

God's children in China

A study of children with disabilities in the Qing Chen orphanage in Mayun County

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Master Children's Rights

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Chapter 1

Introduction

For my master's study of Children's Rights I had the opportunity to conduct this master's research in an orphanage for children with disabilities in a province northeast of China. My interest in children's rights issues, my previous specialization in children with disabilities and my working experience with disabled children made me want to focus on the position of children with disabilities in a non-Western country. In Western countries families of children with disabilities get financial support from the government. Disabled children get the chance to develop within their abilities with the help of physiotherapists, speech therapists, behavioural therapists, music therapists and so on. More and more emphasis is placed on giving people with disabilities the chance to integrate into society.

To me China sounded exotic and exciting. China is known as a big upcoming economic power with a culture quite different from the West. I wondered how disabled children in China live their lives, how people think about disability and what policies are there to support children with disabilities.

1.1 Problem statement

According to Ingstad & Reynolds Whyte (1995) a society reveals itself in the way it handles certain important phenomena. Disability is one such phenomenon. Societal attitudes towards children with a disability affect the child's self-concept, motivation, social skills and adjustment. The cause and meaning of the disability is communicated to the child and influences his or her experiences and the life roles that he or she is expected to achieve (Westbrook Legge & Pennay, 1993).

There are 2 billion children in the world of which 100 million are disabled. According to the Convention on the Rights of the Child all children should have equal access to education, medical care and treatment, and practical support. Children have the right to life and the right to express their views freely on all matters of concern to them. These rights most certainly also count for children

with disabilities (Lansdown, 1998). However, statistics from several UN agencies indicate that in many developing countries 90% of children with a disability will not survive beyond 20 years of age, 90% of children with an intellectual disability do not survive beyond 5 years of age, and only 3% get education beyond the basic minimum. According to Lansdown (1998) many children with disabilities are living in institutions. Disabled children have been excluded from society throughout history, and indeed in many societies still are denied access to education, family life, adequate health care, opportunities for play or work, and the right to participate. Furthermore, this group of children are most vulnerable to abuse and neglect by adults who are responsible for them and least able to stand up for their rights.

According to the written replies to questions posed by the Committee on the Rights of the Child, China has a total of 60 million people with disabilities (Bayefski, 2005). There are 11,696,700 children aged between 0 and 17 accounting for around 20 percent of the total number of disabled people. Among disabled children, 55.5 percent of them are male. The geographical distribution of disabled children is around 18 percent for urban areas and 82 percent for rural areas. Forty-nine thousand children with visual, aural or mental disabilities receive special education. There are 275,000 disabled children of school age who have not yet entered school. However, these numbers are calculated on the basis of the 1987 sample survey of disabled people conducted by the Chinese state. Figures from a more recent national survey indicate that there are nearly 83 million people with disabilities (Chinagate, 2006). The school enrolment rate for disabled children between 6 and 14 years is 63 percent. This means that nearly 900,000 children with a disability do not attend school (Leonard Cheshire Disability, 2006). The statistics make China the country with more individuals with disabilities than any other country in the world (Sonnander & Claesson, 1997).

There is not much in-depth research on the position of children with disabilities in China. China is a rapidly developing country. With regard to square kilometres it is the third largest country in the world, after Russia and Canada. It has 1.2 billion inhabitants, which is 25% of the world's population. Ninety percent of the inhabitants are Han Chinese and live in most of the richer coastal lands and more fertile inland areas; ten percent is made up of cultural minorities, such as

T Tibetans and Mongolians (Lewis, Chong-Lau & Lo, 1997). Especially since the late 1970s when the Chinese government implemented a policy of reform and opening-up, China has experienced rapid economic development. From 1993 to 2000 China had completed nine ‘five-year plans’. The Gross Domestic Product continues to increase with an average of 9.6% per year. However, the downside of the economic growth is a progressively enlarging gap between the relatively rich east- and poor westside of the country (Chunli, 2006). It is not clear whether this development is positive or negative to the position of children with disabilities in China. More research is needed on the position of children with disabilities in this rapidly changing country.

Many factors may influence the position of children with disabilities. Their position may be determined by the way people treat them and think about their future. Cultural factors, like the influence of religion may also affect the way people think about disability. Further, government policies may influence their position in Chinese society. This study explores the influence of all these factors.

1.2 Research questions

This exploratory study is focused on the factors that influence the stakeholders’ perception of the position of children with disabilities in their community. I will focus on the way people perceive disability in general, their thoughts on how children with disabilities are treated, what they expect of the children’s future and what they perceive to be the influence of government policies on children’s lives. The research question I attempt to answer is:

“What are the main policies and explanatory models that are reflected in the stakeholders’ perceptions of the position of children with different disabilities of the Qing Chen orphanage in Mayun County?”

With ‘position’ is meant the status, place, level or rank. Stakeholders are persons with an interest or concern in something. In this case these are the children, staff members, local community members, foster- and adoptive parents and non-governmental organizations (NGOs). Perceptions are concepts, ideas, images or thoughts that exist in the mind and are gained by the process of becoming aware through the senses.

In order to answer the main question the following specific questions will be answered:

1. How do the stakeholders perceive the position of the children with disabilities in the community?
2. How do stakeholders treat the children with disabilities in the community?
3. How do stakeholders perceive the future of children with disabilities in the community?
4. How do population policies and disability policies affect the lives of the children with disabilities in the orphanage?
5. What are the explanatory models of disability according to the stakeholders?
6. What role does Catholicism play in the perception of disability of the stakeholders?
7. What role does eugenics play in the perception of disability of the stakeholders?
8. What role does Confucianism play in the perception of disability of the stakeholders?
9. What other factors play a role in the perception of disability of the stakeholders?

In chapter 2, the theoretical concepts on which this thesis is based and the literature review of possible factors influencing the perceptions will be discussed. Chapter 3 describes the methodologies, which have been used during the study, followed by three empirical chapters. Chapter 4 provides information on the classifications and the explanations of disabilities given by the stakeholders. The focal point in chapter 5 will be on the position of children with disabilities in the orphanage by discussing their daily lives, interaction with others and their perceived future. How government policies affect the lives of children with disabilities will be analyzed in Chapter 6. In Chapter 7 the conclusions and recommendations are given.

Chapter 2

Theoretical framework and literature review

As a preparation to my research I conducted a thorough literature study on several theoretical concepts and factors that are specific to the research topic and Chinese culture and society.

2.1 Theory

The following theoretical concepts are related to the topics of this thesis. First of all I will discuss the theoretical concepts of impairment, disability and handicap and compare the international definitions and the definitions China is using. Then I will discuss the explanatory model of Kleinman with regard to disability.

2.1.1 The concept of impairment, disability and handicap and the explanatory model

It is difficult to specify the concept of impairment, disability and handicap. They are historical and cultural Western constructs and imply stigmas or social inferiority (Ingstad & Reynolds Whyte, 1995:57). According to the World Health Organization (WHO) *impairment* is any loss or abnormality of psychological, physiological or anatomical structure or function. *Disability* refers to limitations resulting from dysfunctions in individual bodies and minds. It is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. A *handicap* is a disadvantage for a given individual resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual. Impairment is related to functions of the body while disability relates to activities of the individual body. Handicap relates to the social consequences of deficiencies of the body (Ibid.:3-6).

In China, a person with disability is officially defined as “a person who has lost all or part of his or her ability to perform normal activities due to loss or impairment of psychological or physiological functions” (JICA, 2002:6). This

definition resembles the definitions used by the WHO. Chinese government distinguishes several types of disabilities, namely visual impairment, hearing and speaking impairment, physical disability, psychiatric disability and intellectual disability. Before 1987, there was no official scientific definition of intellectual disability in China. In 1987, the State Department of China adopted the international definition and standard of intellectual disability (the term 'mental retardation' is more commonly used in China) of the American Association on Mental Retardation (AAMR) (Xu et al., 2005). They define intellectual disability as "a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18" (AAIDD, 2008).

The concepts are based on a biomedical model and the proposed definitions are meant to be universal. However, the meaning of these concepts varies across cultures and is mediated by media, health personnel, development agencies, parents and disabled persons themselves. That is why it is important to study disability in its cultural context (Ibid.:25). Arthur Kleinman uses the term 'explanatory model' for the individual explanation of the nature of illness or impairments, the cause and the appropriate treatment (Ingstad & Reynolds Whyte, 1995:61). Who is labelled as disabled and by what signs, when and for what reason varies across cultures (Ibid.: 59). People can be seen as 'disabled' for several reasons. Ingstad and Reynolds Whyte (1995:53) give several examples from their research in various countries and societies. The Punan Bah, a minor ethnic group in Central Borneo for example, view people as disabled when they are considered witches, are illegitimate children, or adults without offspring. Some *impaired* children are not viewed as *disabled* because people care for them and respect them simply because they are believed to be reborn ancestors.

Research indicates that people in the South are primarily concerned with the cause of impairment. According to the Maasai in Kenya, an impairment can be seen as a projection on the human body of social or cosmic disorder (Ibid.: 61), a fact of life or misfortune (Ibid.: 62), a curse, a result of sorcery (Ibid.: 63) or a consequence of the behaviour of the father or the mother (Ibid.: 64). The Punan Bah believe that some impairments are due to imperfection or absence of one of the souls which a person normally possesses (Ibid.: 46).

In this thesis I will discuss what people label as disability and how they explain and react to disabilities and more specifically to children with disabilities in the orphanage. Factors specific to Chinese culture and society might have a big influence on the explanatory model of disabilities. These factors will be discussed in the next section.

2.2 Background

In the following section I will discuss the potential influencing factors with regard to the explanatory model of disability by illustrating the existing ideologies and religions like Confucianism, Catholicism and eugenics and the current government policies. I will also pay attention the role of NGOs in the area of disability care in China and to the phenomenon of abandonment of children with disabilities.

2.2.1 Confucianism and abnormality

Confucianism is a particular trait often associated with Chinese culture. The basic guidelines of Confucianism are a duty-bound set of obligations of what good people should and should not do. The guidelines also include gender and generation prescriptions. There is a strong patrilineal family structure and women are placed lower in the social hierarchy relative to men (Holroyd, 2003; Zhang, Kao & Hannum, 2007). A central concept of Confucianism is reciprocity. Parents must give to children when they are young, and when these children reach adulthood they must return gifts and services to their parents both during this life and into the afterlife. In addition to this, Chinese children must also respect and obey their parents, particularly their fathers. Women must obey their husbands and younger children their older siblings. It is believed that if family relationships are maintained in the right order, then the state will also be in order. Thus, Confucianism acts as a code for moral conduct that holds both individuals and society in control, brings honour and avoids disgrace to the family name. Confucianism can also elicit fear of unknown consequences and evoke emotions such as shame, blame, and disgust, both personally as well as in public (Holroyd, 2003).

Confucianism has an important influence on the perception of disability by Chinese people. However, as with all ideologies, it is also a matter of

interpretation. Some scholars argue that, historically, abnormality was not necessarily associated with negativity. Popular deities often had abnormal body shapes and facial features. Mythical legendary figures stood out partly due to their strange physical appearance (Xun, 2002). Second, it is argued that Confucius divided the population into nine levels of intelligence. He stated that no one should be denied education. He was convinced that everybody should be taught according to their individual ability and that people with disabilities are one of the responsibilities of society and should be warranted special care (Lewis, Chong-Lau & Lo, 1997). Third, it is argued that any child is likely to be highly valued by a childless couple in China, also a child with a disability. To be childless is considered in Confucian terms a severe deprivation and moral failing and is in Chinese culture socially unacceptable (Johnson, 1993).

Holroyd (2003), who did ethnographic research on Chinese families in Hong Kong who took care of children with disabilities, argues that in the Confucian philosophy an imperfect or diseased body or mind is viewed as incomplete and without moral standing. As a consequence, a disabled child can never become a good person. In advance, parents of children with a disability can never be good parents in the sense that they cannot cultivate their child to full personhood. The regular pattern of reciprocity is undermined. Parents of disabled children fulfil their obligations towards their children while the children are not able to repay their debts. In this way, parents go beyond the demands of mere duty and the care of children with a handicap strains and violates the obligations (Holroyd, 2003). Chen and Simeonsson (1994) who conducted a survey under 101 Chinese families with disabled children concluded that handicap is thought to arise from something that the women or her side of the family has done. Chinese people regard the cause of disability as a punishment from ancestors or deities or bad physical and moral qualities of the mother that negatively affected the foetal development. As a consequence, families with disabled children feel embarrassment, guilt and shame (Holroyd, 2003). The feeling of shame is especially prominent in parents with limited education as they are generally more convinced of the traditional assumptions with regard to the cause of disability (Chen & Simeonsson, 1994). Kleinman and Kleinman (1991) conclude from their ethnographic research in China that if it is clear that a child is disabled from birth onwards, mothers claim responsibility. However, if the disability occurred in the

period after birth the weight of blame is even heavier. The birth of a disabled child can be attributed to misfortune or course of fate whereas mothers have more control over events occurring after birth. Yet, whenever the onset, social messages of blame and shame remain.

2.2.2 Catholicism

Christian missionaries play an important role in the care for both disabled and abandoned Chinese children. They exported Christian concepts of disability and impairment (Stone, 1996). In Christianity disabled persons are viewed as pitiable, vulnerable, resourceless persons in need of help (Ingstad & Reynolds Whyte, 1995, 284). It is a religious duty to show mercy towards them (Ibid.: 87). The foundation for the Christian duty to care for abandoned children can also be found in a Psalm from the Old Testament (Lehmann, 2007): *Even if my father and mother abandoned me, the Lord would take me in (Psalm 27:10)*.

It were the Western missionaries who established welfare institutions in Republican China (Stone, 1996). British and American missionaries in the second half of the 19th century were involved in the initiation of the first modern educational services for young disabled people in China (Lewis, Chong-Lau & Lo, 1997). Special education remained largely organized by religious and charity groups. The welfare institutions were subsequently taken over by the State after the Liberation in 1949 who also adopted the concept of special schools for the education of disabled children. However, the government discouraged the role of religious and charity groups ((Stone, 1996; Lewis, Chong-Lau & Lo, 1997).

The Catholic population in China is estimated at 12 million. There are 110 dioceses, over 6000 Catholic churches, 136 bishops, over 3000 priests and more than 5000 Sisters. Still, Catholics in China only account for 1% of the total Chinese population. For the most part they are poor and uneducated people, mostly concentrated in rural areas. Since 1982, China has the freedom of religious beliefs (Maheu, 2005). The Chinese government approves of five institutional religions: Protestant Christianity, Catholicism, Islam, Buddhism and Daoism. The freedom of religious beliefs is referring to believers of these five religions only (Cheng, 2003). However, a political organization set up by the Communist Party monitors and directs the activities of the approved religions. Eighteen Catholic bishops are in some form of detention. Places of worship need to be registered

according to government regulations. Still, forty-eight Catholic bishops are active in the ‘underground’ or ‘house churches’. These churches are unregistered which makes them illegal and subject to closure and repression (Cheng, 2003; Maheu, 2005). The so-called ‘house churches’ do not necessarily worship in private homes. Some underground churches are relatively large and organized, and may perform worship activities in large buildings or halls. The ideology of the house churches in China is the maintenance of non-interference by the state towards the expression of religious faith. The government is not opposed to religious belief per se, but the possible imperialistic influences connected to Western religions (Cheng, 2003). Catholicism is especially considered a threat by the Chinese authorities because of the assumed involvement of John Paul II in the toppling of Communism in Eastern Europe (Maheu, 2005).

2.2.3 Population policies: Eugenics and the one-child policy

In order to understand the development in Chinese policies related to control over the population one needs to know the political history of China. I added a timeline that can be found in Appendix A in order to make it possible for the reader to contextualize the development of the policies.

Eugenics

Some authors state that eugenics was a European idea introduced in China towards the end of the 19th century as a reaction to the perceived Western superiority in the areas of military, medicine, science and industry. Low birth defect rates were deemed characteristic of development (Stone, 1996). However, Xun (2002) states that eugenic ideas already began to develop in the second century. Some well-educated people in that time perceived people with abnormal physical features as outsiders of the Chinese society, non-Chinese, low, not worthy of attention and a burden of society. Physical and mental disability became a topic worthy of investigation in the period of the Qing reformers. They believed that the wealth and power of the nation were based on the physical strength of its people. Control over the population’s reproduction was seen as a key to a strong nation. Without control the nation was believed to degenerate.

In Republican China (1911-1949) the focus was on ‘science’ (Xun, 2002). Health was said to be determined by the individual’s own actions. For example, it

was claimed that drinking before sexual intercourse could lead to disabled children since it reduced sperm count during the act. The causes of malformation were attributed solely to physical factors. As a consequence, disfigured persons became cases of pathology for medical scientist. The impaired people became the symbolic representation of the racial degeneration of the Chinese nation. They were at the bottom of the social hierarchy. In order to build a strong healthy population, China introduced the policy of selective breeding. Medical scientists attributed causes of ‘defects’ as having a hereditary basis. As a consequence, some people were proposed for sterilization, castration or exile. In 1941, the Ministry of Social Affairs founded the Committee for the Study of Population Policies. They recommended the segregation of physically and mentally disabled persons from normal population and encouraged sterilization. The main target were those being defined as being of the lowest intelligence.

With the arrival of a one-party state in 1949 the desire for control over individual bodies for the sake of the nation’s future only became stronger. However, during the period under Mao (until his death in 1976), class-biased eugenics was officially condemned. Normality and abnormality in that period were measured according to whether a person was born ‘red’ or ‘white’¹ (Xun, 2002).

In 1989 the government under Deng Xiaoping adopted eugenic regulations. In the first 18 months after the adoption of these regulations the provincial officials of Sichuan and Gansu reported the sterilization of 260.000 adults with mental disorders. Another eugenics law was written in 1993 but reformulated in order to meet internationally acceptable criteria. This Law on Maternal and Infant Health Care came into force in 1994. The law states that people with impairments may marry and have children, as long as there is no risk that their children will be born with impairments. When any impairment is detected in a foetus, abortion is strongly advised. A second try at having a baby is permitted as long as there is no indication of hereditary congenital impairments in the family (Stone, 1996).

¹ Red is the colour of Communism and white is the colour of capitalism.

One-child policy

In the mid-1950s the Chinese government started the family planning programme for population control. It was acknowledged that the size of the population would become a crisis and justified the restriction of individual reproductive rights in order to guarantee the quality of life of future generations (Stone, 1996). During the 1950s and 1960s the government focused primarily on the urban regions in the form of education. During the Great Leap Forward and the Cultural Revolution the family planning was interrupted and continued not earlier than in the 1970s. During this time the “Later, Sparser, Fewer” policy was implemented into provincial family planning work. Goal of this policy was to promote late marriage in the rural areas, which was defined as 25 years for men and 23 years for women. A fixed birth interval of four years or over was introduced. First, the government encouraged couples to limit their families to two children. By the late 1970s, one child or at most two was preferred. Education and propaganda were used to promote these ideas. In 1979 the one-child policy was introduced together with an award and penalty system. For example, a couple that had only one child would be awarded with a cash equivalent of 7 to 10% of the value of an average labourer’s annual income. For a couple with extra births, a penalty of the same amount would be imposed. There were also marriage and maternity leaves for parents with late marriages and late childbirths and they would get priority in the distribution of housing plots, their children’s education and health care. In other cases a ‘double contract’ system was used. Under this system peasants delivered grain quotas to the collective and limited their reproduction in order to have the right to farm a given area of land. This system could be expanded in the sense that a whole cadre was awarded or punished on the basis of their individual economic and family planning work (Zhang, 2001). Family planning work was accompanied by measures as IUD insertion, abortion and male and female sterilization (Johnson, 1993; Zhang, 2001). However, the strictness of the implementation of formal family planning programs differed across the country. In certain areas the monitoring was less strict than in other areas or it was allowed to have more children (Xizhe, 2004; Zhang, 2001). Also, the local people found loopholes to prevent punishment. For example, couples claimed their biological child to be an adopted child or hid their children with families or friends in neighbouring villages in order to avoid fees (Zhang, 2001).

However, family planning policy turned out to have negative consequences. An abnormal sex ratio at birth is linked to China's one-child policy. The primary cause is parents favouring boys. Parents want at least one son to carry on the family name because of a traditional notion that a son contributes to the family's income and cares for parents in old age, while daughters leave the house and take care of their husbands and parents-in-law (Andrew, 2007). Couples use sex-selective abortion or abandon healthy or disabled girls. In this way, the policy has produced a greater likelihood of an institutionalized existence for girls, especially those who are born imperfect (Johnson, 1993).

2.2.4 Disability policy

Since the 1950s the Chinese government has made provisions for people with impairments. They were divided in two categories: heroes and orphans. The disabled heroes were people who became disabled in national military service or during work in factories and mines. They are viewed as people who had already made a contribution to Chinese society and were entitled to benefits and employment. Provision from the state for children with disabilities was more limited. The State expected support from the (grand)parents and the wider kinship of the child. In the case of abandonment a child was placed in a welfare institution. However, the main source of support remains the family and the number of welfare institutions is with approximately 860 institutions in a land of 1.25 billion people miniscule (Stone, 1996).

Since the 1980s there is an intensification of government interest in disabled people's lives. In this period the government for the first time addressed the issue of scarce economic resources for families with disabled members. It also included improvement of care for the handicapped (Xun, 2002). In 1987 a first national sampling survey of disabled people was conducted. Disability policy became officially integrated into national, social and economic development planning (Stone, 1996). The Ministry of Civil Affairs, Education, Public Health, Labour and Social Security and Construction are actively involved in disability policies. All other ministries are also members of the National Coordination Committee of Disability (Fisher & Jing, 2008). An annual national day for disabled people was inaugurated. Further, awareness campaigns were being conducted. Another important event is the adoption of the Law on the Protection

of Disabled Persons in 1990. A disabled people's organization, the China Disabled Persons' Federation, who is responsible for the social policy affecting disabled people, was involved in the drafting of this law. The law states that disabled persons should have equal rights in the areas of employment, rehabilitation, education, culture, legal rights, environmental access and urban designs, and welfare. The responsibility for fulfilling the rights of disabled people lies both with the government and society (Stone, 1996). In 1996 the State adopted a five-year plan to improve the quality of life of persons with disabilities and the quality of rehabilitation, formal education, employment and construction of regional facilities. In 2001 they started another five-year plan aimed at the strengthening of projects for persons with disabilities and support for rehabilitation, school entrance and employment support, as well as preparation for social participation (JICA, 2002). The involvement of international and non-governmental organizations (NGO's) influenced these changes in Chinese policy. They adopted the three pillars used by international organizations concerned with disability issues, namely integration, rehabilitation and prevention.

China shows also increased involvement in the international discourse on disability. China was involved in the International Year of Disabled People in 1981 and the subsequent United Nations Decade of Disabled Persons (1982-1992) (Stone, 1996). In August, 2008 they ratified the UN Convention on the Rights of Persons with Disabilities (United Nations, 2008).

However, research by Fisher and Jing (2008) identified a gap between policy and practice. The responsibility of the society and the government towards people with disabilities is to provide structural conditions for their social and economic progress. The government is only expected to provide support in the absence of family support. As a consequence disabled people are more likely to be socially excluded from Chinese society. There is a higher rate of poverty among disabled people (one sixth of disabled people) and there is a high number of disabled people who are homeless. Families bear great responsibility for their disabled children and do not receive formal support to fulfil this responsibility. Even if children are entitled to social welfare benefits they might not receive this because of financial difficulties or other priorities of the responsible local government (Shang, Wu & Wu, 2005).

2.2.5 Welfare provision

China is a developing country and has only limited resources to invest in welfare provision for its people. The system is characterized by a minimal role of the state with an emphasis on the responsibility of the family and rural-urban differences (Shang & Wu, 2003; Shang, Wu & Wu, 2005). Children are the responsibility of the family so have no right to social security or public health provision (Shang & Wu, 2003). The welfare institutes are run by the state. Services provided by the government are only available to registered urban residents. People who are registered urban residents and have no other means of support are entitled to minimum living security benefits and care service provided by welfare institutes. It does not include assistance with housing, medical services or education (Shang, Wu & Wu, 2005; Fisher & Jing, 2008). Benefits, such as pension, housing and health care are offered exclusively to employees working in the public sector (Lu, 2003). The local and provincial government are usually responsible for administering and funding government assistance. Policies are usually not formulated in a precise form and this leaves much room for local governors to interpret and implement the policies according to local situations. As a consequence, the amount of government support is dependent on local resources and capacity (Lu, 2003; Fisher & Jing, 2008).

2.2.6 The role of NGOs

As stated before, Chinese policy has been influenced by non-governmental organizations. NGOs, individuals, private enterprises and churches responded to the perceived social demand for services for vulnerable people (Shang, Wu & Wu, 2005). However, the development of the NGO-sector is rudimentary. The NGOs active in the disability sector are mainly international and view disabled people as victims of circumstance who deserve pity. There are few local initiatives and self-advocacy (Fisher & Jing, 2008). Non-governmental organisations in China face many challenges. First, it is not easy for NGOs to register due to the Tiananmen incident in 1989 (Shang, Wu & Wu, 2005) and the *Falun Gong* incident² in 1999. The incidents reminded the government that it had not maintained strict control

² In 1999 *Falun Gong*, a religious group in China, surrounded the headquarters of the central government with 10,000 of its followers to demand official legalization. As a result, they were banned as an 'evil cult' (Yang, 2006).

over the activities of non-governmental organizations so it tightened its registration and supervision of all NGOs active in China. Since there already is an organization that represents the interest of disabled people (the Disabled Persons' Federation) it is unlikely for other NGOs to be allowed to register (Lu, 2003). Further, according to Chinese law, it is illegal for NGOs to start children's welfare homes (Shang, Wu & Wu, 2005). Another problem is that there is no institutionalized funding for NGOs from the government. The government has no obligation to support NGOs so they cannot demand any assistance from the government. Donations are primarily given by corporations and not by individuals. The corporations usually give donations to state-backed funds instead of small NGOs because these funds can offer more publicity opportunities for the corporations and are thus more attractive. Because of the small amount of donations the NGOs raise it is unlikely that they will be able to offer high-quality services. They are often not able to attract highly-trained and experienced professionals because they cannot offer the salaries and social security provisions that can be found in the public sector (Lu, 2003).

Yet, there are ways in which NGOs can still play a role. It is often beyond the capability of a local government to support all the vulnerable people. What often happens is that the local government turns a blind eye to the illegal NGOs and let them continue to do their work (Shang, Wu & Wu, 2005). NGOs can also build good relationships with officials from government in order to obtain some favours. And in order to get personnel they often hire migrants from small cities or rural areas in the poorer regions and train them on the job (Lu, 2003).

2.2.7 The abandonment of children

The abandonment of newborn babies was a well-known phenomenon in the European past. It is estimated that in the ancient Roman world up to 40% of all urban babies were abandoned at birth. In the 19th century in some of the major cities over a third of newborn babies were abandoned. Already since the 13th century the problem of abandonment was taken seriously and a system of institutionalized foundling homes was developed across Europe. The main reason to help the abandoned children was the concern for their lives and for the fate the dying babies were awaiting while not being baptized (Kertzer, Koball & White, 1997).

Also in China, abandonment is a longstanding phenomenon. It is not more widespread in China historically than in other Western societies (Johnson, 1993). Research indicates that there is a general link between extreme poverty and cases of abandonment. When poor families had too many children to support they would abandon their children. Children born to unwed women and babies with disabilities were also often abandoned. Most parents who abandoned their children had the hope that others would take care of the child. A striking difference between abandonment in Europe and in China is that in China mostly female children would be abandoned whereas in Europe sex made no difference. Since 1949 however, the abandonment of children has declined dramatically. This is mainly due to the improved standard of living of Chinese families (Zhang, 2001). Yet, statistics indicate that the number of abandoned children increased at the end of the 1970. It is suspected that there is a strong relation between this trend and the intensification of family planning campaigns that allows parents only a restricted number of children. Mothers will abandon their girl daughters more often to get the chance to give birth to a son without being punished by the family planning regulations (Johnson, 1993; Zhang, 2001). However, for an urban resident it is very difficult to abandon a child without being detected and punished. Yet there are some cases of 'guerrilla pregnancies' where a pregnant woman leaves her village and goes to live with friends or relatives to give birth. When it is a girl or a disabled child she can abandon it without the chance of being detected and can return to her village in order to get a chance to give birth to a healthy son. Nowadays, it is still the case that nearly all infants found in orphanages are females. Most of the boys that are found are severely disabled (Johnson, 1993).

Adoption and fostering are the two main ways to provide alternative care to abandoned children. Foster families take care of children for a certain period whereas adoption families will practically take care of the child forever. Children with a disability have little chance of being adopted. They may live on welfare for their entire lifetime (Johnson, 1993; Shang & Wu, 2003; Fisher & Jing, 2008). However, Johnson (1993) found in her research that according to orphanage documents disabled children were being adopted in the 1960s and 1970s. The Chinese government changed the Adoption Law in 1992 in order to make it possible for couples that already had a child to adopt a handicapped child,

whereas in the past it was required that a couple be childless in order to adopt any child. International adoptive parents are more likely to accept disabled children than domestic parents (Shang, Wu & Wu, 2005).

Foster care used to be one of the most controversial policy issues in the field of child protection in China. The Communist ideology emphasizes collective values and loyalty to the party. Abandoned children were regarded as *dang haizi*, which means ‘children of the state’. They were the manifestation of the superiority of the socialist country as they rely solely on government resources. They were given the surname ‘Dang’ which means ‘the party’. It was regarded that raising them in a state-run collective welfare institution was a better way to care for these children than to place them in a foster family. However, research of Shang and Wu (2003) shows that because of financial constraints a welfare institute in Datong on a large scale replaced institutional care by foster care. Foster parents in that area were willing to foster children with disabilities.

2.3 Summary

China has officially adopted the Western definitions of disability. Despite the Western definitions of disability Chinese people have a distinct explanatory model. This model is influenced by Confucianism, Christianity and eugenics. In Confucianism disability can be interpreted both positively and negatively. ‘Abnormal’ bodies can both be viewed as either divine or as a punishment from ancestors or deities. It is often the mother who has to deal with feelings of guilt and shame when she gives birth to a child with a disability.

Christian missionaries have also exported their concepts of disability into China. According to their view disabled persons are vulnerable and in need of care. It is seen as a duty to care for these people. As a consequence, welfare institutions and special schools for disabled and abandoned children have been founded by Christians. Although nowadays the Christians, or more specific, the Catholic church accounts for only 1% of the population and the Chinese government can sometimes be called repressive towards Catholics, their influence should not be underestimated.

The ideas derived from eugenics probably have existed in China already since the second century. In order to become a strong and powerful nation reproduction were to be closely monitored. Whenever possible should the birth of

a person with any disability or impairment be prevented because this person would only be a burden to society and a sign of the degeneration of the Chinese race. Eugenic ideas have been translated into national policy. Although policies nowadays have been adapted to the criteria of the international community, China is still very active in the prevention of impairments and disabilities.

Another policy that influences the position of disabled children is the one-child policy. As well as the belief that disabled people decrease the development of the nation, so is high population growth also perceived as a problem. Although the implementation of the policy greatly differs between the counties, the negative consequence of this policy is, among others, the abandonment of disabled children and girls. Although abandonment is not a new phenomenon in Chinese society there is a clear link between the increase of abandonment and the implementation of this policy.

There is an increasing interest of the government in the lives of disabled people. Several policies have been introduced aimed at the improvement of lives of disabled people. Although the way the Chinese government implements certain ideas into policy differs from the international (Western) community it is noticeable that the Chinese government has been influenced by international organizations concerned with disability issues. The international discourse of integration, rehabilitation and prevention is also implemented in Chinese national policies. However, research indicates that there is a gap between policy and practice. Many disabled people are still being disadvantaged. The ability of non-governmental organizations to provide services to people with disabilities is constrained mainly by legislative factors.

This research explores how all these potential factors influence the explanatory model of disability and the position of children with disabilities in the orphanage in a poor province in China.

Chapter 3

Methodology

3.1 Introduction

This research is founded on the constructivist epistemology. According to the constructivist view, there is no objective truth, but meaning is constructed by interaction between people and the engagement with the realities in our world. This means that all people construct meaning differently (Crotty, 1998). The related theoretical perspective is symbolic interactionism within interpretivism, since the central notions of this perspective are that the world and cultures need to be explored and interaction takes place by interpretation and meaning-making (Gray, 2004). The best way to do this, according to symbolic interactionism, is by role taking (Crotty, 1998). This methodology is called ethnography and means that you put yourself in the place of the other and see the situation like the actor sees it, in order to understand the interaction between people and their environment. Since in my research I aim to understand the perceptions of the stakeholders, which are formed by the culture and society in which they live, I am convinced that ethnography is the most appropriate methodology.

The data collection took place over a period of three months, starting in February 2009 and finishing in May 2009.

3.2 The important role of the interpreter

It was my first time to come to China and I did not speak nor understand a word of Chinese. Thus, the first thing I needed before I could do research was an interpreter. In the past the orphanage received groups of Dutch people who came to do volunteer work. The volunteer organization that sends them laid contact with some students in Xi'an who studied English. They functioned as interpreters for the Dutch people. Before I came to China one of the former interpreters managed to find a fellow student willing to help me. His English name was Reggie. He just finished his bachelor in English and had no experience as an interpreter. He also did not have any experiences with disabled children. As a consequence I was concerned whether it would all work out. However, as I during my stay in China, grew in my role as researcher Reggie surely grew in his role as

interpreter. Within several days he bonded with both the children, who adored him, and the Sisters and staff members who gradually became more open to us. Everyone seemed to like him and this made our research job much easier. In this fieldwork period Reggie became so attached to the Sisters and children of the orphanage that he decided to come back to the orphanage and spent another month there to volunteer.

Reggie was almost always by my side during my fieldwork period. We travelled together, he spent the days together with me in the orphanage, we ate together and he slept in the room next to me in the Catholic eyeclinic not far from the orphanage.

During interviews and conversations he directly translated in English what had been said to me. We also tape-recorded the interviews for a second and more precise translation. We did this together whereby he would translate every sentence from the tape-recorder and I would type it down. As we gained more experience the translation became more precise.

Reggie was not only there to translate the Chinese language but sometimes it was also necessary to explain Chinese culture to me. He could explain why people acted in a certain way, how I was supposed to behave to prevent people from being offended or to give me more background information on topics concerning my research. We had discussions about many things concerning China and through him I could better understand this 'strange' world I was living in.

3.3 Study locations

During the fieldwork I collected much information of which some is sensitive. That is why I have chosen not to mention the exact locations where I conducted my fieldwork and used fictive names.

The data were mainly collected in the county where the orphanage was located but I visited other Chinese cities to gather more information. The county has around 300.000 inhabitants. The main economic activities are farming and running small businesses. There are only few factories. One of the factories that produced garments had to close its doors because of the economic recession. The county is located in a province south of the capital city Beijing and is known for its coal industry. The province is relatively poor, very dusty and pollution is a serious problem.

In 1996 Father Chen and the Sisters started to take care of disabled children who were abandoned near the church. The children were taken care of in the convent where the Sisters lived. In 2007 the orphanage moved to a nearby county where it received legal status. Every day I arrived at the orphanage by bus. The orphanage is located at a road at the boarder of two cities. It is a rectangular two-levelled building. Like most buildings it has barred windows to prevent burglary. The windows on the ground floor are covered with adhesive plastic, maybe to prevent people from looking inside. At first sight you cannot see that it is an orphanage. Behind the building there is a large wasteland. Next to the orphanage is a motorcycle distribution centre. Across the street there is a village and a small supermarket. A regular bus line connects the two cities and passes the orphanage.

In order to give the reader an idea about how the orphanage looks like I will give a description of the different rooms. When you enter the orphanage you will come into the so-called 'big room' or 'activity room'. This is one of the two rooms where the children and staff members generally spend their days. The activity room has a television, two big green chairs, playpens, several chamber pots, a wooden seat and a mattress in the middle of the room. The baby buggies are parked along the wall. In the other room, known as the 'small room' is a table where the children's diapers are changed. There is also a green couch and a desk. During the research period they refurnished the room and placed pink bedsteads for the babies, which I helped painting, in this room. They also placed a bed in the room for the staff member who worked at night.

The ground floor also has a storage room, a bedroom for children, a kitchen and a dining room. The bedroom is filled with closets containing the children's clothes and wooden beds that, like most beds in the area, do not have mattresses. Every child has its own bed with a written nametag on it. In the kitchen the food for the children, Sisters and staff members is prepared on a coal stove. Two women in their thirties are always busy making the dough for steamed bread, dumplings or noodles and cutting vegetables. When the food is finished it is placed at a serving hatch where it can be dished up by the Sisters and staff members.

The dining room contains normal-height tables and small tables and chairs where everyone has their meals. There is a special cupboard where the bowls,

plates and chopsticks are placed after being washed and are automatically sterilized at the end of the day. The walls of the dining room contain Catholic images of an angel, two pigeons and two hands that hold bread and fish. The paintings, who already begin to flake, were made by a group of Dutch volunteers who visited the orphanage in 2007.

Then there is a room which was initially both a storage space and a room for a staff member and a child. Later they changed the room into a rehabilitation room. They placed a fresh painted blue table with blue chairs in the room along with a blue and pink-coloured cupboard filled with cuddly toys. There are also several rehabilitation devices like the walking frame and a massage table. The white walls are painted with colourful animals; the famous Dutch rabbit from a picture book called ‘Miffy’ and figures from the famous French cartoon “Barbapapa”.

There are also two bathrooms located next to the narrow hallway leading from the activity room to the small room, one with a shower and the other with a squat toilet and two western-style children’s toilets. This room, however, was never used. The washing room contains two washing machines and is only accessible from the outside.

If we go outside and take the stairs we arrive at the first floor. This floor is mainly the area of the Sisters. Their bedrooms are located on this floor. There is a big living room that functions as both an office and a place where they receive guests. On Sundays this is the place where the Holy Mass is being held. There is a television, a desk, a computer and a sitting area. Two doors in the office lead to two bedrooms that were sometimes used by guests. One of the bedrooms was mine during the week that I stayed in the orphanage. The rest of the time I stayed in the Catholic eyeclinic not far from the orphanage. The office and bedrooms have a rack with a basket, some soap and a small towel. Next to it there is a bucket filled with hot water and a big bucket filled with cold water. This is used to wash the face in the morning and feet in the evening or to wash hands.

The second room at the first floor consists of one bedroom and one classroom. There is a low table with small seats for the children. On the wall you will find papers with Chinese characters, *pinyin*³, numbers from one till hundred

³ *Pinyin* is the ‘translation’ of Chinese characters into Latin alphabet. It is used to teach Chinese children the standard pronunciation of Mandarin Chinese.

and the study programs for some of the boys of the orphanage. There was also a television. Later the television was moved out of the room and the class was moved downstairs into the rehabilitation room. Outside of the room is a cupboard filled with teaching material and drawing materials, mostly never used.

There is also one bedroom for children and a staff member. Next to it there is a room with toilets and a washing machine. The walls upstairs do not have wallpaper and the floors are not carpeted. Along the rooms on the outside there is a walkway with at both ends stairs leading downstairs.

When we go back downstairs we will see that at the back of the orphanage there is a small shed where one of the staff members sleeps. He fulfils the role of janitor. Next to this is a coal stove and a pile of coals. There is a long clothesline, most of the time filled with clothes hanging to dry. There is also an improvised kennel for the dog who has to guard the orphanage. Initially there were two small puppies, but one unfortunately died.

3.4 Study populations, sample size and study themes

In order to be able to hear multiple perceptions on the position of children with disabilities I wanted to find out the perceptions of different stakeholders. I found all my respondents through snowball sampling. There were five study populations. One population consisted of 25 children from the orphanage. The second population consisted of 15 staff members including 11 caretakers, 1 Father and 3 Sisters. The third population consisted of 12 adoption- and foster parents. The fourth population consisted of 5 people who lived near from the orphanage. The fifth population consisted of charity organizations that were linked to the orphanage.

The children varied in age between 0 and 19 years. Fifteen of them were male and 10 female. Most of them (17) were abandoned as a baby. All but one had one or more disabilities. The main disabilities were Cerebral Palsy and cleft lips. Some children could walk and talk, others could only sit or lie down (see Appendix B and C).

Most of the staff members were female (12). The caretakers were mostly not well-educated whereas the Sisters and the Father received higher education. Most of the staff members were Catholic but people with other religions or without religion were also allowed to work there (see Appendix D).

The foster- and adoptive parents were mainly between 40 and 49 of age, were generally low educated and were all Catholic as this was a demand from the orphanage in order to be able to foster or adopt the children (See Appendix E).

I spoke to local people with ages between 28 and 53 and education levels from junior high school to medical school. One couple was Catholic and the rest had no religion (See Appendix F).

There are 5 NGOs connected to the orphanage:

Caritas Shanghai

Their mission is *'to enable international Catholics in Shanghai to confidently support synergistic activities of aid and development within China, in an effort to empower individuals who suffer from poverty, poor health and hopeless circumstance* (Caritas, 2009).

I met the members of this NGO through the orphanage and interviewed them. The members of this Foundation are all Catholic expats living and/or working in Shanghai. They visit the International Church in Shanghai. They receive donations from church members. Next to the support of the orphanage they also support the elderly (including retired nuns), people suffering from leprosy and migrant children. Father Chen came into contact with the Father of the International Church and since then the NGO from Shanghai is involved in the lives of the children from the orphanage.

Operation Smile Charity hospital

Through Caritas, the orphanage got in contact with this hospital. Four babies of the orphanage had an operation on their cleft lips. The hospital is part of the international organization 'Operation Smile'. Their mission is to *'mobilize a world of generous hearts to heal children's smiles and transform lives across the globe* (Operation Smile, 2009). I managed to arrange a meeting with the general manager of the hospital to do an interview. This NGO was started in America. Nineteen years ago the organization became active in China. The organization has volunteers who help to conduct free operations on cleft lips all over the world. They usually cooperate with existing hospitals to perform the operations. Since November 2007 there is a special Operation Smile hospital where they receive low-income patients and can also offer aftercare. It is the first hospital in China

that is specialized in cleft lip operations and offers their services for free. Volunteers have a medical background, like plastic surgeons, orthodontists, speech therapists, nurses but also non-medical backgrounds like cleaners or promotion workers. They receive donations from top-500 companies and individual donors. The NGO cooperates with the government through the National Coordination Committee of Disability, the Women's Association China and the National Population and Family Planning Committee. These organizations will do the screening and inform people about the existence of the hospital.

China Care Foundation

The mission of the American CCF is *'to give special needs Chinese orphans the opportunity for a better life and to empower youth through direct humanitarian service. By providing extensive medical, social and educational programs devoted to children, China Care makes a lasting contribution to our shared future* (China Care, 2009). I met a foster parent who is working for this NGO and interviewed him.

Their main task is to finance operations for children who stay in orphanages. The operations are performed in Beijing. The foundation also supports foster parents who take care of orphans. They pay one foster family that takes care of two children from the orphanage.

Huiling Beijing

The mission of Huiling is *to advocate for people with learning disabilities to have the same rights as others, enjoying equal opportunities and to create an environment in which mentally challenged people have the right to ask for and receive help from society* (Huiling, 2009). I visited this NGO in Beijing to do an interview.

Huiling is a Catholic organization founded in 1990 by Chinese people. There are 10 branches across China. The branch in Beijing was founded in 2000. Sixty per cent of the donations come from foreigners. Some Sisters have done a traineeship at this organization. During my research period they visited the orphanage to give advice on how to improve the quality of life of the children. The organization also takes care of a child from the orphanage.

Stichting Grenzeloos

The Dutch foundation 'Grenzeloos' was started by Dutch people in 2006. Their mission is *'to support the general development (i.e. basic living needs, social, cognitive and emotional development) of children and youngsters inside and outside of The Netherlands and to perform actions that are related to the mission or can advance it'* (Grenzeloos, 2009). There is one project group that focuses on the orphanage. They regularly send Dutch volunteers (mostly young people) to take care of the children and to help the orphanage with practical things like household chores and also donate money for operations and living costs. I gained access to the orphanage through Stichting Grenzeloos that collects money for the orphanage. With their help I was sent to the orphanage where I was both volunteer and researcher.

I spent the nights in a Catholic eyeclinic in the nearby city and went to the orphanage almost every day. My plan was actually to have free weekends but since me and my interpreter also started giving English lessons to some staff members every day and were actually a bit bored if we were not in the orphanage I spent most of my time in the orphanage. Because I was present very often and I gave the English lessons I became more familiar to all staff members and could easily ask them questions and learn more from them. The Sisters also became more familiar with me as me and my interpreter often chatted with them and helped them whenever we could. I was also able to easily talk to other respondents who visited the orphanage. Next to this I actively looked for addresses from foster families and visited them. As I accompanied several babies of the orphanage for two weeks for an operation on their cleft lips in Hangzhou and Shanghai I managed to come in contact with more charity organizations and a foster family. I also talked to 5 local people about the orphanage and disabled children in order to collect more data.

Initially I had made up a scheme in what period I would conduct interviews, do focus group discussions etc. However, in the field I felt more comfortable to work intuitively and would collect data whenever I had the opportunity. Making appointments with people far in advance as is common in

The Netherlands was not necessary in China. If you wanted to visit someone you could call that person and visit him the same day.

The themes I discussed with all the respondents were mainly about the perceived reasons for abandonment of children with disabilities, the way policies work in practice and their perceived influence on the lives of disabled children, the perceived meaning, cause and treatment of disability, the perceived future of the children, the perceived position in society and the perceived way of professionalization of the care for disabled children. With people in the orphanage I also discussed the history of the orphanage (see table 1).

Table 1. Study population, methods and themes.

Study population	N	Methods	Themes
Children	25	Participant observations	<ul style="list-style-type: none"> • Daily routine • Interaction between children • Interaction staff members – children • Interaction local people - children
		Informal conversations	
Staff members	15	Participant observations	<ul style="list-style-type: none"> • History orphanage • Abandonment • Role of government • Catholicism • Financial situation • Charity • Contact with local people • Disability (meaning, cause, treatment) • Future • Education • Fostering and adoption • Position in society • Professionalization • Marriage and parenthood • Gender • One-child policy
		In-depth interviews (8)	
		Focus group discussion (1)	
		Informal conversations	
Foster-and adoptive parents	12	In-depth interviews	<ul style="list-style-type: none"> • Abandonment • Role of government • Catholicism • Financial situation • Charity • Contact with local people • Disability (meaning, cause, treatment) • Future • Education • Fostering and adoption • Position in society • Professionalization • Marriage and parenthood • Gender • One-child policy
		Informal conversations	
		Participant observation	
Local people	5	In-depth interviews	Idem
		Informal conversations	
		Participant observation	
Donor organizations	5	In-depth interviews	Idem

3.5 Data collection methods

I used different qualitative research techniques to collect data. The use of multiple methods allows for methodological triangulation. Since all methods have their own strong and weak aspects, triangulation increases the validity of the

research by providing compensation for the weaker aspects of every technique (Gray, 2004). The data were mainly collected through observations, informal conversations and semi-structured in-depth interviews with the staff members, local people, adoptive-and foster parents and members of the charity organizations. I collected data from the children mainly by observing them. The used methods and the themes per methods can be found in table 1.

3.5.1 Semi-structured interviews

The interview with the Father took place at his room in the eye clinic. He was recovering from a car accident during that time and although it was tiring for him to talk, he talked to me for almost 1.5 hour. The Father is usually a busy and cheerful man. Now he felt a bit depressed because of his slow recovery from the car accident and his worries about the financial situation of the orphanage.

The interviews with three Sisters and four staff members took place in the orphanage. Sister Sofia and Sister Matilda lived in the orphanage. Sister Clare used to be the leader of the orphanage but was now doing a sort of management internship at an orphanage in a city near Beijing. During my fieldwork she only visited the orphanage for a week. The Sisters were young women in their thirties and had studied for eye doctor. Sister Clare was born in a county near the orphanage. Sister Matilda came from a rural county around 80 kilometres from the orphanage. I once visited her parents and her brother and his wife who recently had given birth to a twin. Sister Sofia came from the capital city of the neighbouring province. All the Sisters were very sweet. Sister Sofia is the most talkative woman. She is always smiling and very enterprising. She likes to travel, for example to go somewhere to take care of a child from the orphanage after an operation or to find donors who are willing to give money to the orphanage and she does not seem to like to stay in the orphanage for too long a period. Sister Matilda first seemed very quiet and modest but over time she also became more talkative and really liked to chat with Reggie and me. She was very dutiful in both her religious tasks and the things she had to do for the orphanage. Sister Clare was only there for a week but I noticed in the interview that she was still really involved with the children and the orphanage and was well able to express her thoughts and feelings. She left me some beautiful quotes I could use in this thesis.

I really enjoyed interacting with these women who chose to dedicate their life to God.

I interviewed four staff members. Two staff members both had a disabled child. Ai Shi is a very quiet and modest woman. She does not talk too much but likes to take care of the children. She is also a very sensitive woman. She has a son who is deaf and cannot speak. Xiao Xiao on the other hand likes to chat. She is especially fond of a baby she takes care of. She has a daughter with malformed legs. Wang Yu is one of the only two males in the orphanage. He can be called the janitor of this orphanage. He is an older man but still well able to perform his duties. He is always the first one to get up. Like most Chinese men he likes to smoke. He was nice to me but sometimes I felt uncomfortable because of the way he treated some of the children. He likes to tease them and would also sometimes hit them. However, he is very fond of one of the children he and his wife fostered several years ago.

Adam was the staff member who took care of Tian Ci, the boy who was perceived the most 'difficult' one to take care of. Reggie and I taught Adam English every day. Tian Ci also paid attention during English class because he always greeted me in the morning by saying: "Good morning, how are you? I am fine, thank you." Because we saw each other and talked to each other so much Adam became a friend of ours. It was nice to talk to him and he was very kind. Before we left he took us out for a meal to thank us for the time we were there.

I usually looked for a quiet room where we could talk without being disturbed. However, being in an orphanage sometimes meant that we were disturbed by children or staff members who wanted to ask something. However, I do not think that this has negatively influenced the interviews.

I visited the local people several times and arranged a meeting to interview them. There was one couple in their forties who lived near the orphanage. Together with their family they run a small business. They are from another province and settled in this area since about one year. The couple was very willing to talk to me. The woman thought that it would be better if I would talk to her husband but I actually liked to talk with her because the husband was only trying to give a good impression of China. The interview took place in their house. First we sat downstairs and the husband was also present. On her request we went upstairs to the bedroom. The husband had to leave then because he was busy.

Later it turned out that the lady wanted to sit there so she could make pictures of me with her webcam. Several days after the interview Reggie and I were invited to have dinner with them. After that the family wanted to make photographs with me. The whole family wanted a picture with me so I think we made about 30 photographs. I felt like some sort of superstar which made it quite hilarious. However, I really enjoyed their hospitality.

Another local person was a 28-year old man who worked at the neighbouring motorcycle distribution company. I interviewed him at the office. He was a very nice man who showed a genuine interest in the orphanage. He later even started helping the orphanage by building a website for them.

The other two local people were from a nearby village just across the street. One day I decided to visit the village with Reggie. We just walked through the village and spoke to people we met on the way. One man I interviewed was a local doctor and I interviewed him in the small treatment room. We got offered some tea as is usual in China but it was served in a glass that used to contain some sort of medication. I could still taste it but still wanted to drink it as I did not want to offend the man. However, Reggie gestured that I should not drink it so I did not.

The other local person was a woman in her thirties who owned a hairdressing salon and I interviewed her there. There was also another young lady who cut the hair of a child and two other local women. The lady we primarily talked to was very willing to talk to us. It was an amusing conversation as she was very straightforward in her answers and sometimes showed genuine indignation. Before I left she made a picture of her and me with her telephone and commented on the picture that she looked old. Reggie returned to the village a month after I left the orphanage and he met a nice girl in the village who now is his girlfriend.

I visited the foster parents to do the interviews. One foster family lived not very far from the orphanage. The foster mother was the older sister of Sister Clare. She also joined me on the trip to the hospital with the babies. The foster parents I visited in the rural areas were all very kind, modest and hardworking people. They seemed to love the children they took care of. Every time I visited one family they would offer me a meal. One foster family seemed especially proud to invite me in their home. The foster father picked Reggie and me up with his motorcycle. It was my first experience of sitting on a motorcycle with three

people while people from the village were gazing at us. The father had a big proud smile on his face. After we left their house to have a meal in a nearby restaurant a group of local people had gathered to gaze at me. Some children saw me, screamed and ran away. I was allowed to leave after eating too much and taking pictures with the foster parents and the child and the neighbours.

I also visited a foster mother who was a widow. She used to be a caretaker at the orphanage and especially liked this child, so after she left the orphanage she took the child with her to take care of her.

Two foster parents were also working for an NGO. One of them was David. He visited the orphanage, so I could interview him there. He was well-educated and a true philanthropist as he took care of five foster children (two of whom were from the orphanage) and also did volunteer work during the weekends. He also dedicated his spare time to advice the orphanage about the care of the children and management. He also had a disability and could only walk with crutches. It was very nice to talk to him and we had many interesting conversations. During my fieldwork period he visited the orphanage twice and stayed several weeks.

Then there was Sarah, a foster mother who was an expat living in Shanghai and also active within an NGO. She was originally from Singapore and had a high living standard. With her I had the most personal and emotional interview as she was quite attached to some of the children in the orphanage. I remember her as a very religious, kind-hearted person who contributed much of her time to the orphanage.

While I was staying in the hospital with the babies for their cleft lip operation I was approached by the general manager who gave me his business card. Several days later I could arrange an appointment with him and a co-worker to do an interview.

My last days in China I spend in Beijing. There I visited Megan, a young woman from an NGO that had visited the orphanage while I was there. She was a very kind and enthusiastic young woman who was so kind as to show me around in Beijing and invited me to their headquarters where I could enjoy a show given by people with intellectual disabilities.

Nearly all interviews were tape-recorded and transcribed with the help of my interpreter. Some local people and staff members spoke a dialect different

from Mandarin. This made it sometimes challenging for the interpreter to understand what was said.

The semi-structured interviews gave room to the respondents to freely express their views on the lives of disabled children. In general people were very open and willing to talk to me about the lives of the disabled children. Being a foreigner has helped me to easily gain access to foster families and local people as they felt honoured to welcome a foreigner into their home. Most people did not mind that the interviews were tape-recorded. In interviews with people who did object or in situations where I felt the recorder would negatively influence the conversation I did not use the tape-recorder and I would write down all the information immediately after the interview. I conducted one interview with the Father, three interviews with the Sisters, four interviews with staff members, four interviews with local people, six interviews with adoptive-and foster parents and four interviews with members of charity organizations. I interviewed all these respondents once. In most cases I managed to get enough information in the first interview. If I needed more information after an interview I could ask additional information through more or less informal conversations.

3.5.2 Informal conversations

I had the advantage that most respondents were close and easily accessible. In the case of the foster families they would offer me a meal after the interview. While chatting and enjoying the food together we often kept talking more about the topics we discussed in the interviews and this gave me more information. Informal conversations were also a good way to build trust between the respondent and me. The respondents always felt at ease because it was a more natural situation than the more formal way of interviewing. It also gave me the opportunity to occasionally start a topic I was interested in in a more natural way.

3.5.3 Focus group discussion

I conducted one focus-group discussion with five staff members of the orphanage, one male and four females. Three of them were Ai Shi, Xiao Xiao and Adam, the staff members I also personally interviewed. We did this during their afternoon break in the dining room. Most of the children were sleeping so we were not disturbed and the staff members had time for me. Although I gained

more information through this group discussion I preferred to do individual interviews. In this way I could be confident that the respondent had given consent to participate in the research. In the case of the focus group discussion I was telling the supervisor of the staff members that I wanted to ask the staff members to participate in a group discussion during their break and she immediately assigned some staff members to me without asking their permission. Although I strongly underlined that participation was voluntarily and in no way an obligation I felt that the staff members still felt obliged to participate. This did not make me feel comfortable. The second disadvantage was that it became clear that there were three dominant people but two people who kept quiet. It was obvious that they were not used to discuss issues and the group seemed to strive for consent instead of discussion.

3.5.4. Participant observation

I collected a large part of my data through participant observation. I tried to be with the disabled children as much as possible. For one week I stayed in the orphanage day and night. Through this I could find out how children are interacting with each other, with staff members and local people and to get an insight into their daily lives. My visit to the hospital in Hangzhou with the babies, Sister Matilda and a Chinese foster mother gave me the chance to take a participatory role in the care of the babies before, during and after the operation and gave me the chance to get to know the Sister and foster mother. I was also invited for lunch or dinner by some local people and foster families which was an excellent opportunity to get to know them and understand their way of living and how they thought about certain things. Through this I gathered much valuable information.

3.6 Data analysis

During the data collection I analysed the data regularly. I ordered the data in relation to the study themes. This helped me to get an overview of the data I had gathered, to check what information I was missing and to add study themes if this seemed necessary. For example, I added the NGOs to my study population because it turned out they played an important role in the lives of the children. I compared the information from the different study populations. Surprisingly, the

information from the different study populations was generally complementary and did not show any contradictions.

After finishing the fieldwork I ordered the collected data again to help me interpret all the data.

3.7 Challenges and ethical considerations

Before I started my research I explained my objectives and study methodology to the Father of the orphanage and he gave his consent. Before I began the participant observations, conversations and interviews I asked the respondents for informed consent. To guarantee privacy and to protect my respondents I have used fictive names in the writing of this thesis.

During my research period I faced many challenges and ethical dilemmas. Although it was not always easy I considered this as being a natural part of the research experience and it did not discourage me. I already discussed the challenge of not speaking or understanding Chinese and on having to rely on an interpreter. Now I will discuss the other challenges and dilemmas.

3.7.1 Planned data collection methods that did not work out

When I arrived at the orphanage my mind was filled with ideas on which methods I wanted to use to collect the data I needed. However, in practice it turned out that this was not as easy as I had imagined it.

Drawings

My aim was to also give a voice to the disabled children in my research. After all, they were the experts of their own lives. For this I wanted to use the method of drawing. However, I faced many challenges in trying to use this. First of all, the presupposition of this method is that all children enjoy making drawings (DiCarlo et al., 2000). It turned out that the children in the orphanage who were able to draw actually did not like to draw. Drawing was an obligatory activity they had to do in 'class'. They were not used to draw something by using their imagination. The teacher was always very critical in telling them which colour to use and to draw between the lines. As a consequence, they did not really like to draw. The second presupposition is that using this method does not require

any (verbal) skills (DiCarlo et al., 2000). However, after a drawing is made the researcher wants to talk about it. The children I worked with had problems with talking and pronunciation. Next to this their intellectual capacity was too limited to understand abstract words. This made it quit impossible to get information from the children by using this method. At first I felt that I simply had to try harder. I had much experience in working with intellectually challenged children so if others could do it, I should be able to do it. I wanted to find ways to understand their way of communicating. Instead of drawing I also tried to start a conversation with them with certain topics in my mind. But I soon experienced that open-ended questions were not answered or, even if my interpreter managed to understand what they were saying, I would get an answer that was about something completely different as the following transcript of a conversation with Hai Hai shows:

“What do you like to do?”

“I think I can use chopsticks...”

“Do you like to watch TV?””

“Look, there is a man on the television, you see?”

“What is that man doing there?”

“This is a man, you also have a woman. It is not the same”

(Fieldnotes).

The problem of closed questions was that these questions were often too suggestive or children would sometimes simply answer with ‘yes’ or ‘no’ without being sure if they really meant what they were saying. In these conversations I did not feel comfortable and as a reaction the children did not feel comfortable either. I also doubted the little information I gathered from this.

However, I soon started to realize that in fact the children were communicating all the time. As soon as I set the first step into the orphanage they welcomed me with open arms. They literally took my hand and showed me an insight into their daily lives. They showed me what they liked, what they usually did, what food they liked, which games they wanted to play, which children they liked to play with, or fight with, or cuddle with, and how people around them responded to them. The information was there, right under my nose.

Disposable camera

Tian Su was a 10-year old boy without disabilities. He went to a regular school, liked to watch TV and run around outside the orphanage. As he lived with the disabled children in the orphanage he could give me some useful information so I decided to use the method of photography with him. I bought him a camera and asked him to make photographs of everything in and around the orphanage he liked. He really enjoyed it and was delighted when I returned the photographs he made to him. In the mean time I heard from the Sisters that they thought that he had severe psychological problems. His mother left the family when he was five years old. This was after his father got an accident and lost his eyesight. Because he was not able to take care of his son, the Father who founded the orphanage offered to raise the child at the orphanage. The boy does not want to see his father. He does not like to talk to people very often. If someone tells him not to do something he immediately gets very angry and starts to cry. He is sometimes violent towards other children if he has to share toys. Faced with this information I started talking to him. Although he was very shy I could get a little information about his life. I decided not to talk to him about his past as this would most probably be upsetting to him and thus not ethical. I felt very satisfied that he enjoyed making photographs so much and considered that more important than my research. In the end I did not use the gathered information in the thesis because it turned out not to be so useful.

3.7.2 My position as a researcher

Being a researcher in the field and taking on different roles can sometimes lead to tension and dilemmas one has to face.

Researcher versus professional

Although I did not have any previous experience with Chinese children I did have much experience with children with disabilities both through specialization in disability care in my previous Master and through my work in The Netherlands as caretaker of disabled children. Before I went to the orphanage I was aware of the danger that my knowledge about these children was coloured by Western values. I had to make a switch from being the professional who

advises people on how to treat children with disabilities to the observer who wants to explore how other cultures deal with and think about children with disabilities.

This challenge became most problematic when the Sisters started to ask my advice about ways to improve the lives of the children in the orphanage. In the beginning I did not want to impose my thoughts on them because that would greatly influence the research setting but as my research period was coming to an end I felt it would be unethical not to help the Sisters and the children in the orphanage. The following is an excerpt from my personal fieldnotes and illustrates the tension between the role as professional and as researcher:

[...] Today is the first day I experience the life in the orphanage from 8 a.m. till 9 p.m. It has been a long day and I think it will be a tough week. However, I am glad I am here because today I was there when they put the children in bed. What I saw was horrific and made me feel so sad. The two boys, Tian Cheng and Tian Ya, were tied to their beds. I think that is inhuman and I feel so sorry for the boys. There are so many other ways to prevent children from kicking off the blankets. And you cannot just tie someone's hands to prevent him from touching himself. It is very normal for a boy of Tian Ya's age (teenager) to start touching himself. I am so upset but I understand that the staff members just do what they think is best. They must have noticed that I did not agree but it was too difficult for me to hide [...] (Personal fieldnotes).

Trust and confidentiality

During the period I stayed at the orphanage I managed to build a relationship of trust between me and the children, me and the staff members and me and the Sisters. At the same time I became aware of the hierarchy in the orphanage where the Sisters were higher in 'rank' than the staff members. My loyalty towards the staff members was put to the test as one of the Sisters after some interviews with staff members wanted to know what we discussed in the interview. I managed to give a very general answer as to not reject the Sister and at the same time warrant confidentiality towards the staff members.

Being a 'waiguoren'

Another important issue is that I was the only *waiguoren*⁴ in the county where the orphanage was located. People were obviously not used to seeing

⁴ *Waiguoren* is Chinese for 'foreigner'

foreigners so my stay at the orphanage attracted much attention. It became apparent that my stay influenced the visibility of the orphanage. For example, every day I took the bus from the eyeclinic to the orphanage. People soon noticed that there was an orphanage because they saw me getting out of the bus there. One day a young lady came to me when I was waiting for the bus and told my interpreter that since she saw me getting out of the bus she discovered the orphanage. She ever heard that there was an orphanage but she never knew where the orphanage was. She asked me the phone number of one of the Sisters because she was planning to do volunteer work there. Another example is a young man who worked at a motorcycle distribution company next to the orphanage. Since the day he noticed me walking around in the orphanage it gained his attention and he decided to visit the orphanage. It seemed that my stay at the orphanage as a foreigner made the orphanage gain more status and attracted people's attention.

Emotional involvement

My stay at the orphanage, my chance of being part of the children's lives and talking to so many people has made me become quite attached to the children. It is impossible for me to look at them from a "researcher's distance" because I really bonded with the children. They made me very happy but I could also become emotional as I discovered the difficulties they face in their lives. However, this is far from being a disadvantage. As the children and the people in the orphanage noticed my sincere involvement, they were very open to me, even about some things they rather did not want to talk about.

3.8 Limitations of the study

This study gives an insight into the lives of disabled children in the orphanage and their position in the county where the orphanage is located. However, it is not possible to generalize the conclusions I draw to the situation of all children with disabilities in China. I did not use a random sample but mainly made use of the network of the Catholic orphanage. This might have biased the data. Due to time and money constraints I also did not make a comparison between the situation in rural and urban areas and orphanages started by individuals and national orphanages started by the government. However, since

the position of disabled children is an underresearched topic my study adds valuable information and gives food for future research on this topic.

Another limitation is that I was not able to speak to mothers who chose to abandon their disabled children. I only received information from people who probably have never been in such a situation. However, I did speak to two women who had the experience of having a disabled child. I think that I can be confident that they give reliable information when it comes down to the difficulties and choices a Chinese mother with a disabled child faces.

Chapter 4

The explanatory model of disabilities

The way people explain disabilities influences the position people with disabilities hold in society. In this chapter the classifications and explanations of disabilities given by the respondents will be analysed.

4.1 The type of disabilities

Respondents mentioned several kinds of disabilities in conversations and interviews and in documents from the orphanage. None of these disabilities are in conflict with the Western biomedical classification of disabilities. Reggie and I have tried to give a correct translation of these labels:

- Cleft lip;
- Hydrocephalus (waterhead);
- Clubfoot;
- Cerebral Palsy;
- Tang Syndrome (Down Syndrome);
- Intellectual disability;
- Malformations (ear, legs);
- Congenital heart disease;
- Epilepsy;
- Spina Bifida;
- Autism (see also Appendix A).

It was not always easy to understand the types of disabilities. For example, I read in one of the documents of the orphanage the name “Tang Syndrome.” I had no idea what was meant so I asked one of the Sisters. She explained that people with this syndrome had certain specific facial features and that there was one famous Chinese man who had this syndrome. It was only after she showed me a picture of a girl with this syndrome that I understood that she meant Down Syndrome.

During the interview with Sister Sofia she was talking about something that Reggie translated with ‘starchild’:

[...] Star child, you must know that. It is international. The child is like a star in the sky. Like a star, it is a child like a star. It is a lonely child, like a star alone in the sky [...]

It was only after she showed me an English folder about this type of disability that I understood that she was talking about autism. I think it is a beautiful metaphor.

Cerebral Palsy was the most common disability in the orphanage. The official definition of Cerebral Palsy is “a group of disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder” (Stevens, 2005). The severity of Cerebral Palsy varies. Some children in the orphanage with Cerebral Palsy could only lie down; others could sit or walk around. The term ‘Cerebral Palsy’ is known to most of the respondents as it was mentioned by Sisters, staff members, foster parents and local people.

Cleft lips are also common among children in the orphanage. According to the Operation Smile Charity Hospital, where some children received an operation, is the cleft lip especially common in rural areas. Around 0.18 percent of Chinese newborn children are born with cleft lips. That is a large population compared to other countries, according to Operation Smile.

The definition of spina bifida is “a congenital birth defect characterized by a fault in the spinal column in which one or more vertebrae fail to fuse properly leaving a gap or split.” The severity of the disability depends on the level of lesion and the nerve damage involved. Associated problems include loss of power, mobility, and sensation below the affected neurological level, impaired bowel and bladder control and hydrocephalus. The definition of hydrocephalus is “the accumulation of cerebrospinal fluid that causes raised pressure inside the head and an increase in the size of the ventricles.” Hydrocephalus can be caused by spina bifida but is also associated with other conditions such as meningitis, premature birth, or brain tumors. The severity of the disability varies across children and depends on the areas of the brain most affected. Children can have impaired fine

motor skills, executive functioning, learning, attention, and behavior (Pit-ten Cate, Kennedy & Stevenson, 2002). One boy in the orphanage called Hai Hai had spina bifida and he indeed also has hydrocephalus and impaired bladder control. There were two other children with hydrocephalus. One of them had an intellectual disability. The other one was still a baby who was nearly blind and was expected to have intellectual disability too.

According to the answers from the stakeholders, children with intellectual disabilities are considered more severely disabled than children with physical disabilities. The children are generally diagnosed by a doctor.

NGOs influence the terms used for disabilities. Caritas, the NGO in Shanghai often arranges meetings with doctors in one of the big hospitals in Shanghai for a diagnosis. The people of Caritas are used to consulting doctors about the situation of the children of the orphanage. They inform the potential donors about the children's situation.

4.2. The causes of disabilities

The perceived causes of disabilities mentioned by the respondents are generally similar and are also not in conflict with Western biomedical explanations. Causes mentioned are genetic diseases of father or mother, marriage between family members or medicine use during pregnancy.

[...]I heard from somebody else that maybe before the mother became pregnant...Like Tian Cheng, he has cerebral palsy. Maybe his parents took some medication so this child got some syndrome affecting his brain [...] For example, his mother was pregnant for 5 or 6 months. At that time the child received something from the mother, I don't know how to say that. The child gets nutrition from the mothers' blood. The mother ever caught a cold and had a high fever. If the mother doesn't take medication or injections she will be seriously ill. If the mother takes medication and injections the medication will go into the blood of the mother and the child will get a disease through the blood of the mother. Usually, if the mother is pregnant she will not take medication or injections [...] (Xiao Xiao, staff member).

All respondents expect that some people in rural areas will give more traditional explanations and will think that they are being punished because they, their family or their ancestors did something wrong in their previous life. This way of thinking

would be clearly influenced by Confucianism. However, none of the respondents believed this themselves. Catholics do not believe that people have multiple lives so do not consider this to be a legitimate cause.

[...]Because in China...a harelip for example...when you get a child with a harelip you did something wrong in your previous life. People in the countryside will think in that way [...] (Sister Matilda).
[...]It's a kind of superstition [...] (Sister Clare).

Xiao Xiao, a staff member who has a daughter with a disability said in an interview:

[...]It's my destiny. It's destiny. I am the same as other people. Then why do I get a daughter with a disability? Because it's my destiny [...]

People seem to be well informed about how to prevent disability, for example not to marry family members. Consanguineous marriages are forbidden and a health check is required before marriage to control for genetic diseases in order to decrease the chance of birth of more disabled children.

The Operation Smile Charity hospital informs people about possible causes of cleft lips, i.e. genetic, malnutrition or pollution. According to the general manager of the hospital the exact cause is still not known. Nurses will give advice to mothers on how to possibly prevent future offspring from being born with a cleft lip, for example to eat healthy.

The following table provides information on the mentioned causes of disabilities mentioned by the respondents. The explanations can be divided in biomedical and traditional explanations. The respondents mostly gave biomedical explanations of which medication use during pregnancy and genetic diseases were most often mentioned. Of the traditional explanations, having done something wrong in a previous life was most often mentioned. However, as stated before, this explanation was said to be given by rural, uneducated people and was not believed by the respondents.

Table 2. Causes of disabilities mentioned by the respondents

Explanation		Staff members (N=8)	Adoptive- and foster parents (N=6)	Locals (N=4)	NGOs (N=4)	Total
Biomedical	Medication use during pregnancy	3	3	1		7
	Genetic	2	2	1	1	6
	Consanguineous marriage			2		2
	Medical problems			1		1
	Malnutrition				1	1
	Pollution				1	1
	Congenital	1				1
Traditional	Did something wrong in previous life	4		1		5
	Curse				1	1
	Destiny	1				1

4.3. Treatment of disabilities

The children in the orphanage receive medication, operations, and rehabilitation training to cure the disability (if this is possible) or improve their condition. During my stay two children received medication, four children received an operation and nine children had a training schedule.

Treatment in the hospital

The children in the orphanage, like most people in the area, do not have health insurance and the government does not support the children for their medical costs. This means that the orphanage has to find money to pay for hospital visits, medication and operations. If one of the children needs medical assistance they will bring the child to a local public hospital and pay the hospital in cash.

I visited the Sister and the children twice to the hospital. The following is an excerpt from my fieldnotes:

[..] Kang Kang has a cough and the Sister decides to take him to the hospital. The sheets are replaced by a one-way diaper and he is packed into new warm clothes. The driver picks us up and in the van we drive to the hospital. We arrive at a courtyard with several small rooms. We enter one of the rooms. A doctor in a white coat sits behind a desk. There is a computer, and a treatment table that people use to sit on while they are waiting. There are several parents with children. There is no privacy. One by one the doctor listens to their complaints. She sometimes listens to their breathing by using a stethoscope, measures the temperature or checks the back of the throat. Then she writes out a prescription. The same happens when it is our baby's turn. Sister Matilda goes away to get the things the

doctor prescribed. She returns with a drip and some fluid. The doctor puts the baby on the treatment table and shaves some hair of the baby's head. She sterilizes the bold spot, inserts a needle and attaches the drip. Reggie holds the drip and I make sure the baby lies on one side. Meanwhile we are surrounded by the small group of parents. They look at the baby. One woman mumbles: "poor boy". Another woman tells her child to be as brave as the baby. Sister Matilda is in the mean time getting more medication. When she returns Sister Matilda adds more fluid to the drip. While Reggie is holding the drip, Sister Matilda takes the baby and carries it back to the van that has been waiting outside [...] (Fieldnotes).

Caritas is an NGO that supports the orphanage particular in the medical costs. Children who need operations can come to Shanghai to receive an operation. They receive operations for various impairments, like hydrocephalus, cleft lips, spina bifida, congenital heart disease and clubfeet. The flight, stay and the operation are paid by this organization. During the hospital stay the organization also gives support through volunteer work, for example by arranging volunteers to visit the children and Sisters in the hospital or by offering them housing in the period before and after the hospital stay. They also support the stay of children of the orphanage in rehabilitation centres. Two of the members foster each a child from the orphanage. One of them is trying to adopt the child, but since she is a foreigner the procedure to adopt a Chinese child is very complicated.

During my research period I joined four babies to Shanghai to have operations. The following is an excerpt from my fieldnotes:

[...] Suzy, Sarah, Kathy and Sister Matilda and I get out at the hospital. The babies Piao Piao en De De will be checked by a doctor because of their respectively swollen belly button and testicle. Suzy, one of the members from Caritas, knows a doctor there and arranged a private meeting [...] After a while of waiting we meet him in the waiting room that is totally empty by now [...] He advises both babies to have an operation. Both operations are relatively small and cost 2000 RMB. Despite the waiting lists it can take place tomorrow. This doctor is very influential and can make such decision. The women of Caritas are expats so can, so they tell me, arrange these kinds of things more easily than native Chinese. Is this fair? No. Is it good for our babies? Yes [...]

Sometimes newly found children need immediate surgery to save their lives. They will go to Shanghai as they often do not have a chance of survival in the hospitals

near the orphanage because of less quality. Sister Matilda told me the following sad story:

[...]When we found baby Xiao Xiao he could not eat or defecate. He only threw up a greenish substance. His body was poisoned so his skin had a purplish color [...] We brought him to the hospital where he was released after one week. However, after ten days he began to throw up again and would not eat or drink anything. We went to the local hospital where they said that he could not be cured. Then we contacted the NGO in Shanghai. The baby could come there to go to the hospital. By then he was only skin and bone. They discovered a hole in his stomach. Despite the high risk that he would not survive, they operated in. He did survive the operation. However, two or three days after the operation he finally died [...] (Fieldnotes).

The Caritas Foundation in Shanghai relies on medical advice from doctors and communicates to the orphanage what treatment the child will need.

[...]Without immediate surgery, Tian Dai will definitely go blind and he will also never get to walk and needs to be bedridden as he grew older. According to the neurosurgeon the baby's condition is serious and complicated and would probably need two operations. The first is to attend to his brain cysts and with close observation of 3 - 6 months after his operation, he may need to undergo another operation for his hydrocephalus problem. However, the doctor said that going for these surgeries will prevent him from getting blind and he will have a chance to walk eventually [...] (Email from Sarah to Caritas members).

Operation Smile Charity Hospital also is clear about the treatment of children with cleft lips. They offer plastic surgery, orthodontic treatment and speech therapy. Without operations the children will have psychological problems and problems with speech and eating.

Besides these treatments the Father and the Sisters also believe in the power of prayer. Whenever a child undergoes surgery, the Sister that accompanies the child will send a text message right before the operation to the other Sisters and the Father to ask them to pray for the child. However, they will accept whatever the outcome may be and they have peace with that. [...]Babies who die will go to heaven as Angels [...] (Sister Matilda).

Rehabilitation

One of the Sisters, who did an internship at a rehabilitation centre in Shanghai, created a therapy room with rehabilitation equipment that had been donated and set up training schemes for children. Next is an example of such a training scheme:

Short-term goals Tian Ya.:

1. Can hold handrail while he walks up and down the stairs;
2. Goes to toilet regularly and keeps his clothes clean;
3. Can eat by himself with minimal assistance;
4. Can dress himself and wash his hands and face with minimal assistance;
5. Can understand simple orders like 'come here', 'no', 'hold this', etc.;
6. Can repeat words like 'mum', 'dad', 'aunt';
7. Can express his needs and takes initiative in communicating with others;
8. Can recognize body parts (head, hand, leg, foot, etc.).

Schedule Tian Ya:

9:30-9:45 h.: Walk training: walk up and down the stairs;

9:45-10:00 h.: Rest: drinks water and goes to toilet;

10:00-10:30 h.: Trains ability to hold something with using both hands, like holding a spoon or the pincer grasp;

10:40-11:00 h.: Daily living skills: put on socks and shoes, wash hands and face;

15:30-15:50 h.: Language training: communicate, pronounce 'a', 'o' and 'e';

15:50-16:00 h.: Rest: drinks water and goes to toilet while keeping his clothes clean;

16:00-16:30 h.: Recognition training: recognize environment (persons, things, etc.) (Fieldnotes).

Not all children are included in the training programs. Babies do not have a training program and one boy with cerebral palsy is not included in the training program. It seems like the staff members and Sisters do not know what to do with him. He is tied to a rocking chair and sits there during the whole day. He is also fed in that chair. His back seems to suffer from scoliosis and he cannot stand, walk or talk and is not toilet-trained. Staff members think that he cannot be cured or rehabilitated anymore.

A part of the rehabilitation training is Chinese massage. This massage aims to activate the body and to loosen the muscles. The masseur massages the blood in the direction of the head and pushes between the bones. It is a deep

massage that uses the same pressure points as acupuncture. These points are also called acupoints. It is part of Traditional Chinese Medicine. It is believed that rivers of energy, meridians, flow through the body. The acupoints are located on the meridians. Each meridian corresponds to a specific body organ or whole body system (Lee, 2001). The massage is not used for every child. Children who are already active do not need it. For some children the primary aim is relaxation, for others to strengthen the muscles or to make it possible for children to stand or walk. It can also help to stimulate digestion. The acupoints are also used in case of an epileptic fit. The staff members then press their thumb on a spot inside the mouth above the upper teeth. All children who receive the massage have Cerebral Palsy. The Sister who did the internship in Shanghai learned about Chinese massage and showed how to do the massage to me and the staff members. She believes that, although the staff members are not professionals and do not always massage the right way, children still benefit from it.

Some NGOs also receive children from the orphanage to place them in rehabilitation centres or language training schools and they stimulate the orphanage to rehabilitate the children. Right now there are three children in rehabilitation centres in Beijing. Caritas was planning to visit the orphanage to help them set up a therapy room and to send people with a background in physiotherapy and paediatrics. There are now plans to build a rehabilitation centre on the land next to the orphanage. The orphanage also wants to attract professional therapists and interns. Because of lack of money this will be a long-term goal. However, there is a visible development of professionalization. After a trip to Xi'an a Sister came into contact with other Catholic Sisters trained as special education teachers who came to assess the children and fine-tune their training schemes. A Sister who did a management internship at an orphanage near Beijing and a man of the China Care Foundation who also fosters two children from the orphanage visited the orphanage to give advice on management and caretaking. Staff members were fired (probably because of their age and quality) and younger staff members were hired. The man from China Care held a meeting with the staff members to explain how to take care of the children and interact with them. The rules for staff members were sharpened and a supervisor was hired to monitor the staff members. The following quotes illustrate the wish for professionalization:

[...] Right now we got a way of management just like running a family. Later we will have a more formal way of management, just like a company [...] (Interview Sister Sofia).

[...] You can see that the staff members downstairs are not well-educated. Some of them are illiterate. Some of them couldn't even write their names. This is what I cannot bear so they should be fired [...] (Interview David from China Care).

This chapter showed that children with intellectual disabilities are considered more disabled than children with physical disabilities. Some children do not receive rehabilitation training because their disability is seen as incurable. What does this mean for their position and perceived future? The following chapter will elaborate on that.

Chapter 5

The position of children with disabilities

In order to get an insight into the position the children with disabilities hold in society I observed the interaction between the children and others and tried to find out what people's perception are of the children's position and their future. First I will discuss the daily routine of the children in the orphanage. Then I will discuss the interaction between the children and the interaction between children and staff members and children and local people. Finally I will discuss the perceptions of the stakeholders on the future of the children. Will they be adopted? Will they marry? How will their lives look like when they are older?

5.1 The daily lives of the children with disabilities in the orphanage

5.1.1 The daily routine

The children who live in the orphanage will get up around 7 o'clock. One boy without disabilities, Tian Su, will get up earlier at 6.30 a.m. because he has to go to school. The staff member who works at night changes diapers and puts on clothes. The day staff will arrive at 7:30 hours and take over. Every staff member is responsible for two to four children. Their faces and hands will be cleaned with a cloth and a bowl of water. They will get cream on their face. If there is water the children will get a shower once a week. However, during my stay there often was a lack of water so the children could not frequently shower.

The children have three meals: breakfast at 8 o'clock, lunch at 11:30 a.m. and dinner at 17:30 p.m. When they are able to they will pray before eating. Staff members will have breakfast at home, lunch at 12 o'clock and dinner at 6 o'clock. The babies will have milk or breakfast around 9 o'clock. The children drink milk and eat eggs, steamed bread and vegetables for breakfast. After breakfast the children will go to the activity room and do exercises. Most children have a training program with certain exercises that staff members have to do. For example, they practice walking or standing. Other children just sit or lie down or,

if they are able to, walk around. In between diapers will be changed or children will be placed on a chamber pot.

After breakfast Hai Hai, 10 years old, Tian Zhi, 9 years old and Bing Bing, 12 years old will go upstairs to receive homeschooling from their caretaker called Lily. She neither has an educational background nor any previous experience in teaching children. The boys are less intellectually disabled than the other children and learn to write Chinese characters on Monday, Wednesday and Friday and learn calculations and numbers on Tuesday, Thursday and Saturday. On Tuesday and Friday they also learn to draw. None of the disabled children in the orphanage goes to schools or rehabilitation centres. There are no special services for children with disabilities in this area. In the past several children went to the kindergarten that was set up by the Father. However, they were accused of spreading pamphlets of the *Falun Dong* and the kindergarten was closed. The Father and Sisters believe the real reason is that the atheistic Communist party does not want religious people to run a kindergarten. Tian Zhi went to a regular school for one year but could not keep up. Tian Ci was placed at a special school for the blind in Beijing. The teachers however, could not deal with his disruptive behaviour (aggression, behavioural problems) and within two months he returned to the orphanage. One of the Sisters had sent an application letter to another special school but she did not receive any response.

For lunch children will get noodles or rice with a soup. After lunch children and staff members will rest until 14:30 p.m. After that they continue exercises and will change diapers, place children on a chamber pot and feed the children. For dinner children will get steamed bread, vegetables and soup. After dinner the blinds will go down. During my stay it was still light outside during this time. Diapers will be changed, children will be placed on a chamber pot and babies will be fed. They start bringing the children to bed around 18:30 p.m. Around 21.00 p.m. all children are in bed. In the evenings the four boys usually watch TV and will go to bed around 21.00 p.m. The *ayi*⁵ washes the feet of one boy called Hai Hai. The other boys can do that by themselves. She puts on diapers for two boys, Hai Hai and Bing Bing. They take off their pullovers and leave on the rest. After saying their prayer they will go to sleep. The *ayi* sleeps in the same room with them.

⁵ *Ayi* literally means 'auntie' and is a sort of nanny who takes care of children

The lady who works at night will start at 20:00 p.m. Then the day staff will leave. She will feed the babies twice a night and change diapers three times. She will sterilize the rooms with a sort of UV-light which secretes a certain liquid.

The blind boy, Tian Ci, has its own routine as he needs constant supervision from a staff member. He will do exercises before breakfast. After breakfast he will do activities like playing keyboard, listening to music, singing, reciting poems or do home chores. In the evening he will take a walk or listen to the television. On Saturdays he sometimes will go shopping with his supervisor. He will go to bed around 21:00 p.m. His *shoushou*⁶ sleeps in the same room with him.

On Sunday all children are off. In the afternoon the children who are able to will go to the room upstairs to attend the mass.

5.1.2 Interaction between the children

Most of the children in the orphanage have severe intellectual disabilities. They do not really interact with other children. However, the group of four boys who are less intellectually disabled really interact with each other and the other children. Tian Su goes to school so is only there during lunch and in the evenings. The other boys spend almost 24 hours with each other.

Hai Hai is a rather calm boy and often being teased by Bing Bing and Tian Zhi. Especially Tian Zhi enjoys stealing Hai Hai's food or hitting him on the head. Hai Hai then often gets annoyed. Tian Zhi and Bing Bing also often tease each other. They romp around, chase, hit and kick and steal things from each other. Especially Bing Bing is very good at stealing toys or candy from Tian Zhi. He then pretends to cry in order to attract attention from the staff member. On the other hand is Bing Bing sometimes behaving like an older brother towards Tian Zhi and Hai Hai. He makes sure Hai Hai gets its candy back when Tian Zhi stole that again or he warns Tian Zhi not to steal candy from the cupboard. Hai Hai has a cup between his legs where he can urinate in. He does not always control his bladder and is because of his clubfoot not able to walk to the toilet. Bing Bing sometimes empties the cup for him.

⁶ *Shoushou* literally means 'uncle' and is the male caretaker

Tian Ci, the blind boy, is really fond of Tian Zhi. He likes to cuddle with him or tease him. They often have fun with each other. Tian Ci and Tian Zhi are an interesting combination because Tian Ci is much taller than Tian Zhi.

Although their intellectual abilities and speech are not sufficient to understand and express abstract words like ‘friendship’ or ‘affection’ it was clear to me that these boys are each other’s best friends. The boys have equal relationships. They tease each other and help each other mutually.

The relationship with Tian Su, the boy without disabilities, is more complicated. I observed Bing Bing trying to steal something from Tian Su. As a consequence, Tian Su kicked Bing Bing against his arm. Bing Bing loudly started to cry and ran upstairs. When he returned downstairs he threw a cuddly toy at Tian Su. Tian Su hit the boy again and Bing Bing started to cry again.

Tian Su is both intellectually as well as physically superior over Bing Bing. However, emotionally he is not very strong. He is very easily hurt and reacts either very emotionally or aggressively. He rather likes to play alone or watch television. However, he does like the babies in the orphanage. He likes to hold them and cuddle with them.

Tian Zhi, Bing Bing, Hai Hai and Tian Ci know all the names of all the children. Especially Tian Zhi and Bing Bing sometimes like to play with or cuddle with the other children and babies.

The children also experience children leaving the orphanage for a longer or shorter period because they go to a foster family or adoptive family, undergo surgery or go to a rehabilitation centre. They also have to say goodbye to staff members who leave the orphanage. It is difficult however to find out how they experience this.

5.2 Interaction between the children and the staff members

5.2.1 Education and punishment

The children in the orphanage are being taught to be a good person by teaching them certain values. One important value is gratefulness;

[...] Sister Matilda tells Hai Hai to have a grateful heart because he sits upstairs all the time while others have to do everything for him.

He has to be a good boy; otherwise people will not love him. He has to thank Bing Bing for emptying his cup [...] (Fieldnotes).

Another value is politeness. One of the practical skills Bing Bing has to learn according to his training schedule is to learn polite phrases like “thank you” and “I am sorry”. One day one of the children was forced to make an apology to me and my interpreter. The day before Hai Hai was playing with my interpreter’s cell phone and was angry with us when we took the cell phone from him because we had to leave.

[...] Sister Matilda asks us to come to the bedroom of Hai Hai. He has to apologize to us because he was angry with us yesterday and asked us to buy him a cell phone. He is surrounded by the four of us. He says sorry and then starts to cry [...] (Fieldnotes).

The children are also taught to help each other. Bing Bing is often asked to empty the cup with urine for Hai Hai. He is also the one that brought the food to Hai Hai during the period that he was sitting upstairs during meals. Tian Su, the boy that goes to school, is stimulated to play with other children. The children also help staff members doing chores, for example hanging clothes to dry or folding blankets.

To share is also a value considered important. Although sharing favorite toys was sometimes difficult for the children, they are good at sharing food. Whenever they receive candy or cookies they will share the food with the other boys. It was quite common to see Bing Bing and Tian Zhi running around with candy and to put it in the mouths of other children. Tian Ci, the blind boy, would immediately respond with *xie xie*⁷ and was clearly happy. The children also never forgot to offer me and my interpreter their candies, cookies or fruit.

The children received punishment whenever they did not act in accordance with these values. One example was already given with Hai Hai, who had to apologize to us. Another way of punishment is standing in the corner or outside of the room for several minutes. Another way to get children to do what the staff members wanted was to threaten to withdraw them food. However, they never realized this threat. Sometimes the children also received corporal punishment. This was especially the case for Tian Ci, the blind boy, who was known to be

⁷ *Xie xie* is Chinese for ‘thank you’.

difficult to handle. The punishments varied from a slap in the face to hitting him with a wooden handle of a brush. Afterwards Tian Ci is very quiet and tense and seems to be afraid.

[...]During the English course Tian Ci wants to have the attention from my interpreter. He does not respond so Tian Ci throws a book at his head. His caretaker becomes very angry and gives Tian Ci a hard slap in the face. Tian Ci seems very afraid and as a punishment he has to stand outside. His caretaker tells us that he is afraid that if he will not punish him for throwing the book, he soon will throw chairs or other heavy material [...] (Fieldnotes).

The attitude towards corporal punishment seems to be ambivalent. One of the Sisters once mentioned to me that she learned in Shanghai not to hit children but to talk to them and told me that there were differences between the Chinese way of education and that of other countries. The Sisters and supervisor set up some rules for the staff members. One of the rules is that it is forbidden to shout at or hit the children. By not obeying this rule the staff members risk to get fined 10 RMB.⁸ However, for Tian Ci, the blind boy, it seems that one does not see another way of educating him.

Something that is not meant to be a punishment but does limit the children in their movement is tying them to a chair or a bed. This happens to Tian Cheng and Tian Ya. For Tian Cheng, it is primarily meant to keep him from falling or kicking off the blankets. For Tian Ya it is primarily to prevent him from clapping his hands or masturbating.

5.2.2 Play and physical contact

The primary task of the staff members is to take care of the basic needs of the children. They feed them, wash them, clothe them and do rehabilitation training. They sometimes tease the children by softly hitting them or grab the arm of one child and softly slap the other child. They sometimes show their affection by taking children on their lap. One of the staff members expressed that she would really miss the baby she was taking care of if he would get adopted. However, some children especially seem to be favorites. One of them is a baby with a cleft

⁸ *RMB* (renminbi) is the Chinese currency. 1 Euro is around 8.5 RMB. The salary of the staff members is around 600 RMB.

lip with normal intellectual disabilities. Another one is a girl with cerebral palsy who is favored by the janitor who for a short period fostered her in his home. Some children receive less attention, such as the boy with cerebral palsy who sits in a rocking chair all day. He does not seem to respond to people. Another one is a boy with hydrocephalus who is nearly blind and lies in bed most of the time. It is not that staff members do not like these children, but it seems that it is too hard for them to connect with them.

5.3 Interaction between the children and the local people

5.3.1 Abandonment

All children who live in the orphanage are abandoned by their parents. It is very hard to find out what the motives were of the parents because their identity is not known. However, the stakeholders do have some ideas about the reasons. If I asked the stakeholders why children were being abandoned they often responded that it was because of their disability. However, I wanted to find out what the reasons were that parents felt unable or were unwilling to take care of their disabled child. The reasons the different groups of stakeholders gave were generally quite the same.

One of the reasons mentioned was that especially people from rural areas who were often not well educated thought of disability as a punishment for doing something wrong in their previous lives. It could be that the father or mother did something wrong or the family or ancestors. As a consequence, having a disabled child was accompanied by the feeling of shame and loss of face. Other people would look down upon them.

Other reasons were that children with disabilities were thought of as a burden, both to society and family. The child who is disabled is a burden to society because it cannot make a contribution to it. The child is a burden to the family both emotionally and financially. It is emotionally challenging for a mother to raise a disabled child because of feelings of shame and worry. However, the main reason for viewing children with disabilities as a burden was, according to the respondents, because of the financial burden. First of all there are the medical costs involved when having a child with disabilities. They often need medical attention in the form of doctor's visits, medication and operations. Most families

in the area where the orphanage is located do not have enough money and often do not have health insurance. Another reason is that children with disabilities often need extra supervision and care. This will mean that either the mother would have to stop working or hire an *ayi*. Both options are not possible to realize for poor families. They simply cannot afford to stop working or to work less or to hire an *ayi*. Another consequence of having a child with disabilities is that it can be very hard to let the child get married and start his or her own family. Especially in the case of a boy it will be difficult because there are already not enough girls due to a imbalanced sex ratio in China with far more boys than girls being born. The child will most probably stay with his parents all the time and will not be able to support the parents when they become old. There is also a problem for the brothers and sisters of the disabled child. Despite the one-child policy many families in this area have more than one child. If parents are no longer capable of taking care of the child with disabilities, the responsibility will go to its brothers and sisters. This can decrease their chance of getting married.

From the stories of my respondents it seems obvious that the responsibility for raising and taking care of a disabled child in China lies on the shoulders of the family. There is no support from government in the form of health insurance or other ways of financial support to help carry the burden of the family.

Although some staff members and foster parents judged parents who abandon their child as bad persons, the above-mentioned reasons also show that people do understand the decision of some people to abandon their child. One story told by Sister Matilda illustrates the difficult situation some parents face. One day there was a child who was left with a note stating her birthday and explaining that she had a high fever and parents could not afford to seek medical care. The only way to let her survive was by abandoning her in the hope that she would be found by someone who could take care of her.

There is also the story of a child who was abandoned but whose family came back several years later and demanded to have the child back. The children from the orphanage were taken to the city centre to play. One boy, who recently had an operation on his cleft lip, was recognized by a family member of the biological parents and informed the parents. The mother and her mother-in-law visited the orphanage to bring the child back home. After verifying the date of abandonment and date of birth the Father from the orphanage was convinced that

these were the parents of the boy. He allowed the parents to take the child back home. However, several days later the parents returned the child because according to them it had a birth mark that their real child did not have. The boy returned to the orphanage and was later adopted by a family from another province. However, the family returned to the orphanage again and wanted to have the child back. They did not want to believe the child was already adopted. One day when I was also in the orphanage I noticed an older and a younger woman visiting the orphanage. They walked around and talked to the staff members. When they left I noticed the older woman crying. When I asked the staff members the reason of their visit they explained that these were the mother and mother-in-law again asking for their son respectively grandson.

[...] Abandoning your own child, how must that feel? What must have happened that mothers make such an extreme choice? I don't know what to think of it. Sometimes I just feel angry that those mothers left their baby alone. Yet, I think it is too simple to just say that these people are bad people. Listening to the reasons Sisters, staff members, foster parents and local people come up with when I ask them what they think is the reason to abandon a disabled child it seems that it must be really hard for a poor family to raise a disabled child. I wish I could speak to some of these mothers and hear their story and really try to understand their motives [...] (Fieldwork journal).

5.3.2 Contact between the children and the local people

One of the first things I asked myself was whether the local people knew about the existence of this orphanage. Sister Matilda did not expect many people to know this orphanage.

[...] You see, our former attitude was... we were afraid to promote this orphanage to society. Now we are changing that attitude. We think we should let people know this orphanage. We were afraid to promote this orphanage at the beginning. We were afraid we couldn't take care of too many children. Our attitude is changing, whether we have money or not we will put the board outside the orphanage. One time I went to buy tofu in a village. I bought several kilos. The seller asked me: for which company are you working? I said I worked at the orphanage. Where is the orphanage, the seller asked. He didn't even know where the orphanage was, although the seller lived very near from the orphanage [...] (Sister Matilda).

A man I interviewed who worked in a company next to the orphanage found out about this orphanage when he started working at the company a year ago. Other local people living only 300 metres away from the orphanage heard of the orphanage by coincidence. They talked to someone passing by and learned from him where the orphanage was located. A staff member admitted that before she came to work at the orphanage she had heard about the orphanage but did not know where the orphanage was located. The people I spoke to in the village across the street from the orphanage all seem to know about the orphanage. They could also tell me what kind of disabilities the children had. Through Sister Matilda I found out that there was a conflict between some people from the village and the Sisters from the orphanage. The local people used the land of the orphanage to dry their corn on which the Sisters found very inconvenient. However, the local people were positive about the orphanage and thought it was a good thing that the Sisters took care of the 'poor' children. Yet, they did not visit the orphanage. People who do visit the orphanage are most of the time Catholics who attend the local church. They play with the children or bring them some candy. They also often state that they think these children are poor.

[...] Today a woman has visited the orphanage. She brought with her six children of which three were her own. Sister Sofia knew the children from the catechism course. The children play with Tian Ya and Tian Su. Especially Tian Su is very delighted. He runs around at the courtyard and he enjoys it very much. I have never seen him so happy since I've been here. I feel so happy for him being happy [...] (Fieldnotes).

5.3.3 Local people and charity

Local Catholic people visit the orphanage sometimes and bring with them some candy or clothes. However, neither the locals nor the local Catholic church donate money to the orphanage. One Sister mentioned that people do not give money to the orphanage because the living standards in the orphanage are much better than the average living standards of local families. People do not have enough money to be able to donate money to others and do not find it necessary for the orphanage to receive extra money. Sister Matilda thinks that another reason is that people are not used to doing charity.

[...]It is because of their way of thinking. We Chinese don't have this kind of habit to donate money to somebody else. I heard that superstars in foreign countries should do something with charity so you get support by fans. Even when you're a football star, you have to do something with charity like donating money. We Chinese, we don't have a lot of people who do that [...](Sister Matilda).

However, as I spoke to the foster parent that worked for China Care he thought that the attitude towards charity was slowly changing.

[...] There are a lot of people who don't know about these kind of things. They don't worry about this problem. They don't worry about orphans. Charity is not a well-known phenomenon in China. But it is beginning to develop. It's just the beginning [...] (David from China Care).

I also experienced that my stay in the orphanage as a foreigner attracted much attention from the local people. People became curious about the orphanage. For example, a 28-year old man who worked at the neighbouring motorcycle distribution company, decided to visit the orphanage after seeing me walking around in the orphanage. He decided he wanted to help the orphanage. Another time I met a young Chinese lady in the bus. She drew my attention because she helped an old lady to get into the bus and on to a seat. The next morning she approached me at the bus station and told my interpreter that she saw me stopping at the orphanage every day. She had become curious about the orphanage and wanted to do volunteer work there. She asked for a phone number and my interpreter gave her the phone number of Sister Matilda.

5.4 The perceived future of the children

5.4.1 The relationship between future and type of disability

The way the respondents perceive the future of the children is dependent on the type disability of the child. The future of children with intellectual disabilities is perceived more negatively than children without or only minor intellectual disabilities. Children with cleft lips are expected to be adopted and live a regular life. Respondents are also more positive about children with certain skills. For example, Tian Ci, a blind and intellectually disabled boy, can sing and

play keyboard. Some staff members have hope that he can make a contribution to society by using these talents. Other children only have minor intellectual disabilities and are believed to learn skills and use their hands to make handicrafts. Children with more severe disabilities like Cerebral Palsy are expected to stay in the orphanage for the rest of their lives.

[...]There are few children who will be able to live by themselves. I think most of the children in this orphanage need to be taken care of for their whole lives. They don't have futures. [...](Sister Clare).

How the lives of these more severely disabled children will look like and how the orphanage will manage to take care of them is not an easy question for the Sisters. One of the Sisters I talked to even felt reluctant to think about this question. She answered that she simply did not think about the future of the children. Another Sister said:

[...] Maybe in the future this place will be divided in two parts: one part is the orphanage; the other part is a place where we take care of children for their whole lives [...](Sister Sofia).

I also wondered what people would think of the chances that these children will experience a regular family life with husband or wife and children. One local I interviewed was surprised when I asked her about marriage.

[...] Marriage? Do people with disabilities get married? They will never marry. They will always be alone. No one wants to marry them, except when they also have a disability. I recently watched a disabled couple getting married on television. They were both in a wheelchair [...](Local woman).

The staff members expected the children with cleft lips to get married after the operations. Also boys like Bing Bing or Tian Zhi were considered having a chance to marry in the future. Children with more severe disabilities are not expected to get married. However, during the focus group discussion the staff members agreed that the disability of the children was not the only reason for them not to get married. Because of the imbalanced sex ratio in China it is hard to marry even for healthy people.

[...] Right now in China there are more boys than girls.

- There are so many normal people who can't get married let alone these children.

- Right now the balance is unequal.

- If there are 3 men and 2 women it is for sure that one man can't get married. It's not a problem about disability [...] (Focus group discussion).

5.4.2 Adoption and fostering

The future that the Sisters wish for the children is ideally that they will all get adopted by families. The next best thing is that they will be fostered.

[...] We think having a family is very important for children [...] We just want these children to experience a warm environment [...] (Sister Matilda).

The chances of being adopted or fostered are small for children with intellectual disabilities. There are five children being fostered in the same province where the orphanage is located. They have disabilities like autism, a clubfoot, a cleft lip, genetic malformation of the body and Down's syndrome⁹. The families receive a compensation of 400 RMB or 47 euro a month. The families live in rural areas and the foster parents earn a living as peasants or working at private companies. Generally they have received no more education after elementary school or junior high school. All of them are Catholics as this is a demand from the orphanage in order to be able to foster or adopt a child from the orphanage. Most of the time the Father or Sisters of the orphanage know the foster parents. One foster parent is a former staff member of the orphanage. Another foster mother is the sister of one of the Sisters. The other foster parents came into contact with the orphanage through a Father and a Brother of the Catholic church.

One of the families will adopt the child that they are fostering. During my stay one baby was adopted by a family from a nearby province. The reason that they want to adopt the child is because they cannot have a child by themselves. I wondered if it is a shame in China if one is not able to get a child. I asked the parents and they only said that they do not talk about that and changed subject.

⁹ The foster parents did not seem to know that the child had Down Syndrome or an intellectual disability but she had this syndrome according to the documents of the orphanage

Out of respect for them I did not continue asking about this obviously sensitive topic.

Another motive for fostering or adopting the children was the will to help the ‘poor’ children. As Catholics most respondents I talked to felt it as their responsibility to look after less fortunate or ‘poor’ people.

There are also children fostered by people linked to Catholic NGOs. I talked to a foster parent who lived in Beijing and a foster mother who lived in Shanghai. Both are high educated. The foster father is linked to China Care and the foster mother to Caritas. The foster father fosters two children from the orphanage and three other children. He has one biological daughter. The foster mother in Shanghai is not able to have children by herself. She is planning to adopt her foster daughter.

Fostering children from the orphanage is very easy. The foster families stay in touch with the orphanage. The Sisters of the orphanage regularly visit the foster parents who live near the orphanage to pay the money in cash and to check whether the children are doing well. The foster parents in Beijing receive money from China Care. The foster parents in Shanghai do not receive money since their high living standard enables them to take care of the children without financial help.

Adopting a child from the orphanage is also rather uncomplicated for Chinese citizens. The orphanage demands that the foster parents are Catholic, married and have the means to support the child. They will visit the parents in advance to check this. The parents need to go to the local government to show some documents, like a residence permit and a marriage certificate. If the local government gives its permission for the adoption the parents need to go to their own local government to register the child there. If the parents do not have certain necessary documents they still can adopt the child if they have good relations within the local government. This is what one of the foster mothers who wanted to adopt her foster child told me. An adoption can be arranged within a month.

It is a different story for foreigners who want to adopt a child from the orphanage. The foster mother from Shanghai very much wanted to adopt her foster daughter. However, because she was from Singapore the adoption process was very complicated and would take a very long time without a guarantee that she would succeed.

All foster children who are old enough go to school except for one child. Her foster mother says that the reason that she does not go to school is the fact that she cannot speak.

The children in the orphanage seem to live isolated lives. If they do not have a severe intellectual disability they have a chance of getting fostered or adopted. Some might have a chance of marrying and others are expected to stay in the orphanage forever. In the next chapter we will take a closer look at the possible influence of government policies on the lives of the children.

Chapter 6

The influence of Chinese government policies on the lives of children with disabilities

6.1 The orphanage within the legal framework

I received information concerning the position of the orphanage within the legal framework from the Father and the Sisters. As the orphanage started in 1995, the orphanage was not registered. According to Chinese law, individuals cannot run a welfare institution. As a consequence, the local government was not willing to register the orphanage. The local government was also not willing to send foundlings to a national orphanage and turned a blind eye to the illegal orphanage who took on the care of all the foundlings. In 2007 a government leader of another municipality, with which the Father maintained a good relationship, offered him to move the orphanage to his municipality so it could be registered. Apparently in 2007 it had become possible within the legal framework to register orphanages run by individuals. The Father accepted the offer and now the orphanage has a legal status. With this legal status the children in the orphanage could get a registered identity. All children in the orphanage now carry the surname *Dang*. *Dang* means ‘party’. This surname indicates that the children are the children of the Communist Party. The children have the right to minimal support but only half of the children really receive the minimal support. Whether children get money from the local government depends on where they were found. If they were found within the municipality they have the right to get the minimal support from the local government. Around 16 children receive 120 RMB (14 euro) each month. However, in order to maintain good relationships with the government leader the orphanage needs to pay back 30 to 40% of this money each year. The government leader also needs to be bribed with presents. By failing to do this the orphanage will lose its legal status and this will severely complicate it for children to get an identity and to go through official adoption procedures.

As a consequence, the financial situation of the orphanage is not good and has worsened in the past year due to the financial crisis. With the Father and the Sisters I discussed the financial situation and took a look into the cashbook of the

orphanage. On average the orphanage needs 18,000 to 26,000 RMB a month.

They spend the money on:

- Coals (20,000 RMB each winter);
- Rent for the building (27,450 RMB each half a year);
- Salary for caretakers and two foster families (between 5,000 and 8,000 RMB per month);
- Medical costs (doctors' visits, hospital stays, medication);
- Study costs Sisters (1000 RMB each month)¹⁰.
- Food and drinks;
- Baby products (diapers¹¹, milkpowder);
- Water and electricity;
- Transportation costs (gasoline, toll);
- Housekeeping expenses;
- Reparation costs;
- Phone bills;

The income is mostly from individuals (acquaintances of the Sisters, religious people, foreigners) and the NGOs. However, there is no structural income except for 20,000 RMB every three months from Caritas, a Catholic NGO from Shanghai. Unfortunately, the financial crisis also affected this organization. Most of the donors are expats from Singapore or the United States of America working in Shanghai. Due to the crisis many companies send their people back to their native country. Because of this the amount of donations declined and the organization cannot guarantee the structural donation to the orphanage anymore. The shortage is set off by Father Chen who uses a part of the earned money from the Catholic eyeclinic to help the orphanage survive. However, since the government arranged that national hospitals can pay people 75 per cent of their costs back there has been a decline in patients visiting the Catholic eyeclinic. Previously, Father Chen also used income from the kindergarten for the orphanage but as mentioned before, the kindergarten has been closed by the

¹⁰ The study costs for Sisters are not really study costs. One sister went to a rehabilitation centre in Shanghai and another sister to a welfare institute in Beijing for a sort of internship almost for free. The above mentioned costs are the living costs of the Sisters.

¹¹ Since last year the diapers have been replaced by cotton sheets to save money

government. The Father is trying to make money to support the orphanage but this is very difficult.

[...] I really want to start an organization to support the orphanage. I used to run a kindergarten. Later the major closed the kindergarten. The major didn't allow me to continue that kindergarten. It's a pity. That kindergarten was the best kindergarten in the city [...] I also bought another land. I want to use that land to make money and use the money to support the orphanage. Because of the financial crisis last year and this year it's difficult to make money by using that land [...] (Father Chen).

Despite the financial problems the Sisters stay confident:

[...] We believe God will help us. We depend on our religion [...] Of course we do not only wait for bread from God. We try our best to do this. For example, like business men, when they don't have money to do business they will feel anxious. We at least have religion. We believe we can continue to do this if we try our best [...] Facts prove that if there are five children we can support them, if there are 10 children we still can support them. If there are 20 children we still can support them [...] (Sister Clare).

Next to financial support the orphanage also receives material goods from the NGOs in the form of clothes, toys, educational material, revalidation equipment and medical goods. This is not always used because the directions for use are mostly in English (which they do not speak) or because of a sort of frugality. For example, I suggested I could buy some toys for the babies because I never saw them playing with anything. Sister Sofia however told me that they have two big boxes with toys that are never used. The staff members are afraid they lose the toys or break it so they do not dare to use it.

6.2 Children and the one-child policy

In the county where the orphanage is located it is allowed to have one child. If people get a second child the government will fine them. According to the local people a fine is between 940 and 1175 euro. Knowing the salary of the staff members (around 600 RMB or 71 euro a month) this is much money. However, if you have relations with someone working at the government you can bargain in order to lower the fine. Despite the fine, some people still get a second

child. According to the local people and the staff members the reason is that the firstborn is a girl and they rather want to have a boy.

If the firstborn is a child with a disability, you can get permission from government to have a second child without having to pay a fine. However, some of my respondents were not aware of this exception and thought that people still would be obliged to pay a fine.

It is not easy to get permission from the government to have a second child. The procedure to get a permission certificate is said to be very complicated. Because of this Father Chen and several staff members stated there is a correlation between the one-child policy and the abandonment of disabled children. Because of this policy there is a bigger chance that a child will be abandoned and will end up in the orphanage.

6.3 Children and eugenic policies

Most people I talked to were aware of the measures the government took to prevent disabled children from being born. Before you can get a marriage certificate from the government you need to do a health check. If you have any genetic or venereal diseases you are not allowed to have children. People who are relatives will not be allowed to marry because of the increased risk of having disabled children.

However, people in rural areas do not strictly follow these rules. People marry without having a health check and just get children. They can buy a marriage certificate or get a certificate through personal relationships within local governors. One female peasant stated:

[...]The local government does not care whether you have diseases or not. You just get married [...] (Fieldnotes).

An often heard explanation for the abandonment of disabled children was the wish of parents to have a healthy or 'normal' child. Disabled children were sometimes thought of as a burden because they cannot make a contribution to society.

6.4 Children and disability policies

Families with children with disabilities do not receive any support from the government. They are on their own when it comes to taking care of their disabled child. One lady from a nearby village stated:

[...] Never will the government support families with disabled children
[...] Especially in the rural areas will the local government not support these children [...] (Fieldnotes).

I reached the same conclusion when I talked to two staff members who happened to have children with disabilities. However, adults with disabilities can get a disability certificate from the China Disabled Persons' Federation. They need to show a proof of disability which they can get at the hospital. With this disability certificate they can get money to build a house if you do not have a house or the house is in bad condition. There are disability certificates for different types of disabilities, i.e. visual, hearing, verbal, intellectual, physical and mental disability. I met an adult on the street who missed an arm and he told us that he also had a disability certificate.

The government is also making attempts to create working places for people with disabilities. For example, there was an instant noodle factory in a nearby city where they hired people with disabilities. One of the staff members sent her disabled daughter to this factory. The other staff member told me of a plan of the local government to start a rabbit breeding farm where people with disabilities could work. In the end however, the plan did not come to realization.

There is no visible attempt from the local government to educate or rehabilitate the children in the orphanage. The NGOs involved in the orphanage try to fill the gap between policy and practice. They want to try more than just give financial support. They also want to change the way of thinking about children with disabilities. The message often expressed by these NGOs is what can be called the message of *normalization*. According to this view, the children should not be viewed as persons with deficits but persons with possibilities. The children are considered pupils who need to develop themselves and live like 'normal' people (Wibaut, Calis & Gennep, 2006).

[...]I think these children should not be living like pets because they are human beings. Although they have a disability like cerebral palsy, they are still human beings. They should receive education so that they can be real human beings [...] (David from China Care).

[...]I was quite shocked when I saw D. peeing while he was eating. This is not what normal people would do, so he should learn not to do that during dinner either [...] (Megan from Huiling).

Chapter 7

Conclusions and recommendations

During a period of three months I conducted a qualitative study in an orphanage in China to explore the position of children with disabilities in their community. The main research question of the study was:

What are the main policies and explanatory models that are reflected in the stakeholders' perceptions of the position of children with different disabilities of the Qing Chen orphanage in Mayun County?

The information I collected has been discussed in the previous chapters. During my research I did not only listen to the adult stakeholders (the Father, Sisters, staff members, local people, foster parents, adoptive parents and NGOs) but also got involved in the daily lives of the children themselves to try to learn from them. In the next sections, the conclusions of the finding will be discussed. First I will discuss the explanatory model of disability. Then I will elaborate on the position of disabled children in society. Further, I will discuss the influence of policies and the role of NGOs on the lives of children with disabilities. I will conclude by giving recommendations to improve the position of children with disabilities and on further research in the field of disability.

7.1 Explanatory model of disability

The way the stakeholders in my research explain disabilities is mainly in accordance with the Western definitions of disability. The children are diagnosed by doctors, mostly in bigger hospitals in Shanghai. The orphanage got into contact with these hospitals through an NGO.

The mentioned causes for disabilities are medication use of mother during pregnancy, genetic diseases of father or mother or consanguineous marriages. The respondents state that people in rural areas would have more traditional explanations of disabilities influenced by Confucianism. Some rural people who

are less well educated may believe that having a disabled child is a punishment for doing something wrong in their previous life. They will feel shame and are afraid to lose face. This is in line with the statement of Holroyd (2003) that ‘abnormal’ bodies are viewed negatively by Confucians and is considered a punishment from ancestors or deities. However, I did not meet anyone who was personally convinced of these explanations.

The children of the orphanage are treated in hospitals and revalidation centres. There is a big difference in the quality of the local hospitals and the hospitals in the bigger cities, like Shanghai. One of the NGOs offers financial support to make it possible for the children in the orphanage to receive necessary operations. They also brought the orphanage into contact with another NGO that offers free cleft lip operations for children who otherwise could not afford this.

The NGOs offer some of the children treatment in a revalidation centre. Under the influence of the NGOs the orphanage also started to use recovery training to improve the condition of the children. Chinese massage is one of the treatment methods they use. According to the Sisters prayer also plays an important role in the treatment of disabilities.

It seems clear that the predominantly Western biomedical way of explaining disabilities is greatly influenced by the NGOs involved with the orphanage.

7.2 The position of the children in their community

All children in the orphanage are abandoned by their parents. This makes them ‘unwanted’ children. Possible reasons for abandoning the children as mentioned by the stakeholders are the emotional and financial burden for families to take care of a disabled child. The explanatory model of disabilities of people who live in rural areas may differ from the more Western biomedical explanatory model and makes them feel ashamed and afraid to lose face if they give birth to a disabled child. Children with disabilities often need medical care that poor families in this area cannot afford. The children will need supervision most of the time so the family will lose income if parents have to stop working or work less. Further, the child cannot take care of its parents when they grow older. After the parents die the responsibility to take care of the child will lie on the shoulders of

one of the siblings of the child. This may negatively affect their chance of getting married. The government provides little support to adults with disabilities but no support to families who have to take care of the disabled child.

The children are taken care of by the Catholic Sisters and the staff members. The children are seen as poor, vulnerable and in need of care. Like the early Christian missionaries, the Sisters see it as their duty to take care of these children. They view the disabled children as God's children as is reflected in the title of this thesis. As Sister Clare stated it:

[...]We have to take care of them. They are God's children. Nobody takes care of them, so we should take care of them [...]

The life of the children and the interaction with others mainly takes place between the walls of the orphanage. Here the children develop friendships if they are capable of doing that and receive the warmth of the Sisters and staff members who work there. There is not much contact with the outside world. The orphanage is not known to all the local people. Some staff members did not know where the orphanage was located before they came to work there. The Sisters admitted that in the beginning they felt reluctant to promote the orphanage because they were afraid it would attract more foundlings. However, this attitude is changing according to the Sisters. Next to the Catholic people who sometimes visit the orphanage to bring food or clothes, to play with the children or to talk to the staff members, I met at least two people from 'outside' who became more interested in the orphanage. It seems that the presence of foreigners makes the orphanage more attractive. The local people want to help, but the idea of charity is apparently not yet widespread in China. However, some respondents talked about a changing attitude towards charity.

The children with intellectual disabilities have a small chance of being fostered or adopted. The general expectation is that these children will stay in the orphanage for their entire lives. By some stakeholders they are considered as children without futures. The way the future looks like for fostered children depends on the family. The living standards of foster families in bigger cities like Shanghai and Beijing are much higher than the living standards of local families.

Some children from the orphanage end up in a poor rural area whereas other children live in a beautiful apartment in the rich centre of a big city.

7.3 Children with disabilities and the role of the government

Since the orphanage is a Catholic orphanage, it is strictly monitored by the government. The orphanage received legal status in 2007. Due to the legalization the children found within the local municipality can have an official identity and can officially be adopted. However, this legal position can only be maintained by bribing government officials. A large part of the minimal support for the children is used for this.

Different state policies affect the lives of the children in the orphanage. The eugenic policies aimed at minimalizing the chance of children being born with disabilities is not very strictly followed in the rural area where the orphanage is located. A health check is required before marriage to detect any genetic or venereal diseases. However, the local people marry and have children without doing the health check. The eugenic idea of a 'healthy nation' is reflected in the wish of people to have healthy children who can make a contribution to society. Disabled children as a consequence are viewed as a burden because they cannot contribute to society.

Another policy that influences the lives of disabled children is the one-child policy. According to the one-child policy it is possible for parents to get permission to have a second child when the firstborn is disabled. Some people I talked to were not aware of this exception. However, it is rather difficult to obtain permission from the government. The one-child policy could therefore, in the perception of the stakeholders, increase the chance of disabled children being abandoned.

Although several policies have been introduced aimed at the improvement of the lives of disabled people this research indicates that there is a gap between policy and practice. The children do not receive any support from the government for their education and medical care. The non-governmental organizations play a big role in filling this gap. Their contribution to the improvement of the quality of life for the children in the orphanage runs like a red thread through this thesis. They help the children to receive education and medical care and play a big role in the process of professionalization taking place in the orphanage. The first steps

have been taken to achieve the normalization of children's lives in which they learn and develop within their abilities.

7.4 Recommendations

7.4.1 The voice of children in research

Future research should be careful when gathering information from children with disabilities through participatory methods like drawings. My findings indicate that whether children like certain activities is culture specific. Further, interpreting what children with intellectual disabilities try to say can be highly suggestive. It is important to give children with disabilities a voice when doing research concerning their lives but this should only be a mean to collect useful data. Not the use of the voice of disabled children but doing good research that gives us a better understanding of their lives should be the goal. Using participatory data from children with disabilities does not make research good research per se.

7.4.2 Children with disabilities in China

More research is needed in order to get an insight in the lives of children with disabilities in China. Future research should concentrate on the interesting role of the NGOs in China and the development of charity.

Future research should offer a more critical and realistic view on China. It often happened that I told people about my research topic and people responded: "I am sure the situation for disabled children in China is terrible". On the one hand it has to break the prejudices of people who think only negatively about China and its disabled population. On the other hand we should not be blinded by the rapid economic growth of China and its positive implications for the future. As one of the members from Caritas mentioned in an email:

[...] To many foreigners who have never been in China or stay in China's big cities like Beijing and Shanghai, China is a fast growing economic power that offers great opportunities for future. Little do we know that most of China is still very under-developed [...]

The international community should not close its eyes for this underexposed side of China. This research shows that it is not enough for governments to sign conventions that guarantee the rights of children and disabled people and to develop policies. The gap between policy and practice needs to be closed. Corruption is one of the reasons why policies are not rightly implemented and needs to be rooted out. Further, the government should acknowledge the great work of NGOs to improve the lives of disabled children and meet their rights and should support their work in every possible way. Finally, more attention needs to be given to families in rural areas who carry the burden of having a disabled child all by themselves. Government and NGOs should offer them financial and emotional support. They should be provided with more information on the possible treatments of disability. Medical care, education and rehabilitation need to become available for all. Through this having a disabled child will become more bearable for families so that abandonment of a child can be prevented.

Abbreviations

AAMR	American Association on Mental Retardation
CCF	China Care Foundation
NGOs	Non-governmental organizations
RMB	Renminbi
UN	United Nations
WHO	World Health Organization

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APPENDICES

Appendix A. Simplified timeline of the history of China

1894-1895	Sino-Japanese war
1911	Fall of the Qing empire
1911-1949	Republican China
1941	The Committee for the Study of Population Policies, founded by the Ministry of Social Affairs
1939-1945	World War II
1945-1949	Civil war (Xun, 2002)
1949	Liberation: the establishment of the People's Republic of China (Stone, 1996; Lewis, Chong-Lau & Lo, 1997)
Mid-late 1950s	Rapid collectivization, provisions for people with impairments (Stone, 1996)
1959	China's first modern school for children considered mentally retarded (Lewis, Chong-Lau & Lo, 1997).
1960s	The Great Leap Forward
1963	Famine (Lewis, Chong-Lau & Lo, 1997)
1966 – 1976	Cultural Revolution: thousands of people lost their lives and many community structures disappeared. Academic credentials and other forms of intellectual achievement were devalued and teachers were reviled (Lewis, Chong-Lau & Lo, 1997). The Chinese government made efforts to raise women's social status (Zhang, Kao & Hannum, 2007)
Mid-1970's	Reestablishment of peace (Lewis, Chong-Lau & Lo, 1997)
1973	The "later, sparser, fewer" policy was formally introduced (Zhang, 2001)
1979	Deng Xiaoping: market-oriented economics: economic prosperity is the end goal of the Chinese government. China still straddles the North-South divide, has no national security system and is hell-bent on modernization (Stone, 1996). One-child policy implementation (Xun, 2002)
1980's	Re-opening of China's doors to the West and increased involvement of the Chinese government on the world stage (Stone, 1996)
1981	Involvement of China in the International Year of Disabled People
1982	Adoption of the Constitution of the People's Republic of China, stipulating the right to education for all citizens (Lewis, Chong-Lau & Lo, 1997)
1986	Law relating to compulsory education where regional governments were urged to establish special schools or classes for the blind, deaf and mentally retarded (Lewis, Chong-Lau & Lo, 1997)
1987	First national sampling survey of disabled people
1989	Adoption of eugenic regulations
1991	Law on the Protection of Disabled Persons
1928-1992	Involvement of China in the United Nations' Decade of Disabled Persons (Stone, 1996)
1992	Adoption Law (Zhang, 2001).
1993	Draft of eugenics law
1994	Law on Maternal and Infant Health Care (Stone, 1996; Xun, 2002).

Appendix B. Information about the children in the orphanage according to orphanage documents

Name	Sex	Disability	Birthday	Adoption date	Information about abandonment
Dang Tianci	Male	Blind, mentally retarded and epileptic	01-01-90	08-11-01	Found by religious citizen
Dang Tianbing	Male	Had an operation because of congenital heart disease, is mentally retarded	01-05-96	08-12-98	Found in county by religious citizen
Dang Tiancheng	Male	Cerebral palsy	01-04-97	01-12-97	Found in county by Brother
Dang Tianya	Male	Cerebral palsy	01-03-98	25-03-02	Found in hospital by hospital personnel
Dang Tianzhi	Male	Had an operation because of spina bifida, has a clubfoot and water head	01-05-98	01-05-98	Found in city by citizen
Dang Tianhai	Male	Minimal water head, malformation of right ear	01-10-99	26-05-01	Found by policemen
Dang Tiansu	Male	None	01-03-00	01-01-05	Blind father, mother left family.
Dang Tianhui*	Female	Malformation of left leg	01-02-01	22-04-01	Found near company in city by Sister
Dang Tianbao	Female	Cerebral Palsy	01-01-02	01-03-02	Found near old orphanage by Sister
Dang Tianli	Female	Cerebral palsy	01-06-03	21-03-04	Found by staff member near old orphanage
Dang Tianning	Male	Cerebral palsy, congenital cataract (clouding of the lens of the eye)	01-03-04	01-03-04	Found by religious person
Dang Tianlu*	Female	Clubfeet	01-10-04	16-02-06	Found by local government
Dang Tianxue	Female	Cerebral palsy	01-01-05	09-03-06	Found by local government
Dang Tianyu*	Female	Infantile autism, cleft lip	01-01-05	16-02-06	Found by local government
Dang Tianen	Female	Cerebral palsy	01-02-05	30-07-05	Found in county by religious person
Dang Tianduo*	Male	Genetic disease, asymmetric body	10-10-06	10-10-06	Found by local government
Dang Tianpan*	Female	Tang syndrome, congenital heart disease	10-10-06	27-08-07	Found by Sisters near orphanage
Dang Tianfei	Female	Cerebral palsy, clubfoot	01-01-08	30-10-08	Found by Sister in eyeclinic
Dang Tianpiao	Female	Had an operation on cleft lip and umbilical (belly button) hernia	10-03-08	10-03-08	Found by local government
Dang Tiangong	Male	Had an operation on cleft lip	28-04-08	28-04-08	Found by Sister near eyeclinic
Dang Tiangkang	Male	Had an operation on cleft lip	20-07-08	24-07-08	Found by Father in nearby county
Dang Tiande	Male	Had an operation on cleft lip and hypospadias (abnormally located opening in the penis)	20-08-08	24-08-08	Found by local government
Dang Tianchang*	Male	Damage to brain centres caused by increased levels of bilirubin	27-09-08	03-10-08	Found by Dutch foreigner from donor organisation near church in city
Dang Tiandai	Male	Waterhead	08-10-08	25-12-08	Found by citizen near eyeclinic
Dang Tianhe*	Male	Narrowing or absence of a part of the intestine	20-10-08	24-10-08	Found in nearby county by Father

* These children are fostered or recently adopted and do not live in the orphanage

Appendix C. Characteristics of children at the orphanage (n=25)

Characteristics		Number	Percent
Sex	Male	15	60
	Female	10	40
Age	0-1	8	32
	2-3	2	8
	4-5	6	24
	6-7	1	4
	8-9	3	12
	10-11	2	8
	12-13	1	4
	14-15	1	4
	16-17	0	0
	18-19	1	4
Age of abandonment	0-1	21	84
	2-3	1	4
	4-5	2	8
	6-7	0	0
	8-9	0	0
	10-11	1	4
Disability	Waterhead	3	12
	Clubfoot	3	12
	Cerebral Palsy	8	32
	Epilepsy	1	4
	Malformations	2	8
	Intellectual disability	2	8
	Cleft lip	5	20
	Congenital heart disease	2	8
	Spina bifida	1	4
	Autism	1	4
	Tang Syndrome	1	4
	Others	7	28
	None	1	4

Appendix D. Characteristics of staff members from the orphanage (*n*=15)

Characteristics		Number	Percent
Sex (<i>n</i> =15)	Male	3	20
	Female	12	80
Age (<i>n</i> =12)	20-29	1	8
	30-39	4	33
	40-49	3	25
	50-59	2	17
	60-69	2	17
Education (<i>n</i> =12)	None	1	8
	Elementary school	2	17
	Junior middle school	3	25
	Senior middle school	2	17
	Higher education	4	33
Religion (<i>n</i> =14)	Catholic	8	57
	Christian	3	21
	None	3	21
Family composition (<i>n</i> =11)	Married, no children	0	0
	Married with children	5	45
	Not married, no children	5	45
	Divorced, no children	1	9

Appendix E. Characteristics of foster- and adoptive parents (n=12)

Characteristics		Number	Percent
Age (n=10)	30-39	3	30
	40-49	5	50
	50-59	1	10
	60-69	1	10
Education (n=8)	Elementary school	4	50
	Junior middle school	2	25
	Senior middle school	1	13
	Higher education	1	13
Religion (n=12)	Catholic	11	100
Family composition (n=12)	Married with children	7	58
	Married, no children	4	33
	Widow	1	8
Profession (n=8)	Private company	3	38
	Non-gouvernemental organisation	1	13
	Peasant	3	38
	Not employed	1	13

Appendix F. Characteristics of local people (*n*=5)

Characteristics		Number	Percent
Sex (<i>n</i> =5)	Male	3	60
	Female	2	40
Age (<i>n</i> =5)	20-29	1	20
	30-39	2	40
	40-49	1	20
	50-59	1	20
Education (<i>n</i> =5)	Junior middle school	1	20
	Senior middle school	1	20
	Higher education	3	60
Religion (<i>n</i> =5)	Catholic	2	40
	None	3	60
Family composition (<i>n</i> =4)	Married with children	3	75
	Not married	1	25
Profession (<i>n</i> =5)	Private company	3	60
	Hairdresser	1	20
	Medical practitioner	1	20

