giving birth to a child with intellectual disability will choose to do so, and that the more access a person has to take the tests, the more chances are there to avoid it.

3.2 Disability and the family: Filial piety and social security

In a study on Confucian conceptions of civil society, Richard Madsen identifies what he sees as a distinct feature of East Asian culture: the inclusion of filial piety, into the law. One example of this, Madsen argues, is that family laws “in most East Asian countries mandates that children must take care of their aged parents.”¹⁰⁷ China is no exception. Fisher and Li conclude that the family constitutes the main structure and unit for economic security and care in China: “Official Chinese social policy is that welfare is primarily the responsibility of

¹⁰⁴ Xie *et al*, 2008:1036

¹⁰⁵ 100 CNY=10,35 EURO (01.06.09)

¹⁰⁶ Xie *et al*, 2008: 1035

¹⁰⁷ Madsen, 2002: 197

citizens within a family support system.”¹⁰⁸ Linda Wong confirms this in her study and notes to what extent this is the case: “Most individuals obtain their material, emotional, physical care and social needs in the family.”¹⁰⁹ Wong also notes that the development in China has further stressed the importance of the family’s role. She claims that while China had a planned economy, the family’s “contribution to individual well-being was paramount wherever one lived.” After the economic reform of the late 1970’s, “the family was even more crucial in determining life chances since it enjoyed less support from other agencies.”¹¹⁰

The importance of the family can partly and traditionally be traced to the Confucian ideal and virtue of, amongst others, filial piety; to love and respect one’s parents and to worship one’s ancestors. In a 1990’s study by Matthew Kohrman of people with disabilities in an island community in the South China Sea, he observes that the “rules and practice of filial piety and ancestor worship were strictly followed. All males were expected to extend their fathers line by marrying and producing heirs. [...] The rules of filial piety and ancestor worship required that children respectfully care for their parents until their parents die.”¹¹¹ Though this can be identified and traced back to culturally based norms and moral virtues, the family’s role in securing its members wellbeing can also be identified in various laws in China. Kohrman further notes: “according to the law, the family shall be the main source of protection for the aged and infirmed.”¹¹²

Taking Kohrman’s statement seriously, I have made an empirical review of Chinese laws, aiming at identifying the laws he may refer to. The first clear evidence is found in the “*Constitution of the P. R. China*”, Article 49, which states that: “Parents have the duty to rear and educate their minor children, and children who have come of age have the duty to support and assist their parents.”¹¹³ In the “*Marriage Law of the People’s Republic of China*” (the Marriage Law),¹¹⁴ this view is also strongly upheld. Here the plight of the various members of a family is outlined. With regard to the case of intellectual disability, this is relevant as it reveals both the potential and probable impact that having a child with intellectual disabilities

¹⁰⁸ Fisher and Li, 2008:172

¹⁰⁹ Wong, 1998: 3

¹¹⁰ Wong, 1998: 4

¹¹¹ Kohrman, 2005: 150

¹¹² Kohrman, 2005: 240

¹¹³ *The Constitution of People’s Republic of China*, 1982. Official English version. Available online at: <http://english.peopledaily.com.cn/constitution/constitution.html>. (Accessed 07.05.09)

¹¹⁴ *The Marriage Law of the People’s Republic of China*, 1980/2001. Official English version. Available online at: <http://www.nwccw.gov.cn/html/41/n-140641.html>. (Accessed 07.05.09)

has upon the family. The groups the Marriage Law refers to are:

Husband and wife, who mutually shall support each other (*Article 20*); the parents, who shall support their children when the child is a child; and the children who shall support the parents when having reached adulthood (*Article 21*); the grandparents, who shall support their grandchildren when these have no parents to do it for them and the grandchildren who in return shall support their grandparents when the grandparents have no children to do it (*Article 28*); finally, the elder brothers and sisters shall support younger siblings when parents can not do it. Those younger siblings shall in return support their elder brothers and sisters if and when needed (*Article 29*).¹¹⁵

One of my informants has through the job at the China Research and Rehabilitation Centre, worked closely with people with various disabilities. I asked him how it was for people with disabilities to get married in China. “It is very difficult,” he said “and they often end up marrying other disabled people.”¹¹⁶ He also said that having a disabled person in the family affected how the rest of the family members could marry. The reason for this, he explained, was grounded in the fact that it is the families who have to support the family members with disabilities. When the parents no longer would be able to do it, the responsibility would shift on to the other family members. An additional problem following this system, he added, is for the disabled person: Because the idea that the family has the responsibility to support the person with disability is so strong, the person with disability lacks the incentive of doing anything him- or herself to change the situation.¹¹⁷

When the family constitutes the main social and financial security for a person, it is important to have a family. It is also important to raise a child that can ensure your own future. If that child is incapable of doing so, for example, if the child has intellectual disabilities and cannot find or cannot do a job, it has serious implications for the family. The law shows little consideration for situations where the child is unable to support the family, or where the individual will not have children to ensure his or her own survival to old age. The only exception is found in the Marriage Law’s article 29, which states that the older brother and/or sister should support the younger, in stages of life where the parents are dead or for other reasons are not able to care for their child themselves. If the person has no older (or younger)

¹¹⁵ See Appendix for the full wordings of the articles.

¹¹⁶ Interview M. (Interview conducted in Chinese.)

¹¹⁷ Interview M. (Interview conducted in Chinese.)

sister or brother, which has been the case for many after the implementation of the “one child” family planning policies, who then is left to provide support? When interviewed, one of the leaders of Huiling commented on the life situation for parents having a child with intellectually disability:

“If the disabled children’s parents are not categorised as extremely poor, then there is no aid [from the government]. Even when the child has reached eighteen, he has no income. He cannot support the parents, and will in addition be an economic burden for them. The parents are very tired. Many people from the countryside don’t have any insurance. If they don’t have a job, then they don’t have a single Yuan. It’s their child who must give them money to eat, to buy clothes. But the disabled children don’t get a job or can’t take a job, so it’s difficult. In China it is difficult.”¹¹⁸

The most evident challenge to the family is economic, though there are reasons to believe that most such families also suffer emotional stress and isolation. Cindy De Clerck, a Belgian who studies autism in China, and who has been working with parents of children with intellectual disabilities in China over a long period of time, gives this interpretation of the situation:

“What I hear from parents is, for instance if you go to a doctor for diagnoses of your child, you go to the hospital. You come in and you have ten minutes with the doctor. They give a diagnosis in ten minutes. And then the doctor can say “*You can go to this organisation to train your child.*” or he don’t say anything. The parents are most often all alone, and they don’t know what to do. For the large majority, there is nobody to talk to; there is no professional place, not something like a social worker that can give some kind of consultation. [...] You leave it as a family concern, and then you get so isolated that the only thing you can do is to blame it on other people in the family, or blame it on yourself.”¹¹⁹

In the Marriage Law, which has been shown to stipulate the duty each family member has for one another, there are also articles prohibiting certain people from marrying. There are two groups of people who, according to the law, are not allowed to marry. The first group is made up of “linear blood relatives,”¹²⁰ and the second group consists of couples where one or both parties are “suffering from any disease that is regarded by medical science as rendering a person unfit for marriage.”¹²¹ The articles, to which I refer, articles 7, 8 and 10 in the Marriage Law, are all vague, both with regard to who is determined “unfit” for marriage, and most significant, why they are considered unfit. Chinese statistics from 1989 show that while only 4 percent of

¹¹⁸ Interview E. (Interview conducted in Chinese, translated to English by me.)

¹¹⁹ Interview J. (Interview conducted in English.)

¹²⁰ Marriage Law of the Peoples’ Republic of China. Art. 7a

¹²¹ Marriage Law of the Peoples’ Republic of China. Art. 7b

the “general population” aged 30-34 had never married, the situation for the “disabled population” was different, with as much as 25 percent in the same age group having never been married.¹²² This can be explained not only by strong social stigma, which makes it difficult for people with disabilities to find a spouse, but also as a result of the law:¹²³

The Marriage Law, Article 7

Marriage shall be prohibited in any of the following circumstances:

b) if either the man or the woman is suffering from any disease that is regarded by medical science as rendering a person unfit for marriage.

The Marriage Law, Article 8

The man and woman who apply for marriage shall go to the marriage registration authority in person to get registered. If they meet the requirements of this law, they shall be registered and be given a certificate of marriage. [...]

The Marriage Law, Article 10

If any of the following circumstances occurs, the marriage shall be invalid:

c) if any party has suffered from any disease that is held by medical science as rendering a person unfit for getting married and the disease has not been cured after marriage.

As marriage per se can not be considered to pose anyone harm, it is reasonable to believe that these articles have little to do with determining fitness for marriage, and rather much more to do with determining fitness for child-bearing. If so, this brings up the question of just what is and is not a wanted human being. It also has implications for the people prohibited from marriage and/or reproduction. In the beginning of this section I cited Kohrman, on the Confucian virtue of filial piety. The Chinese scholar Qiu Renzong¹²⁴ further notes its importance in the Chinese society. In the article “Medical Ethics in Chinese Culture”, he discusses China’s family policies:

“Under the influence of Confucianism, a man or woman without a child would bear a heavy psychological burden. One of the requirements of filial piety is to extend the life of ancestors to future generations. [...] There are three vices, which violate the principle of filial piety, and the biggest of these is to be without offspring. [...] The burden is especially heavy for women.”¹²⁵

¹²² Kohrman, 2005: 177, referring to Di Ya, *Zhongguo 1987 Nian Canjiren Chouyang Diaocha Cailiao* [Data from China’s 1987 Sample Survey of Disabled Persons], Beijing: *Office of the National Sample Survey of Persons with Disabilities*. 1989, 134-137, 1002-43

¹²³ See Kohrman, 2000. See Appendix I for the full wordings of the articles.

¹²⁴ Qiu Renzong was at that time the Bioethics programme director, at the Chinese Academy of Social Sciences. Available online at: http://www.bionet-china.org/pdfs/Reporting_Bioethics_Workshop.pdf (Accessed 07.05.09)

¹²⁵ Qiu, in Veatch, 2000: 330

With this in mind, I proceed to a brief introduction on China's Law on Maternal and Infant Health Care from 1995. This is relevant, because at its core, it is a law that regulates and controls births, if only by denying the option for some citizens to reproduce.



Exhibit 1, Left: “Eugenic (causes) happiness” or “Excellent births (gives) happiness”. Exhibit 2, Right: “Fewer births (gives) better births. Promote and develop China vigorously”.¹²⁶

These two posters date back to 1987, a decade after Mao Zedong's death, and a decade into the new reform area under Deng Xiaoping. While the images are old-fashioned and arguably outdated, the slogans are still in use today,¹²⁷ and stress the development of a healthy and strong nation and population through the stress on ‘quality before quantity’. What does this actually mean though, and what are the impacts of such a quality over quantity ideal regarding the national population? Does it have any significance in the way parents, family, or society at large decide to regard people with an intellectual disability or any other condition that might not allow them to meet this standard of perceived excellence?

The Articles 8, 10, 16 and 18 are key excerpts from the “*Law of the People's Republic of*

¹²⁶ Chinese propaganda posters from the collection of the Dutch Sinologist Stefan Landberger. Available online at: <http://www.iisg.nl/~landsberger/pop.html>. (Accessed 07.05.09)

¹²⁷ One example is in the webpage of Hebei province (2007). Available online at: <http://www.hebei.gov.cn/article/20071101/461095.htm>. (Accessed 07.05.09)

China on Maternal and Infant Health Care” (Law on Maternal and Infant Health Care), which came into effect in 1995.¹²⁸ All of them deal with actions to be taken in order to prevent the birth of children with severe diseases. The medical controls used to prevent such births shall, according to the law, occur at two stages. The first at a pre-marital stage, aimed at identifying any disease, which would make one, or both persons in the couple unfit for child bearing (*Articles 8 and 10*). Are those found “unfit” for marriage in the Marriage Law, identical with those found “unfit” for childbearing in the law on Maternal and Infant Health Care, discussed earlier? One difference between the laws is that while the first prohibits marriage if one or both of the partners are found “unfit”, due to medical reasons (*the Marriage law, Article 10 c*), the latter permits marriage even when a disease is discovered; if the couple agrees to “take long-term contraceptive measures or to undergo ligation¹²⁹ operation and be left sterile” (*Articles 10 and 16*). The second medical check-up is to occur after conception, and has the following purpose (*Article 18*)¹³⁰:

“The physician shall explain to the married couple and give them medical advice for a termination of pregnancy if one of the following cases is detected in the prenatal diagnosis:

- (i) the foetus is suffering from genetic disease of a serious nature;
- (ii) the foetus is with defect of a serious nature; and
- (iii) continued pregnancy may threaten the life and safety of the pregnant woman or seriously impair her health.”

What appears to make the case of China different from, for example Norway, is that the choice of whether to terminate a pregnancy or not, seems to be the physician’s instead of the parents’. In the article “Respecting persons with disabilities and preventing Disability: Is there a conflict?” Ash, Gostin and Johnson, refer to the practise in China, as a “use of compulsion to reduce the numbers of infants born with disabilities.”¹³¹ If we take another look at the earlier-mentioned Chinese survey from 2006 on prevalence of intellectual disabilities in children, it is worth noting the researchers’ concluding remarks: Intellectual disabilities are

¹²⁸ *Law of the People’s Republic of China on Maternal and Infant Health Care*, 1995. English version. Available online at: http://www.unescap.org/esid/psis/population/database/poplaws/law_china/ch_record006.htm. (Accessed 07.05.09)

¹²⁹ ‘Ligation’ refers to ‘tubal ligation’, a common method for female sterilisation by tying the fallopian tubes. Encyclopaedia Britannica. Available online at: <http://www.britannica.com/EBchecked/topic/608145/tubal-ligation> (Accessed 07.05.09)

¹³⁰ See Appendix I for the full wordings of the articles.

¹³¹ Ash, Gostin and Johnson, 2003: 334

“still prevalent,”¹³² but the “prevalence of intellectual disabilities appears to be a decreasing trend.”¹³³ Both the words “still” and “trend” indicate an idea that it is possible to extinguish intellectual disabilities, and that it is a relative condition, not one that is to be found naturally in human kind.

3.3 Disability and the state: China Disabled Persons’ Federation

China Disabled Persons Federation (CDPF) was officially founded in 1988, as a state organisation established to deal specifically with disabled people. The founder of the CDPF, Deng Pufang, is the son of China’s leader from 1976 to 1997 Deng Xiaoping. Deng Pufang is himself a person with disability, although his own variety was the result of an attempted suicide when he jumped out of a high building after months in captivity by the Red Guards during China’s Cultural Revolution.¹³⁴ He broke his spine in the fall, and received no adequate treatment after the incident, leaving him paralysed as a result. Years later, in 1980-81 he was sent to Canada for rehabilitation. After having experienced the benefits of rehabilitation, he left Canada for China in order to establish an organisation that could introduce rehabilitation for and to China’s disabled population. According to a biography of Deng Pufang, written by Wang Minpei, his reasons for leaving Canada were the following:

“When thinking of the thousands upon thousands of disabled people in my country who were desperately crying for appropriate rehabilitation services, I decided to go back home immediately to help establish our own rehabilitation centres.”¹³⁵

The founding of the CDPF came at a time when China was striving for international recognition and healing its broken self-image after the Cultural Revolution. It was also incidentally when disability was high on the international agenda, with the introduction of the International Year of Disabled Persons in 1981, and the subsequent UN Decade of Disabled Persons (1983-1992). How a society treated the “weakest” part of its population, including those with disabilities, became an increasingly important standard by which one could evaluate a society’s level of both development and modernity.¹³⁶

One part of the preparations in establishing the CDPF was to collect statistics on how many disabled people there were in China. An extensive national survey on disability was

¹³² Xie *et al*, 2008:1036

¹³³ Xie *et al*, 2008:1036

¹³⁴ Kahrman, 2003:12

¹³⁵ Wang Minpei, referred to in Kahrman, 2003: 118

¹³⁶ Kahrman, 2003: 11, Kahrman, 2005: 24

conducted and the results were ready by 1987, coinciding with the formal foundation of the CDPF. The State Council had established a disability classification system with five sub-classifications for the national survey: visual impairment, hearing and speech impairment, mental retardation, physical handicaps and mental disorder. According to the first survey, the prevailing rate of disabled in China was 4.9 percent.¹³⁷

A second national survey on disability took place almost twenty years later, in 2005. The results are referred to in the Communiqué On Major Statistics Of the Second China National Sample Survey on Disability, stating that 82.96 million of China's more than 1.3 billion people at that time lived with one or more disabilities. This significant number accounts for 6.34 percent of the total national population, a considerable increase since the first national survey in 1987.¹³⁸

According to the official program, the CDPF has three main functions. Firstly, they “represent the interests of people with disabilities in China and help protect their legitimate rights”. Secondly they “provide comprehensive and effective services to them”. Finally, the CDPF is “Commissioned by the Chinese government to supervise affairs relating to people with disabilities in China.”¹³⁹ In addition to this, the CDPF is, according to the same statute, committed to “Promote humanitarianism; the human rights of people with disabilities and their integration in all aspects.”¹⁴⁰ And they have the responsibility of monitoring the law for protection of the people with disabilities in China.¹⁴¹

Their second function, to “provide comprehensive and effective services” to people with disabilities is no less a comprehensive task than the first in a country with 83 million people identified as disabled. The support of those people varies throughout China by location as well as by the type of disability. Even more, it seems that some disabilities have gained priority in the amount of services they receive, with the blind, the deaf and disabilities in the lower body, receiving the most attention and financial support. Kohrman confirms this, when

¹³⁷ Kohrman, 2005: 80

¹³⁸ China Disabled Persons Federation (CDPF), *Communiqué On Major Statistics Of the Second China National Sample Survey on Disability*, 2006. Available online at: <http://www.cdpf.org.cn/old/english/top-7.htm>. (Accessed 07.05.09)

¹³⁹ From the web page of CDPF. Available online at: <http://www.cdpf.org.cn/english/aboutus/aboutus.htm> (Accessed 27.08.08)

¹⁴⁰ From the web page of CDPF. Available online at: <http://www.cdpf.org.cn/english/aboutus/aboutus.htm> (Accessed 27.08.08)

¹⁴¹ Degener, 2003: 174, and Law of the People's Republic of China on the Protection of Persons with disabilities 1991, 2008, Art. 8f.

describing various projects of the CDPF. One example is the ‘Three Rehabilitation Projects’, a large assistance program initiated and supported by the CDPF from the mid-80s to the mid-90s, where people with intellectual disabilities and psychiatric disabilities were excluded from services.¹⁴² According to Kohrman, this pattern of exclusion has been continued throughout the 1980s and 1990s. One informant from Huiling, who has a child with intellectual disability, argues that the years 1998-1999 represented a change in China, as the government then started to offer training schools (*peixun xuexiao*) for children and youth with intellectual disabilities:

“Before, there were no possibilities for people with intellectual disabilities to study. They could only stay at home. Nobody cared about them, nobody took the responsibility. Now it is better. It is much better.”¹⁴³

As we have seen, both in China’s Marriage Law and the Constitution, much of the responsibility for securing the rights and wellbeing of disabled people lies with their family. According to the CDPF’s statistics, only 26,000 youth under the age of fourteen with intellectual disabilities received any support from the government in 2006.¹⁴⁴ Though the numbers are low compared to the large number of people with intellectual disabilities in China, when asking my informants about the development that has taken place in China with regard to public services for people with intellectual disabilities, the answers are almost all positive. Compared to how it was, the situation for people with intellectual disabilities has – according to my informants - improved, as this lengthy account indicates:

“There are more openness and acceptance for disabled people in the society now. Before, about twenty years ago, the government did not care about people like my son [who has severe, multiple disabilities]. I have since he was young been contacting the government. I have been to the CDPF on all levels, not for economic support, but I have wanted to know which offers the government has for people in our situation. Before, they did not even permit me to enter the building. The leader at that time told me: *“It is your own child. You care for him yourself; it is not the concern of the government.”* This was in the late 1980s. The CDPF had a leader at that time that was particularly bad. In my opinion he was not good for the disabled people. Now, some days ago, I went to Beijing City CDPF with one of the trainees from Huiling. They were all very nice towards us. The relationship between the Chinese government and the citizens has improved to the unrecognisable, and the work for disabled people has improved a lot.”¹⁴⁵

¹⁴² Kohrman, 2005: 127

¹⁴³ Interview G. (Interview conducted in Chinese, translated to English by me.)

¹⁴⁴ Statistical Communiqué on Development of the Work for Persons with Disabilities in 2007. Available online at: http://www.cdpf.org.cn/english/statistics/content/2008-04/10/content_84890.htm (Accessed 7.4.2009)

¹⁴⁵ Interview L. (Interview conducted in Chinese, translated to English by me.)

Nevertheless, in all the fields in which the CDPF has been working people with intellectual disabilities and psychiatric disabilities get, according to Kohrman “far fewer resources”¹⁴⁶ than the others. One reason may be that the CDPF has had its strongest focus on medical rehabilitation of disabilities, much in line with the medical model.¹⁴⁷ Some disabilities are more easily “rehabilitated” than others, with more visible results demonstrating improvement. These results can prove a stronger justification for further allocations of monetary resources toward rehabilitation. A provincial director of the CDPF commented on their challenges in distribution of resources:

“Since China is so big and there are so many provinces in China, the country has a large population. This means that we have many disabled people. In each province CDPF focuses on different aspects. Like here [in our province], we focus on hearing rehabilitation [offering hearing rehabilitation to children up till 14 years old]. In other provinces they may have more professionals on other kinds of disability. So the focus is different and also the support, the financial support is different. It depends on how much money you get from the charity and foundations and on how many professionals you have.”¹⁴⁸

The CDPF’s at provincial and local level receive funding primarily from the Central Government. The provincial centre that I visited focused on hearing rehabilitation, but had also a section that offered people who had lost a leg, prostheses. The year I visited, in 2008, they had in addition initiated a relatively large project on an eye sickness. Six thousand people in the province were to get treated. The director commented on the situation:

“Before we did not have so many projects [for the disabled]. We really had to fight with the other provinces to get economic support from the central government. But now this year we are afraid of getting more projects because we don’t have enough staff. And we really have to stand out. If we ask for so many projects can we really accomplish them all in one year?”¹⁴⁹

According to the homepage of the CDPF, there are “about 80 thousand full-time workers” working for the CDPF in China, indicating that there is one worker for every thousand people with disabilities. The citation from the director may indicate that there is a general awareness

¹⁴⁶ Kohrman, 2005: 129

¹⁴⁷ Fisher and Li, 2008: 178-9

¹⁴⁸ Interview F. (Interview conducted in English, but with a Chinese assistant of the informant translating the questions into Chinese, and translating the answers into English.)

¹⁴⁹ Interview F. (Interview conducted in English, but with a Chinese assistant of the informant translating the questions into Chinese, and translating the answers into English.)

and increased priority given on rehabilitation on disabilities by the Central Government. It further indicates two things. One is that there are not enough trained people working in the field. Second, that the disabilities that are the easiest to cure, and measure, may be given the highest priority. Intellectual disabilities may, if this interpretation is correct, not be high priority, as it is difficult to measure improvement and impossible to cure.

Various measures have been taken in order to increase the general chance for people with disabilities to improve their life situations and attain a larger degree of independence in China.¹⁵⁰ One of these measures has received attention for its rather radical character. In every state-owned enterprise, government department and public institution in China, 1.5 percent of all the employees shall be workers who are officially recognised as disabled.¹⁵¹ For those workplaces who do not fulfil the requirement, they must pay a fine, which goes to the CDPF,¹⁵² and which subsequently and in return shall benefit people with disabilities. This initiative appears to be in line with the social model, with the ideal of integration of people with disabilities into the society and into the work field. Still, the law does not specify any category of disability; meaning that formally and in principle people with disabilities corresponding to each of the categories should in principle be equally valued as employees towards fulfilling the requirement. According to staff in Huiling, they have difficulties finding employers willing to employ people with intellectual disabilities. In order to make it easier, Huiling has offered potential employers a special deal, where they send a social worker with a potential employee for a test-period, which sometimes stretches over three months. The social worker assists the person with intellectual disability, ensuring that he or she does a good job. In an interview I had with a social worker in Huiling, who was in charge of looking for jobs for people with intellectual disabilities, she told me about the challenges they face:

“We look for the workplaces where they haven’t met the 1.5 percent-criteria. We search for them, contact them and ask if they are willing to let some of the people from Huiling work there. Some of these workplaces tell us that they can hire the person with intellectual disability formally, and then tell us: “*But they don’t need to come; we can give you the money instead.*” We don’t need that kind of workplace. Many people think that if they let people with intellectual disability come there, it can embarrass them. They are worried that they have to teach them everything, and look after them. Then they prefer to give the money, without the disabled person actually

¹⁵⁰ Blanch and Schartz, 2003: 371

¹⁵¹ See Kohrman, 2003: 5 and Li Caimao, “Paralympics opens new vistas for China’s disabled”, Xinhua News Agency, 27.08.08. Available online at: http://www.china.org.cn/paralympics/2008-08/27/content_16342387_2.htm (Accessed 7.4.2009)

¹⁵² Wong, 1998: 133, Interview J. (Interview conducted in English.)

coming there. Not many people agree to let them come and work. There are not many people willing to hire them.”¹⁵³

The intention behind the 1.5 percent law is to encourage employers to hire people with disabilities, and to increase the chance for people with disabilities to live independent lives, a measure much in line with the social model on disability. In the example above, the employer considers an employee with intellectual disability to be a burden. If the person with intellectual disability had accepted the offered salary, but not done the work, what implications could this potentially have had? Two possibilities are: the claim or right to money without the performance or completion of duty (work) would not necessarily lead to a more independent life for the person with intellectual disability. The purpose of the law then is left unfulfilled. The second is that by using money as a solution in order to keep the disabled out of the workplace, there will be no room for changes in attitudes, and the barriers facing employers to undertake intellectually disabled employees would not be challenged or changed. If the person only gets his/her right, but has no chance to do the duty that should follow, he or she will remain marginalised and stigmatised in the society. A leader of the CDPF confirmed the difficulties in finding employers willing to employ people with disability, but said nothing about how it could change. “It takes a long time. We don’t expect everybody to accept disabled people over night.”¹⁵⁴ If the law actually was fulfilled however, this could bring the disabled population a long way towards self-fulfilment and it would, I imagine, increase the chances for even more employers to take steps in order to employ people with disabilities.

One group among the disabled that have had more chances in finding employment is the blind. In China, blind people are encouraged to study massage, as they are perceived to be better massage-therapists than others. In the Law on the Protection of Persons with Disabilities of 2008,¹⁵⁵ the only group of disabled people explicitly mentioned in the chapter concerning employment, was the blind. Article 32 states that: “The governments and the society shall set up welfare enterprises for persons with disabilities, blind massage institutions, and other enterprises and institutions of welfare nature to offer concentrative job opportunities for persons with disabilities.” Further, in Article 38 it is stated: “The State shall take measures to

¹⁵³ Interview A. (Interview conducted in Chinese, translated to English by me.)

¹⁵⁴ Interview F. (Interview conducted in English, but with a Chinese assistant of the informant translating the questions into Chinese, and translating the answers into English.)

¹⁵⁵ *Law of the People’s Republic of China on the Protection of Persons with Disabilities*, 2008. Available online at: http://www.cdpc.org.cn/english/lawsdoc/content/2008-04/10/content_25056081.htm (Accessed 12.12.08)

protect the lawful rights and interests of visually impaired persons working in therapeutically or health care massage businesses.”

For the blind, a group of the population who might otherwise be largely excluded from the work force, this unquestionably creates opportunities for employment and independence. On the negative side, it can also be regarded as a measure that actually hinders the individuals who “belong to” that specific group, from developing and exploring other potential abilities and talents that they may have. Further, one can argue that these affirmative actions uphold a simplified conception and stereotype of a group’s collective abilities *and* limitations. In the neighbouring country of South Korea, only blind people can attain legal permission to work as massage-therapists. This is justified with the argument that blind people cannot find work other than as massage-therapists. National Human Rights Commission of Korea argues that: “The blinds’ right to live is a more urgent problem than the non-blinds’ right to freely choose their occupation.”¹⁵⁶ Though this is a more radical step than what we see in China, it exemplifies the point that the blind populations’ right to freely choose their occupation is not considered. It also may further stigmatise the group as a different category of citizens. While the law may be made in the best interest of the disabled, it can be seen as having detriment to their choice of desired occupation and so also to their development.

Likewise in Japan, the government introduced a quota system as early as in 1960, aiming at having more of the population with disabilities included in the workforce. In the law, called “The physically disabled person’s employment promotion law,”¹⁵⁷ it was stated that 1.3 percent of the employers in private workplaces and 1.6 percent in the public were going to be people with disabilities. When launched, these requirements were only morally binding, not legally, but due to the economic growth in the 1960s and early 1970s employers were hiring more people with disabilities than the required quotas. The Japanese government has since then developed and extended the quota system several times, following national needs and international pressure and trends. By 1998, the quota had risen to 1.8 percent in private workplaces, and 2.1 percent in public. There are now introduced punitive measures, such as significant fines for those not fulfilling the required criteria. Workplaces that do not fulfil the requirements have to work out a plan on how to change this and will, if needed, receive

¹⁵⁶ National Human Rights Commission of Korea. Available online at: http://www.humanrights.go.kr/english/about_nhrck/introduction_01.jsp (Accessed 12.12.08)

¹⁵⁷ *The physically disabled person’s employment promotion law*, 1960. Available online at: <http://www.dinf.ne.jp/doc/english/law/japan/30select.html#employment>

financial support to ensure that they can hire people with disabilities. The financial support is coming from the fines paid by workplaces not fulfilling the requirements.¹⁵⁸ The German sociologist Katharina Heyer notes that an unexpected consequence of this affirmative action has been that large companies establish special “barrier-free subsidiary companies” (*tokwei kogaisha*),¹⁵⁹ with the government encouraging it. The goal of people with disabilities having employment opportunities is fulfilled, but at the same time, this has led to a new form of segregation, with the workplaces for the people with disabilities being separated from the workplaces of their able-bodied colleagues.

These examples illustrate an interesting tendency in East Asian countries when it comes to the inclusion of the disabled into society. According to Heyer, it is possible to identify two general approaches on how states structure the society for people with disabilities. The first is what is seen in for example USA and Canada, which has evolved from civil right movements. The goal in this model is ‘equality of opportunity’, and this is achieved by forbidding any discrimination on the basis of for example disabilities. The second model is found in Europe and also, Heyer claims, Japan. In this model, the goal is ‘equality of results’, which is achieved by providing those with special needs special assistance and special consideration, for example through quota arrangements. The state is regarded as having a duty to protect differences. When studying the development of relevant legislation and measures taken to protect people with disabilities in Japan, this appears valid. The government has initiated significant measures in order to give people with disabilities increased chances to live “normally”, but doing it by establishing *special* structures, for education and jobs.

According to Theresia Degener’s analyses, this is comparable with what we see in the Chinese Law of the People’s Republic of China. In it, employment opportunities for people with disabilities are provided in “special welfare enterprises and institutions.” And only within these; “discrimination against persons with disabilities regarding recruitment, employment, promotion, determining professional or technical titles, payment, welfare and other aspects is prohibited.”¹⁶⁰ This appears to contrast the intention behind the quota system, aiming at including people with various disabilities into *every* work unit, not only “special” ones. One thinkable weakness of the system is that CDPF can be regarded as having an

¹⁵⁸ Blanck and Scharz, 2003: 372

¹⁵⁹ Heyer, 2000: 115

¹⁶⁰ Degener, 2003:168

economic interest in workplaces not fulfilling the quota, as they get the money deriving from the fines. If this is so, then there is a disparity between the intentions of the law and the practise. Despite securing people with disabilities ‘normal’ opportunities, such as employment opportunities, it appears both in Japan and China most often to be in segregated units, on the side of the normal society, not inside of it.

As I have described earlier in this chapter, in 2006 China Disabled Persons’ Federation and other relevant departments in China, conducted a major survey, aiming at identifying the prevalence of intellectual disabilities among children in China. The group was to “provide scientific evidence for formulating relevant policies and delivering rehabilitative care services for them.”¹⁶¹ The investigators received training courses before they started screening for disability and for diagnosing when disabilities were detected.¹⁶² It is noted in the article “*Sampling survey on intellectual disability in 0-6-year old children in China*”¹⁶³ that there are problems identifying intellectual disabilities at so young age as 0-6 years: “Children start to study cultural knowledge from the age of 4 years, so mild intellectual disabilities can be detected from this age onwards through failure in their studying.”¹⁶⁴ This reference to failure indicates a narrow ideal of “the normal”, which may make acceptance of “abnormalities” difficult. With regard to children with intellectual disabilities, it may be particular difficult, due to a general stress on education, and on being a good student in China. A mother I met in Beijing cried when she told about her daughter with intellectual disabilities: “I was one of the best students at the university. How come I got a daughter that can not learn anything?”¹⁶⁵

We can see this tendency also in the normatively charged terms used in the test in the survey referred to above, where four domains of function were evaluated: personal-social, fine motor adaptive, language and gross-motor: “Performance on age-appropriate tasks within these domains is scored to determine how a child is classified, i.e. *developmentally delayed*, caution or within normal range.”¹⁶⁶ If there were observed: “Two or more delays in any domain, [it] constitute an *abnormal performance*, and one delay or two cautions constitute a *questionable or suspect performance*.”¹⁶⁷ Finally, “[...] categories of within normal range (i.e. pass),

¹⁶¹ Xie *et al*, 2008: 1030

¹⁶² Xie *et al*, 2008: 1029-31

¹⁶³ Xie *et al*, 2008

¹⁶⁴ Xie *et al*, 2008: 1037

¹⁶⁵ Private conversation, 2008

¹⁶⁶ Xie *et al*, 2008: 1031

¹⁶⁷ Xie *et al*, 2008: 1031-2

suspect, and delayed (i.e. fail) for each participant were defined.”¹⁶⁸ Which consequences can a pass/fail label have on children and their parents’ aspirations for them? The specialists who conducted the survey did, in addition to surveying which rehabilitations the children actually did have (table 1), suggest which kind of rehabilitation the children *ought* to get (table 2):

Table 1: “*Status of services provided to 0-6 year old children with intellectual disabilities*” (2006)¹⁶⁹

| | |
|---------------------------------------------------------|---------------|
| At general hospitals | 1.61 percent |
| At clinics | 2.68 percent |
| At hospitals, specialising in disability rehabilitation | 1.79 percent |
| At home by parents | 57.50 percent |
| In other settings | 0.54 percent |
| Not receiving rehabilitation | 35.89 percent |

Table 2: “*Demands for rehabilitation, as judged by the paediatric specialists.*”¹⁷⁰

| | |
|--------------------------------------------------------|---------------|
| At general hospitals | 6.61 percent |
| At clinics | 15.89 percent |
| At hospitals specialising in disability rehabilitation | 25.36 percent |
| At home | 52.14 percent |

This point is important to note, as the experts who conducted the survey must be understood as having an authority, also with regard to their opinion on which rehabilitation option was considered the best. As the result show, there are limited options, with “rehabilitation at home” being the predominant form. Although Xie and his co-authors conclude: “Home rehabilitation has been widely recognized as the main form of rehabilitation for intellectually disabled children [...],”¹⁷¹ there are no elaborations in the article on what this rehabilitation entails, if and where the parents can receive support and training, and importantly, if this is considered one of the best options also when the child grows older.

¹⁶⁸ Xie *et al*, 2008: 1032. (My italics)

¹⁶⁹ Xie *et al*, 2008: 1035

¹⁷⁰ Xie *et al*, 2008: 1034

¹⁷¹ Xie *et al*, 2008: 1037

Despite the recognition of ‘home-based rehabilitation,’ Fisher and Li notes that a problem for the families with a disabled child is that there are limited access to places offering assistance and training. In the study on disability care in China they write: “We did not find evidence of formal support for families of disabled children, such as home-based or personal care or skills development.”¹⁷² This is a finding not contrasting the statistics from the survey above; that more than fifty percent of the children with intellectual disabilities are at home. What it does question is if that many children receive home-based *rehabilitation*, and if so, what it actually refers to.

Home-based rehabilitation is, as we have seen, officially recognised as an alternative to institutionalisation of people with intellectual disabilities. Whether an alternative to strive for or not, depends amongst other things, on what is meant by “home-based rehabilitation”, and on the degree of assistance and training the parents will receive, as they ultimately will be the main providers of this rehabilitation.

With reference to the medical and the social model on disability, they both seem to be part of official policy, but the medical model may be seen to have greatest practical influence. Confirming this, one informant, working with rehabilitation of people with disabilities under CDPF argued in an interview, that the sole focus for people with disabilities in China were on medical rehabilitation. I asked him if he thought this was something that would change gradually, whether it would be best first to start with the medical rehabilitation, and then move forwards towards working with the society at large, little by little. “No,” he replied, “there would have been room for doing all this, at the same time; working with stigma, attitudes, vocational training *and* medical rehabilitation.”¹⁷³ There are signs of change though, several of the informants noted. The fact that the informant working for the government said what he did might also be interpreted as such, a sign of change.

The laws and initiatives taken by the government are in many regards corresponding with perspectives in the social model, but appear to have low real influence and impact in terms of practical use and integration of people with intellectual and other disabilities into the society. I observed an example of this before the Olympic Games and the Paralympics were going to be held in 2008. In a public rest room, under the sign for “Woman” and “Man”, there was now

¹⁷² Fisher and Li, 2008: 179

¹⁷³ Interview N. (Interview conducted in Chinese, translated to English by me.)

being introduced Braille, the written language for the blind. The problem was that the placard was not touchable; it was hanging rather high on the wall, behind several things, hindering any blind to find the sign. Similar observations were made in a building of CDPF and at a university in Beijing. In both places, ramps had been installed to give people in wheelchairs access to the buildings. But in both places, the ramps were not built all the way into the building, and the person would need to walk up some stairs in order to reach it.¹⁷⁴

The Braille and ramps for those using wheel chairs may have a strong symbolic in addition to practical value. But, as discussed, it takes much work to change attitudes and spread information, for these to be of practical and significant relevance for people with disabilities. That said; the social model, with its stress on societal changes, is the more recent of the two, and is a challenging one. The provincial director of the CDPF I interviewed may be proven right, that changes will come, but come slowly.

3.4 The state and the society: Formal relationship

Before the founding of the People's Republic of China in 1949, there had been many voluntary associations in China, many of which were run by foreign missionaries. In the social area, Linda Wong notes, "their contributions were especially prominent."¹⁷⁵ After 1949 though, this was all to change. Wong elaborates:

"Under an authoritarian ideological context, voluntary associations of all kinds [...] were politically suspect. [...] After the Communists came into power, these were banned almost immediately. [...] By 1953, their welfare projects had passed into the state's hands. For over thirty years, China did not have any voluntary organisations."¹⁷⁶

When Huiling was founded in 1985, there were no other institutions, whether state-run or privately operated, for people with intellectual disabilities in China. From then on though, the situation was to change again. Only ten years later in 1995, the number of privately operated facilities in Guangzhou - the southern city where Huiling had been first established - that cared for, in particular the elderly and the disabled children, had increased dramatically. With thirteen 'people-run facilities' by 1995, Guangzhou was at that time referred to as "a pioneer

¹⁷⁴ Interview J. (Interview conducted in English.)

¹⁷⁵ Wong, 1998:131

¹⁷⁶ Wong, 1998:131

in non-state care in the country.”¹⁷⁷ The number may not seem significant, but when knowing that from 1953 till the mid-1980s, there were no non-state facilities at all, the number gives an indication of the development in this field that has taken place in China. Wong regards the increasing number of social organisations as a sign of liberalisation: “State surveillance on civil society became noticeably more relaxed under the open door policy.”¹⁷⁸

The new social groups that emerged, Wong says, can be divided into “semi-independent” (*ban minjianhua*) and “independent” (*minjianhua*) groups. China Disabled Persons Federation is according to Wong an example of the first, as it is “instigated by the state” and “maintains close contact with certain bureaux.”¹⁷⁹ Critiques of the CDPF have argued that its top-down structure leaves it too far away from the real issues concerning disabled people, and makes access difficult for grassroots members of the society. A teacher, who has worked in Huiling since the founding, stated:

“The people from the government don’t come to see us. You can welcome them; invite them, but no. A lot of foreign embassy people have come here. But they, the government, they think that there are so many Chinese people, and their work is too busy. They wouldn’t have come here.”¹⁸⁰

Allowing more non-governmental agencies to be engaged in the field of disability, cooperating with and listening to them could potentially reduce this type of criticism directed at the CDPF. In the study of welfare in China, Fisher and Li look at how laws aimed at securing people with disabilities in China are implemented. They conclude:

“Without a developed method of assisting and promoting local non-governmental organizations for disabled people, their families and community members are discouraged from organizing their own support services.”¹⁸¹

Now, there appears to be changes in this respect: In the law entering into force in July 2008, China’s Law on Protection of the Disabled, (*Zhonghua renmingongheguo canjiren baozhangfa*),¹⁸² the role of non-governmental actors were included as the third actor, in addition to the family and the state, having a responsibility in ensuring that people with

¹⁷⁷ *Shehui Gongguo Yanjiu*, 1995, 4: 37-40, quoted in Wong, 1998: 134

¹⁷⁸ Wong, 1998: 132

¹⁷⁹ Wong, 1998: 132-3

¹⁸⁰ Interview G. (Interview conducted in Chinese, translated to English by me.)

¹⁸¹ Fisher and Li, 2008: 181

¹⁸² *China’s Law on Protection of the Disabled*, 2008. Available online at: http://www.cdpc.org.cn/mrxx/content/200805/09/content_25055884.htm

disabilities can enjoy their rights: “The State shall encourage and facilitate non-governmental forces to establish welfare homes and fostering institutions for persons with disabilities” (*Article 49*). In addition to the specific mentioning of “non-governmental actors” in Article 49, there are references to “society,” (*shehui*), in 11 of the 68 articles of the law.¹⁸³ Though the word “society” is undefined, in all of the articles, it is written either in the combination “the State and society,” (*guojia he shehui*) or “the government and society,” (*zhengfu he shehui*). This may be understood in two ways. First, not as something completely independent from the state, but as what Richard Madsen in the article “*Confucian Conceptions of Civil Society*” calls “a ‘transmission belt’ between the state and the lowest realm of the society.”¹⁸⁴ Second, the usage of the word “society” may indicate that it is something else than the government and the state. Whether in reality independent, semi-dependent or dependent, this means that the state is acknowledging and formally welcoming actors like Huiling to work in the fields of disability. A reason for this, an informant who has been working in Huiling since its start argues, is that these are relieving the state from responsibility for assisting people who otherwise would not have received proper assistance.¹⁸⁵

3.5 Conclusion

From the laws discussed in this chapter, we can conclude that the family still in practise has the main responsibility for the wellbeing of people with intellectual disabilities in China. Moreover, the laws seem to a large degree to be influenced by Confucian family virtues. Nonetheless, what we can further see is that the state, since the mid 1980’s became more strongly involved in the disability-issues, with the founding of the China Disabled Persons Federation, the CDPF. As the state entity explicitly in charge of disability-issues, the CDPF faces a considerable challenge, when taking into account that China’s disabled population (including intellectually disabled) exceeds 80 million people. The service and care offered to the disabled people seem to vary from province to province, and also from one type of disability to another. With the Law on Protection of the Disabled of 2008, non-governmental forces are included as care-providers. This may give room for more grassroots organisations to provide services where needed, and where the CDPF does not have adequate resources or expertise, or make other priorities.

¹⁸³ *China’s Law on Protection of the Disabled*, 2008, *Articles 7, 12, 19, 21, 32, 43, 44, 45, 46, 52, 54*

¹⁸⁴ Madsen, 2002: 193

¹⁸⁵ Interview O. (Interview conducted in Chinese, translated to English by me.)

Chapter 4

Disabilities in an East Asian perspective: Japan

In this chapter I will examine the role of state, family and non-governmental organisations in the work for individuals with disabilities in Japan. The reason why Japan is included in this thesis is that it can provide grounds for comparison with and understanding of how work for people with disabilities is organised and responsibility allocated in China. Japan shares many cultural facets with China, which may play a role in how for example welfare is arranged for in the society.

An additional reason for including Japan is that staff from Huiling has studied neighbouring countries, and how other organisations are working with intellectual disability. What are there to be learned from this neighbour in the East? One informant from Huiling explains:

“Staff from Huiling often go to other countries to study, because the developed countries have already been working with intellectual disability for a long time. We are only in the phase of studying, and we want to study the methods that have proven useful. If we continue to only do the same, we will waist even more time. If we study what others already have used a long time to find out, we can improve faster.”¹⁸⁶

My information on Japan derives from secondary literature only. I will not go into detail about particular organisations or disabilities, but instead try to identify some general structures and tendencies on how disabilities are dealt with in the Japanese society. The chapter will be divided into three parts. In the first part I will discuss the families, more specifically the mothers’ role as care providers for people with disabilities. Second, I will discuss the role of the state, and its role as provider of legal protection for the people with disabilities. Third, I will look at the disability rights organisations in Japan.

4.1 Disability and the family: Gendered welfare

In an East Asian context, Japan’s history of social policies is a long one, “beginning to take

¹⁸⁶ Interview L. (Interview conducted in Chinese, translated to English by me.)

shape during the Meiji Restoration (1868-1912).”¹⁸⁷ From this period and onwards it is possible to identify two characteristics that have influenced Japanese welfare system. One is the role non-state actors, including the family, are given. The other, and correlating, is the ideal of citizens’ independency from the state. An individual in need has been secured socially and economically, primarily through the family, philanthropic or religious organisations/institutions, or at the workplace. Only when neither of these has been able to help, the state is understood as having a responsibility. Paralleling this tendency is the strong ideal of non-intervention of the state into people’s private affairs. According to Roger Goodman, a researcher on Japanese welfare politics, a general ideal in Japan is that it is “better to be independent of, rather than reliant on the state.”¹⁸⁸ This, he claims, has significant impact on the development of Japanese social welfare.

A survey conducted in 2007 revealed that more than half of all Japanese men agreed on the statement “A husband should work outside, while a wife should be a full-time homemaker”¹⁸⁹ Of the women asked, as many as 43.3 percent agreed to the same. These attitudes are further reflected in the statistics of labour participation. The average year for a woman to get married was 28.3 years in 2007 and the average year for a Japanese woman to get the first child was 29.4 years.¹⁹⁰ With these numbers in mind, studying the statistics of women in labour seems to indicate a correlation. Only 63.2 percent of women between 30 and 39 years old were in 2007 working, while almost every male, 98.1 percent, in the same age group was.

The reason why I include these statistics when discussing disability in Japan, is that the societal and economic structures may have an influence on how people with disabilities are cared for. In a society where women are expected to be at home with their children, and where they are expected to care for those in need; such as children and elderly family members, mothers are more often than not the main care person for individuals with disabilities, also when these grow older. This can be understood not as much as a result of formal requirements

¹⁸⁷ Lin, 1999: 71

¹⁸⁸ Goodman, 2001: 21

¹⁸⁹ The Centre for the Advancement of Working Women, Japan. Available online at: <http://www.miraikan.go.jp/english/statistics/001/04.html> (Accessed 24.03.09, closed when checked 08.04.09) Alternative webpage, for the same: Gender Information Site, Japan. Available online at: http://www.gender.go.jp/english_contents/women2004/news/n04.html (Accessed 08.04.09). Although the numbers still are high, they have been decreasing significantly from 1972, when almost 84 percent of both women and men agreed to the statement.

¹⁹⁰ Ministry of Internal Affairs and Communications, Statistics Bureau and the Director-General for Policy Planning, Japan. Available online at: <http://www.stat.go.jp/english/data/handbook/c02cont.htm>

as of societal expectations. With women having the role as care taker, there has been a low degree of demand for public or other external assistance in Japan. Disability rights organisations reflect the extent to which this is the case, in how they are campaigning. According to Yoda Hiroe, a Japanese sociologist working with disability studies, these organisations have had to come up with new ways of promoting individual rights. Requiring services outside the house is thus promoted not as a sign of “selfishness” but as a measure to ensure a public good. Additionally, the view on people with disabilities as passive and in need of care, due to low visibility and few public demands has to a large extent been upheld and unchallenged.¹⁹¹

4.2 Disabilities and the state: Legal assurance

Japan has a significant legal framework for the protection of people with disabilities. The development of the laws and the changes in content have come due to internal pressure, primarily from disability-rights organisations, and from international agencies and agendas, such as the United Nations (UN), the International Year of Disabled People (IYDP) and the International Labour Organisation (ILO).

In 1981 the United Nations put disability high on the agenda, when it designated the year to be the International Year of Disabled People. With one of the central slogans being “full participation and equality,”¹⁹² IYDP has been referred to as a turning point for how disability has been regarded around the world. A new way of thinking on disability was introduced and recognised: not as being a concern primarily for medical rehabilitation but primarily a rights concern. Equal rights, self-determination and participation became high on the agenda. The launch of and standards set by IYDP, the following United Nations Decade of Disabled Persons (1983-1992), and the Asian and Pacific Decade of Disabled Persons 1993-2002, are all believed to have affect on how countries have arranged the services for people with disabilities.¹⁹³

In China, the founding of China Disabled Persons Federation came only few years after the launch of IYDP, in 1987. Also in Japan IYDP had an influence on how disability was

¹⁹¹ Hiroe, 2008

¹⁹² Heyer, 2000: 106

¹⁹³ Kohrman, 2005: 21-22, and Ingstad and Whyte, 1995: 10, quoted in Kohrman, 2005: 21. UN ESCAP Asian and Pacific Decade of Disabled Persons 1993-2002. Available online at: <http://www.unescap.org/esid/psis/disability/decade/about.asp>

regarded publicly and was regarded in the legislation, from a welfare and medical issue, to one where independent living and equal rights became the formal goal. Japan adopted “the principle of normalising”¹⁹⁴ people with disabilities in the society as their guiding line. But despite these changes in legislation, Katharina Heyer describes it still to be rooted in ‘the medical model on disability’. The reason for this, she explains, is that people with disabilities have been recognised as having special needs and the solutions offered in Japan have been to give people with disabilities special rights, such as rehabilitation and welfare, but most often “in institutions separate from the rest of the society.”¹⁹⁵ This has resulted in a form of new segregation, with people with disability not being integrated, and normalised in the society, as was the goal, but left on the outside because of their “special features.”

4.3 Disabilities and the society: Activism and care

Noteworthy with regard to disability in particular and welfare in general, is the fact that the state plays a “passive” role with regard to services for the people with disabilities in Japan. It appears that the Japanese state both accepts, and acknowledges responsibilities allocated to private institutions and organisations. Historically, this is a contrast to China, where the state since 1949 monopolised all welfare services, and only the last two decades gradually opened up to and to a certain extent has credited and encouraged private initiatives in this field.

The designated role for the Japanese state appeared to increase with the new law, the “Mental Health Law” of 1988. In the law it was emphasised that the government should establish an adequate number of workshops for people with disabilities, but the result were weak, with only a limited number actually being established. Ten years later, in 1998, the Ministry of Health and Welfare publicly recognised, accepted and even “encouraged a private, market-oriented approach to welfare.”¹⁹⁶

One field in which this privatisation of welfare became visible was in the field of psychiatry. The large majorities of psychiatric patients in Japan have been and still are in closed, privately run hospitals. There are limited accesses to alternative methods of treatments, despite research revealing that a large percentage of them could have been better off in other types of

¹⁹⁴ Heyer, 2000: 117

¹⁹⁵ Heyer, 2000: 107

¹⁹⁶ Heyer, 2000: 122

facilities.¹⁹⁷ This limited access to, and also, it appears, low recognition of alternative services than in-home care and hospitalisation, appears to be a shared tendency in both Japan and China, despite the institutions in China primarily being run by the government and in Japan by private organisations and institutions.¹⁹⁸

What does exist in Japan, in addition to the privately organised hospitals, is a large number of privately organised, sheltered community workshops. These are by far outnumbering the workshops initiated by the two ministries who officially were in charge of disability issues, the Labour Ministry and the Health and Welfare Ministry.¹⁹⁹ When first founded in the 1950s the intention behind, was to give people with intellectual disabilities employment opportunities, as the government and the law to a large extent had ignored this group.²⁰⁰ The government has later acknowledged that the large numbers of private workshops reflects a need for their existence and a lack of public alternatives.²⁰¹

The disability-rights organisations have played a strong role in Japan. The first generation of activists was working for people with disabilities with special needs. This, Heyer claims, has resulted in extensive rehabilitation facilities, well developed, but segregated from the rest of the society, much in line with the medical model described in Chapter 2.²⁰² The new generation, starting from the mid-1980s, Heyer further claims, “have been working towards a rights-based model that demands full participation, self-determination and integration into all levels of society.”²⁰³ These are using a rights-based language strongly influenced by disability-rights movements in the USA.²⁰⁴

As a consequence of the structures described above, with women to a large extent being considered the care-takers of people with disabilities, the disability rights movements in Japan have campaigned for independent living for people with disabilities, with a dual target: First, pressuring the government to secure structures in society for people with disabilities to live

¹⁹⁷ Hiroe, 2008: 6

¹⁹⁸ See for example Xie *et al*, 2008

¹⁹⁹ Heyer, 2000: 115

²⁰⁰ Heyer, 2000: 115. First in 1988 people with intellectual disabilities were included in the Japanese government initiated quota system.

²⁰¹ Heyer, 2000: 115

²⁰² Heyer, 2000: 122

²⁰³ Heyer, 2000: 122

²⁰⁴ Heyer, 2000: 126. Examples are the Japanese branch of Disabled People International (1986), and the network of Independent Living Centres, united in 1991 under the Japan Council of Independent Living Centres.

independently. Second, change attitudes at the family level, to let people with disabilities get more independency, and to change the popular image of them as being dependent by nature. The strong image people in the Japanese society have of people with disabilities as being dependent is according to Yoda Hiroe, “the most difficult challenge faced by persons with disabilities in Japan.”²⁰⁵

According to Hiroe again, the family can be a source of oppression for people with disabilities in Japan. This is why, she explains, ‘independence *from* the family’ (*datsu-kazoku*) has become a central slogan for the disability movement in the country.²⁰⁶ When people’s disabilities are understood as a care concern to be handled by the close family only, there will be a low degree of public pressure, a pressure that in other countries often come from this group; the families of and the individuals with disabilities.

Low public pressure appears also to be a challenge in China. Other reasons may be identified to be behind this, but the roots are perhaps the same: that disabilities in both countries appear to be considered primarily as a family-matter.

In contrast to China, the Japanese non-governmental organisations play active roles in many fields; as lobbying activists; as ‘watchdogs’; as service providers, and as public activists, whilst non-governmental agencies and disability activists in China still can be said to play at best a minor role. I believe this is where we have to look to understand the relevance of studying Japan for Chinese non-governmental organisations working with intellectual disability, such as Huiling. There are longer traditions for civil actors working in this field in Japan than China, but they appear to face similar challenges. One of these is how to advocate disability as a public concern, not as one primarily concerning the families involved. When family-based care for people with disabilities is the main option, people with (intellectual) disabilities may not be given adequate chances to develop their potentials the way they could have, if given opportunities to live independent *in* the society and independent *from* the family.

4.4 Conclusion

There appears to be greater differences than similarities in the way disability issues are worked with in Japan and China. The main difference is observed in the role private

²⁰⁵ Hiroe, 2002: 9

²⁰⁶ Hiroe, 2002: 3

institutions and initiatives play in Japan and in China. The other difference is the role the governments play in the two countries. It appears that the Japanese state provide legislation to ensure that the interests and rights of people with disabilities are protected, but allocate the responsibility to care for and offer service and treatment, to the private sphere. In China the State, together with the family, formally has the main responsibility. What the two countries have in common is that despite an increase in offers for people with disabilities, the large majority – in Japan and in China – are still at home.

Chapter 5

Huiling: Structure and strategies

As laid out in the Introduction, Huiling serves as my main case in this study on intellectual disabilities in China. To better understand this organisation and the way it works, I have found it necessary first to understand the larger society in which it is established. The foregoing chapters have been an attempt to do this. In this chapter I describe and discuss Huiling's organisational structure and working methods. The underlying question for this chapter and the following, Chapter 6, is: What are the general and more specific strategies Huiling is pursuing in the organisation's work with and for people with intellectual disabilities?

I will start this chapter with an account of the first years of Huiling, from its founding more than two decades ago. Second, I will describe what I identify as the main entities of the organisation. Third, I will look at the relationship between them, in light of what I identify as Huiling's learning strategies. Fourth, I will discuss the organisation's economic situation in order to see whether this affects the way the organisation is structured. Fifth, I will look at Huiling's choice to establish itself in cities, rather than in the less populated areas.

5.1 The founding of Huiling

There appears to be a general connection between personal awareness of or experience with intellectual disability, and the degree of involvement in disability issues. In his study of state run orphanages in Japan, Roger Goodman writes: "When parents with political and economic power have handicapped children they will use that power to protect the best interests of their children." In Japan, there have been at least two stories involving famous persons and disabilities. One is of Eito Yashiro, a politician with a physical disability who in 1977 was elected to the parliament. He later became chairperson of Disabled Peoples' International in the Asia and Pacific Region, and is said to have pressured Japan's government to take serious actions for the disabled population.²⁰⁷ The other is of the Japanese Prime Minister Nakasone Yasuhiro (1982-87). According to Goodman, several of his informants informed him that the

²⁰⁷ Katsui, 2008: 17

former prime minister's granddaughter had Downs Syndrome. Although Goodman was unable to confirm this, there was evidence that "the state's support for Downs syndrome children increased substantially during his prime-minister ship."²⁰⁸ In the study *Disability and Culture*, Benedicte Ingstad and Susan R. Whyte discuss one of the ways attitudes to and measures for people with intellectual disabilities may change in a society:

"It was significant that the seed of this change in the people's perceptions – from the disabled as people to be protected and treated/trained separately to citizens of equal right – should come from a parent of a mentally disabled person. People with mental retardation necessarily have to be represented by their parents or close kin, some of whom are influential as lawyers, doctors, teachers and so on. The same thing is known to happen in developing countries. The birth of a mentally retarded child to a politician or other influential person greatly strengthens the cause of disabled people."²⁰⁹

In China the by far most influential figure with regard to disability issues is Deng Pufang, the paralysed son of Deng Xiaoping. With regard to intellectual disabilities, famous "cases" are far more difficult to spot. To my knowledge, no public person in China has given voice to people with intellectually disabilities and their families by standing up, voluntarily, in public.

The woman who started up Huiling, Meng Weina, had no personal connection to people having intellectual disabilities. There were no one in her family or close personal network with any kinds of disabilities, and as Meng Weina said, she had only *heard* about people being referred to as *canfei*, not actually met any.²¹⁰ In the book "Marginalisation and Social welfare in China," Linda Wong notes that in China, the driving force behind private initiatives like that of Huiling often derives from what she describes as: "a mixture of social activism, humanism, and frustration with the state neglect of the needs of deprived citizens."²¹¹ This appears to fit well with the founding of Huiling.

The first personal meeting Meng Weina had with disability was, as mentioned earlier, when a colleague at the factory she was working at, invited her to meet his child who had a severe intellectual disability. There was no public information at that time about how many people who had similar disabilities, where they were, or under what kind of conditions they lived. The parents of the boy gave her the address of a doctor in Guangzhou who had showed great

²⁰⁸ Goodman, 2001: 181

²⁰⁹ Ingstad and Whyte, 1995: 179

²¹⁰ Interview, 2008. (Interview conducted in Chinese, translated to English by me.)

²¹¹ Shue, 1995, referred to in Wong, 1998: 136

concern for them. Meng Weina went there, and the doctor provided her with a list of more than five hundred names of families with children having disabilities. She wrote letters to all of them, inviting them to come for an information meeting about the founding of an organisation that would serve people with intellectual disabilities. Almost all of them came:

“Hundreds of people were crying, saying that nobody had been concerned about their child before. Imagine yourself. In the beginning I felt I was doing something good. But after that meeting I started to become scared. To get the responsibility for several hundreds of people, I hadn’t imagined it would be like this. I was terrified. They put all their hopes on me.”²¹²

When preparing for the initiation of the organisation, Meng Weina was in need of both expertise and financial support. She tried to seek help from the government, but to no avail. She then contacted an acquaintance in Hong Kong, who put her in contact with Caritas, a Britain-based charity organisation. Caritas became interested in her project, and agreed to cooperate. Soon after, a training course for future staff was arranged for in Guangzhou, where twenty people were given training over a two-month period. According to Linda Wong, Caritas Hong Kong “donated a total of 3 million Hong Kong dollars over a period of ten years, as well as with the help of staff training and programme planning.”²¹³

The next step was to reduce the number of people, as Huiling would not be able to assist all the five hundred who had been contacted. After instructions from Caritas, the staff had to sort out all those having other disabilities than intellectual disabilities. Caritas recommended Huiling to start with a maximum of thirty youths, since the staff had no previous experience working with people having intellectual disabilities. Meng refused their suggestion. The number was negotiated, and Huiling soon started its service with ninety-six children and youth aged between six and fourteen years. In addition to economic assistance from Caritas, Huiling has since the start asked for a fee from each of the trainees using the services. For the service fee, Huiling rented a large building. There, all the children and youth were sleeping in the same room. They got food and they were kept clean, but rarely left the building. This was the start of it all, as recounted by Meng Weina.

Just after the founding of Huiling, there was going to be an important congress meeting in Guangzhou. The employees and the parents of the youngsters with intellectual disabilities

²¹² Interview I. (Interview conducted in Chinese, translated to English by me.)

²¹³ Wong, 1998: 134

from Huiling agreed to visit the meeting, to advocate the cause of the organisation, and to ask for financial support. They carried the children with intellectual disabilities on their backs, and entered the meeting room. Meng Weina recalls:

“The leader of the congress meeting accused me for hijacking their meeting. At that time, the government officials didn’t want problems. But the problems it would cause at that time were not as big as they would have been if we did the same today. One of the subordinates, also he a leader, was very touched, and was willing to give us money. But the highest leader of the meeting was very angry, and shouted: “*This is sabotage!*” He called the police to come, but the police said that we hadn’t done anything illegal. The police were on our side. Later that leader, who had called the police, actually got a granddaughter with intellectual disability. After three years, he came to us, bringing his daughter and granddaughter. I felt it was very strange. The leader knew about Huiling, and he knew that we were good, as he had seen us. Now they are in USA. They don’t need to be at Huiling, because they have a lot of money. From time to time the mother comes back to China, to help other mothers in Guangzhou who have children with intellectual disabilities.”²¹⁴

This story is illustrating for the fact that intellectual disability is something that can occur in any family, and consequently could be of everyone’s concern. It also illustrates what Goodman notes, that parents who get children with disabilities, do what they can do for them. The leader in the story is one of the influential persons Ingstad and Whyte refer to, who possibly could have demanded improvement and changes in treatment of people with intellectual disabilities. But, according to the account above, in the case of the mentioned leader and his family, the influence they have had on services for and attitudes towards people with intellectual disabilities inside China are limited. They have chosen not to use the services that now do exist in China, but to live and use services outside the country. This corresponds to another informant’s answers on the question whether there in China are famous people whose child has intellectual disability, and who are public about it:

“No. Well, we have some people with intellectual disabilities who are famous for performing [in the CDPF art troop]. Besides those, I don’t know about any. I don’t know if any of the people from the government have children with intellectual disabilities. But if they had, it wouldn’t have led to changes in attitudes. For example, if Hu Jintao had a child with intellectual disability, there would have been lots of people hired to take care of that child. To make sure that the child got food, got dressed, lead a good life... That child wouldn’t have any difficulties in life. Society is not equal.”²¹⁵

²¹⁴ Interview I. (Interview conducted in Chinese, translated to English by me.)

²¹⁵ Interview G. (Interview conducted in Chinese, translated to English by me.)

A second informant was surprised to hear that there are famous people in Norway being open about their child having intellectual disability:²¹⁶ “Are they letting people know that their child has intellectual disability?”²¹⁷ She knew only one example where it was made public in China:

“There was one case that got publicity, as a famous couple was travelling by air with their child that had intellectual disability. The child made so much noise that those responsible for the airplane refused to let him fly. This got much attention, but it was not because the parents were open about it, it was because the journalists followed them. This doesn’t really help changing attitudes.”²¹⁸

People with intellectual disabilities have a low degree of public visibility in the Chinese society.²¹⁹ Realisation and recognition of this, appears to have significant impact on how Huiling, gradually, has structured its organisation and what strategies it has used, aimed at changing attitudes and making people with intellectual disabilities visible. Illustrating this claim, I will now proceed to a description and analyses of Huiling’s organisational structures and strategies.

5.2 Basic structure

According to accounts made by my informants, there appear to be two general changes in Huiling of particular interest. The first is a change from regarding people with intellectual disabilities as a group, to regarding them as individuals, with all that that entails. The second change is towards what I understand as a “de-institutionalisation” of Huiling’s service structure. I will start with the first, illustrated by the words of an informant, who both works in Huiling, and is a parent of one of the trainees:

“I seldom brought her out of the house, because she was not willing to go out. The only thing she needed was mum, dad and to eat. Living was only for living. After

²¹⁶ Among the influential examples are the actress Wenche Foss whose son had Downs Syndrome. She was one of the first persons in Norway being open about her child having intellectual disability, and has since been advocating their rights. The second example is the son of the famous couple Henrik Syse and Cecilie Willock, both children of former prime ministers. Their son has also Downs Syndrome, and they have been active and public in their efforts for improving the conditions for people with intellectual disabilities. The third, Princess Martha Louise, do not have children with disabilities her self, but has been an active and outspoken advocate for people with intellectual disabilities.

²¹⁷ Interview M. (Interview conducted in Chinese and English.)

²¹⁸ Interview M. (Interview conducted in Chinese and English.)

²¹⁹ There have been a positive, however small, change observed. China arranging Special Olympics in 2007 may prove to be an example of this (Interviews F, N), although it is difficult to say to what extent. There were for example reports that people with severe intellectual disabilities had curfew during the Special Olympics.

coming to Huiling, she has gotten used to go out. She has gone to the cinema, to the library, to a swimming pool, to the markets to buy things. She feels happy, and she is free. Earlier, when staying at home, she did not have that freedom. Her needs have grown larger. In addition to needing mum, dad, and to eat, she now has the need to talk with other people, the need for friendship.”²²⁰

Needs and abilities appear now to be regarded as connected to the individual, not to a perceived common feature of the group the individual was considered part of. With regard to the correlation between attitudes and structural changes, an informant told that ten years ago, when she started to work in Huiling, she would never think of people with intellectual disabilities as individuals, but only as a group, and all their needs to be the same. The staff worried how to find enough money to ensure these needs, which were understood as being rather basic. Now, she said, their concern had changed: they still needed money, but the concerns were larger, because the employees considered the needs of the trainees to be much more complex:

”Before we worried because we didn’t have enough money in Huiling. Now we are not only lacking money, there are a lot a lot of things we are lacking. We don’t have enough people; we lack a lot of skilled workers. We need more training, and we need to improve our service methods.”²²¹

It appears to be possible to make a connection between how people with intellectual disabilities are understood, and how services are arranged and organised. If a person is understood as having few needs, the services, it can be assumed, will be less comprehensive (and possible less expensive) than if a person’s needs are considered as more complex. When looking at Huiling, the apparent shift in attitudes described above, from regarding people with intellectual disabilities as a group to regarding them as individuals, seem to materialise in how the services are organised and structured.

This leads me into what I argue is the second major change, to what I have called a de-institutionalisation of Huiling’s structure. With this I refer to a physical change, from the organisation using one building for all purposes, to using many buildings, one for each purpose, and the buildings being spread throughout the respective city. The following text may serve as an illustration on this point. It is inscribed on a placard on the wall outside the day centre at Guangzhou Huiling:

²²⁰ Interview G. (Interview conducted in Chinese, translated to English by me.)

²²¹ Interview A. (Interview conducted in Chinese, translated to English by me.)

“In 1996 a vulnerable group of our brothers and sister began to live here. Within its walls the so-called “Residential Centre for the Disabled” was part of the surrounding community of able-bodied people, yet in essence very far from being integrated into it. Ten years have passed and the old Residential Centre has now become a “Day activity Centre”. Now, in starting to lead more normal lives in newer community-based Huiling Homes, our present-day eighty guests say “Goodbye!” to the collective life-style of the old. (Guangzhou Huiling, 16th Annual National Month of the Disabled, 2006)”

It is interesting here to note the self-criticism being made public like this. The words at the placard stipulate a new turn, aiming at integrating people with intellectual disabilities into the society, but also states a criticism of their earlier approach. Opening an institution *in the midst of* the society does not per se and necessarily lead to integration *into* the society. The publicly announced turn can also be interpreted as setting an example; to the public, to families of children with intellectual disabilities and to governmental institutions for this group. Closed institutions are no longer considered the optimal mean for reaching the goals of integration and normalisation of people with intellectual disabilities into the society, and Huiling does by admitting its own shortcomings and with its new initiatives, set a new standard.

These changes are more concretely observed in how the organisation now is structured. Huiling’s services are of two basic kinds; places for daytime activities, and places used to live in, referred to as ‘Family Homes’.²²² The daycentres and the workshops are the places where the trainees work or study in the daytime. In Beijing Huiling for example there are two daycentres and one workshop. The trainees are using the centre most suiting for their abilities and needs. The trainees with more severe intellectual disabilities are using daycentres with activities and basic training in various practical everyday-skills, as well as in subjects such as music, dance and painting. Both in the daycentres and the workshop excursions are arranged to public places and events several times a week, with a focus on the practical knowledge the trainees gain from using the public space.

The Family Homes are where the trainees at Huiling live. Not all of the trainees do though. In Beijing Huiling less than half of the trainees were living in the Family Homes, the rest were living with their parents or other relatives. In Xining on the other hand, most of the trainees were living in the Family Homes. A reason for this, I was told, was that many of the trainees

²²² The number of departments varies in the different cities, depending on the number of trainees, their ages, needs and so forth.

came not from the city itself, but from the countryside or other smaller cities in the province. A father I met, whose daughter had recently started in Huiling, lived 800 kilometres away from Xining. In Beijing Huiling the Family Homes offer a place for the trainees to live in the workdays only. In the weekends, the trainees return to their families. In other cities, at least in Guangzhou, Xining and Tianjin, the trainees can stay there the whole week, returning to the families only on holidays, or not at all. Tianjin Huiling differs from the other places, as several of the trainees there were orphans. For them Huiling substituted the orphanage.

In each Family Home, six trainees are living together. The Family Homes I visited were all in normal standard apartments, located in normal living areas. They had two or three bedrooms, which the trainees shared. In each Family Home, a 'Family Mother' (*jiating mama*) or a 'Family Father' (*jiating baba*)²²³ was employed. This person lived together with the trainees, full time. Huiling paid him or her, but the salary was relatively low (in Beijing Huiling about 800 Yuan, or about 80 Euros, a month), in addition to getting the lodging and food expenses covered. There are mostly women doing this job and as the job requires them to live in the apartment with the trainees twenty-four hours a day, five or seven days a week, not everyone can do it. Some of the Family Mothers employed were alone; either as widows, being divorced, with a husband who worked far away, or as there were some examples of, as Catholic nuns. Some of the Family Mothers had children with intellectual disabilities, and were living together with their child in the Family Home. In addition to the Family Mother or Family Father, there was one person from Huiling coming to assist in the evenings and mornings. In Beijing, these were persons who at daytime worked either in Huiling's day centres, at the workshop or at the office.

In Guangzhou, Huiling has in addition to the abovementioned structures, opened up a kindergarten, one of the first of its kind in China.²²⁴ Here, children with intellectual disabilities are together with non-disabled children. Additionally, Huiling offers schooling for children with intellectual disabilities, youth centres, work training centres, and now last, a project aiming at giving services to elderly people with intellectual disabilities at farms located in the countryside, outside Beijing and Guangzhou. According to informants working with this project in the two cities, the intention is to offer a quieter place to live for the oldest

²²³ The usage of both the terms and the homes, are part of the organisational structure of Huiling, as a normalisation of offers given to people with intellectual disabilities.

²²⁴ According to one informant there are kindergartens like this also in Beijing.

of the trainees and alternative workplaces at the farm for the younger trainees.

5.3 Learning strategies

One more point to be made about the organisational structure of Huiling is that although the cities in which Huiling is established are spread all over China, there are frequent contact between them, both with regard to the staff and the trainees. This contact can be observed in many ways, and I will start by telling about one, where the contact does not go between different cities, but between the different departments *in* a city. In order for the staff to learn and gain as much experience as possible, each employee has after a certain amount of time to change their workplace. The employees working in one of the day centres has to change either to the other day centre, or to the workshop. This system appeared to be applied also from one city to another. Many of the employees I spoke with had for a period of weeks, months or years been working in Huiling in a second city. When I visited Huiling in Xining, I met one of the staff there on her way to Guangzhou Huiling, where she was going to stay for three months. The reason for this, I was explained, was that Guangzhou Huiling had long experience in working with children with intellectual disabilities, while Xining had little. The woman was sent to study the methods of Guangzhou Huiling, and would return to Xining three months later to apply the methods she had studied.

The contact between the different cities does also involve the trainees. At several occasions during my internship, events were arranged where trainees from two or more of the cities got together. One example of this is that Beijing Huiling once a year arranges a holiday for the trainees, visiting Huiling in one of the other cities in China. During Special Olympics in 2007 almost one hundred of the trainees from eight different cities, travelled together to Shanghai as a “Huiling cheering squad”. During the autumn 2008, three of the Huiling organisations joined for an “Art Tour,” to Guangzhou, Xian and Beijing, where the trainees held a theatre and music performance together.

In addition to the purpose of learning from each other, the frequent contact between the Huiling organisations also may create an organisational identity, which goes beyond the local Huiling organisation, and which may be seen as creating a stronger and more sustainable organisation. Much of the contact has the purpose to let the staff study and learn from those in the organisation that has gained the most experience and knowledge. The contact between the

different units is also significant in order for the organisation to remain one, in the sense that the structures and methods applied are, if efficient and approved of, used in all of the organisations' locations. A Family Mother, who has been working in the organisation since its founding, explains Huiling's strategy:

“This new way of serving should be developed little by little, because we have not had this kind of service before. I hope Huiling will develop even further so that the trainees can develop even more. If you do the same every day, every day paint, do handicraft, read... They need new things to do. This is why Meng often goes abroad to study, because the developed countries have already done this for a long time. We are only in the studying phase, and we want to study that which is useful. If we only continue to do the same, we will waste even more time. If we study what others already have used a long time to find out, we can improve faster. I think this way is a good one.”²²⁵

To sum up then, what we can identify here is a strategy for learning that is considered efficient in order to ensure that the staff can learn from more experienced staff's knowledge and experience. The first level of learning is what I described above; *inside* Huiling in the specific city, where the employees are changing workplaces. Through this system of rotation, the idea is that they will gain experience and knowledge about working with people with intellectual disabilities of all degrees and kinds, and also on the various methods applied in each unit - be it the day centres, the workshop or the Family Homes. What we can call the second level of studying is the learning from one Huiling organisation to another, as illustrated by the example of the teacher in Xining Huiling who went to Guangzhou Huiling to learn from their experience with children with intellectual disabilities, and then returned to Xining with her new knowledge. The third level of learning is Huiling studying the countries where services for people with intellectual disabilities have a longer history than in China. Those countries include Japan, where amongst others non-governmental organisations working with intellectual disability, both as care providers, and rights activists, have existed for a long period of time.

5.4 The economy

There are two state institutions Huiling can apply to for financial aid. The first is the Ministry of Civil Affairs, that “has jurisdiction for social welfare”²²⁶ in China. The other is the CDPF who is in charge of services for the disabled. Huiling had, I was told, not been given

²²⁵ Interview L. (Interview conducted in Chinese, translated to English by me.)

²²⁶ Wong, 1998: 9

substantial monetary support from either of these. In 2007, Guangzhou Huiling asked the Ministry of Civil Affairs for economic assistance, and was given “1.7 Yuan (about 0.2 Euro) for each disabled person per year.”²²⁷ When I asked why the amount was so small, the informant replied: “We asked the Ministry of Civil Affairs to support us, and they did it.” Another informant, who has been involved in the work of Huiling since its founding, elaborated on what the informant understood to be the main difference between the Ministry of Civil Affairs and CDPF:

“We don’t get anything from the CDPF, because we sometimes criticise them, and they don’t like it. They use feelings to manage, not law. If they would use the law, it would be easy, but when they use relations and feelings, then there’s a problem. For instance, we can get some money, some times, from the Ministry of Civil Affairs, as it is much more open-minded. The reason for this is that they are not serving ‘the disabled’ in particular, they just do service for ‘the people’. The Ministry of Civil Affairs is occupied with many things, and is much more open and developed. A few years ago the central government asked the Ministry of Civil Affairs to be in charge of the non-governmental organisations. We are a non-governmental organisations and we are also doing work for the disabled people. So if the CDPF won’t help, because we are a non-governmental organisations, we can still go to the Ministry of Civil Affairs.”²²⁸

In all the interviews I had with people in Huiling, I asked whether they wanted economical assistance from the government or the CDPF, or if they regarded economic assistance as a restriction on their autonomy. All of them replied that they hoped for economic support, as financial difficulties are regarded as a major challenge for the organisation. Those of the informants who did discuss the connection between financial support and autonomy argued that there would not be any conflicts, as Huiling and the government ultimately have the same goal here: to assist people with intellectual disabilities. According to a survey by Kin-Man Chan, on what Chinese non-governmental organisations claim are their most urgent needs, 49.2 percent replied ‘more government funds’.²²⁹ This, the author argues, is a reflection of the difficult financial situation non-governmental organisations are in today, having to rely on private donations.²³⁰

One of the informants from Qinghai Huiling told that Huiling had established contact with a representative from the CDPF. The representative had met with them, and had praised the

²²⁷ Interview C. (Interview conducted in English.)

²²⁸ Interview C. (Interview conducted in English.)

²²⁹ Chan, 2005: 31

²³⁰ Chan, 2005: 32

work they do in the organisation, but had not given Huiling any financial aid. The informant commented on the outcome: “The government felt that our work was good. But they could not give any help. They could only give verbal support.”²³¹ This is a great challenge for the organisation. Fund-raising takes effort and time that could be used differently and more efficiently if the government covered some of its basic running costs. A leader in another department of Huiling explained: “The government tells us to continue our good work, but they do not give us as much as one Yuan in economic support to ensure that we actually have the possibility to do so.”²³² A teacher who had been working in Huiling since the mid-1980’s had the same concern: “We would very much like to get economic help from the government. There are so many things we should have improved here that we can’t afford as we lack money.”²³³

There can be several reasons why the government is not giving the organisation economic support. One person working in Huiling as a teacher explained the lack of economical support with the mere fact that the organisation is a non-governmental organisation:

“We would like the government to give us money, but until now the government hasn’t given any. Until now: Nothing. Why? It is because this is an organisation started by a private person.”²³⁴

Kin-man Chan notes the ambivalent relations the government has with non-governmental organisations. On one hand, the state needs the non-governmental organisations to “help meet the social and economic needs that have emerged”, but on the other hand, the government fears that the non-governmental organisations will turn into “an independent political force that challenges the regime.”²³⁵ A problem perhaps corresponding to this is the NGO’s limited access to official channels where they can inform people about their existence and service. A person working in Huiling’s social department, responsible for informing parents with intellectually disabled children about Huiling’s service, explains:

“A great challenge is how to let more people get to know about us. I think it would be different if we were not a non-governmental organisations, then the government would have told the parents of the people with intellectual disabilities that they could have

²³¹ Interview D. (Interview conducted mainly in English.)

²³² Interview E. (Interview conducted in Chinese, translated to English by me.)

²³³ Interview B. (Interview conducted in Chinese, translated to English by me.)

²³⁴ Interview G. (Interview conducted in Chinese, translated to English by me.)

²³⁵ Chan, 2005: 30

used our services.”²³⁶

According to my informants, the government has, as we have seen, given praise but not much economic support to Huiling. There are two noteworthy exceptions though, where the CDPF has given more substantial support. In two cities, the CDPF has provided Huiling with free locations to be used for its services: to Chongqing Huiling in 2006, and to Xian Huiling the summer of 2008. Four months prior, one of the senior staff from Huiling in the latter city commented:

“Every year we ask the government for assistance, but they don’t want to give it. We don’t necessarily want them to help us with money. We want them to let us use a larger place to stay, as they have a lot of buildings. We hope that the government can give us a building we can use, so that we can use all our energy and resources on finding good teachers and staff, not on the economy of housing. For the moment there is a lot of un-willingness in the government. We need to constantly work with them, tell them about our needs.”²³⁷

The government listened, it is possible to conclude, but they had one requirement for letting Huiling use the building; that the CDPF get to have their name attached to the services Huiling offered there. The buildings they are using now have, in addition to Huiling’s, also the CDPF’s logo over the entrance. The leader of Huiling commented like this on the request:

“The government notices that our trainees are laughing and smiling, so they come to see what we do. The CDPF and the government are like this. They give us a building to use, but they require that we hang up their logo on the building. They help us, but we also help them by serving these people. Why do they do it? It is because it gives them a lot of good ‘face.’”²³⁸

In another city where Huiling is established, Xining, I was told that they were not permitted to have the Huiling-logo visible from the street, but only on the facade of the building they rent, which is located in the far end of a semi-closed courtyard; practically impossible to find and see unless one knows about them being there. In this city and province, there were no other services offered for adults with intellectual disabilities than that of Huiling.

How the CDPF acts towards and deals with other organisations working with intellectual disability, seem, according to my informants, to vary. The central government in China sets

²³⁶ Interview H. (Interview conducted in Chinese, translated to English by me.)

²³⁷ Interview E. (Interview conducted in Chinese, translated to English by me.)

²³⁸ Interview I. (Interview conducted in Chinese, translated to English by me.)

out the goals and ideals of the CDPF, but it is the CDPF at provincial and local level that have the responsibility to implement these. What is done, how, and for whom, seems to vary with the respective department's resources, priorities and competencies.²³⁹

Although staff from Huiling utter a wish for economic support from the government, one informant, a senior in Huiling, points to what can be interpreted as a positive effects of the organisation having to rely on means coming from other places than the government:

“The services offered by the government differ from us, as they are in a closed building. They also differ from us as they are protected financially. Think about us. We are trying to change attitudes towards people with intellectual disabilities, but we also need to raise money to do this, so we *have* to find a solution and a way. We have to think about many ways.”²⁴⁰

This may even be regarded as a “market” mechanism of ‘quality control’: In order to attract economic and other support, and even in order to attract families with children with intellectual disabilities, Huiling has had and still has to offer a good service, one that differ from the government's services, and one good enough to make people willing to support it, and for those needing it, to use it.

5.5 Urban locations only

The large majority, seventy-five percent of people with disabilities, are according to one of the informants at CRRC living in rural areas in China.²⁴¹ Despite this, all the twelve Huiling departments are situated in cities, and in central areas of the cities, with the farm project for the elderly being the only exception. There seems to be three reasons for this choice: The first is economical, primarily related to fund-raising. The second is both economical and practical, as urban areas have more developed structures that may be used than what is found in rural areas. The third relates to Huiling's attempt to change peoples' attitudes towards people with intellectual disabilities. I will address these in turn.

Huiling receives, as I have discussed above, limited economic or material support from the government. It depends upon fund-raising, in addition to the service-fees from the parents of the trainees, and the incomes from sale of the trainees' various products. In order to raise

²³⁹ Fisher and Li, 2008:181. Interview F.

²⁴⁰ Interview I. (Interview conducted in Chinese, translated to English by me.)

²⁴¹ Interview N. (Interview conducted in Chinese, translated to English by me.)

money from local people, the model Huiling is developing is one where the organisation is situated in the heart of the big cities. One informant, who has a leading position in Huiling, and who has been working in the organisation since the start, explains:

“You cannot find money in the countryside. You can only find money in the big cities. If we go to the countryside, we can find money, but not coming from China, from abroad. So again we make China dependent on foreigners. Because what will happen? We have to look for money from big organisations. If they give us money we can run. If they stop to give the money we are lost. We cannot depend on foreign countries. Instead, we now try to influence two aspects: One is to make the rich Chinese people help other Chinese people. The second is to help the government to improve their policy. This is the real progression of China.”²⁴²

The low degree of economic support from the government and unwillingness to depend on foreign help appears to be one explanation behind Huiling’s choice of building up settling in the city centres. Depending on private donations and support, it is generally easier to find money in the cities than in the countryside. Related to the economic argument is also the fact that in the cities there is a broader range of services than in the countryside. This can be seen as a second argument for Huiling to be established in big cities. According to the informant referred to above, having all the locations in the centres of cities, gives Huiling access to the public services:

“Huiling offers a community-based service. It signifies that we use the public places; we do things in the community, use the community utilities, like libraries, schools, everything you can find already in the community. We use the community resources. We give services to the disabled in the middle of the society in a very open way. It saves a lot of resources.”²⁴³

To establish the organisation in urban areas is considered more efficient than in rural areas, also with regard to the degree of influence the organisation may have, which can be seen as a third argument. The organisation aims at changing non-disabled peoples’ attitudes towards people with intellectual disabilities. It further aims at making non-disabled people recognise that people with intellectual disabilities should have equal rights to be part of the society and to have an integrated place in it. One informant, in a leading position in Huiling, explains:

“With this structure, we can give another service, not to the people with disabilities, but to people in general: We try to let them learn to accept the people with disabilities. We have these very big difficulties, even with the local government. We have

²⁴² Interview C. (Interview conducted in English.)

²⁴³ Interview C. (Interview conducted in English.)

problems, because they want to clean the city for this kind of people. The better way would be to have the services in the countryside. But we don't want to clean the city. We have the aim to help the people with intellectual disabilities to be integrated like normal people.”²⁴⁴

The trainees at Huiling use the libraries, the parks, the restaurants, the sports fields' and more. When doing so, the trainees become visible and recognisable. The active usage of public space is also regarded as having a positive affect on the trainees' self-understanding and self-esteem, as people with the same rights to be part of the society as anyone else. Social stigma is arguably a severe challenge for people with intellectual disability, in China, but also elsewhere. Huiling's choice of urban locations, and frequent usage of the public space, is one measure against the stigma surrounding people with intellectual disabilities. Erving Goffman, a Canadian sociologist, notes the following in his study on this issue:

“A central characteristic of social stigma is when a group of individuals are denied their individuality, and that in some sense the person with the stigma is not fully or really human. This is especially the case when the common feature of the individuals is a disability.”²⁴⁵

What the stigma really consists of can be hard to identify. Martha Nussbaum, an US philosopher who has been writing on disability, argues that social stigma has a broad influence, even upon how “normal” people react when seeing “abnormal” people performing “normal” actions.²⁴⁶ The structure of Huiling is intended to let a broad range of these “normal” citizens get used to see people with disabilities perform normal activities, thus making the abnormal normal, and the unusual usual. Getting the chance to see people with intellectual disabilities perform normal activities, in informal and familiar environments, may have an effect in de-stigmatisation and normalisation of intellectual disabilities. It may even increase the chances for people with intellectual disabilities to live ‘normalised’ lives. With ‘normalised’ I do not here refer to people with intellectual disabilities becoming *like* people without intellectual disabilities, but to a process of broadening the conception of normality, to also including people with intellectual disabilities. One may argue that with the help of Huiling, the trainees may possibly ‘reclaim’ a place in the society by being visible and challenge stereotypical images that may exist about them.

²⁴⁴ Interview C. (Interview conducted in English.)

²⁴⁵ Goffman, quoted in Nussbaum, 2006:191

²⁴⁶ Nussbaum, 2006: 191

5.6 Conclusion

The way Huiling now is structured appears to represent a significant change, both compared to how it was in the beginning, but also to accounts and observations on how other existing services for people with intellectual disabilities in China are structured. In order to understand Huiling it is necessary to understand the society in which it belongs. My claim is that by studying Huiling, it gives us an indication on the general situation for the people with intellectual disabilities and their families in China. The methods applied in the organisation and the way the organisation is structured can be understood in three ways: First, as compensating for a lack of certain types of services; second, as providing an alternative to the other services existing; and third, as an organisation that through its methods represents a public example in the Chinese society of how people with intellectual disabilities can, and in at least some peoples' view ought to be regarded and treated.

Chapter 6

Huiling: Rights and responsibilities

Is it at all possible in a country like China, where the state arguably has a major defining power, to influence attitudes and policies towards intellectual disabilities outside governmental frames and channels? More specifically: to what extent and in what sense can a small non-governmental organisation Huiling be expected to change anyone's attitudes, or influence general societal norms on how to regard and give service to people with intellectual disabilities in the Chinese society? In order to answer this, I will look at some of the organisation's methods as described in Chapter 5, and compare them to accounts from my informants on changes they have observed; relating to the trainees and to the society that they encounter in their daily life.

6.1 Influencing the trainees: Rights, responsibilities and the problem of excessive love

According to the informants I have spoken to, the trainees in Huiling are not regarded primarily as receivers of care, but to a large extent as individuals who have as much responsibilities for their own lives as possible. Each one of the trainees is in the organisation given different responsibilities considered suiting for the individual's abilities. They all have the responsibility to perform this as well as they can. One Family Mother explains:

“Here in the Family Home all the trainees have different things they must do: *XX* must get dressed by himself. *NN* must close the door when being at the bathroom. When he started here I even had to help him with that, but I told him he had to do it himself from then on. It is not like in a normal family where the mother maybe does everything for the family members. If they came only to get food and get dressed, they wouldn't make any progress at all. They are going to learn as much as they can.”²⁴⁷

Another of the Family Mothers told me that the goal is that the trainees living with her in the Family Home are going to make significant progress: That they reach a higher level of independency and have more practical living skills than they had when coming. If they don't make any progress, adjusted to the individual's actual potential, then, she said, Huiling has

²⁴⁷ Interview L. (Interview conducted in Chinese, translated to English by me.)

not reached its goal.²⁴⁸ The Family Mother referred to above further elaborates:

“I have witnessed great changes. One of the trainees, after he came here he has learned how to wash his own clothes, and he showers all by himself. The trainees all have to tidy up their beds every day; it is not done for them. When we make dinner, they cut the vegetables. When we eat, I will only make the food, the rest is up to them to do. If they don't help to put on the table and prepare it, they will not eat. They have to do that which they are capable of doing. They can do it, and they do it. *DD* for example, he cannot help with tidying, because of his physical condition, but he makes phone calls. This is his job. He dials the numbers himself. This he couldn't do before. Huiling's goal is not to say “*I will look after you*”, it is to say that the person should make progress from before coming to Huiling. The highest goal of Huiling is that the person can live an independent life. If they are depending on the parents it has no meaning. When you let them see that others can eat by themselves; they will understand that they can do it to.”²⁴⁹

This last point she mentions, let them see that others can do it, corresponds to two challenges facing people with intellectual disabilities in China. The first refers to the fact that most people with intellectual disabilities are living at home, having a low degree of contact with other people in similar situations. One informant, a father of one of the trainees at Huiling, who also works in the organisation, argued that he has witnessed a change with his child's level of independence after she started in Huiling. This, he argued, derived partly from the fact that she now had contact with people she compared her self with, and through that was encouraged to do more things by herself.²⁵⁰ The second challenge refers to the problem that arises when people with intellectual disabilities are treated as *incapable* of performing simple and normal actions.

There may be several reasons for non-disabled people acting *for* people with intellectual disabilities. One is that people act for them with the purpose of helping or assisting, out of good will. A second reason may be practical, as it may take longer time for people with intellectual disabilities to do certain things, than for non-disabled people to do it. A third reason derives from the idea that they cannot learn. According to informants from Huiling, this represents a significant challenge for Huiling to work with. The perception of people with intellectual disabilities being ‘child-like’ results in non-disabled people doing too much for them. This good-intended assistance will unintentionally be in danger of making the person helpless and passive.

²⁴⁸ Conversation, 2008

²⁴⁹ Interview L. (Interview conducted in Chinese, translated to English by me.)

²⁵⁰ Interview G. (Interview conducted in Chinese, translated to English by me.)

I witnessed several examples of such good-intended assistance during my internship in Beijing, and in one, I myself played a role. Most of my stay in Huiling, I spent in the workshop, but occasionally I joined one of the day-centres for excursions. After a trip to a public swimming pool, a trainee and I were the first ones finishing in the shower. She could not speak, and I did not know how much of the dressing she was capable of doing by her self. She pointed to her long stockings, and held it out to me. I asked if she wanted me to help her, and she nodded. After having got one foot inside the stocking, one of the Huiling employees entered, saw me helping her and became angry with the trainee. She asked the trainee why she was behaving like a child who could not dress herself. The employee then told *me* that she were perfectly capable of dressing, and should not be helped like that.

The story is not of the most serious kind, but it illustrates a central strategy in Huiling: to increase the trainees' independence. The trainees are encouraged and, as the example reveals, required to do what the individual trainee is or can be expected to be capable of doing. This can be the ability to get dressed; to be able to call with the telephone; to know that the toilet door should be closed when using the toilet and so forth.

Another example, and more serious I would say, as it appeared to influence the health of a person with intellectual disabilities, is the story of a mother I met while in Beijing. Her son was in the late twenties and overweight. He did no longer use the service of Huiling, but instead a governmental welfare centre (*fuliyuan*). The man did not appear to be severely disabled, but was treated as if he was in extensive need of help. We visited a restaurant together, and the mother ordered a lot of food for him. When it came, she started to feed him. The man was completely passive, except when he was asked not to be. When he was not fed, the mother kissed him on his cheek and asked him to kiss her back, which he did. After the dinner a large plate of fruit was served. The mother peeled a banana and fed her son with it. He was still passive, except for the chewing. She peeled one more, and pushed it into his mouth. When she took the third banana, he made a slight movement with his hand, which could indicate that he did not want more, that he wanted to peel it himself or only to hold it. Replying to his gesture, the mother stroked him gently over the cheek, before she peeled it, and fed him again. The pieces of fruit put into his mouth were each time so big that most people automatically would have taken their hand to the mouth to hold the fruit, but the young man did not.

Judged only from what I saw that afternoon, and compared to the trainees at Huiling's level of self-dependency in practical matters, the young man appeared to suffer not from lack of ability, but from what can be identified as learned dependency; being unable to connect any needs he might have with the possibility to act. According to one informant, who is a leader in one of the Huiling-departments, this is a general tendency in Chinese society:

“We have a trainee who is more than forty years old, and still people tell him: “*Listen to what I say; don't you cry...*” Even some of our employees sometimes talk like this, as if they were children. But this is wrong. We give training to all our staff, telling them that this doesn't work; that they have to call them by names, and that they cannot care for them, but have to treat them like every other person, equally. If he cries, you don't need to comfort him. We do a lot of this training. Much has to do with Chinese people's attitudes. Many people think that they are like small children: that they don't understand. This is wrong. People even call them “child”, saying: “*Let's go, child*” and so on. Here in Huiling they are to be treated just like anyone else.”²⁵¹

When referring to this problem, one of the Family Mothers called it a problem of “excessive love”, which she argued, was unfortunate for the progress of the individual.²⁵² The following example may illustrate this: A couple of times during my fieldwork, Huiling invited all the neighbours in the area to visit the workshop. Several of the older women in the area came, and the trainees served them tea and snacks and had prepared a music performance for them. After this, one of the teachers invited all of them to participate on a quiz, where both the trainees and the guest could guess the answers. One of the trainees could not speak, except from saying one word or sound: *er*. All the staff knew this, but the neighbours did not. During the quiz, she raised her hand and wanted to answer. The teacher let her, and after having said “er”, the teacher complimented her for trying, but told her that the answer unfortunately was wrong. I believe this example illustrates the Family Mother's point. The teacher gave every one the same possibility to participate. What is more, she did not try to interpret the trainee's sound, but said sincerely as was the truth, that the answer was wrong.

Significant when describing the methods used in Huiling, is the organisation's stress on trainees having responsibilities, not only in caring for themselves, as discussed above, but also in doing well and caring for others. They are expected to follow the rules of the society, and acting properly when in public. I will give three small, but illustrating examples concerning

²⁵¹ Interview E. (Interview conducted in Chinese, translated to English by me.)

²⁵² Interview L. (Interview conducted in Chinese, translated to English by me.)

this, from my stay in Huiling.

Every morning at the workshop, all the trainees were sitting down around a table for a morning meeting. Various plans, topics or news would be talked about and discussed. One of these discussions was about the use of public transportation. In the Beijing-buses, a certain number of seats are reserved for groups regarded as particularly needing. These are pregnant women, injured soldiers, old people and disabled people. The question raised that morning was what the trainees were to do if they were sitting in one of the seats reserved for the needing, and an old woman would enter the bus? Who should have the priority? Every trainee had to say his or her opinion on this topic. The conclusion derived at, was that the elderly were more needing than the disabled.

The other example I also find illustrating: One of the trainees, an adult woman who were living with her parents, had the day before been yelled at by her father. She earns no more than a couple of hundred Yuan a month at Huiling, and the father had referred to her as “completely useless”. The teacher at Huiling decided to discuss this in the morning meeting, and told the woman’s story to all the trainees. Then she raised the question, if it could be accepted to call anyone “useless.” All of the trainees had to give their opinion on this, one after another. Also this time there was broad consensus: that no one was ‘useless’, and that therefore no one could call other people this. Then, the teacher asked the trainees to reflect on the woman’s abilities, and tell her what they reckoned she was good at. Also here, every one of the more than twenty trainees talked, complimenting her for being good at dancing, for being good at caring for her friends, for showing sympathy with others, and for always doing her designated tasks and duties at Huiling.

A third example I witnessed when returning to Beijing in October 2008, when a new system had been implemented in the workshop. Next to the entrance door was a board, where all of the trainees’ names were written, one under another. Horizontally, there were drawn lines, and next to the names there were placed small golden stickers. Every Friday, in the end of the day, the teachers and the trainees would gather to evaluate each person’s work and effort in the week that had passed. The teacher would read up one name at a time, point out if any thing noteworthy had happened, and ask the trainees which reflections they had made on that persons contribution that week, and to what extent the person had done his or her job, been nice with others and so forth. After the discussion, the trainees were to vote on the person,

whether he or she had been a good example to follow or not. The two or three trainees who had gotten the most votes would be awarded with golden stickers, displayed in public on the board. During the long session, there were two episodes I found interesting. The first was when a trainee refused to vote for himself, as the only one among them. The teacher asked him why, and he replied that he had been a little lacy, not doing all the things he should have done. The other trainees encouraged him to vote for himself, but he still refused. The other episode was when they were going to vote on one trainee, who was absent that day. That trainee had over a longer period bullied some of the other trainees. When his name was read, and they were to vote, only one trainee raised her hand. The teacher asked if she really could stand for that statement, that she thought he had been an example for the others to follow. After discussing, she took down her hand.

Agreeing on the methods or not, these examples illustrates the stress Huiling places on the trainees, on fulfilling their duties, small or large. The trainees would not be excused if they did something wrong or were lacy, but had to take the consequences of it, for example through lack of votes in the evaluation session. Taken one step further, the practice may be seen as corresponding to an understanding of ‘citizenship’ that entails “a blend of rights and obligations.”²⁵³

The way Huiling works appears to be partly based on a belief that practical skills, including the handling of money, can increase people with intellectual disabilities’ degree of independency in the society. At least twice a week Huiling arranges excursions. Normally the trainees are eating at the activity centre, where warm lunch is served, prepared by the trainees who have kitchen service and a chef. To cover the expenses for the food, the families of the trainees must every month pay a certain sum. When there are outings, there is no lunch prepared at Huiling. One day in advance the chef hands out ten Yuan to each of the trainees. This money is supposed to cover the lunch during the outing. What the trainees actually chose to do with the money is up to them; the only requirement being that they have something to eat during the lunch. Normally the staff and the trainees would find a cheap restaurant, where everyone could decide from the menu what they wanted to order, and how much of the money they wanted to spend. Some of the trainees would bring lunch from home, saving the ten-Yuan bill, others would use half of it, and some would use it all. The first day I joined for an

²⁵³ Heywood, 2004: 196

outing, all the trainees were going to a shopping centre in Beijing where there in the basement were lined dozens of small stalls selling fast food from one Yuan and up. By then I knew that all of the trainees had ten Yuan each, but I did not know if they would handle the ordering and use of money. I followed one of them, who I was responsible for. I wanted to help him with the money, but he was faster than me, ordering a drink, a plate of noodles and a snack, making it to be eight Yuan. The employees at Huiling explained that they did this regularly, and that there were few of the trainees that would need assistance with the money and use of it after some training.

In addition to learning how to use money, the trainees working at the workshop, who are identified as having mild and moderate intellectual disabilities, do also *earn* money. The salary they will receive is not equal, but measured according to productivity, and on the fulfilment of the individual's duty at the workshop. One of the employees explains:

“In our workshop, the trainees are doing some work, for example to make necklaces and handicraft. They are also assisting other factories when they can help to produce various things. In the end of the day, every trainee has to write down how much she or he has made during the day. In the end of the month it will be calculated how much they get in salary.”²⁵⁴

In the other cities where Huiling are established, it appears that the same system is followed. One of the employees in Beijing explains:

“It is the same system as for us. If you can do many things, for example you can draw very well, and then you can earn 100 Yuan. One trainee may not like to work too much; maybe she will earn 80 Yuan. It's not equal, not all of the trainees earn the same. In China a leader may earn 5000 Yuan a month, but me, I earn merely 2000 Yuan. She works hard and is tired; I work hard and am tired. So it is not necessarily equal. In China it is like this. If you have the skills, then you can earn a lot. We have an unequal system, with unequal salaries.”²⁵⁵

Another of the employees, from Xian, tells the same story: “If they make one bracelet, they will get one Yuan in salary. If they don't make it well, then they don't get any money.”²⁵⁶

When explaining why Huiling has used the same salary system as elsewhere in the Chinese society, the employees give two general answers, referring to justice and to a fear of trainees becoming lazy. If a trainee does not have the will to make anything, he or she will not receive any salary, as one informant explains: “How much they get, is depending on their effort. For

²⁵⁴ Interview A. (Interview conducted in Chinese, translated to English by me.)

²⁵⁵ Interview Q. (Interview conducted in Chinese, translated to English by me.)

²⁵⁶ Interview E. (Interview conducted in Chinese, translated to English by me.)

instance one of the trainees here, although he knows how to draw he doesn't do it. He gets a low salary. But he is the exception here. Most of them do as much as they can and they know that the salary is measured after what they do."²⁵⁷ She continues:

“If they all would get the same, I don't think that would be fair. Some of them work very hard, some draws a lot of paintings, and very beautiful. I think to have an unequal salary, gives them encouragement. If all of them would have gotten two hundred Yuan, and they see that one person is not working, he would also not want to work. I think there are good sides and bad sides with both. If a trainee makes a bad product, I don't think he should be rewarded. I think this is the best way, not to give equal salary. It is the same system as we have.”²⁵⁸

When talking to one of the leaders of Huiling, who had been to North-Europe for a study trip, she argued that life appeared too simple for people with intellectual disabilities there, “every thing being given to them from the government.”²⁵⁹ This argument reflects what I have found to be a strong norm in the way Huiling works; the stress on the individuals' duties, and not only rights.

6. 2 Huiling's influence in the society: Negotiating space

All Huiling's locations are in the midst of cities, and situated in normal and central areas of the respective cities. According to the informants from Huiling, this has not been unproblematic. In Xian Huiling neighbours living in the floor under a Family Home complained about the trainees making too much noise:

“We had rented an apartment on the second floor. Some of the trainees had moved the chair so that it made a scratching notice. The neighbour at the first floor then shouted to us: “*Can't you teach them anything? Move to the countryside, to a place where there is no other people!*” We moved from there to an apartment at first floor. Under us there were no neighbours, so no problems. Now all our apartments are at first floor. We cannot have a second floor apartment, because the neighbours are not happy with the trainees living over them.”²⁶⁰

In Beijing, my informants note, there have also been similar problems with the neighbours. In one of the locations used as a day centre the organisation received so many complaints from the neighbours that it eventually had to move:

²⁵⁷ Interview H. (Interview conducted in Chinese, translated to English by me.)

²⁵⁸ Interview H. (Interview conducted in Chinese, translated to English by me.)

²⁵⁹ Conversation, 2007

²⁶⁰ Interview E. (Interview conducted in Chinese, translated to English by me.)

“The neighbours have not been welcoming. It is because these people are very noisy, they are talking very loud, like one of the trainees here who weans and shouts. In one of the locations we used, we were all the time asked when we could leave, with neighbours telling us: “*We need peace; we don’t need you coming here.*” The location we have now is good, because there are not so many neighbours. In general, we have not been welcomed where we have stayed. But as time has gone, the relationships have improved. We have gone to talk with them and we have helped them with different things. Little by little, they have gotten to know us better.”²⁶¹

Despite the negative reception Huiling has met, the attitudes towards the organisation’s presence appear to change after some time. One of the informants, who have been working in the organisation for two decades, talked about the experience in a school run by Huiling:

“In the beginning when we brought the children out to have a walk, nobody talked with them or wanted to have any contact. Now when we go out for a walk, a lot of people in the neighbourhood give the children sweets and they even come with gifts to the school. The teachers at the school focus on teaching the children politeness, so that they can relate to the neighbours in a normal way.”²⁶²

As I have written above, Huiling’s ‘de-institutionalised’ structure, where the trainees work in one place and live in another, has developed gradually. One consequence of this new structure is that the trainees have to walk or take public transportation between their home and the location of their daytime activity every day. Through this minor event they become visible, each morning passing neighbours on their way to work, and each afternoon returning. This is in Huiling regarded as part of a normalisation-process; the trainees do what everyone else is doing around them. They get a chance to learn about and relate to the complexity of society, and they get to learn practical skills important for increasing independency. One informant, who works as a Family Mother, explains:

“The way Huiling is working is to let the trainees be in contact with the society. That means that the society has to admit them. Now the neighbours here are treating us very well. Everybody knows us and they talk with us when we pass them.”²⁶³

Gradually the trainees have become “normalised” in the neighbourhood, in the sense that for example seeing them walking on the street, no longer is an “abnormal” sight, or perceived as unheard of. The trainees have not only been visible in the local neighbourhood; with regular excursions, Huiling has brought the trainees into arenas where, according to the informants, people with intellectual disabilities not always have been accepted.

²⁶¹ Interview G. (Interview conducted in Chinese, translated to English by me.)

²⁶² Interview B. (Interview conducted in Chinese, translated to English by me.)

²⁶³ Interview L. (Interview conducted in Chinese, translated to English by me.)

“I remember the first time I was with the trainees taking a bus [two years ago]. There was a pregnant woman there. The pregnant woman didn’t say anything about the trainees talking to themselves and these things, she only said “*Oh, no problem, no problem.*” But other people on the bus did, and one man was shouting at us: “*They are sick; they should stay in their homes!*” I was upset. Why did he have to say things like that? Why should people with intellectual disabilities stay in their homes? If I had not been working that day, if I had been one of the other passengers on the bus, I would have asked the man who shouted, what he meant by saying that they should stay at home. I think what he said was really not any good. His opinions made me angry. If *they* shouldn’t be allowed to go out, then *he* shouldn’t be allowed to go out too.”²⁶⁴

I asked all my informants from Huiling what changes they had seen in how people were treating the trainees. The responses I got all reveal that they have met both negative and positive reactions from people when being in public together with the trainees. Looking at the answers though, it appears that there has been a general change in attitudes: from being critical to, to even being positively accepting towards people with intellectual disabilities:

“Sometimes when we are taking the public transportation, there are people who start to chat with the trainees, asking where they are going and these things. They tell us that they think the trainees are doing so well, so nice that they take the bus and get the chance to go and see different places. There was one occasion when we went out, and one of our trainees became very thirsty when we were on the bus. We wanted to wait till we came to a place where the trainee could buy something to drink, but a stranger who had overheard it, offered her own bottle of water to the trainee. I feel very touched when these things happen. Even we, the staff, wouldn’t share the bottle, and then she - the stranger - did it.”²⁶⁵

A tendency in the answers is that the informants noted more negative responses before than now, like these two informants, the first being relatively new to Huiling, having worked in the organisation for about two years, the second being a parent of an adult son with intellectual disability, recount:

“When I started to work here in Huiling [about two years ago] and we went out, people would give us bad looks everywhere. Now it is better. Now when we go out, people will offer the trainees their seat on the bus. That would never happen then.”²⁶⁶

Similarly the parent of a man with intellectual disability has noted a difference:

“Before we would call the people with intellectual disability for *shazi*, meaning that they were very stupid, understanding nothing. When they were going to the

²⁶⁴ Interview G. (Interview conducted in Chinese, translated to English by me.)

²⁶⁵ Interview H. (Interview conducted in Chinese, translated to English by me.)

²⁶⁶ Interview M. (Interview conducted in Chinese, translated to English by me.)

supermarket, they would be denied entrance. Now, when we here in Huiling are going out with the trainees, people treat us very good, helping the trainees, talking with them, show concern for them. When we cross the road, there are people coming to help us. In the shop, there are people who open the doors for us.”²⁶⁷

I can think of two basic reasons why many of the informants reported these changes. One can be that there have become a broader and more general awareness about and openness about intellectual disabilities in the Chinese society. The other explanation can be that it is not the attitudes towards people with intellectual disabilities in general that has changed, but the trainees at Huiling. By getting used to being in the public; being familiar with using public transportation; handling the use of money; having participated in a broad range of activities and having visited many places, the trainees may not stand out as much as and in ways they might have done.

To which extent Huiling has played a role in changing attitudes towards people with intellectual disabilities is difficult to measure. The methods applied though, appear to have a significant degree of influence, due to the stress on making people with intellectual disabilities visible in the society, and on the openness that also includes, as the citation under tells, informing and educating people about intellectual disability. One informant gives this account, about the importance of both these; letting the trainees getting used to be in the public, and also informing those not used to seeing them, about intellectual disability:

“When we bring the trainees out, there may be someone who is not too confident about us. For instance we have a trainee who talks to himself. When we go out and take the bus, people are almost never standing next to him. First they stand next to him, but always after a while they move further and further away. Once, a person next to me asked if he had drunken too much alcohol. I replied that he was one of the trainees at our organisation, that he had an intellectual disability. I told him that he shouldn’t be anxious and explained the reason he did what he did. He then said: ‘*Ah, I see. No problem.*’”²⁶⁸

Another informant, who also is the father of a trainee, explains Huiling’s strategy in letting more people be aware of the service Huiling offers:

²⁶⁷ Interview L. (Interview conducted in Chinese, translated to English by me.)

²⁶⁸ Interview H. (Interview conducted in Chinese, translated to English by me.)

“We bring the trainees out to enjoy various things in the society. People get to see that so many people with intellectual disabilities are out together, and that they are happy.”²⁶⁹

According to the staff at Huiling, they face several challenges with regard to reaching parents. First, in making parents willing to show publicly that their son or daughter has an intellectual disability. Second, in convincing them that being in an organisation like Huiling can increase their son or daughter’s life-quality compared to staying at home. According to one informant at Huiling, whose work partly consists of coordinating contact between Huiling and the families of the trainees, it is a common idea among parents, as well as in the society at large, that people with intellectual disabilities are unable to make any significant progress, and that their needs are simpler than others. This makes many parents unwilling, or in many cases unable, to spend extra resources on letting their son or daughter with intellectual disability use the services offered. A mother of a young man with severe intellectual disabilities who is a trainee in Huiling illustrates the point:

“When I started to have contact with Huiling [in 2000], I did not have the same thoughts as I have today. I only thought that I couldn’t have too high expectations for my son. My son never had the chance to go to school because of his disability. I thought that as long as he eats well and felt happy it would be fine. But now, my hope for him is that he will be able to study more, and that he gets the chance to travel. I want him to be able to communicate with people, because I know he likes to talk.”²⁷⁰

This citation touches upon an issue that my informants in Huiling explained was one of their greatest challenges: to convince parents that their son or daughter with intellectual disability could learn more and most probably would learn more by attending Huiling’s day centre or workshop than by staying at home only. One informant from CDPF notes that the governmental organisation has the same problem: having to convince the parents that their sons and daughters have the ability to learn, and therefore would profit from using the services that are offered. By noticing this, he gives an indication of the predominance these attitudes have in the Chinese society:

“Some parents have stereotypical ideas: Since their children already are disabled, there is no use in sending them to school, or since their children have intellectual disabilities, they would not learn anything. Let them see that there is hope. [...] This way the attitudes will change.”²⁷¹

²⁶⁹ Interview F. (Interview conducted in English, but with a Chinese assistant of the informant translating the questions into Chinese, and translating the answers into English.)

²⁷⁰ Interview L. (Interview conducted in Chinese, translated to English by me.)

²⁷¹ Interview F. (Interview conducted in English, but with a Chinese assistant of the informant translating the

When people have low expectations to what people with intellectual disabilities can do and can learn, it may have an influence on the priority they are given, on how services for them are provided for, and also on who provides for it. It appears to be possible to identify a relationship between expectations to and the degree of provision for people with intellectual disabilities. If the general expectations are low, the responsibility may be narrowly allocated, for instance as involving the family or the individual only. If the general expectations are high, the services offered arguably may be more complex in its content, and also in who is given the responsibilities, involving the family, the society as a whole, the government and other relevant non-governmental forces.

6.3 Conclusion

In this chapter I have discussed the influence Huiling's model may have and are observed to have on the trainees, and on the society. I have looked specifically on the effect the open structure and frequent usage of public space may have, and on the stress placed on the trainees having responsibilities, both in order to make personal progress, but also as a measure for them to be understood as "normal" in the society. This normalisation-strategy goes two ways. One is to make the trainees adapt to the normal. The other is to influence and change what is perceived as normal in the society, to also include people with intellectual disabilities. The trainees have to, whenever possible act properly and respectful - when in public as well as and in private. Huiling is, as discussed in this chapter, working actively, on two fronts: one is to influence people in society – parents included – to accept people with intellectual disabilities; to change the perceptions that may hinder and affect the chances people with intellectual disabilities get to learn, to develop their individual potential and to live more independently in the society. Second, in the direct work with the trainees, Huiling breaks with norms and attitudes, by focusing on them having a complex set of rights, and as we have seen, responsibilities.

Conclusion

In conclusion I would like briefly to highlight three issues. The first relates to Huiling's work with intellectual disability, seen in light of the social and the medical model of disability. The second relates to Huiling's learning strategy, and the third to the organisations relationship with the state and the wider society.

1. How does Huiling fit into the two general ideas of disability, as reflected in the medical and the social model?

The main focus of the social model on disability is on the society, and on how the society has to change so that it can accommodate differences. Stretching it, one may say that the social model is one where it is the society that is blamed for people with intellectual and other disabilities not getting the same possibilities as their non-disabled fellow men. The medical model, on the other hand, has an emphasis on the individual. It aims both at medical treatment of the individual, but also, one may argue, on a more general level, at changing the individual in order to adapt to "normal" society. Both these two models can be understood as challenging in some aspects, if applied too rigid. In the medical model, a challenge is how to broaden the concept of rehabilitation. If only understood as individual medical rehabilitation, the individual with disability may be confined to institutions only. The social model can be understood as challenging too, due to its stress on societal, not individual, changes.

Huiling's model can be seen as a compromising and practical model, where both the medical and social model may be relevant, with some modifications. Huiling appears to have a double objective with its services: One seems to correspond to the social model, as it tries to influence society to accommodate a broader range of people, including people with intellectual disabilities. The other seems to correspond to the medical model, as it tries to influence the trainees, in order for them to better adapt to society. One small example of the first is what I discussed in Chapter 6, about Huiling's use of Family Homes. When neighbours living under the Family Homes complained about the trainees making noise, Huiling responded by moving in to apartments where these specific complaints could be avoided, instead of demanding tolerance and acceptance from the neighbours. There appears to be an idea that changes in the society will come, but come slowly and with Huiling actively and

carefully assisting it. This introduces the second point that I argue may be understood as relating to the medical model: Huiling's stress on the trainees adapting to society. The aim of the organisation is that the trainees learn and develop practical and social skills, so that they can master the environment in an as independent manner as possible. Rehabilitation, which is stressed in the medical model, is then understood in a broader term; not as a medical rehabilitation, but as one where the trainees get to develop various skills, and through them become more independent and more "normal" in the society. Summarised, this may, as I see it, be referred to as Huiling's double normalisation strategy, which includes: First; the trainees adapting to society; and second; expanding society's normality standard. Yoda Hiroe indicates, on a general level, that such a strategy may prove efficient. People with disabilities living independently, she argues, "ensures that society will respect their rights as citizens."²⁷²

In order to increase the trainees' independence in Huiling, the trainees are not only encouraged but also required to do what he/she is capable of doing. The trainees have responsibilities: to act when they can act, to act well and care for others; to follow the rules of the society; and act properly when in public. Taking into consideration their disabilities, they are, at least ideally, treated just like anyone else, not being exempt from basic duties or opportunities because of their disabilities.

Huiling is working in a way that makes sure the trainees are frequently in contact with the society. When Huiling in this thesis is described as open, it is therefore not only in the sense that the organisation has moved away from applying institutional and closed buildings, and in this sense contrast the medical model. It is as much because of the stress on the trainees using the public space. The trainees participate in normal activities in the cities they are situated in on a regular basis. This, if done regularly and persistently, may be an efficient measure against those barriers in the society that affect people with intellectual disabilities' real chances to participate on equal grounds; not due to restraints deriving from their disabilities, but to restraints deriving from attitudes and prejudices on their *perceived* inabilities and traits.

2. *Huiling's learning strategy*

As argued, there have been profound changes in how Huiling is working with and for people with intellectual disabilities since the organisation's founding. These changes have not come

²⁷² Hiroe, 2002: 9

by coincident, but appear to be the result of a chosen and applied learning strategy. First, Huiling can be said to learn from others, including studying how people and organisations in other countries are working with intellectual disability, in order to learn from those with longer experience than themselves. Meng Weina explains:

“Our changes came because we saw that people with intellectual disability were behaving and acting different in other places [abroad]. We continued to study, continued to watch. We asked ourselves; how come they are acting so different? Can people with intellectual disability be so happy?”²⁷³

Second, the staff at Huiling also studies each other; those who have more knowledge than others, or have attained special experiences, being copied. This happens between the departments in one city, but also between the Huiling organisations in various cities. This is regarded, according to my informants, as an efficient system, for at least three reasons. One is that it ensures that the methods that are found suitable are applied in all the departments. Second, it ensures that the staff in the organisation do not lose time, by learning every step, one step at the time, when there is someone who has taken them before them. Third, there appear to be an openness on the organisation’s own shortcomings and faults, which makes it possible to learn from own experience, both mistakes and accomplishments.

3. *Huiling and the state*

When analysing the organisational structure and service model of Huiling, *visibility* is a term that can be used to describe a significant part of the strategy, both with regard to service models and the organisational structure. Relying on the accounts from my informants and my own observations during my almost three years experience living and travelling in different parts of China, it seems plausible to argue that people with intellectual disabilities to a large extent have been, and still are, absent in the public space. Recognition of this appears to have impact on how Huiling has structured its organisation and the strategies it has used aimed at changing attitudes and making people with intellectual disabilities visible. If we look at what effects invisibility, and also visibility of people with intellectual disabilities in the society may have, it becomes possible to see why Huiling is working the way it is. Huiling may be said to be a radical organisation, in a Chinese context at least, because of the efforts taken to make people with intellectual disabilities visible individuals in the Chinese society

²⁷³ Interview I. (Interview conducted in Chinese, translated to English by me.)

In a society where people with intellectual disabilities are staying mostly at home or in institutions that prevent them from having contact with the broader society, and prevent society from having contact with them, they may not represent a “problem” of priority. According to Meng Weina, Huiling’s public approach towards intellectual disability has had effects even on the government. She explains this in an interview:

“If you are not talking about the situation for people with intellectual disabilities, the problems are invisible. Before, when people with intellectual disabilities stayed at home only, there appeared to be no problem. When I went to talk publicly about it, the people from the government considered me as troublesome, instead of saying that they would do something with the problem. After that, when the government saw what we in Huiling did, they felt embarrassed and started to offer services, they too. The society is changing fast now. The government has had many changes in their attitudes towards intellectual disabilities.”²⁷⁴

Whether this description is correct or not, I do not know. Still, the citation may serve as an example of how Huiling considers visibility a successful strategy that can be connected to awareness of and actions to be taken for people with intellectual disabilities. Despite the immediate resistance by the government there was as Meng explains it, no point of return; when someone had introduced a service to people with intellectual disabilities outside the family sphere and in public, neither the government nor any one else could ignore it.

As the accounts of several of the informants reveal, there appear now to be a change in the situation for, and general awareness on people with intellectual disabilities situation in China, and the change appears to be for the better. Still, the challenges that are left, the same informants tell, are many. Some of the methods applied in Huiling may for the reader appear unfamiliar and tough, perhaps in particular the unequal salary-system based on productivity and effort, and the stress, at least ideally, on the individuals having responsibility for own life. Perhaps one way of understanding Huiling’s methods, is as contrasting those challenges that are perceived to be the most important to face and overcome. Then, to use the example of the performance-based salary system again, it can be understood as a public statement; to the trainees, to their families and also to the wider society: that people with intellectual disabilities are not “useless;” that they are not “like children;” that they are not “unable to learn” and “unable to make progress;” that they do not need to depend entirely on others; and

²⁷⁴ Interview O. (Interview conducted in Chinese, translated to English by me.)

that they ought to be treated like others, not excluded or in other ways being denied access to an independent life, as citizens.

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APPENDIX

The Marriage Law of the People's Republic of China (1980/2001)

Article 7

Marriage shall be prohibited in any of the following circumstances:

- a. if the man and the woman are lineal relatives by blood or collateral relatives by blood up to the third degree of kinship;
- b. if either the man or the woman is suffering from any disease that is regarded by medical science as rendering a person unfit for marriage.

Article 8

The man and woman who apply for marriage shall go to the marriage registration authority in person to get registered. If they meet the requirements of this law, they shall be registered and be given a certificate of marriage. The obtaining of a certificate of marriage means the establishment of the relationship of husband and wife. Those who live as husband and wife without registration shall go through remedial registration procedures.

Article 9

Having gone through the registration procedures, the woman may become a member of the family of the man and the man may also become a member of the family of the woman, whatever is agreed upon by both parties.

Article 10

If any of the following circumstances occurs, the marriage shall be invalid:

- a. if either party is a bigamist;
- b. if both parties are in the kinship that is forbidden from getting married by law;
- c. if any party has suffered from any disease that is held by medical science as rendering a person unfit for getting married and the disease has not been cured after marriage;
- d. if any party has not come up to the legitimate age for marriage.

Article 20

Husband and wife shall be under the obligation of supporting each other. Where either party fails to perform the obligation of supporting the other party, the party that needs support shall be entitled to ask the other party to pay aliments.

Article 21

Parents shall be under the obligation of upbringing and educating their children, and the children shall also be under the obligation of supporting their parents. Where the parents fail to perform their obligations, the underage children and the children without the ability to live an independent life shall be entitled to ask their parents to pay aliments.

Where any child fails to perform his or her obligations, the parents thereof who are unable to work or who are living a difficult life shall be entitled to ask their child to pay aliments.

It shall be forbidden to drown or desert infants or commit any kind of infanticide.

Article 28

Capable grandparents and maternal grandparents shall be under the obligation of upbringing the grandchildren and maternal grandchildren whose parents have deceased or are incapable of upbringing their underage children. Capable grandchildren and maternal grandchildren shall be under the obligation of supporting the grandparents and maternal grandparents whose children have deceased or whose children are incapable of supporting them.

Article 29

Capable elder brothers and sisters shall be under the obligation of supporting their younger brothers and sisters whose parents have deceased or whose parents are incapable of supporting them. The younger brothers and sisters who have been brought up by the elder brothers and sisters shall be under the obligation of supporting their elder brothers and sisters who are without labor capabilities and without sources of living aliments.

(Official English version available online at the webpage of the National Working Committee on Children and Women under the State Council: <http://www.nwccw.gov.cn/html/41/n-140641.html> (Accessed 07.05.09))

Law of the Peoples Republic of China on Maternal and Infant Health Care (1995)

Article 8.

Pre-marital medical examination shall include the examination of the following diseases:

- (1) genetic diseases of a serious nature;
- (2) target infectious diseases; and
- (3) relevant mental diseases.

After pre-marital medical examination, the medical and health institution shall issue a certificate of pre-marital medical examination.

Article 10.

After pre-marital medical examination, physicians shall, in respect of the male or female who has been diagnosed with certain genetic disease of a serious nature which is considered to be inappropriate for child-bearing from a medical point of view, explain the situations and give medical advice to both the male and the female; those who, with the consent of both the male and the female, after taking long-term contraceptive measures or performance of ligation operations, are unable to bear children may get married. However, the circumstances under which marriage may not be contracted under the Marriage Law of the People's Republic of China shall be accepted.

Article 16.

If a physician detects or suspects that a married couple in their child-bearing age suffer from genetic disease of a serious nature, the physician shall give them medical advice, according to which the said couple shall take corresponding measures.

Article 18.

If one of the following cases is detected in the pre-natal diagnosis, the physician shall explain the situations to the married couple and give them medical advice on a termination of gestation:

- (1) The fetus is suffering from a genetic disease of a serious nature;
- (2) The fetus is with a defect of a serious nature; or
- (3) Continued gestation may jeopardize the safety of life of the pregnant woman or seriously impair her health, due to the serious disease she suffers from.

(Available online at the webpage of United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP):

*http://www.unescap.org/esid/psis/population/database/poplaws/law_china/ch_record006.htm
(Accessed 12.12.08))*

Summary

According to the latest official survey (2005) there are 5.54 million people with intellectual disabilities in China. The large majority of these are still confined to the home, depending on their families for any needed assistance. One of the organisations that *do* provide services for people with intellectual disabilities is Huiling. Huiling is a Chinese non-governmental organisation currently operating in twelve cities all over the country. When founded in 1985, it was the first organisation offering services to people with intellectual disabilities in China. The two questions discussed are: First, who has responsibility for the welfare of people with intellectual disabilities in China? Second, what are the general and more specific strategies Huiling is pursuing in the organisation's work with and for people with intellectual disabilities? The short answer to the first question is the family, yet there has been some changes in the last two decades that may indicate there is an increased awareness on disability-issues in China, and as a result the government is offering more services to people with intellectual disabilities, and is also opening up for more non-governmental organisations to do the same. The short answer to the second question is that Huiling, from starting out as provider of care in the form of covering the most basic needs, like eating and a place to sleep, has developed and now works towards the more ambitious goal that "persons with intellectual disabilities should have the same rights as others." The organisation now works actively, and with several approaches, towards giving people with intellectual disabilities a more visible and independent role in society. Huiling can be said to have a double objective with its services: On one side it tries to influence society to accommodate people with intellectual disabilities. This is primarily achieved through the organisation's stress on an active use of the public space, and through what may be called a "deinstitutionalised" service model. On the other side, it tries to influence and train people with intellectual disabilities, in order for them to better adapt *to* society. In this regard, the organization not only stress each individuals equal rights, but also the responsibility to do ones best, relating to work, relations to others and self development.