

China Vision

英华残障人教育基金会

Supporting rights for people with
disabilities in China

CRPD LIVES

Collecting Testimony and Identifying Actors in China's Independent

Disability Rights Movement

May 2013 – July 2014



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EXTRACTS FROM INDIVIDUAL STORIES

All the participants in the CRPD Lives project had read the 'CRPD and Me' pamphlet before writing down their individual stories. They come from many parts of China, both rural and urban, and the selected quotations below reflect authentic experiences of disability in China today.

EDUCATION

"I have a congenital disability which has given me a deep inferiority complex and I've grown up with discrimination. I was ridiculed by my classmates at primary school. (...) Once, when everyone went downstairs to do exercises I was the only one left in the classroom together the teacher, who was about to go back to the staff room. Another teacher from the class next door passed along corridor and when he saw that I hadn't gone out he asked if I wasn't well. Then my teacher said something I've never forgotten: ' Oh, he's a just a cripple (残废 canfei).' I don't know how the teacher in the class next door responded, but my eyes reddened I wanted to say, Teacher, it's just that my feet are no good, I'm not a cripple! I can manage on my own, I can go to school, I can work, I could become a scientist (that was my dream when I was little).... But, I couldn't get the words out, or else I simply didn't dare to say that."

Chen Zhongbao, Jiangmen, Guangdong

"In my third year at high school my aunt accompanied me to school. My parents paid her 2,000 yuan each month (1,000 was for a service fee, and 1000 was for my daily living expenses), so in a single year these fixed costs amounted to around 20,000 yuan, and this didn't not include my tuition fees and the cost of books, clothes, etc. It was also very hard for my aunt to accompany me because the classroom was on the second floor: she's small woman and she had to carry me up and down stairs several times a day."

Xiong Su, student with physical disabilities, Hubei

"Jingmen [City] has only one public "special education school". It is limited by various policies and only a very few children with autism can attend the school for free. The rest of the children have to attend private institutions. Older children have to stay at home. This has resulted in tremendous financial and psychological pressure on parents. Most of these children cannot enjoy their right to education, as defined in the CRPD. Most children with autism and their parents don't know anything about the Convention. They don't know how to protect their own rights."

Tang Qijun, parent of child with autism, Jingmen, Hubei

"Li Xiaoxue, who has a visual disability, is from the city of Zhongwei in Ningxia Huimin Autonomous Region. Her uncle and aunt were both teachers in the village school and so the school was forced to accept her as an 'auditing student'. This status came to an end after three years because to pursue a higher level of education she would have had to leave home for the town, which was too far away. Cai Zhenzhou is a visually impaired young man. His primary school language

teacher mocked and ignored him because of his disability. This made him so depressed that he left school.”

Xie Jianjian, teacher with visual disability, Shaanxi

“Before learning about disability rights I thought that it was excusable that my classmates and teachers excluded me, ignored me and locked me up in the classroom to keep me safe. But after I read the CRPD pamphlet, I felt that this was all discrimination against us disabled people and that there was a lack of understanding about disabled people. It violated Article 5 of the CRPD: equality and non-discrimination. And Article 8 says: raise awareness. They failed to treat me fairly and make things convenient for me according to my individual needs, and they also failed to act according to the inclusivity target of providing education for all without discrimination. There was a violation of Article 24 of the CRPD: Effective support measures appropriate to individual circumstances are provided in an environment that is most conducive to the development of learning and social skills.

Wang Yurong, self-advocate with a visual disability

“We long for genuine public activities and policy advocacy to help all special children along the road of inclusion; for example, talks on inclusive education for teachers in the ordinary schools system, short films for the public on inclusive education, or help with teaching materials so that children can attend inclusive schools. We envisage this kind of future: all school principals and teachers will understand what inclusive education is and recognize its positive significance. Each student will happily accept their out-of-the-ordinary classmates and understand them and get along with them, and happily give them the help they need. Each of these special children will not only have their own place in the classroom but will also have their own friends. Inclusive education will no longer be an unfamiliar word, but will be the civilized way to go!”

Ke Qian, parent of child with autism, Shantou, Guangdong

“I have been discriminated against as a disabled person in education and in work. When I was in the first year of primary school, I was excluded from the education I should have received at school because of my visual problems. So my primary school life was spent going from pillar to post and from then on I had lessons at the homes of nine different relatives and it was only when I was 10 years old that I returned to my parents’ home. But because my grades were not up to the level required to enter middle school, it meant that once again I left my parents to study outside, and it was only when I was working that I finally returned to be with them. After I started work, again because of my visual problems, my employer excluded me.

Duan Hongbo, self-advocate with visual disability, Baiyin, Gansu

EMPLOYMENT

"We mostly depend on government quotas for employment when looking for work, but if you choose this method, then it means you lose the right to enter society. From my point of view, this dependency system is a system in which the employers just do what the government asks them to do. Every month you are given a few hundred yuan, every day you are made to stay at home with nothing to do. Seen like this, it's equivalent to the enterprise giving us charity, it doesn't in any real sense give us the right to work.."

Guo Yilin, county south of Beijing

"I am physically disabled in my upper limbs. At work I use my feet to operate a computer. My feet can type as agilely as someone's hands. Originally I was responsible for work connected with levying the disability protection fund, and I was pretty competent. But I took part in a meeting chaired by a leader, and when he heard my boss say that I used my feet to do my work, he criticized my boss saying that this kind of work involved daily contact with enterprises and institutions, and that someone who typed with her feet would affect the image of our workplace and I should be replaced immediately. Isn't this discrimination against me as a disabled person, and not recognizing my abilities?"

Zhang Weifang, physical disability, Nanning, Guangxi

FAMILY AND SOCIETY

"Xiaoji is autistic, an intellectually disabled teenager, who has never been diagnosed, but just grew up in a village home in silence. Parents, relatives, neighbours, teachers and school classmates usually ignored him and no one ever mentioned his "condition" or tried to help. His family might have been afraid of losing face, which is a typically traditional Chinese view of having a disabled child. And for the school-teachers it meant giving up on him just as long as he wouldn't disturb the other students, so it was only by chance that Xiaoji got just two marks in his final school exams."

from Jiang Anxi's consultancy report on Wang Li's project

"Surveys show that most disabled parents [in China] choose to have their child brought up by grandparents. There are many parents who, either because they are completely blind or have some other visual disability, decide not to become involved in their child's upbringing, entrusting their upbringing and education to a sighted person or someone who is more able."

Han Yao, self-advocate with a visual disability, Shenyang, Liaoning

"The project in Gaofeng and Zhongxin villages proved an effective way of raising awareness of disability. It led to a better understanding of disabled people's living conditions as well as the attitude of non-disabled villagers towards disabled people. It encouraged disabled people to leave their homes and go outside and integrate with the community, and it helped non-disabled villagers to understand the concerns of disabled people. Xiong Su's personal growth and changes in her own family should also not be overlooked."

from Cai Cong's consultancy report on Xiong Su's project

"In everyday life, not having the power to make decisions or choices, almost all disabled people are passive recipients."

Xiong Su, student with physical disabilities, Hubei

ACCESSIBILITY

"You don't often see wheelchair users on the streets of Urumqi because there are obstacles everywhere. It's difficult to go out so disabled people tend to stay at home. The less you go out the more the tactile pavements are obstructed, the more the toilets for disabled people are locked up or used for storage. It becomes more and more of a problem and so it's a vicious circle. 'Accessibility' has just become a slogan or something that is just for show."

Zhang Yongxia, wheelchair user, Urumqi, Xinjiang

"There's a very strange phenomenon in China. There are as many as 84 million disabled people – and this number doesn't even include old people. This is a population bigger than the entire population of many countries. But we rarely see disabled people on the streets, in malls, parks or other public spaces. I think on one hand this is the result of the non-accessible environment, and on the other, it's also because disabled people and their families are embarrassed at being stared at in public."

Liu Yan, Beijing

THE CRPD

"The CRPD touches on issues deep in our hearts. It is a legal weapon, stressing several principles: human dignity, individual autonomy, being treated without prejudice, and integration into society. Article 27 talks about work and employment and the necessity of integrating into society through work. In future, every family must face this and I hope that each family will read this Article carefully."

Sun Daimei, parent of child with intellectual disability, Jingmen, Hubei

"I've just looked at the document [the CRPD pamphlet] very carefully, but I think many of the descriptions are based on the CRPD and this convention does not have much validity in law. Its implementation can only rely on people's compassion and social responsibility. The quality of citizens is going up steadily, but if there is nothing legal to support it, the CRPD will just be seen as a beautiful vase."

Guo Yilin, county south of Beijing

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disabilities in China

CRPD LIVES

*Collecting testimony and identifying actors in China's independent
disability rights movement*

INTRODUCTION

The main purpose of this project is to build on the China Vision, IDA, HKU, One Plus One and other NGOs have done over the past three years, in order to engage with the next stage of CRPD monitoring.

1. [Background and project description](#)

Monitoring CRPD compliance in China is a long and complex process. The CRPD Committee's Concluding Observations, published in September 2012, identified a number of key areas of concern, some of which relate to fundamental differences in concepts of disability, human rights and social inclusion. China's government and Party institutions, including the China Disabled Person's Federation itself, are largely rooted in the medical and welfare models of disability and, while the CDPF often uses the language of rights in its publicity, its approach in practice (including its response to the CRPD Committee's questions) demonstrates a poor understanding of the rights-based model and a general failure to accept the social/human rights paradigm.

There is still a wide gap between the obligations China undertook when it ratified the CRPD in 2008 and the realities on the ground. Yet the CRPD remains a powerful tool in the hands of international rights bodies, Chinese political reformers and civil society activists. There is at least a consensus that implementation of the Convention is a long-term process involving engagement with multiple stakeholders.

One problem that has become apparent is the paucity of concrete testimony and case studies to illustrate the experience of disabled people in China. A second concern is the difficulty in identifying disabled people around the country who are active (or potentially active) in engaging with disability issues from a rights perspective. Our approach in this project has been to work with individuals outside the state institutions, who have a profound, experiential understanding of the realities facing disabled people and are willing to work within their communities to promote and monitor compliance with the CRPD's principles.

During this first year (2013-14) we have invited testimony from disabled individuals around the country, and followed this up by selecting 10 outstanding advocates to run small-scale, local projects

or activities. Rather than concentrating participants in one centralized meeting, this devolved, localized approach has allowed for a more focused use of resources and the collection and analysis of real life testimony, while encouraging engagement by people within their own communities.

2. [Project structure and implementation](#)

Since 1st May 2013 this initiative, implemented jointly by China Vision and Beijing One Plus One, has mainly made use of the existing human resources at our disposal and has not required any additional full-time staff. The project was coordinated mainly by Lu Han and Stephen Hallett (China Vision), with support from Cai Cong and other staff at One Plus One. During the first half of the project a pamphlet - *CRPD and Me* (我与CRPD) - was produced and widely distributed both in print and electronic versions (see details below). A panel of five consultants was assembled to read submissions, select local advocates, provide distance mentoring and observe community-based activities. These consultants were:

Jiang Yitong (Rights Practice – formerly PIDLI)

Zhou Haibin (ILO)

Fu Gaoshan (OPO)

Cai Cong (OPO)

Jiang Anxi (China Vision)

Lu Han (China Vision)

Initial distribution of the pamphlet was accompanied by a call for submissions of around 1,500 characters each, sent online or by mail. We explained that these testimonies should combine the writer's new understanding of the CRPD and disability rights with her/his own experience of being a disabled person in China. A small grant (RMB 5,000) would be awarded to each the 10 most promising candidates to organize a one-day workshop or other advocacy within their own communities, to be observed by one or more of our panel of consultants during the second half of the project (Nov 2013 - April 2014).

By November 2013 we had received a total of 78 submissions. The project team read all of these and logged them on the project database, before beginning to make recommendations for the 10 most compelling submissions. These were judged on the basis of relevance to CRPD principles, illustrative power, advocacy potential and other criteria. Consultants then contacted successful candidates by telephone, discussing their testimony and mentoring them in preparation for each of their respective mini-projects. Each consultant worked with one or more advocates.

Between February and April 2014 each consultant travelled to advocates' home provinces to observe activities and get a more in-depth perspective on their lives and the local situation. During the final phase of the project consultants discussed their findings with the project team, wrote up their evaluations and provided supplementary information for the project database.

3. [Project activities](#)

- May – June 2013: project preparation. Writing and editing of pamphlet “*CRPD and Me*”. This involved consultation with several groups, including OPO, RARL, Ni Zhen, Yirenping and Tinajin Yuesheng, some of which contributed content. The pamphlet contains the following

sections:

“CRPD and Me”

Introduction and how to submit your own testimony

(1) What is the CRPD? Background to the CRPD and concepts of human rights and equality which it enshrines; how the CRPD was conceived and drafted; process of ratification, monitoring and states parties obligations etc.

(2) Comments about the CRPD by young people from other developing countries

(3) 10 important articles in the CRPD:

Article 5: Equality and non-discrimination

Article 8: Raising awareness

Article 9: Accessibility

Articles 12, 13: Equal recognition before the law; access to justice

Article 19: Independent living and inclusion in the community

Article 21: Freedom of expression and access to information

Article 24: Education

Article 27: Employment

Article 28: Adequate standard of living and social protection

Article 33: Implementation and monitoring

(4) Questions and answers: the CRPD in the words of disabled people themselves

- *What is the difference between “canji” and “canzhang”?*

- *What are the implications of real equality?*

- *What is inclusive education? How does it differ from special education?*

- *Who makes the big decisions for us?*

- *How can I use the CRPD in advocacy work?*

(5) How you can participate (how to write and make submissions to this project)

(6) Key vocabulary

The pamphlet was designed and printed in July 2013. 100 copies were initially printed and an electronic version of the pamphlet has been widely distributed via OPO, Yirenping, Talang and other websites. Further copies have also been printed as required, as many other groups around the country have asked to use the pamphlet in their own advocacy work. “CRPD and Me” has been very well received and we think that it will provide the basis for future CRPD advocacy beyond the current project, with content added as required.

- Ongoing pamphlet distribution through various different disability rights networks including:
 - OPO network
 - YRP network
 - Talang network

August 2013: Kick start for collecting submissions at OPO’s “Young Leaders with Disability Workshop”:

From August 25th to 31st, OPO organized the 2013 Young Leaders with Disabilities Workshop in Wuhan. 40 disabled self-advocates from over 20 provinces and cities came to Wuhan to participate in the workshop. During that week participants learned about the background and content of the CRPD, and engaged in lively discussions about disability rights. During one of the evenings Xie Yan and Lu Han also introduced the CRPD Lives project and discussed details with the participants.

Most of the participants were in their 20s and 30s; many read the pamphlet and had already written their submissions before the workshop. From our conversations we could tell that they all had stories to tell and most had experienced profound difficulties in their lives. As a result, they all thought a lot about their living conditions and the environment they lived in. Many of them had already started trying to make changes through local advocacy. Learning about the CRPD and being together with so many self-advocates from all over the country gave them incredible confidence and a sense of solidarity. (Lu Han)

- July – Dec 2013: Collecting and reviewing submissions.
- Sept-Nov 2013: forming consultant group. So far this includes Lu Han, Cai Cong (OPO), Jiang Yitong (Rights Practice), Maggie Sun (HI) and possibly Yu Fangqiang (TXG) and Liu Jiajia (EJI). (The last two still need to be confirmed, depending on their time and availability.) The first consultants meeting, reviewing initial submissions and planning for follow-up, will be held at the beginning of December 2013.
- Dec–Jan: Consultants review individual submissions and make notes.
- Jan-Feb 2014: Consultant team meetings - selection of short list of 19 candidates for mini-projects
- Feb 2014: Call for mini-project proposals from short-list. Consultant team meetings: selection of final 10 mini-projects based on candidates’ personal story submission and proposals.

Consultant team meetings – design work strategy, assign advocates to consultants.

- March-April 2014: Consultants work with selected advocates on revising their proposals and preparing for implementation.
- March-April 2014: Editing *CRPD & Me* pamphlet to an advocacy-only version, printing the new version and mailing to advocates for further distribution or workshop use.
- April-May 2014: Implementation of individual mini-projects/ Consultants visiting project sites
- May-July 2014: Advocates and consultants report writing.
- June-July 2014: Reporting and translation of selected testimonies/project reports. Project staff and consultants discuss effectiveness and significance of the project and consider future actions.
- July-Aug 2014: Project report writing

4. [Submissions](#)

Up to mid-November 2013 we received 76 submissions for CRPD Lives in total. We have continued to distribute the “*CRPD and Me*” pamphlet and hope to use it as a basis for ongoing training and advocacy work. Cai Cong, the project assistant at One Plus One, is launching a second round of pamphlet publicity activities during the second half of November, so we expect further submissions coming in from now until the end of December.

These 76 submissions came from disabled people or their family members from over 20 different provinces, and about half of them are from small towns or rural areas. For most people, reading the pamphlet “*CRPD and Me*” was the first time they had learned about the Convention and the concept of disability rights. However, many reported that the Convention echoed with what they had experienced and what they had been thinking throughout their lives. The main issues raised include:

- The lack of information to disabled people (especially in rural areas)
- Problems in the current education system (or not having access to education at all)
- Employment issues (lack of choice/training/discrimination in work places)
- Accessibility in both cities and rural areas (mainly transportation and public spaces)
- Discrimination (biased social attitudes and overprotection by parents or family members)
- Problems with national policy implementation at the local level (e.g. the disabled persons

employment levy)

5. [Next steps: recommendations for action beyond the current project phase](#)

CRPD Lives really seems to have caught people's imagination, including participants and many others who have read "*CRPD and Me*" and some of the testimonies, or who have simply heard about the project. Because of this we feel that there is now a strong basis for extending the project in future, by:

- Revising the "*CRPD and Me*" pamphlet by adding testimonies and other materials from this project term;
- Building a "CRPD Lives" website, with concise, easy-to-read content about the CRPD, and using materials collected from this project to link the Convention to grassroots disabled people's personal stories, frustrations and aspirations;
- Giving further support to individuals who have shown enthusiasm, ability and commitment during this project term;
- Widening pamphlet distribution and testimony collection over the next few years leading up to the CRPD Committee's second review of China compliance. (This date is still uncertain, as China's submission of its States Parties Report has been delayed for at least a year).

6. [Comments by Project Coordinators](#)

[Thoughts on the relevance of CRPD Lives – Lu Han \(China Vision\)](#)

I see this project as a way to collect original testimonies from grassroots disabled people in various different regions of China. The project also acts as a form of inspiration for grassroots disabled people, as it's a way to introduce the concept of rights in a simple way while providing an opportunity for them to participate.

From reading the submissions, I realized that, other than being an important human rights document with all its legal and political significance, for many disabled people, CRPD is also simply a way of living. It summarizes the essence of living with dignity. People can apply these principles in all aspects of life and all areas of the society. If our general goal is to spread the seeds and gradually influence the public, it is not necessary for all participants of the CRPD Lives project to become disability rights advocates in the future. Some of them will, if not already, become participants of the civil society in their home regions. Some might go on living their lives as students, professionals, members of families and communities. By gaining more control over their lives, they will start to influence people around them. With more disabled people in China realizing their own rights and recognizing the importance (and possibility) of living with dignity, not only will the atmosphere

improve in terms of disability rights, but the effect will also extend to human rights in China and the society at large.

These are the broader and more general implications of the project. On a different level, there will always be individuals who would reflect not only on their own living conditions, but also the conditions in their immediate surroundings and in society as a whole. The second phase of the project term was designed to help these potential disability advocates to grow, and gain more experience working in the field of disability rights.

Many grassroots disabled people who had participated in CRPD Lives were interested in doing advocacy work from the beginning. They see the problems in their own communities and have innovative ideas on how to solve these problems. Some of them also have extensive networks in their local areas. What they are lacking most are professionalism, appropriate advocacy tools and a small amount of money to begin realizing their vision. Our consultant team was able to provide these candidates with support in designing mini-projects, implementing them, and reflecting back on the process when projects were completed.

In the future, the testimonies collected can be used as advocacy tools, as well as evidence for the CRPD shadow-reporting process. Future phases of the CRPD Lives project will continue promoting the Convention while supporting grassroots disabled advocates in helping to build capacity and raising awareness in China.

(Lu Han, China Vision Project Manager and CRPD Lives Coordinator)

[CRPD Lives Project Analysis – Cai Cong \(OPO\)](#)

The objective of the CRPD Lives project is to promote the UN Convention on Rights of Persons with Disabilities in China, and to discover grassroots disabled people and disability rights activists through this advocacy process. The project then provides the most promising individuals with a small amount of financial support, in order to help them run projects in their local communities. The CRPD Lives project invites outside consultants to observe and evaluate the implementation of these small projects. In the future, by providing further support and guidance, some of these individuals will become disability rights activists, exercising and promoting the principals of the CRPD in their communities.

The duration of the project was one year, which can be divided into six stages:

1. “CRPD and Me” pamphlet writing
2. Pamphlet distribution
3. Testimony collection
4. Selecting small grant recipients
5. Small project implementation
6. Project evaluation

The “CRPD and Me” pamphlet was received extremely well among disabled people, and was reprinted several times based on the high demand. The following reasons contributed to the

popularity of the pamphlet: firstly, the main content of the pamphlet was written by disabled people with extensive advocacy experience in promoting disability rights; secondly, the pamphlet only emphasizes 10 crucial articles of the CRPD, instead of trying to interpret every article of the Convention; lastly, the pamphlet incorporates various different formats including a Q & A section which is easy to understand. All case studies in the pamphlet are from mainland China. This makes the content very relevant for grassroots disabled people.

The main distribution channel of the pamphlet was OPO's annual Young Disabled Leaders Training Camp. This proved to be very effective as the event enjoys high popularity among grassroots disabled people. By the end of January 2014, we had collected over 90 high quality submissions. *(Note: for details, see the collection of testimonies.)*

The project consultant team, which consisted of consultants who have had extensive experience of running disability rights projects, selected candidates based on the following four criteria: personal story, disability rights awareness, ability to run project, and connection to local disability community. After a few rounds of careful selection, the team agreed on 19 candidates who have rich personal stories and a good understanding of disability rights issues. These candidates also had to be familiar with the local community and show a certain level of capacity throughout the selection process. They were asked to submit a simple proposal that would allow them to realize some of the ideas they brought up in their initial submissions. In the end 10 grantees were chosen, and the consultants helped them revise their proposals and gave suggestions on how to implement these projects. The 10 projects covered the topics of education, employment, marriage and family, accessibility, awareness-raising, legal issues etc.. Surveys, case studies, focus groups, training, documentary shooting and various other methods and tools were utilized by different grantees based on their personal background and capacity.

During the implementation of these small projects, in order to help grantees grow, the project consultants worked with them on a one-on-one basis via phone calls and the Internet, to give guidance in the areas of capacity building, financial management and rights awareness. Each consultant also visited project sites and worked with the grantees in person. The goal is to observe grantees' ability and awareness, in order to evaluate their potential. This process turned out to be one of the highlights of the CRPD Lives project. Although some of the consultants had reservations about a few project proposals during the grantee selection process, they later discovered that working on these projects brought them new understandings on grassroots disabled people's living conditions and public opinions regarding disability rights issues in certain areas in China.

All of our consultants have been working on disability rights projects for several years. Even with rich experience in project implementation and disability rights advocacy, they were impressed by the innovative approaches the grantees exhibited, as well as their deep understanding of the local culture.

For example, Wang Ruilong, who is from Baoji, Shanxi Province, was one of the final 10 grantees. He proposed an outing activity for local disabled people to visit Famen Temple. Initially, the consultants thought the project seemed like a typical government-run outdoor activity for disabled people, with no advocacy component. But after visiting Baoji and working with Wang Ruilong, our consultant Zhou Haibin saw that Baoji was lacking in accessible public facilities and the public had a very low awareness of disability rights. Meanwhile, disabled people have very little access to useful information and little connection with the outside world. Because of this, disabled people rarely leave home, and they don't even communicate much with other disabled people in the area. We could start with providing an opportunity for disabled people to get out of their homes, to connect

with other disabled people and the general society. This will help them obtain information about disability rights and be more confident and comfortable living in the community.

Xie Jianjian is another grantee whose project evoked some questions from the consultants at the initial stage. The concern was that being a teacher from a Chinese blind school, Xie would be likely to run his project largely within the realm of the school system, which would result in an over-simplified and not very useful project. But Xie didn't limit the project within the school, but rather extended it to the local rural areas his students were from.

Besides being inspired by the grantees, the consultants also came up with new approaches to help them with project implementation. Since all of our grantees are grassroots disabled people who are inexperienced in running projects, the consultants would always encourage them to exercise their ideas first, before giving them concrete advice that targeted their specific problems. This gave the grantees confidence while ensuring a smooth execution. (*For details, see consultants' reports in appendix.*)

During the evaluation stage of the CRPD Lives, the consultants made the following general observations:

- (1) Distributing easy-to-read CRPD pamphlets proved to be more effective compared to simply handing out the original text of the CRPD or running workshops
- (2) Calling for submissions opened a door for grassroots disabled people who were interested in working in the disability rights field;
- (3) Giving out small grants was a reliable way to evaluate individual capacity, while connecting the principals of the CRPD with their day-to-day lives;
- (4) Discovering grassroots advocates can plant seeds for disability rights work in the future.

As for future project extension possibilities, the consultants had the following thoughts after discussions:

- Selected submissions, reports and proposals can be edited together with the existing *CRPD and Me* pamphlet and printed for long-term use, to attract more participation from disabled people, giving guidance to their work.
- The same content can be used to build an online platform for easier and more efficient access.
- Choose candidates from amongst capable grantees who showed strong interest in advocacy work, and give them long-term support in the future.
- Invite grantees from the previous project to participate in the new project year as consultants, for they not only have fresh perspectives, but also have more understanding on the situation on the ground.

(Drafted by Cai Cong, CRPD Lives project assistant.

Translated by Lu Han, CRPD Lives project coordinator)

(Narrative report written and compiled by Stephen Hallett, China Vision, August 2014)

Testimonies and Project Reports

WANG RUILONG

王瑞珑



Advocate/Grantee: Wang Ruilong
(Baoji)

Consultant: Zhou Haibin

Project: Day-trip activity to Famen Temple in Baoji, Shaanxi province, to share information about the CDPF

Extracts from Wang Ruilong's Testimony

I was born in November 1983 in Baoji in Shaanxi province and have had many debilitating illnesses since childhood. When I was four or five I had an uncontrollably high temperature and was prescribed long-term hormonal drugs to bring the temperature down. When I was eight or nine, the side effects of these drugs became apparent and my hip became dislocated. The disease in my joints worsened, my whole body changed shape and my spine bent into an S shape. For two years I was completely bedridden and treatments bore only the slightest results. After lengthy periods of bone-setting and physiotherapy, I gradually recovered and am now able to walk with two sticks.

Before 2010, during my 10-year fight against serious illness, apart from the two years when I was bedridden or was too weak to do anything, everyone I had contact with was able-bodied. In 2010, I made contact with several disabled people through the internet and it was through talking to them that I began to gain a deeper understanding of this community. After setting up the online 'Community of Disabled Friends' website, I collected together many disabled friends, offline and in other ways as well. Those whose physical condition was a little better could work and support themselves, but those whose physical condition was really bad had to stay at home. I discovered that many disabled people cut themselves off and are not willing, or find it difficult, to make contact with people and mix with mainstream society, and if they don't cut themselves off and stay at home, then they only have contact with disabled people.

So after all sorts of activities, I attracted people willing to participate. On the one hand the plan was to give disabled people the help and services they needed, but more than that, it was to bring disabled and able-bodied people closer together, to promote mutual understanding and remove barriers. In 2013, we founded and registered the 'Baoji Rainbow Bridge Service Centre for Help to People with Disabilities'.

We want to use this platform to do what we can in the areas of voluntary service for disabled people, employment promotion, integration into society, fighting for rights, etc.

Extracts from Wang Ruilong's report

Project results

1. Allowed disabled participants to break through psychological and physical barriers, to have the courage to go outside, to have equal communication with able-bodied people, to have contact with and to understand the outside world, to understand what the public knows about disabled people, and for disabled people to take their first steps to integrate with the world outside. By the end of the event, the disabled participants had developed close contacts with each other. There was a big change in Guo Baohong in particular. He has a severe disability and he actively put his name down to take part in the 'National Help the Disabled' charity event on May 18th.
2. Allowed volunteers to gain a much deeper understanding of disabled people's real thoughts and requirements. They learned from disabled people the things that non-disabled people do not have and to give them the chance to have equal opportunities in their future life and education.
3. Experienced a barrier-free environment and facilities in the tourist site and suggested improvements, for example, by adding ramps and handrails and removing the fee for renting a wheelchair.
4. Problems about the service centre emerged in the course of the project. For example: not all the participants received training, which meant that some people were not clear about the aims and meaning of the event. They thought that it was just an ordinary outing. Staff members were not clear about the division of work and some of them did not participate in the activities. The whole outing was too long which meant that the study and communication part was compressed, and the expected results were not attained. Some of the staff were not familiar with the CRPD, which meant that participation in the training and communication part was not high. To sort out these problems, we had a discussion with staff representatives after the event about improving things in the future to ensure that each participant would change and effect change in the people around them. By looking at the gaps, every function of the service centre would improve and in future they would be able to provide an even better service for disabled people.



Participants in the outing to Famen Temple

Report by Zhou Haibin (project consultant)

1. Analysis of Wang Ruilong

Wang Ruilong is one of the main people with responsibility at the Baoji Rainbow Bridge Service Centre for the Disabled. This service centre is a non-governmental organization. Wang has a physical disability. He does online design, technical services and other work for enterprises, and in his spare time does work for the service centre. The centre was registered at the end of 2013 at the Baoji Civil Affairs Bureau under the municipal CDPF. The work is poorly funded and activities are often paid for out of people's own pockets. If there's not enough money the participants share the costs. Another founder of the organization, Zhang Wenhui, is a staff member of the Baoji CDPF employment service centre. The Baoji Rainbow Service Centre has just been licensed by the municipal CDPF and is able to use the CDPF's reception room at a fixed time each week.

To begin with the service centre was specifically set up to give disabled people social assistance. There were about 50 volunteers with regular daily contact (most of them non-disabled). There were three or four key members who were responsible for daily operations. On 5th March 2014, the centre organized a group of able-bodied volunteers to go to an area of low-cost housing for disabled people to help out and do some sweeping, cleaning and housework. Apart from Wang Ruilong, all the volunteers were able-bodied. Usually the voluntary activities would include a few disabled people whose physical condition would allow them to take part (mildly physically disabled or with speech disorders). The organization's former identity was the 'Baoji Disabled Friends' Club'. It was an online community in the Baoji area, set up specifically for disabled people to communicate with each other at certain times. After it had been going for a while, Wang Ruilong saw that a growing number of volunteers were becoming involved in activities to help the disabled. Some key members got in touch with him and after six months of planning they were big enough to register. Wang Ruilong believes that many disabled people are in urgent need of external support and he hopes that the

centre will promote the idea of 'helping the disabled' to the whole of society, especially amongst younger people.

In June 2013, Wang organized an outing to a park for a group of disabled people. The centre also joined in the annual National Help the Disabled Day, fund-raising activities, promotion of sign language, a 'flash mob' sign language dance, etc. On 3rd December 2013, Wang's service centre and World Vision held an event to promote accessibility. In a big hall, they divided disabled and non-disabled people into small groups. The people with disabilities and the non-disabled volunteers talked amongst each other to come up with a plan of inspection. Then, each group went to shopping centres, public facilities, schools and hospitals, etc to test out accessible facilities using film, recordings, pictures and writing to put together a report to give to the CDPF, the Construction Committee, and other agencies. When they received the report, these agencies just passed the buck, saying 'This has nothing to do with our department'. Wang Ruilong and his colleagues also made some radio programmes and appealed to the urban construction bureau, the municipal CDPF, the department of transport, traffic control and other departments for 'accessibility reform' but all to no effect. Wang said Baoji has some accessible facilities, but their actual usage is not high. For example, there is a ramp in the square but since disabled people have no means of entering the square, 'however much it's improved it's no use'.

Wang Ruilong also attempted to work together with local media, hoping that they would report the above activities but met with only the slightest success. 'They mainly like to report positive stories, concern and love for disabled people, etc. They weren't willing to report anything about improving accessibility'.

On the question of why they wanted to go to Famen Temple, Wang said that in the past they had done some small-scale activities. It was fairly convenient to do things within the city area but some of the moderately disabled people wanted to go to the sacred Buddhist shrine at Famen Temple. Wang made communication the aim of the activity because many of the volunteers had had no previous contact with disabled people and a joint excursion like this would help them to understand each other and bring them together. The consultant thought that this was too simple and did not promote the core elements of the CRPD. They should also write up reports about people's experiences, analyze the deep-seated causes of lack of accessibility, etc, and then do some advocacy work together with the media and social organizations. Wang Ruilong felt there was sense in this but he was concerned that his organization lacked capacity to take on a more in depth activity and there wasn't enough time either. 'After two or three years of development we could organize a more large-scale activity'. There are not enough activities for disabled people where Wang comes from in Baoji in Shaanxi province, so Wang and the consultant decided after some discussion that the part about the excursion to Famen Temple could be retained and there could also be some short performances or talks about the CRPD. Wang felt that the disabled people wouldn't be able to do the talks or short performances. In the end a compromise was reached and it was decided that there would be some training about the CRPD, and through recreation and interaction everyone, both disabled and non-disabled, would join in discussions to learn about it. (For various reasons, this goal was not reached).

Wang's method of solving problems tended to be 'doing things in the accepted way'. When problems had appeared in the past, he didn't think about them enough and so the same problems would occur again and again. (For example, not enough media reports, inefficient time-management). The result of this way of dealing with problems would probably mean that the project would not achieve the expected results. The design, modifications, the limited ability to make adjustments all made it difficult to respond to changeable situations. Throughout the entire

communication process, there was a lack of smooth communication with the consultant. There were a lot of errors in the timing and the agreed plan couldn't be completed on time. In his understanding of the CRPD, Wang stressed 'integration of disabled and healthy people' and 'disabled people must surpass themselves'. Although the consultant proposed changes a number of times, in the concluding report these kind of expressions still appeared. This showed that Wang Ruilong accepted this philosophy internally. He had insufficient understanding of 'disabled people being independent, and taking initiative' and the 'rights-social model'. Wang still had no clear observations or understanding about social systems or discriminatory views that create barriers for the enjoyment of rights by disabled people. He could use daily life to understand a part of the CDPF but his understanding of the core essence of the CDPF needs to be strengthened.

2. Review

The main part of the project involved 20 private drivers and volunteers and 20 disabled people going on a trip to Famen Temple. It was a three-hour drive from Baoji to the temple. They set off 40 minutes late. When they got there was another delay of 20 minutes because disabled passes needed to be presented to buy tickets, and the whole sightseeing trip took one hour longer than planned. Lunch finally only ended at 3pm, so there were fewer than two hours left to talk about the CRPD.

The service centre had designed special signs, with the main themes of 'breaking down barriers, promoting integration' which were stuck on the front of the cars and useful for arousing the enthusiasm of the participants. But what people didn't understand was that the service centre had only designed badges that said 'volunteer' and the disabled people themselves had no badges, which immediately separated the 'volunteers' from the 'disabled people'. Wang Ruilong had not mentioned this in his plan.

The accessibility facilities at Famen Temple were of very poor quality. The volunteers had to carry six wheelchairs up and down steps and the disabled people said many times how guilty they felt about this. They expressed their gratitude to the organizers of the activity, almost all of them said things like: 'This is the first time we have been somewhere as far away as Famen Temple, it fulfils my dreams'. This shows that these disabled people from Baoji still face many difficulties in going out and in their everyday lives.

The session about the CRPD had three main parts. First, Wang Ruilong took 45 minutes to explain the background to the CRPD and its core articles. This was followed by two prepared speeches, one was given by a woman with a physical disability who was involved in customer service work. She spoke about her search for work, and being employed. Another person with physical disabilities spoke about the importance of education for disabled people. Then four more disabled people appeared on the scene to talk about their feelings about the day's outing. The consultant then spoke for 10 minutes on the background to the CRPD.

Because there were so many delays, the amount of time for discussing the CRPD was reduced by half. Wang had prepared some videos about disabled people's life and work in Baoji but because time was too short he could only show them during lunch. The restaurant had no sound system so the results were not ideal. Apart from this, there were also other problems that affected the results of the activity: first of all there were no ice-breaking activities, no one understood each other well enough; secondly, Wang Ruilong's talk about the CRPD was too long and the content and form relatively simple and there was no interaction. Thirdly, the disabled people who spoke read from a

script and there were no specific stories or cases. The audience had no way of responding with their own feelings. There was no reference to the CRPD itself. Fourthly, after lunch most of the non-disabled volunteers left the room to have a rest. So most of the volunteers did not participate in the interactive activities and did not hear the explanation about the basic content of the CRPD. It could be seen that many of the volunteers were not clear what the main purpose of the activities was and the organizers had given no prior explanation or training about this. All in all, not enough preparation had been done, there was little quality control, and it was not possible to meet the project's objectives.

3. Future work

Throughout the project Wang Ruilong showed much enthusiasm about helping disabled people. He showed a lot of initiative and was very considerate towards disabled people's feelings. His design and execution of the project showed that he needs to gain more experience in planning, organization and coordination, and he also needs to take part in more capacity-building activities about the CRPD. In working together with Wang Ruilong, the consultant found that, compared to coastal organizations for disabled people, Baoji and the whole of the Shaanxi region were comparatively weak in advocating the CRPD. This was reflected in the fact that the project implementer was still not clear about what 'rights' were and what 'charity' was.

The consultant also felt that the one of the functions of the service centre ought to include guidance for disabled people about employment. There were many successful cases of helping disabled people find work. Wang Ruilong has a lot of experience in these areas. He is patient and warm, and he wants to help disabled people. Another core member of the service centre, Zhang Wenhui, works in the CDPF's employment department and understands the relevant policies and resources. The service centre is starting to help create work for disabled people, providing training in interview skills and other soft skills, etc. These functions all have an extremely positive significance in breaking down social discrimination and promoting the integration of disabled people into employment. Therefore, in future, Wang's Ruilong's work could be establishing a support centre for disabled people going into employment, based on the existing service centre, providing training, advice, answering questions and bringing in more people, enterprises, human resource companies and even social workers, etc to support the disabled people of Baoji to work from home or to be integrated into employment.

WANG LI

王丽



Advocate/Grantee: Wang Li (Suzhou)

Consultant: Jiang Anxi

Project: Video documentary about the life of the grantee's autistic younger brother Wang Xiaoji

Extracts from Wang Li's Testimony

As a relative of someone with intellectual disabilities, I have always felt anxious and confused about such people, their integration into society and how they adapt themselves to life. Are people with intellectual disabilities able to integrate into society and can they have the same barrier-free daily life that non-disabled people have? After reading the pamphlet on the CRPD and the CRPD itself, I found two phrases which helped me understand two of my concerns: 'relative equality' and 'reasonable accommodation'.

I did media studies when I was at university in Beijing and now work in Wuxi. I did well in my studies when I was a child and had good social skills. At first, vanity did not allow me to truly accept my younger brother's condition. On the one hand I felt inferior, excluded and on the other hand I had the extreme idea that the better my grades were, the more I'd feel sorry for my brother as if I had stolen something from him.

Leaving home to study at college took me further away from understanding how to protect my brother's rights, but it also opened up my way of thinking and gradually trained me to gain a more positive understanding.

This June, my brother took the middle school exams. Before the exam I went back home. My brother gave me a note that his teacher had written him, clearly telling him all the things he needed to know about going to the hotel to take the exam. My brother told me his teacher was afraid he would forget, that he should take it home to show the family and if there were any problems he should phone him.

Extracts from Wang Li's report:

Summary of short film:

First of all, I would like to thank China Vision in London and One Plus One in Beijing and other organizations for giving me - from faraway Anhui – such a special role in explaining through my film the CRPD and Wang Xiaoji's situation and transformation. I also wanted to make a short film that could be shown in many places to many people.

I am a young person who has just entered the film profession and have dreams about the CRPD. My brother Wang Xiaoji's intellectual disability made me realize more than ever the necessity of this choice.



Wang Li and her brother Wang Xiaoji

I had never gone out of my way before to talk about Wang Xiaoji's special circumstances, or at least I did not freely let friends know about it. But because I made this film, I and many others, old friends and new ones, and even people I didn't know well, discussed and debated it at home, in cafes, at the cinema, on the bus, in the park, and at work. What is it about? This film is about Wang Xiaoji, about our family, about each person's understanding, about what we want to say, about taking the initiative, about integrated education, about differences amongst people, about helplessness, about dreams....about what we can do for Wang Xiaoji, and people like him.

No one really knows what it takes to change things, but more and more people are participating and now know about Wang Xiaoji. They have an objective idea about understanding and respecting people like him, i.e. about how to treat the friends around us.

Wang Xiaoji is like any other ordinary child. He may be a little slow and may fail a little more than others. It takes him five or six times longer to understand a subway map. He is curious and likes strange surroundings. He also has dreams. He wants to be a singer. All these details have been put into our film. We have presented these normal things for all to see. From start to finish the film contains simple emotions. It's neither happy nor sad nor looking for sympathy; we just want people to understand and watch. We just hope people will become close to him, close to others like him.

Report by Anxi Jiang (project consultant)

From April to June 2014 Wang Li has been working on a film idea entitled "The Forgotten Boy - Wang Xiaoji", a story about her brother, who is autistic.

Although she had read the little handbook "CRPD and Me" she had very little idea about what the film should be about, how to tell the story, what messages to deliver and from which angle she should film this portrait of her brother.

As a sister, her concern and care led her into this filmmaking, but I thought that she should start by studying the CRPD to build up a clearer vision and then decide which principles she should focus on when telling the story.

Xiaoji is autistic, an intellectually disabled teenager, who has never been diagnosed but just grew up in a village home in silence. Parents, relatives, neighbours, teachers and school classmates usually ignored him and no one ever mentioned his "condition" or tried to help. His family might have been afraid of losing face, which is a typically traditional Chinese view of having a disabled child. And for the school-teachers it meant giving up on him just as long as he wouldn't disturb the other students, so it was only by chance that Xiaoji got just two marks in his final school exams.

Wang Li had studied film in college. When she made her first trip home after starting work on the film, she was worried about bringing strangers like me, or a cameraman, home with her, as she was afraid that I would ask her parents about this unmentionable topic of her brother's disability. As a result, the first attempt at filming was very unsuccessful, though we worked hard before her trip on how to speak about this subject to her parents in different situations, and how to bring their concerns and emotions into the open. Obviously, Wang Li failed terribly as she couldn't put herself forward to talk about this topic, and without a director's clear mind or the help of a cameraman she couldn't do much filming that time.

But what happened after Wang Xiaoji came to Wuxi and Suzhou with his sister eventually opened Wang Li's eyes and changed her thinking completely.

What is Self Determination? What are Independent Living and Social Integration? How do education, work and employment relate to Xiaoji and other people with disabilities? Wang Li started to really think about these questions and tried to understand more about her brother Xiaoji's life and changes.

Conversation on WeChat: *Sister - come and live in the city...Brother - no, I don't want to... Sister - I will not like you if...Brother - I've told you that I am not coming!*

For Wang Li, this was the first time she realized that her brother had his own mind and voice!

Later on Xiaoji came to live with Wang Li in Wuxi. He really liked playing the guitar and humming songs though without a tune. But he kept playing and started asking: "Sister, could you make me a singing star?" Wang Li and maybe everyone who knows Xiaoji had never heard him talk in this way and didn't mention the singing, but on a driving trip everyone was surprised when he sang, out of tune: How many times have I fallen on the road; How many times have I had broken wings; Now I no longer feel anxious, and I want to go beyond my ordinary life. ("Full bloom of life", a song by Wang Feng)

Wang Li didn't believe that this was her little brother Xiaoji, whom nobody had taken any notice of during his 17 years of life! She started to think seriously about what went wrong with the love the family had given her brother, and how his school teachers and society had subconsciously neglected and abandoned him. Now, in Wang Li's eyes, Xiaoji is no longer a nobody.

Xiaoji has slowly built up his strength and his ability to make choices; for example, communicating with lots of "sisters" and "brothers", who are Wang Li's colleagues and friends. Going to talk and meet these young people made Xiaoji more and more determined, and for the first time he tried to speak Mandarin, instead of his hometown dialect, on WeChat voice messages, and also started to write messages in Chinese characters. If Xiaoji got only two marks after nine years of compulsory education, then his teacher should now try to WeChat him and see how many characters he can write and use in his communication with friends!

In June Xiaoji started going to a charitable organization in Suzhou, where all the teenagers are intellectually disabled and join in all kinds of activities, like making soap bars and other arts and crafts. Many teachers, carers and university student volunteers work there.

In the mind of Xiaoji, the film is about Xiaoji going to work, making those products and waiting to be paid a salary, just like anybody else. Going to work has made a big difference to Xiaoji: he has become like new person, who uses his mobile to wake up early, prepares his breakfast the night before, dresses himself and then walks to the subway station. He has to change trains twice to get to work. Imagine, only three months ago Xiaoji didn't even dare to go out on his own for a fast food meal.

Wang Li can hardly keep up with the speed of her brother's change. This has made her think hard about how this can happen in just three months. Her film failed many times as the content was unclear, lacked footage, had muddled dialogue and lacked a central theme. Things became clearer through the struggle of making this film and working on the script. Wang Li felt, and still feels, that this journey of making a short film is also a journey of the mind, in which the most important principle in life is equality for all and non-discrimination. Her family and others wanted to love Xiaoji but it turned out to be an act of discrimination, just letting him survive. At the same time, all her young colleagues and friends in the new city are surprisingly open and positive towards Xiaoji. They treat him just like the brother of a friend, and they talk or play with him naturally, without making any fuss. Xiaoji is a teenager with some differences, that's all.

In Wang Li's film, she showed a small plant growing under a glass cover many times; she repeatedly took the cover off and replaced it, expressing her struggle and realization of how Xiaoji could live. Love is not about covering him up and keeping him safe, as her family, school and she did for the last 17 years. Love should see Xiaoji as an equal person and let him develop in the open, so he can grow happily in his own way. Just like the words in the "Full bloom of life", Wang Feng's song, with which Wang Li ended her film:

I want life in full bloom,

Like flying in the vast sky,

Like walking in the boundless wilderness,

With all the power to break free!

Tomorrow, for the first time Xiaoji will become a volunteer and accompany a group of visually impaired people to go to Hangzhou on a day trip! (Of course, with his sister Wang Li)

Wang Li earned respect from working on this small film, and her company is giving her six months with all the help needed to make this little film a more complete work. Therefore, Wang Li is thinking hard again and trying to rework the film from the beginning.

A good film with a good subject will create an important impact in society. We are expecting an even better version of "Forgotten Boy - Wang Xiaoji."

TANG QIJUN

唐启军



Advocate/Grantee: Tang Qijun
(Jinmen)

Consultant: Zhou Haibin

Project: CRPD workshop for parents
with autistic children in Jinmen City,
Hubei

Extracts from Tang Qijun's Testimony

My name is Tang Qijun, 42 years old, and father of an 11-year-old autistic child.

Right now, in Jingmen [Wuhan, where Tang is from], there are 1,300 (young) people with autism, among whom the oldest is 29 and the youngest just over 2 years old. All of them are rather weak when it comes to taking care of their daily lives. Some can't take care of themselves at all. This has brought tremendous financial and mental pressure for the families. At the moment, the children who are under 16 can still participate in trainings at public or private organizations, but the older children can only stay at home, which becomes a heavy burden for their parents. There's an urgent need to provide these children with vocational training, to enhance their abilities in life and work.

Jingmen has only one public "special education school". It is limited by various policies and only a very few children with autism can attend the school for free. The rest of the children have to attend private institutions. Older children have to stay at home. This has resulted in tremendous financial and psychological pressure on the parents. Most of these children cannot enjoy their right to education, as defined in the CRPD. Most children with autism and their parents don't know anything about the CRPD. They don't know how to protect their own rights.

Extracts from Tang Qijun's report

New awareness:

Before this meeting I had never taken on sole responsibility for an entire project. In previous events for the Jinmen Autism Self-help Society, I had always played a secondary role. I learned a lot from this meeting: Zhou Haibin helped me revise the short framework for the activities in the meeting. I realized that the design of the event had to be rational and rigorous. In arranging the chairperson, choosing speakers, receiving the project consultant, finding a venue, making the banner, buying refreshments, etc, I gained a lot of experience for all kinds of future events.

Most of the Society's council members and parents had known nothing about the CPRD. Before the meeting, we put the CPRD on to the Society's website and asked everyone to take a look at it. At the meeting we gave each participant a short pamphlet about the CPRD [produced for project by China Vision] so council members and parents now know something about it.

Of course, it will take a long time to promote the CPRD. Most disabled people and their families now have a much clearer understanding of the CPRD, and the society they live in has also changed a lot. The CPRD is an international convention and China was one of the first countries to sign it. But disabled people and families cannot rely directly in the CRPD to protect their rights. Policy-makers, welfare providers and other bodies are looking for high efficiency, low cost solutions. So in the long term, we must look at the local situation and find peaceful methods to promote the CRPD. For example, each year on April 2nd, government department and CPRD leaders will be invited to take part in the 'International Autism Day' and 'International Help the Disabled Day' as well as social activities organized by our Society and we will distribute and discuss information about the CRPD. We want to raise the awareness of government leaders and the public about the CRPD in order to help disabled people and their families gain their lawful rights.



Tang Qijun at his CRPD workshop in Jinmen

Report by Zhou Haibin (project consultant)

1. Tang Qijun and the Jingmen Autistic Society

Tang is a parent with a 12-year old son with Asperger's Syndrome. His son finds it difficult to get on with others and is currently a pupil at an ordinary primary school in Jingmen. Tang's organization, the Jingmen Autism Self-help Society, has over 80 members and 10 trustees. Tang is one of the trustees and is also the deputy secretary. The Society usually meets only for specific reasons and there is no fixed meeting place. There are no professional staff members and everyone is part-time. Not long ago they registered as an independent non-profit organization under the local CDPF. The Society has its own website (<http://www.jas.org.cn/>) and regularly updates its membership. There is a 50 yuan membership fee for families. Each year, 20,000 yuan are spent on activities. With the autistic children of some of the families approaching adulthood, some key members of the Society are keen to establish a 'sheltered workshop' and a health farm (农疗农场) and are applying for new types of creative or service projects offered by provincial and municipal organizations. The views of parents differ, some considering that 'their own children are not suited to go out to work and that it would be enough in future just to have a place to grow old in.'

The members of the Society have powerful local resources. The head of the Society is a local entrepreneur and is planning to make use of the large farm under his name to open up a health farm (农疗康复). On the day of the activity, the head of the Society and the secretary invited the local media and the Jingmen CDPF secretary and vice-chairman, municipal CDPF inspectors and the head of the municipal Association of Persons with a Physical Disability, as well as other CDPF leaders of the Jingmen CDPF. Most of them participated in everything and formed a close relationship with the Society's board of directors. Some members were retired cadres from the local branch of Sinopec and the local steel plant and had an influence on local government policy makers. Another indication of the Society's influence is that two years before, it encouraged the Jingmen municipal education department and the CDPF to set up an autism rehabilitation organization. However, because of a lack of expertise, the children received little support. Some parents have already withdrawn their children from state-run rehabilitation organizations, turning to external organizations with stronger structures.

The Society's secretary is also an employee of the Jingmen municipal government. He has good organizational abilities and has been seconded by the China Association of People with Mental Disabilities in Beijing, where he is vice-secretary of the autism committee. The Society is considering giving Tang more administrative work. This is a big challenge for him because in the past he was not involved in planning activities for the Society or in the overall work plan. So in this respect, he lacks ability and this was reflected in the symposium. For example, when members spoke, he did not follow up the content, and he was not specific enough in giving information to participant members. The result was that during the meeting some members' reports were too long and off-topic, while others, who were scheduled to speak, in the end did not. Some participants were not sufficiently involved and this shows that not enough information was given in advance.

Tang didn't have enough experience in arranging activities and he had a limited idea of how to plan a discussion about the CRPD. After doing a lot of work with him on creating a basic framework, his proposals were taken up by the Society, and the board of directors mobilized external resources. Responsibility for managing and designing the symposium was transferred to the board members. Tang swiftly and efficiently implemented the board's revisions. From the first proposal to the final plan, his results were basically good, but overall he did not meet all the expectations. He appeared to have no grasp of the direction of the project or the expected goals, had done no research before

the design meeting or any evaluation after the meeting, which made it impossible to make an objective assessment of the results.

Tang was keen to understand a lot more about the CRPD and actively sought out simple material about it. But his understanding of the CRPD was still not enough, especially in the area of 'rights', independent living, support for making one's own decisions, the right to work and other issues. After private discussions, it emerged that he really had no clear answers and no initiative to do anything and in this respect he needs a lot more support.

2. Results and assessment of activities

In the past, the Society had invited Director Zhang Wei from the Enable Disability Studies Institute to do some training on the CRPD. The results were good and the participants gained a lot as Zhang Wei went through each article of the CRPD. This was also why Tang was inspired to hold the first symposium on the CRPD. To begin with, Tang hoped that the consultant would be the main speaker and that the head of the Jingmen Rehabilitation Centre would speak on rehabilitation. The consultant's expectations were that the project would gain the active participation of members of the Society who would become more closely and actively involved in the process of self-determination and self-management. Therefore, the consultant designed a 'participatory training' agenda focusing on the CRPD and how to achieve things in life.

Tang said: Parents' awareness is not that great in the Jingmen area. Not many people are prepared to listen to direct discussion about what the CRPD is or about the law to protect the rights of disabled people, and are not willing to come specially to hear about it. Many children and parents do not have the level of knowledge required by the CRPD. So Tang and the consultant designed a game to break the ice. They asked five parents (in fact, two parents had no preparation and did not speak) to ask questions about education, employment and health and to share their own stories about these topics in order to get parents to participate.

The municipal CDPF secretary made a simple opening speech, saying that there were 193,000 people in Jingmen with disabilities. After the ice-breaking activities, the first person to speak, Mr Cai, spoke on the topic of 'Understanding the CRPD'. He gave a simple introduction to the history of the CRPD: 'according to the CRPD, you could live the same life as an able-bodied person.' His 15-year-old grandson is autistic. For nine years he had been all over the country for a cure to his 'illness'. He first went to Wuhan for two years to participate in rehabilitation training, then went to Zhengzhou for three years of training. But the school fees were too high, about 6000 yuan a month, of which 4000 yuan were for the training. Not long ago he and his grandson returned to Jingmen and went to the Jingmen Children's Rehabilitation Centre for treatment. Cai raised the question of educational equality for disabled people and allocation of educational resources. He summarized the four universal problems that his autistic child faced as follows:

1. Difficult to get in through the school gate. Autistic children are not accepted for pre-school education, ordinary schools wouldn't accept him and special schools didn't want him either. 19 non-disabled children of parents jointly signed a letter to drive out autistic children already at school. This was discrimination against autism. The country's 'special education' could provide a service for deaf-mute and intellectual disabilities, but had no special schools for autism. At present Jingmen has a special training class thanks to the leaders of this special school. This is the only one in Hubei.

2. Difficult to find the money for school fees. Although the state has basic rehabilitation for 0-6 year old autistic children, after the age of 6 fees were usually in excess of 2,000 yuan. Funds had to be

raised privately and so many autistic children were prevented from rehab services and were not able to go to school.

3. Difficult to ensure quality. In autism organizations and in special schools there was still a lack of experienced teachers and a stable teaching team.

4. Difficult to raise parental awareness, insufficient knowledge about patterns of autism and lack of confidence. Some parents had little knowledge about the responsibility of legal guardians to protect children, and voluntarily abandoned their children's training.

Mr Cai gave a real life interpretation of Article 24 of the CRPD and many parents applauded him. The suggestions he then made were agreed to by the other members as follows:

'The public should fully embrace people with disabilities; care about protecting the rights and interests of autistic people, improve the laws; expand education on popularizing the law and in future include autism as a target for social aid; expand the capacity of existing schools to allow autistic children to study in classes in ordinary schools; set up a support system to help autistic children, provide subsidies for families in difficulty; and help autistic families with training. The government should increase research into autism and give financial aid to research.'

The second person to speak was Sun Daimei, another director of the Society. Her topic was 'My achievements and failures over the past few years working with autistic children'. She said that before the age of 10 children were under the illusion that they were the same as other children. But she discovered that the best opportunities were already lost if treatment and rehabilitation was given only after the age of 10. So she said to other parents: 'We use our own bitter experience to provide a negative example to parents in the future'.

'The CRPD touches on issues deep in our hearts. It is a legal weapon, stressing several principles: human dignity, individual autonomy, being treated without prejudice, and integration into society. Article 27 talks about work and employment and the necessity of integrating into society through work. In future, every family must face this and I hope that each family will read this Article carefully.'

The third person to speak was Zhang Daoming. He has three grandsons. One of them, born in 2003, has multiple disabilities because of a serious lack of oxygen during his birth. He has cerebral palsy and severe autism. He had six years of treatment and rehabilitation at the Hubei Provincial Maternity and Children's Hospital. By 2008, 400,000 yuan had been spent. He is now able to stand up and walk by himself but emotionally he is becoming increasingly violent.

"The spirit of the CRPD is precisely to move from '残废' (canfei – "disabled and useless") to '残障' (canzhang – "disabled and obstructed"). China was amongst the first group of countries to sign the CRPD. While 'canfei' is a reflection of society's pity, 'canzhang' emphasizes rights and interests. What is the difference between 'rights' and 'interests'? I believe that if legal rights and interests are preferential policies and aid determined by the state, they are not the same as equal rights. It is something natural, it is everybody enjoying the same rights together, not something that can be denied by any government. So the CRPD emphasizes the protection of rights. The rights of disabled people in China and Jingmen in the last few years have made great progress. China has established the CDPF and, in response to parents, Jingmen has established the Menghua Rehabilitation and Training Centre. The Autistic Society has also developed rapidly. I hope that the government will implement the CRPD better and increase the protection of children with disabilities especially as regards comprehensive protection in medical treatment and assistance, and establish an integrated database of disabled children, enhance the prevention of disability, increase the development of care

and rehabilitation organizations, and set up good care bases, so that parents do not have to worry about things.”

The three speakers aroused a lot of emotion and many parents voiced their agreement and applauded. The consultant spoke for 10 minutes about the basic framework of the CRPD and responded to the views of the three speakers. Afterwards, when discussing the future action of the Society, many parents became more and more outspoken. Especially in the presence of the representative from the city's CDPF, the issue of accountability became fairly heated. Parents pointed out:

“How will autistic children will live in their old age, how will they be cared for? Now that the Society has become bigger it should have the influence to ask the government to solve these problems.”

Some parents said that the government should provide support assisted by commercial activities. The Society could call on enterprises and foundations and with government support set up care homes for autistic people.

Some parents talked about employment problems: to establish special work places in accordance with their children's interests.

Right at the end of the meeting, the outgoing Secretary-General of the Association Sun Yanmei made a statement. In some of the discussions, some parents had expressed dissatisfaction with the work of the Society, in particular that the Secretary-General was about to move to Beijing to work. The parents thought it would affect the development of the Society. She mentioned that in China parents regard the protection of rights and interests as the main issue but their rights awareness is limited. She said she was about to take up office in the China Autistic Society, which has more than 180 institutions as members. She will serve as Deputy Secretary of the Autism Committee and she will work together with the China Autism Parent Support Association on pilot projects. The Association will soon hold the National Autism Association Education Conference and the World Conference on Education for Autism, the Xing'er Summer Camp, and other projects, so there will be a lot of resources for parents. She encouraged parents to continue to learn, not to complain, not to wait, not to be dependent on others, and after her work in Beijing she would continue to support the Society and look for resources.

Evaluation:

Tang said that generally the event went smoothly. It brought parents together and through the sharing of practical experiences and stories, clarified the objectives of young parents. Some parents talked about the difference between 'interests and rights', and explicitly advocated the path of 'rights', rather than the path of 'safeguards', 'rights' being one of the most important aims of the CRPD, and this was clarified. The event was also covered by the local media, which expanded the understanding of autism and the Society. This would help to dispel social discrimination and promote social integration. Of course, this success is also greatly related to the powerful media connections of the Society's members and local resources. In addition, the symposium was Secretary Sun's first response to members' concerns. The development of the Society has undergone a transformation. The symposium explored how to coordinate all forces and how to form a unified programme of action. This was an unexpected bonus for One Plus One and China Vision.

Unsuccessful parts: the parents' discussion of the action plan did not achieve its target. The parents were not guided in the discussion and it was rather chaotic. It was all complaints about the government and there was no specific discussion about how to get members to participate in rights

advocacy work. There were also problems in the design of the interactive sessions. The chairman did not fully engage the enthusiasm of the participants. It was too rigid, and this was because of poor communication with the participants before the meeting. Some parents did not know why they were participating in the activity, and seemed to stay rather aloof, not taking part in the discussions and not speaking. There needs to be improvement on how to control the pace of such meetings and the assessment of the meetings.

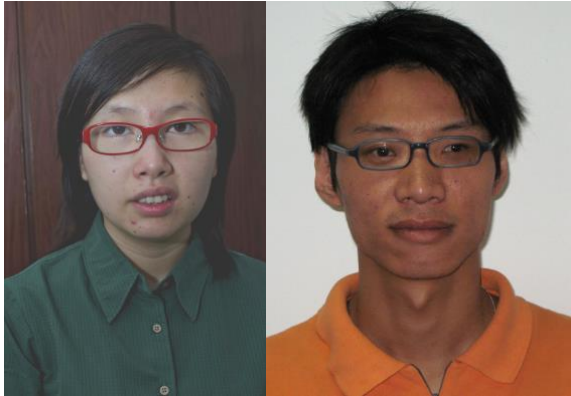
3. Future work

Throughout the project Tang Qijun displayed an ability to coordinate participants, communication skills, organizational skills and the adaptability required in a civil society organization. He was also enthusiastic about DPOs and concerned about disability rights issues. His eagerness to learn and his modesty will help him to improve his organizational ability, strategic design, and project management in the future.

The Jingmen Autism Society is an excellent platform for Tang. The consultant takes the view that Tang Qijun can undertake more work in the future. By participating in more capacity-building activities, he could expand disability rights advocacy from Jingmen out into Hubei province, and in deepening the experience of the Jingmen Autism Society influence even more parents and disabled people.

HAN YAO

韩瑶



Han Yao

Sun Zhiyuan

Advocate/Grantee: Han Yao and Sun Zhiyuan (Shenyang)

Consultant: Lu Han

Project: CRPD workshop for visually impaired parents in Shenyang

Extracts from Han Yao's Testimony

I grew up learning Braille. When I was small my grandfather made up for the fact that I wasn't able to go to kindergarten, teaching me by writing very large characters on a card, but after I went to school more and more of the classes and materials were in small print, so I gradually changed entirely to Braille. After entering university, I was attracted by the optical and electronic visual aids used by my classmates. So on the one hand, I looked for suitable magnifying glasses, and on the other chose to learn characters by myself as one of my elective courses at university. Within three years I had accumulated all kinds of optical and electronic visual aids at home, and had copied out the Xinhua Dictionary three times, and my level of characters was such that I could read fairly easily. But I wonder how many people can get as far as I did. And I got there too late.

Nowadays we advocate disabled people's participation in society, but imagine that they don't even dare go outside, that if they encounter difficulties they have no means of expression, so how can we talk about participating in society? Let visually impaired people go out, let their families and children go out. If we can talk together about our experiences, perhaps one day, they'll no longer be the experiences of one person, one family, or one group.

Extracts from Han Yao's report

A. Involvement of parents with visual disabilities

1. *Parenting:* Surveys and statistics show that most disabled parents choose to have their child brought up by grandparents. There are many parents who, either because they are completely blind or have some other visual disability, decide not to become involved in their child's upbringing,

entrusting their upbringing and education to a sighted person or someone who is more able. This was the case with more than half of the seven families with children at the meeting. But facts show that where parents are absent, the children without parents and who are brought up by someone else are, psychologically and educationally, irritable, timid, unable to get on with others, etc.

2. *Methods of parenting*: In this session, there were two consistent views: whether or not to introduce education to motivate a child; and for children to accept the reality of parents' disability from a young age.

3. *Going out and social contact*: Amongst the visually disabled families were a husband and wife with low vision and low competence. They did not often take part in parenting and did not go outside the family. For the majority of visually disabled families there were few opportunities to go out, especially for parents to go out together with their children. Because of factors such as work and housework, the parent with better vision in a visually impaired household had little chance of accompanying their child.

4. *Education*: For the majority of visually impaired families, allowing visually impaired parents to participate in their children's education is a process that takes courage to realize. One way for visually impaired parents to be involved in children's education is to use techniques and aids, but what is most important is for children, family members and school teachers, classmates and parents to accept and understand visually disabled families. This is also an important precondition for ensuring visually disabled parents' involvement in education.

B. 'Parenting workshop for disabled people' Shenyang Family Activities, Conclusion and Analysis

1. *Children's involvement in society*: As regards children's involvement in society, much attention must be paid to the needs of children in visually disabled families who are brought up by grandparents. Attention must also be paid to children who are too introverted or too sensible. To some extent, these children may also interact less well with other children.

2. *Role play for visually disabled parents*. This was divided according to parents' circumstances:

a) Totally blind parents who, because of their own disabilities, have completely given up on becoming involved or interacting with their family or society. Apart from their lack of involvement in their children's upbringing and education, the parents' negative emotions also affect the wellbeing of the child.

b) Parents with low vision who did not label themselves as being visually impaired. There was a big difference between parents' abilities and the child's needs.

c) Parents who allowed their children to accept the visual impairment. These children were fairly clever and sensible.

d) Parents who were not involved with their child's upbringing because of work. The child missed out on the company of one parent and his/her character would become rather one-sided. The parent with the visual disability and low capacity would be the main force in the child's upbringing.



CRPD workshop for visually impaired parents with their children in Shenyang

Report by Lu Han (project consultant)

Background

Sun Zhiyuan and Han Yao are both visually impaired, and they became parents two years ago. Sun Zhiyuan is originally from Tianjin, and Han Yao from Shenyang, in northeast China. Before their baby girl, Sun Yixin, was born, the young couple moved to Shenyang, and settled down as a new family. During the past two years, besides raising their daughter, Zhiyuan and Han Yao have also reflected on their experience as disabled parents, and what this experience has taught them about their life as disabled people.

Soon after Zhiyuan and Han Yao became parents, they realized that there is very little accessible information on child-rearing for visually impaired people. While many visually impaired people struggle with making the decision on whether or not they should have a child, due to worries related to genetic diseases, many who do have children end up handing their children to the grandparents because they are regarded as not fully capable of taking care of small children.

Although being new parents is a difficult task, Zhiyuan and Han Yao still consider it to be an essential experience in life for both parents and the child. Many of the parents they met in Shenyang have various types of visual impairment, and they have always been the ones who were on the receiving end of help and support in their families. Having children has provided a chance for these young parents to reassert themselves in their families, especially when it comes to taking care of and educating their baby. Since many of their children are non-disabled, these disabled parents are thrown into an “inclusive” environment with no reasonable accommodation, facing the challenge of discrimination and accessibility issues from their children’s schools, public spaces, and society as a whole. To battle these stereotypes and discrimination from both within the family and from the society, Zhiyuan and Han Yao consider the Convention on the Rights of Persons with Disability to be a tool to empower such parents.

Yi Xin – A New Organization

In April 2014, Zhiyuan and Han Yao registered a non-profit organization in Shenyang, called Yi Xin Disabled Persons’ Culture Center. As the beginning of Yi Xin’s activities, on 21st April 2014, they

organized a CRPD workshop for eight parents (four fathers and four mothers) with various degrees of visual impairment. Before the workshop, most of these parents had been communicating as a group on QQ (set up by Yi Xin) for a short period of time. Many of them had also known each other in the past.

First visually impaired parents workshop

The workshop started with Mr. Hou, the president of Shenyang Association of the Blind, greeting all participants. He and a couple of other officials left right after the opening speech, leaving the organizers and participants to communicate with each other in depth.

After introducing themselves, Zhiyuan and Han Yao talked about the purpose of the workshop and gave a brief introduction about both Yi Xin and the CRPD.

The discussion among parents lasted from 10 am to 3p and covered topics such as a) personal understanding about disability, b) family dynamics between disabled parents and grandparents/children who are non-disabled, c) education for their children and social attitudes at school, d) accessibility and reasonable accommodation in public spaces, e) reproductive rights.

With each topic, Zhiyuan and Han Yao tried to collect the challenges these visually impaired parents face in life and connect these to the principals of the CRPD. After the workshop, Zhiyuan and Han Yao also conducted a detailed survey using an extensive questionnaire they designed. All of the data collected will be used to compile a brief report, as well as to design the next step of Yi Xin's advocacy action plan.

On April 27th, Zhiyuan and Han Yao organized a non-visual photography workshop for both parents and their children together. The families were very eager to participate as parent-child activities that are available for disabled parents and their children are very limited. These two events act as a starting point for future Yi Xin activities for the visually impaired parents' group.

Possible future Yi Xin project activities

- Child-rearing workshops for visually impaired parents
- Mobile Advice Clinic for preschool children with visual impairment
- Non-visual photography and podcasts will be used as tools for activities and wider communication

Advantages

- Zhiyuan and Han Yao are themselves parents with visual disabilities. They are invested in their own child as parents, and there is a natural bond between them and the other parents who are in the same situation as they face similar problems, such as accessibility and negative public attitudes.
- Zhiyuan and Han Yao were both former 1+1 employees and they were trained with a rights agenda. Zhiyuan was a professional radio producer and photography trainer. Han Yao was a stenography trainer when working for 1+1.
- Han Yao's family is from Shenyang, and the couple has a solid connection with the local CDPF and Association of the Blind.

Challenges

- Yi Xin needs a sustainable model to glue these parents together. But if the organization only provides leisure activities and child-rearing tips for these families, it won't really raise public awareness on disability issues and truly advance the rights agenda.
- Yi Xin will have to be able to advocate for these parents for the problems they face in life, whether it's social attitudes/discrimination or accessibility/ reasonable accommodation. It is not clear whether Zhiyuan and Han Yao have yet the advocacy skills to do this, and whether or not they have an action plan to try to develop these skills in the near future.
- The organization is very new. It will need a period of time to build its network among DPOs and NGOs in China, and find their place in the disability rights movement.

KE QIAN

柯茜



Advocate/Grantee: Ke Qian
(Shantou)

Consultant: Jiang Yitong

Project: CRPD workshop for mothers
with autistic children in Shantou

Extracts from Ke Qian's Testimony

When our daughter Yiran, who is autistic, was seven years old, we registered her at the local primary school. The principal and teachers had never had any contact with this sort of child and found it very difficult to accept her. They stressed again and again that this was an ordinary school system not a special school and they told us to go to the CDPF and other places to find a solution. But the whole of Shantou city had no special organizations that would take autistic children of school age. All we could do was to force ourselves to ask the principal for a favour. In the end, seeing that we parents were also teachers, the school agreed that we could look for an 'auntie' to sit with her in class for a probationary one-month period.

Later, all sorts of things kept happening. We kept being asked to go to the principal's office to 'drink tea', the principal and teachers tactfully kept on trying to persuade us to take Yiran out of the school. Time and again, we would ask to be allowed to keep trying. And so it went on: we'd try again, and try again, and this went on for nine years. Although we experienced much anxiety and dejection in these nine years, we were still happy to have met with understanding from the principal, teachers and classmates. After middle school, the leaders of the high school looked after us and made an

exception for Yiran to sit in on classes. We felt extremely grateful even though she wasn't on the school register.

Before school started, all the subject teachers and students in the class communicated fully with us. Yiran once again was fortunate to integrate into a new community.

But an integrated education cannot depend on the determined efforts of the parents of each special child, neither can it count on the sympathy of school principals and teachers. Many special children are unable to find their place in school and there are many news reports of special children being 'excluded from school' or 'kept apart'. There are also a lot of other parents and children who just don't understand us. We long for genuine public activities and policy advocacy to help all special children along the road of inclusion; for example, talks on inclusive education for teachers in the ordinary schools system, short films for the public on inclusive education, or help with teaching materials so that children can attend inclusive schools. We envisage this kind of future: all school principals and teachers will understand what inclusive education is and recognize its positive significance. Each student will happily accept their out-of-the-ordinary classmates and understand them and get along with them, and happily give them the help they need. Each of these special children will not only have their own place in the classroom but will also have their own friends. Inclusive education will no longer be an unfamiliar word, but will be the civilized way to go!

Extracts from Ke Qian's report

Aim of the project: Parents of autistic children, in particular their mothers, have to take on the daily burdens of the education of their children, and also have to withstand the pressures from inside and outside the family. These pressures are great and long term, and they have no one to talk to. They are apprehensive and pessimistic about the future. Opportunities need to be created for them to communicate with each other, come together for support, and receive regular psychological counselling and transfer of positive energy.

Activity experience:

Parents were asked to choose their three most pressing concerns at present. These were: a wish that there would insurance services to cover autistic children; a wish that when they grow up autistic children would receive regular technical training and work would be arranged for them; a wish that welfare organizations would help parents fight for their child's rights and interests.

We also hope that we will be able to design more advocacy activities according to parents' needs, and get the guidance and support of public welfare foundations.

Report by Jiang Yitong (project consultant)

The event 'Star¹ mothers Discover Themselves' was held on 20th April 2014 at the Slow Life Café at Haibin Road Guesthouse in Shantou. 25 parents of mothers of autistic children participated.

Overview:

The main aim of the project was to give the mothers of autistic children ('star mothers') opportunities to receive psychological counselling and to communicate with each other. The session lasted about three hours and two psychologists were present throughout. The session was divided into three parts: 1) psychological counselling; 2) parents' discussion, and 3) sharing experiences. In the first part, the psychologists suggested ways of relieving stress. In the third part, several students shared with parents their research on public attitudes towards children with autism. This was followed by Ke Qian's experience of parenting, aimed at giving parents a positive view of their children and changing their attitudes. The most important part was the discussion amongst the parents. The participants were divided into two groups, each led by one of the psychologists, in which their worries and needs were discussed.

Comments:

Ke Qian did a lot of serious preparation for this project. She had repeated discussions with the psychologists and the consultant about the content. The parents who took part in the workshop were very enthusiastic. More parents participated than expected (25 rather 20). It was evident that parents of autistic children in Shantou suffer from a chronic lack of communication, so they saw this event as important and participated actively. Ke Qian played a positive role in guiding parents, and her personal influence and experience gained their trust.

The aim of the CRPD Lives project is to tap into participants' own abilities and for them to grow and improve in the course of the project, so the consultant did not interfere too much in the organizer's activities. But generally speaking, the activities could be improved in the following areas:

1. The aims could be clearer. The aim of the event was to allow parents to come together to support each other and talk to each other about their troubles and needs. But there was not much relation between the aims of the project and what, for example, the students and psychologists actually talked about.

¹ 'Star' here is a euphemism for people with autism, so 'star' mothers are the mothers of autistic children.

2. Prominence was not given to rights issues. Although this was the first time that a workshop had been held for parents, some attempts could have been made to incorporate such issues. Instead, the event concentrated more on psychological communication and guidance.

3. There was no follow-up plan.

4. The organizational capacity could be improved. Although each parents' discussion group was led by a psychologist, the discussions were still rather disorganized and participants were not effectively directed to listen carefully to each other's stories. The part where the psychologists talked did not meet the expected targets and parents did not show much interest.

5. The role of the psychologists should be reconsidered. According to the discussions before the meeting, the psychologist was to be like a guide, encouraging parents to speak from the heart and controlling the course of the whole meeting. But in actual fact, the psychologists failed to have effective controls and there was no effective discussion in the groups. Next time, it might be worth considering inviting a supervisor.

Consultant's Assessment of the Project

Ke Qian treated the project pretty seriously and completed the activities and report on time. She was also active during the course of the project. But her understanding of rights needs to be improved and her management and implementation skills need to be strengthened. Also, being a high school teacher she has students who could be volunteers but they only have time on Sundays. Ke Qian is planning to set up a parents' organization with other parents (registered as an NGO) and hopes to do some advocacy activities in days to come.

Generally speaking, Ke Qian is keen to continue such activities. She is about to set up a parents' organization and from this can start to build up her project management skills. Her time also needs to be considered (once a week) so she can take on what work she can.

XIE JIANJIAN

谢建建



Advocate/Grantee: Xie Jianjian
(Shaanxi)

Consultant: Fu Gaoshan

Project: Research on disabled children's education prospect in northwest regions of China

Extracts from Xie Jianjian's Testimony

As everyone knows, when you build a building you first have to dig a foundation and then you can build it up floor by floor. Studying is also the same. If you want to have a high school education, you must first complete the primary school curriculum. In this way things are linked up. But in the case of the special school in the Northwest where I work, there are violations of normal educational practice - and this is just trying to build castles in the air. Specifically, many disabled children who have not received a basic education are taught middle school occupational skills. This creates huge difficulties in teaching and certainly reduces standards.

There are many aspects to the appearance of this strange phenomenon. Below are a number of specific factors:

Extracts from Xie Jianjian's report:

Deficiencies in elementary school education for local people with disabilities

1. Lack of information

Population density in the area is relatively low, there is a low economic level, and channels of information are not sufficiently open. People depend mainly on radio and television for information about the outside world. Not many people use the internet. Radio and television are passive channels of communication and are not effective in spreading information about education for disabled people. The public lacks direct means of obtaining information. As the cases of Li Zhichao, Li Xiaoxue and Wang Zengyun show, even if parents want to send their disabled children to school, they don't know how to do it.

2. Family reasons

I interviewed a blind Tibetan woman named Zhou Macuo from Guinan county, Hainan prefecture, in Qinghai province. Her father was a primary school teacher but he never considered taking her to school and didn't show the slightest interest in her basic living conditions. In Luonan county, Shangluo city in Shaanxi province, there was a young man named Zhang Kang, who is physically and intellectually disabled and from a single parent family. His father takes no notice of him and so there is no way he can go to school.

3. Lack of educational resources

4. Low inclusivity

When Tie Shi, a young man with a visual impairment from the city of Pingliang in Gansu province was at middle school, his records clearly stated that he had the status of auditing student. Li Xiaoxue, who also has a visual impairment, is from the city of Zhongwei in Ningxia Huimin Autonomous Region. Her uncle and aunt were both teachers in the village school and so the school was forced to accept her as an 'auditing student'. This status came to an end after three years because to pursue a higher level of education she would have had to leave home for the town, which was far away. Cai Zhenzhou is a visually impaired young man. His primary school language teacher mocked and ignored him because of his disability. This made him so depressed that he left school.

5. Policy restrictions

Although the area has some special schools, many people with disabilities are excluded from education because of government rules. For example, after Li Zhichao's sight started to fail, he thought of going to the blind-deaf-mute school in Xian, but the school would only admit students who were Xian residents. Shaanxi province's technical secondary schools are mainly for Shaanxi, Gansu, Qinghai and Ningxia. Students from other areas are not able to register as students because of Ministry of Education regulations. Lanzhou School for the Blind can admit only a fixed quota of local students, and so many students go to neighbouring provinces to study, or else drop out.

6. Poverty

7. Lack of reasonable accommodation

Guo Baohong has a physical disability. He is from Chencang district in the city of Baoji in Shaanxi province. He was forced to terminate his studies because the middle school was too far away, and because the school didn't have wheelchair ramps, so he was forced to drop out. Even more shocking is that in a certain city in the Northwest the tactile pavement is not made of brick, but is a just level pathway painted yellow.

8. Prejudice against disability

9. Personal barriers

Personal barriers here not only include the physical shortcomings that disabled people themselves have to cope with, but also include the lack of acceptance of physical shortcomings by non-disabled people.



Xie Jianjian and one of his interviewees

Report by Fu Gaoshan (project consultant)

Background to the project

Xie Jianjian has low vision and comes from Hubei province. Because he had asked for a large-print college examination paper he was excluded from the special education institute at Changchun University. He studied and passed the IELTS and Japanese second grade examinations. He then applied to study abroad but wasn't able to go because, amongst other reasons, he failed to gain a scholarship. After he graduated, he took part in the Shaanxi provincial civil service examinations and entered Baoji technical secondary school as a teacher, which is where he is now.

Baoji technical secondary school is the only technical secondary school with a special education centre, funded by the Department of Civil Affairs. It covers Shaanxi province and surrounding areas in the northwest region. The school does not charge fees and also provides a stipend for living expenses. Most of the students are poor, with visual, hearing or intellectual disabilities, and most of the teaching focuses on vocational education. Most of the students have not completed the nine years of compulsory education, and there are even some students who are illiterate when they enter. As a traditional industrial city, Baoji has fairly developed transportation systems and a fairly diverse population.

Xie Jianjian is one of the few disabled teachers and one of the few young teachers at Baoji's technical secondary school. Compared to the other teachers and administrative staff (who make use of their connections [*to avoid work*]), he has a lot of responsibilities and pressure. Apart from this, he also has a lot of daily contact with his students, helping them in everyday life and in other areas. He has established very good relationships with them. The few days that I was in Baoji he was on the phone continuously, answering students' personal questions (including from those who had already graduated). Baoji technical secondary school is a fairly well-known school. One of the reasons for this is that it is directly under the Shaanxi civil affairs department, so the school is regarded as an official provincial organization and its status is recognized in local society. As a disabled teacher, Xie Jianjian is regarded as a local model for disabled people.

Project implementation

The project had a fairly long duration. Its main focus was to find poor, disabled people in the northwest region and its aim was to share teaching experiences and to record and summarize the problems of education faced by poor people with disabilities in the region, and to make recommendations. The final ten cases covered Shaanxi, Gansu, Ningxia and Qinghai provinces, so Xie Jianjian spent every weekend for two successive months going out on visits.

In the initial stage of the project, Xie Jianjian and the consultant talked about the main direction. Because Xie had had a lot of experience at the technical secondary school, it was finally decided to concentrate on the basic education of disabled people in poor areas of the northwest. The focus would be on individual cases and the reasons for not enrolling into or for dropping out of school.

After obtaining their agreement, interviews with some of the individuals involved were recorded, since it was felt that what they had to say would have far-reaching value. This would provide a solid foundation for when the report would be revised and distributed.

Observations about the growth of the project implementer

Before Xie Jianjian worked on the project, he didn't fully understand the CRPD. His only opportunity had been in 2013 when he took part in a discussion about regulations on education for disabled people organized by One Plus One. After becoming involved in the project and talking with the consultant he developed a fairly good understanding of the CRPD's core concepts, and so was able to think again about local conditions.

Xie Jianjian had taken part in a training activity with One Plus One when he first entered his profession. This was a joint activity between the school and One Plus One. But because of bureaucratic constraints, Xie Jianjian did not use the school's resources on this occasion, but exploited his good relationships with his students to find individual cases. The weekend that I was there, he and I not only interviewed each individual, but I also had a lot of contact with his own network of disabled organizations and parents. It was clear that Xie Jianjian's coordination and his ability to make use of all kinds of resources had made great progress.

With his low vision and his considerable travel experience Xie Jianjian displayed a lot of initiative. But he also has serious night blindness and because the research took one to two days to get there and back it meant he had to travel at night. But this also strengthened his sense of autonomy.

Consultant's summary and recommendations

1. Firstly, China's implementation of the CRPD and the government's aim of raising overall living standards mean that the question of education for people with disabilities now occupies a very important position. Although there still needs to be a lot of discussion and advocacy about the idea of integrated education versus special education, the issue of disabled people of school age who do not enter school must be vigorously addressed, whether by the government or by the public. According to CDPF statistics, at present 84,000 disabled children of school age are not enrolled in school and the actual figures are probably far higher than this. Only by fully understanding the background and the reasons for these children not enrolling in school, can effective policies and actions be implemented. Xie Jianjian's investigation and research is of really great value.

2. Specific cases are far more valuable than statistics for research into non-enrolment into schools and dropout rates. Research needs to be led and participated in by disabled people themselves,

since they have natural communication and analytical advantages when it comes to fully understanding an individual's background and life experience and analyzing the key factors.

3. As regards Xie Jianjian's report, in future he could go further in analyzing each case, and include more specific information. One Plus One also plans to invite Xie Jianjian to do media and policy advocacy about the process of his research and the details of each case.

4. In future, Xie Jianjian could make use of local resources to continue research on this subject and also develop other research topics. Baoji being a transport hub has clear advantages in the northwest region.

5. Through this project, Xie Jianjian has also established good connections with another partner from Baoji, Wang Ruilong and we knew about the value of Wang Ruilong's work. One of the individuals for the case studies came to Xie Jianjian on Wang Ruilong's recommendation. This person had dropped out of school because of being given the wrong medical treatment but the fundamental reason for this was because no support whatsoever about disability was provided. Although Wang Ruilong's methods were traditional, he solved the problem of lack of communication between local people with disabilities. Through his work, he has really built up communications within the community. Xie Jianjian and Wang Ruilong plan to develop more activities for disabled people to go out and gain the opportunity to communicate with each other.

XIONG SU

熊苏



Advocate/Grantee: Xiong Su (Hubei)

Consultant: Cai Cong

Project: Research on the living conditions of rural disabled people in Hubei

Extracts from Xiong Su's Testimony

I became disabled because of a muscle disease. I can't stand up straight because my muscles are weak and my skeleton has become deformed. I use a wheelchair to get around. My home is in the countryside. My father accompanies me in my studies and I am at university in Wuhan.

For example, in my third year at high school, my aunt accompanied me to school. My parents paid her 2000 yuan each month (1000 was for a service fee, and 1000 was for my daily living expenses). So in a single year these fixed costs amounted to around 20,000 yuan and they did not include the tuition fees and the cost of books, clothes, etc. It was also very hard for my aunt to accompany me because the classroom was on the second floor; she's a small woman and she had to carry me up and down stairs several times a day.

I'd like to say, a disabled person's development still depends mainly on the family and often a disabled person's educational needs are on the whole greater than those of ordinary people and a family is limited by its material circumstances. In the last few years, although I have a monthly subsidy of 90 yuan for living expenses, I am fairly limited in what I can spend. This kind of economic restriction is especially apparent in the countryside where incomes are universally low. My father later said that if I continued my studies at home, things would be a little easier. But my mother said they were willing to do it. As a result they had far, far more hardships than other people, but in return I was guaranteed everything I needed to study.

My parents worked hard to meet my material needs. My aunt accompanied me in my studies and provided backup support. I was told to study hard to get higher examination grades and in this way

break through tangible and intangible barriers to education (obviously there would be psychological pressure).

Extracts from Xiong Su's report

Project implementation

Let's talk about publicity first. I thought that I would circulate the questionnaires at the wholesale centre (where people from the two villages gather together). The questionnaires included a general questionnaire and a questionnaire for disabled villagers. Firstly, this was to lay the foundation for obtaining support for the interviews, and secondly, to arouse the villagers' interest in participating, to create a little change in awareness, and not just for research purposes.

I had a few reasons for these ideas. My parents had always felt inferior because they had a disabled daughter. Perhaps villagers would say things in secret behind their backs. It was like this even though, through their hard work, my parents' economic circumstances were slightly higher than average. It was not until I came back from school, especially after going to university, that gradually things began to change. But no matter whether it was my old feeling of inferiority or later some feeling of pride, I felt that neither was a normal attitude towards disability. Through this activity, I hoped to change myself, my parents and the people around us.

Talking again about sustainability, sustainable integration. This was in the follow-up phase of the interviews. The method was to give participants 200 yuan to spend on a specified amount of goods at the non-staples food store. They were allowed to choose to spend this either on items for daily use or food during a 20-day period. Each time they were allowed to spend between 10 and 30 yuan and would have to sign their name. Apart from making a small improvement to their standard of living, I hoped to provide disabled people with a reason for leaving their homes and I offered a venue where they would have the opportunity to meet people. There is not much fun going on in the countryside. Generally speaking, going out means buying some daily items or pickles or something at the shop. The central collection and distribution centre would meet these needs exactly and at the same time the questionnaires could be distributed, achieving two goals simultaneously.



A villager from Xiong Su's village

In the original design, I had thought of paying the interviewees something, but the consultant said that the interviewees shouldn't receive a cash payment because it might influence the validity of the content, and so some changes were made. The design was also based on my own experience as a disabled person. I didn't go out, not because there were no obstacle-free facilities, but because there was no reason to go out. In everyday life, not having the power to make decisions or choices, almost all disabled people are passive recipients. So I had this sustainable idea.

Report by Cai Cong (Project Consultant)

Xiong Su's Background

Xiong Su has weak muscles and uses a wheelchair. When she is in reasonably good health she can push her wheelchair, but in poor health is able to do hardly anything by herself. She is now a third-year student at Zhongnan College of Finance. Her home is in a rural area of the city of Honghu in Hubei province. (For further details of her story please refer to the report, unnecessary details are omitted here.)

Project Implementation

Xiong Su's own health and study circumstances meant that the project went through many phases. It was finally decided that she would become an advocate for disabled people in the villages of Gaofeng and Zhongxin, her home area. For specific details about the project please refer to Xiong Su's project report. The key details of the project are as follows: The original plan was to interview ten disabled people in the two villages. These cases would reflect the daily lives of disabled villagers and the attitude of non-disabled villagers to disabled villagers. It was also decided that each interviewee would be supported with a donation of around 200 yuan's worth of items for daily use.

After discussion, Xiong Su made a new proposal. The interviews would be conducted as before, but the contribution towards living expenses would be allocated in a different way. In future, the 200 yuan per person for living costs would be deposited at the wholesale store at the junction of the two villages. Each interviewee would go to the store to sign to collect their supplies (excluding cigarettes and alcohol) and each time for no more than a certain amount.

This change meant that the interviewees not only received some financial support but were also encouraged to venture out repeatedly from their homes and go to places where people normally gathered. On the one hand, it helped non-disabled people gain an understanding of disabled people; on the other it encouraged disabled villagers to go outside, integrate with the community, find ways of overcoming environmental barriers, and build up confidence.

The project also included the distribution of 200 questionnaires to non-disabled people to ascertain their attitudes to people with disabilities and a small gift worth two yuan was given as remuneration for filling in the forms. This was also done at the wholesale shop. Since the shop was located between two villages, it was usually where the villagers would stop to chat and so it was here that the project achieved the greatest publicity.

Xiong Su used her own experience of the local geographical and cultural environment to indigenize the project.

Observations

The project in Gaofeng and Zhongxin villages proved an effective way of raising awareness of disability. It led to a better understanding of disabled people's living conditions as well as the attitude of non-disabled villagers towards disabled people. It encouraged disabled people to leave their homes and go outside and integrate with the community, and it helped non-disabled villagers to understand the concerns of disabled people. Xiong Su's personal growth and changes in her own family should also not be overlooked.

First of all, although Xiong Su is herself physically disabled and was housebound for six years, she actually knew almost nothing about disabled people in the two villages before she started working on the project. The project encouraged her to gain a basic understanding of disabled people in the two villages and surrounding areas and spurred her interest and enthusiasm to design more projects to change the lives of disabled villagers.

At the same time, the influence of the attitudes of Xiong Su's family towards disability meant that before she started the project she had never had the experience of going back home from school on her own. During the project, the consultant, who also has a visual impairment, travelled with Xiong Su from her school in Wuhan, took taxis, walked, travelled by long-distance bus, etc. thus helping her to complete the first trip she had made independently away from home. This helped her to leave home to look for work after she graduated and to have the confidence and determination to live independently.

During the project, Xiong Su had numerous contacts with villagers who had a low level of knowledge about disability. This helped Xiong Su gain an understanding and acceptance of her own identity.

Conversations with the consultant meant that Xiong Su not only gained a deeper understanding of the Convention but also more knowledge about disability. In the past, Xiong Su, like most other local people, had considered that cerebral palsy and autism were intellectual disabilities.

Secondly, at family level. The Honghu region lies on a plain with many lakes and much rain and so most of the villagers' houses are built on high ground with basically no facilities for disabled people. During the preliminary stage of the project and during the middle interview period, Xiong Su was very busy with her studies and so needed the help of other family members. Her father, older paternal uncle and aunt and younger paternal uncle and other relatives, all participated. In talking with Xiong Su, the family's attitude towards Xiong Su and towards disabled people changed, and they began to recognise the social obstacles they faced and the individual strengths disabled people possessed. Even when Xiong Su was not at home, the attitude of other relatives towards disabled people changed, and this in turn would have a long term impact on even more villagers.

Thirdly, at community level. During the project, Xiong Su went everywhere interviewing villagers, either by herself or with relatives. She used personal cases to change villagers' ideas about her and people with disabilities, established contacts with disabled people, and in this basic way took the first steps towards developing many more in-depth projects in the future.

Summary

The project chose a rural area in central China to conduct a basic investigation into the lives of disabled people and the attitudes and knowledge of non-disabled people towards disabled people. Although only ten families with disabled members in two villages, and 200 non-disabled people were selected, much experience was gained from the design and implementation, and from the development of future projects.

Project design and implementation

1. The interviewer had specific knowledge of disabled people and local life, which ensured smooth implantation of the project and better-than-expected results.
2. The consultant had a completely equal relationship with the interviewer, respecting her local knowledge in the implementation of the project.
3. The consultant offered the interviewer professional advice and ideas about project

implementation as well as financial guidance to ensure a successful outcome.

Future development of the project:

1. The project has shown that a small amount of payment for living expenses based on local circumstances will achieve good results.
2. The implementation of specific rights. In rural areas, especially in economically underdeveloped areas, consideration should be given to combining livelihood projects with community integration projects. On the one hand this would bring about economic empowerment, while on the other, organizing community activities centring around disabled people would attract the participation of both disabled and non-disabled people.
3. Thirdly, an investigation into the basic circumstances of rural disabled people needs to be carried out. Every aspect of disabled people's disabilities and lives needs to be understood and there needs to be a targetted development project to build a foundation for their rights.

ZHANG QIANXIN

张倩昕



Advocate/Grantee: Zhang Qianxin
(Guangzhou)

Consultant: Cai Cong

Project: Investigation into the
dilemmas faced by visually impaired
women in relationships and marriage

Extracts from Zhang Qianxin's Testimony

I was born into an ordinary family, the only child of the family. I've had a visual impairment since I was small but never had any 'preferential' treatment from my parents. I understood the efforts my parents went to. They wanted to raise me as an ordinary child, wanted me to study independently and that's why I was always at an ordinary school placed in an ordinary class.

Having a visual impairment, I had many problems and difficulties not encountered by ordinary people. When I fell down, I got up and walked. If the print was too small to read, I used a magnifying glass. If I couldn't see the blackboard, I would listen and understand. In class I couldn't write things down in my notebook. After class I would spend time looking at power point presentations. I read very slowly and found it hard to search for things online. I tried hard to find a suitable way of studying. If there wasn't enough light during examinations I used a desk lamp with a battery.....In 2010 I was in Guangzhou No.4 Middle School and with the help of the school and the CDPF I took part in the ordinary university entrance exam using a special large-print exam paper. I lived up to expectations - not only my own expectations - got a score of 626, and was accepted by the social work department of Huanan Agricultural University.

Doing more investigation and research into the field of disability social work and services

I have a lot of social work and practical experience. I have taken part in many large-scale social activities for disabled people and undertaken important organizational and planning work. I've also been responsible for chairing meetings and activities and taken part in important meetings in the disability field, such as the 6th representative meeting of disabled people in Guangdong. At present, I am the vice-chair of the Guangzhou Lizhi District Association for the Blind and on the board of directors of the Guangdong Province Association for the Blind. I have many more opportunities to use my own expertise and skills in the service of people with disabilities.

There are always many difficulties and frustrations along life's road. As a woman you can't avoid the emotional aspect and this brings me, as a single person, a lot of loneliness. Because of my disability, there are worries about study and work, it's an emotional journey dealing with worries and privations. But after meeting many visually impaired women in more or less the same situation as I am, I really want to explore things further with them, and support each other. Perhaps we all need this opportunity to come together in a group.

Extracts from Zhang Qianxin's report

The main factors are summarized as follows:

1. An individual's values in terms of love and marriage: including knowing what love and marriage are all about, and having an understanding of oneself.
2. Building a family: this includes the composition of family members and the economic circumstances. Responsibilities after marriage are directly connected to this.
3. Personal life skills (ability to control one's own behaviour).

Experience and suggestions

On one occasion at the beginning of the project, I became too emotionally involved and upset during the interviews so I talked things over with the consultant and finally made some changes to the project.

By hearing other people's stories during the project I learnt a lot about the problems of love and marriage. I haven't yet had any experience of love. I am now looking forward to my future emotional

journey but am also apprehensive and worried. I'm really just standing on the sidelines at the moment and don't really have a clear understanding or accurate grasp of these issues.

Generally speaking, working on this project gave me a lot of food for thought about life and love.

Suggestions for future work

We need to be calm and objective when confronting all sorts of experiences at work, learn to control our emotions, and avoid becoming one-sided and emotional.

Report by Cai Cong (project consultant)

Background to the project implementer

Zhang Qianxin is visually impaired. At present she is a 4th year student in the social work department of Huanan Agricultural University. She has already been accepted to do a Master's degree. She has never had any romantic attachment. Of the six related families on her father's and her mother's side, she is the only child of the next generation.

(For her detailed story please refer to her full testimony. Unnecessary details are omitted here.)

Project Goals and Implementation

Zhang Qianxin based the project on her own needs and experience. It focused on her visual disability, her formal education to high school level, being single, and the love and marriage relationships desired by a young woman. Many modifications were made to the project. Her situation is described in detail in the implementation report. The main points are described here.

It was anticipated that the project Zhang Qianxin had originally designed would identify the reasons why a visually impaired young woman with a high school education was single and it would propose ways of resolving this situation. Zhang Qianxin's own needs and anxieties lay behind the project. The method would be to carry out individual interviews and psychological analysis. However, as project consultant, I thought that the outcomes were unrealistic given the limited period and scope of the project and proposed some changes. To gain Zhang Qianxin's agreement, I sought the advice of PhD student Ma Zhiying from the Anthropology Department of Chicago University, who had many years of experience implementing projects and doing research. Ma could give Zhang Qianxin some guidance.

After modifications were made to the project, Zhang Qianxin located women with visual impairments who were in the same situation as herself but came from different backgrounds. She started to conduct individual interviews, focusing on analysing the possible factors that might influence their view of love and marriage. The project produced results and, in addition, it was sustainable.

However, unexpected problems arose in the course of the project. Zhang Qianxin's original intention was to base the project on her own experiences and needs. Her aim was to solve the problems she was facing. But after the interviews began, she became so involved in the first case that it affected her psychologically. She felt that she could not continue with the project and asked for it to be ended.

I thought that if the project stopped, it would have a huge negative effect on Zhang Qianxin's state of mind and on her future. After discussion it was decided that individual interviews would be conducted in a group, as a way of providing psychological support for everyone. I also participated in the group activities. From the gender point of view (since I am male) this prevented psychological bias emerging amongst the group members.

The group achieved their aim, and because the project had been modified, there was a surplus in the support funds. This surplus can be used to support future group activities and to explore ways of dealing with adverse influences as they arise.

Zhang Qianxin's observations about the process

As a student of social work, Zhang Qianxin knew how to do research and she responded well to social worker research methods. When designing the project, she took her own experience and needs as the starting point, combining this with rights advocacy and the CRPD. She based the proposal on her own situation, but for her own reasons modifications had to be made to the project. She considered she had the following advantages: she was educated, had the ability to do research, was herself a disabled person, had a position in the local Guangdong Blind Association, and was rooted in the disabled community. This was why she had an advantage in doing research in this community and why she was able to find interviewees with different backgrounds.

Zhang Qianxin's own background and experience, together with her specific abilities, appropriate local resources, her ability to find the right community of people, and the expert guidance offered to her, proved to be a good way to popularize the CRPD and implement disability rights at a local level.

But Zhang Qianxin had never received any systematic CRPD training and had no project experience. In the course of the project she encountered many setbacks. She did not have the flexibility to make changes to the project, and design issues were too biased in a psychological direction. This was a weakness in her research as related to disability rights.

When problems arose in the course of the project there was timely communication with myself and adjustments were made. This encouraged Zhang Qianxin to seek support in the future and learn from her experience, and to establish contacts with professional DPOs like One Plus One for support in project design, management, implementation, and the concept of disability rights.

The project was Zhang Qianxin's first experience of conducting this type of research. Apart from being a research project, it also proved to be an effective model for community development, especially because it brought people with the same background together and had the support of the community. In this way she gained even more material for further research.

Consultant's summary

This project depended on Zhang Qianxin's own competence and local community resources, with her own identity as a disabled person being integrated into the project design and its development. Although many big adjustments were made to the project overall - in design and implementation and as regards future project development - it was a worthwhile research experience.

Project implementation and design:

1. Not only research skills and academic background are required to do qualitative research. Being part of the community and having experience will result in a more diverse range of people to research and to being accepted by the community.
2. If a project is based on personal experience and needs, it will be easier to find points in common with interviewees and this will benefit research. But the researcher needs the timely support of a consultant in order to prevent him or her becoming too immersed in the project, leading to a lack of objectivity and the researcher's own mental state becoming affected. In future, attempts must be made to try to switch roles when doing research. For example, as a visually disabled woman, Zhang Qianxin could research people with hearing disabilities or physical disabilities. In this way, while the project would be based on the shared experience of having a disability, it could also explore the unique experience of different types of disability. It would be

easy to integrate with other people who were also disabled but there would be less chance of becoming emotionally involved.

Future project development:

1. Funds were left over because changes were made to the project. Guided by the consultant, Zhang Qianxin designed a series of group activities to explore the possibility of sustaining future individual research projects.
2. The primary goal of the research was to identify and analyze problems and then propose a workable plan. If a researcher builds on his or her individual experience and needs and persists in looking for ways to solve problems, a small project could expand into something bigger.
3. As regards concept, project management, design and implementation etc., DPOs, which have professional experience, should work together with individuals to their mutual advantage, enabling a small-scale project to become sustainable.
4. If the group in this project comes to an end, the group activities could continue in the future. On the one hand, people could come together to support each other emotionally and ease the pressures they are under. On the other hand, group activities would also provide a good basis for future research projects. The results of such activities remain to be seen. If an effective model can be found for small-scale activities in different areas and a community leader can be found to popularize them, then this kind of community-based model, responding to community needs, could be developed quickly and effectively.

DUAN HONGBO

段宏波



Advocate/Grantee: Duan Hongbo
(Baiyin)

Consultant: Jiang Yitong

Project: Research on disabled
people's legal needs in Baiyin city,
Gansu

Extracts from Duan Hongbo's Testimony

My name is Duan Hongbo. I am 30 years old and have a visual impairment. I live in Baiyin district in the city of Baiyin in Gansu province. The town is an old industrial base, built 50 years ago. There have been many transformations in the city and geographically it is very cut off. Most of the people in the town are old people who came from all over the country in the 1950s and 60s to help develop the Northwest, and their children.

I have been discriminated against as a disabled person in education and in work. When I was in the first year of primary school, I was excluded from the education I should have received at school because of my visual problems. So my primary school life was spent going from pillar to post and from then on I had lessons at the homes of nine different relatives and it was only when I was 10 years old that I returned to my parents to study. But because my grades were not up to the level required to enter middle school, it meant that once again I left my parents to study outside, and it was only when I was working that I finally returned to be with them. After I started work, again because of my visual problems, my employer excluded me.

I think maybe the main reason for all this is people's attitudes and that includes disabled people themselves and society, or those involved in particular incidents. The main problem disabled people have is a sense of inferiority. Two ways of solving this are 1) to use legal measures to resolve specific violations of rights, to protect the rights of disabled people, promote recognition of this in society and respect the rights and interests of people with disabilities; and 2) through one's own work influence the people around one to make them understand that disabled people are the same and enjoy the same rights and interests as they do.

Extracts from Duan Hongbo's report

Conclusion

Firstly, we discovered that more than 50% of disabled people did not know about the Law of the People's Republic of China on the Protection of Disabled Persons, the Convention on the Rights and Interests of Disabled People (CRDP), the 'Regulations on Employment for Disabled Persons', the 'Regulations on Constructing an Barrier-free environment', ' the Gansu Province Employment Measures for the Disabled' and other laws and regulations. Generally speaking, disabled people in Baiyin have a low level of understanding of such laws.

Secondly, surveys show that most disabled people in Baiyin believe that laws and regulations play an important role in everyday life. Most disabled people, when they encounter violations of their rights and interests, resolve them or hope to resolve them via the law and they expect to be supported. It is clear that most disabled people have an in-depth knowledge of the importance of the relevant laws and the role of the law in resolving disputes.

Furthermore, most disabled people in Baiyin want to have a deeper understanding of the CRDP, the 'Law of the People's Republic of China on the Protection of Disabled Persons' and other relevant laws. At the same time, some disabled people encounter problems related to the law. Something that needs to be urgently resolved is the legal problems related to the labour and employment laws. Also a few disabled people need urgent resolutions of legal questions related to civil cases, etc.

All in all, disabled people in Baiyin have a low level of understanding and knowledge of the laws relating to disability. However, they have a fairly good understanding of the law in everyday life. Most disabled people want to know about the CRPD, the 'Law of the People's Republic of China on the Protection of Disabled Persons' and other relevant laws and regulations. It is important for

disabled people to understand such laws in order to protect their legal rights and interests and to strengthen their ability to use the law.

Report by Jiang Yitong (project consultant)

The project 'Research on disabled people's legal needs in Baiyin city, Gansu' took place between March-June 2014.

Project Overview:

The project spanned quite a long period. Its main components were as follows:

1. The design of questionnaires and delivery phases. Several modifications were made in the initial period between March and April 2014. The aim was to distribute 200 copies.
2. Home interviews. The consultant and the project implementer (Duan Hongbo) did interviews with a number of hearing impaired and physically disabled people in Baiyin district and Shunan village in Shuichuan township, and they obtained good results.
3. Focus group interviews. The consultant chaired all the focus group interviews. He first talked about the CPRD to give the participants some basic ideas about the rights of people with disabilities, and he then collected together and analyzed the needs of the disabled people who were at the meeting.
4. Report writing stage. Duan submitted the final report on 20th June.

Overall comments:

This western city of Baiyin has scarce resources, so there is a great need for such activities. Before the project, Duan thought that disabled people knew little about rights and had no interest in rights activities. But when we went into people's homes we discovered that disabled people were very enthusiastic about rights. They were not only concerned with their material life but were also extremely interested in their spiritual and cultural lives. A lack of resources means that disabled people in western cities of China have little opportunity to take part in activities that take them outside the home, and consequently they are forced to stay indoors for long periods. But they all expressed a deep interest in rights-related activities or in 'helping other people' and they were all willing to become volunteers in a new organization. Their stories and experiences emerged in the

interviews and this opportunity made the disabled people who took part in the interviews really happy.

The interviews also changed Duan's previous outlook. His own work gained recognition and brought in many new volunteers, giving him confidence in his own new organization and future work. These new discoveries were probably the activity's greatest success.

Limitations and shortcomings:

Although Duan was very enthusiastic about work with disability and although he had some awareness about rights, certain limitations became apparent during the course of the project:

1. The objectives were not clear. Duan was very enthusiastic about disability work and took on a lot of work related to this, but he didn't have clear aims and this meant that many of the project activities could not be effectively implemented. Special attention needs to be paid to this if the new organization is to develop new activities.
2. Multiple identities limited work efficiency. This was a serious problem with the project implementation. Duan worked with the CDPF and in other places and, apart from this project, he had also taken on other disability work which meant that his time was limited. The focus group interviews and home interviews should have been completed by April 11th and all the questionnaires collected and the draft report submitted by the end of April, but for a variety reasons, this was delayed to June 20th. It is recommended that in future the project implementer should be more efficient and complete the work on time.
3. The most suitable project participants were not chosen. Since the project had no clear goals, the participants showed little interest in the project activities, especially in the focus group interviews. Altogether 10 people (including Duan) took part in these interviews. Full-time members of the CPDF were told about the meeting only the day before or on the day itself. Since people were not interested in the meeting, it meant that – for a variety of reasons - they kept leaving throughout the meeting. (The meeting was held at the CDPF office. Many of the participants worked in the same building and would go back to their own offices to carry on working.) In the end, even Duan himself left because he had something else to do. This meant that sometimes there were only two participants and so there was no way of achieving the expected results.

4. Constraints due to being part of the CDPF. Duan is a CDPF member, so although this gave him access to a lot of resources, it also restricted him.

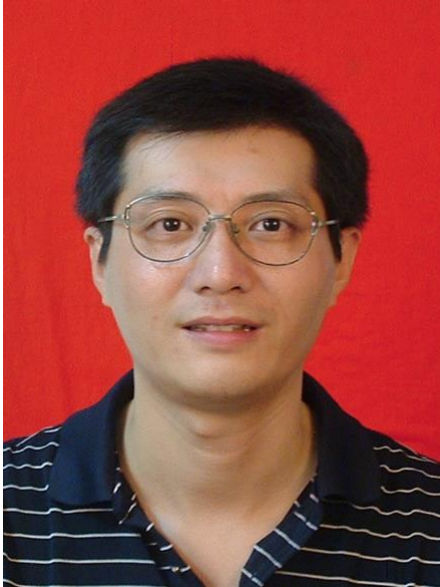
5. The quality of the evaluation report could be improved. The basic evaluation report covered the results of the survey, but there is still much room for improvement. The present report is just a simple statement of the answers to the questions on the questionnaires, but there is no deeper analysis. There are also no gender statistics (the consultant gave many reminders about this beforehand). The consultant suggested that Duan ask an expert with a social approach to help with the statistics and data analysis, but regrettably the results of these expert statistics and analysis do not appear in the report. The home interviews and focus group interviews do not appear in the report either, (the consultant gave many reminders about this beforehand). The report leaves a lot of room for improvement.

Duan himself was very enthusiastic about the work. The members of his team and the volunteers he assembled during the project are useful human resources. But since no one was professional, everyone's time - including Duan's - was limited. Duan has set up a new organization and in future there is a lot of scope to do much more. But he needs a lot more training in organizational and management skills to make his work more focused and effective.

Gansu and other western regions have great potential. The lives of disabled people in the rural west should not be forgotten. It is suggested that similar types of project be developed in the future to mobilize the west's resources.

ZHOU YAN

周彦



Advocate/Grantee: Zhou Yan
(Nanjing, Jiangsu)

Consultant: Fu Gaoshan

Project: Support group for
disabled women in Nanjing
area (with testimony collection)

Extracts from Zhou Yan's Testimony

I am 49 years old, with physical disability. I became disabled in 1981 due to an illness, and started working as a community disability specialist in 2006. At that time I started to realize my shortcomings in disability awareness and working capacity. Over the next five years, I worked to become a certified social worker.

In Nanjing, the capital of Jiangsu Province, there is a fairly comprehensive welfare system for disabled people. However, not many people realize that disabled people also have psychological and emotional needs.

In my work I like to respond to the needs of disabled people in my community – not only supporting their daily rehabilitation and sports/arts activities, but also paying attention to issues such as accessibility, family/relationship counselling, and employment. Disabled people, especially women with disabilities, have very little chance to participate in society. Therefore, for me, it is important to encourage them to step out of their homes and voice their opinions on social issues and their own needs.

Extracts from Zhou Yan's report:

At the beginning I wanted to organize a support group for single disabled women in the community. But the recruitment process turned out to be more difficult than I thought it would be. After some private consultation, some of my target group members told me that they thought the word “single”

suggests a rather sensitive and private matter, so they didn't want to sign up. When the support group was adjusted to include all disabled women, I was able to recruit 34 women altogether for five separate sessions.

During the five sessions, group members shared their life stories with each other. We also discussed disability-related topics, such as difficulties disabled families face and general social acceptance and inclusion for disabled women. By the end of this project I collected 10 life stories from disabled women in the support group.



Report by Fu Gaoshan (project consultant)

Background to the project

Zhou Yan is a 49-year-old community disability specialist from Nanjing, Jiangsu. His physical disability was a result of an illness when he was 16. As the oldest grantee of the CRPD Lives mini-project, Zhou Yan was self-taught and passed the social worker examination. In his spare time he likes writing and photography.

As the capital of Jiangsu, Nanjing has an abundance of public resources. Gulou, the community Zhou Yan lives in, provides quite comprehensive social support and welfare structures for disabled people who hold local *hukou*. But the policies rarely respond to disabled people's psychological and social needs, especially regarding their desire for community inclusion and independent living. This is exactly the weakness of the government's disability policy at the moment. As a community disability specialist, Zhou Yan is not only very capable in his daily work, but also pays close attention to disabled people's needs beyond the obvious welfare model. In China, some community disability specialists are disabled, while some are not. The main difference between the two is in their understanding of the true needs of disabled people. However, since these specialists still work under a rather conservative framework, they lack in-depth understanding of the rights model.

Project implementation

There was quite a long communication process during the planning stage of this project, going through a total of five different plans. Since Zhou Yan was busy working on a Disability Day event in May and a social worker exam in June, the project didn't really start until the end of June. The

project lasted two months, with five support group sessions running during the weekends, making adjustments to the discussion topics for each session as the project progressed.

Zhou Yan experienced a lot of difficulties during the initial recruitment process. We suggested that he should remove the word “single” and simply look for disabled women instead. Zhou Yan was also advised on how to run support groups and techniques for collecting testimonies and organizing discussions. The outcome of the project would be collecting anonymous testimonies from members of the support group, as well as compiling the material into 10 life stories of disabled women in Nanjing.

Observations about the growth of the project implementer

As the eldest project implementer among all 10 grantees, it was slightly more difficult for Zhou Yan to take on a new perspective on disability. But he has genuine concerns regarding disability issues on the community level. He is also sensitive to the needs of his constituency.

During the initial planning stage, Zhou Yan had designed his support group sessions to cover all types of disabilities. But after more thought he decided to focus on people with physical disabilities, the area with which he is most familiar. By making this shift, he realized that it is important to be professional and utilize one’s own resources when working in the disability field.

To begin with Zhou Yan also brought up the idea of putting together a committee for the project, recruiting members from the local Association of People with Physical Disabilities. This arrangement might have been beneficial for him to allocate government resources for the project, but it could also have negatively affected the support group as it could change the goal of the project. In the end, Zhou Yan decided to run the project independently, and the Association would only take on a supportive role.

As the project progressed, upon the request of the consultant, Zhou Yan was able to provide reports, photos and financial records. During the two months of project implementation, he had improved quite a lot in terms of his organizational skills and reporting capacity.

Consultant’s summary and recommendations

1. Firstly, when working with older grassroots disabled advocates, it is crucial to provide them with a fresh perspective when looking at disability issues, which can be done by working on projects together.
2. Although Zhou Yan had given up on recruiting single disabled women for the support group activities he designed initially, he can still revisit the idea later on when he has his working model established, and gains more experience and resource.
3. If the project outcome (10 testimonies) turns out to be interesting, One Plus One will collaborate with him on the subject of “disability and gender” at the end of 2014.
4. Zhou Yan is a very active and motivated individual, both locally and within the disability network. He has also acquired professional social work skills and the capacity to work independently. In future he should be able to continue running support groups for other disabled people or disability rights training sessions for other social workers in his community.

OTHER TESTIMONIES

Chen Zhongbao

I have a congenital disability which has given me a deep inferiority complex and I've grown up with discrimination. I was ridiculed by my classmates at primary school. I couldn't bear to be like this and was even sorry I came into this world. Once, when everyone went downstairs to do exercises, I was the only one left in the classroom together the teacher, who was about to go back to the staff room. Another teacher from the class next door passed along corridor and when he saw that I hadn't gone out he asked the teacher if I wasn't well. Then my teacher said something I've never forgotten: 'Oh, he's a just a cripple (残废 canfei).' I don't know how the teacher in the class next door responded, but my eyes reddened I wanted to say, Teacher, it's just that my feet are no good, I'm not a cripple! I can manage on my own, I can go to school, I can work, I could become a scientist (that was my dream when I was little).... But, I couldn't get the words out, or else I simply didn't dare to say that. Because I knew that my disability (残疾 canji) was something that could not be changed. I couldn't make my mother give birth to me again, let my right foot develop properly before giving birth to me. I didn't have the courage to uphold my dignity because I knew too little about disability (残障 canzhang). It was only after I grew up and my social circle expanded, that I realized there were other friends with disabilities like me in the world. Disability (残疾 canji) is not an illness, it's perhaps just that the body lacks some parts or the intellect has not developed as fast as other people's.

The government has special policies and measures of care for people with disabilities (残障者 canzhangzhe). There are concessions for travelling by public transport and free entry to parks and museums. But I've found that some disabled friends don't know that a disability pass can be used in these ways. They haven't been outside much since getting the pass and even feel that it's better to avoid admitting to themselves that they are disabled. But I told one of these disabled friends that you could travel on the subway for free with this pass. He said there's no need, if someone comes over specially to open the door, if other friends have to wait for you, it's better to pay. Perhaps in his eyes this kind of preferential treatment is not essential, there's no need to think of such 'petty things'. But I think this is not about having pity for disabled people. It's about us having our legitimate rights. Like there are special preferential policies for old people, children, and soldiers. It's a law put out by the government to ensure that vulnerable people get more support. You're not given a pass out of pity! We ourselves ought to know more about 'disability' (残障 canzhang). Only if we accept ourselves can others accept us.

It is very important for disabled people to understand disability and accept themselves. Disabled people also need to be proactive in having contact with the outside world, such as taking part in sporting activities, studying, working, etc. There are objective reasons why people with disabilities find it more difficult to take part in sports than most able-bodied people. But this shouldn't be a reason for not doing sport or for setting us apart. In my experience I know that in the disabled community there are table-tennis contests, badminton contests, swimming, athletics, etc. Every year Jiangmen, where I live, holds all kinds of activities together with Guangzhou, to encourage disabled

people to go out, challenge themselves, mix with society. When I was 10 years old I was put forward to take part in a table-tennis contest. I didn't need any special skills. There was special training, a group of disabled friends accompanied me and from then on I started to create my 'family', my little social circle. Although in the early stages I showed reluctance and my mother spent a whole evening persuading me to take part, after half a month of persuasion and contact with others, I really reaped the benefits. I made many good friends, I got to hear other people's stories, I learnt a sport, I developed courage and confidence! This 'sports meeting' in which only a few dozen people took part, gave me so much. Compared to the usual support given to disabled people, this way gave me much more practical help. And I also got to know some disabled ex-army sports people at the Guangzhou Lizhi Stadium who played wheelchair badminton. They had their own work, but apart from work they met together for recreational activities, just like able-bodied people, dashing around the sports hall.

We often say that 'knowledge changes one's fate'. We start studying when we are little, but as far as people with disabilities are concerned this is not something that can be taken for granted. Very few disabled people go to school with able-bodied people and graduate and work together. Far more disabled people are unable to attend ordinary schools. Hearing, visual, intellectual, physical disabilities, all these things may fetter them. The better off ones might go to special schools for example, the Guangzhou English Training Centre for People with Disabilities, Anhui Fuyang Aixin School, etc. to learn English or a technical maintenance skill and when they enter society they may have some basic life skills. But the majority of disabled people live in remote villages and the education of most children is a problem, let alone for this special community of people. The government needs to consider administrative expenses, not to say that every village will be able to have a school that needs one. Moreover they need to consider special education training and hiring of teachers and other problems. So, in this aspect of education there are many things that need to be improved.

Just having disabled people themselves taking the initiative to fight for equal status and their legal rights and interests is far from enough. In recent years, NGOs, government etc. have all encouraged the inclusion of disabled people into society, and the general population to understand and have contact with this community of people and so they can also develop.

Zhang Weifang

In the third quarter of the year of 2012, the average salary of a government official in Nanning City was 2980 yuan, but very few people around me were on this wage level, most of them getting between 1000 to 1500 yuan. In 2013 the minimum wage in Nanning was 1200 yuan and the minimum social security for urban residents was 400 yuan per month. The living standard of disabled people in Nanning is relatively low and they are basically poor. Although many disabled people have work, their wages are low and some are lower than the minimum wage, barely meeting their everyday needs. I am a disabled person living in Nanning. I have work and can earn 1400 yuan a month, and fortunately am single and live with my parents so this salary can support my basic needs. But if I had to raise a child then it would be very hard to live on this level of income.

I am physically disabled in my upper limbs. At work I use my feet to operate a computer. My feet can type as agilely as someone's hands. Originally I was responsible for the work connected with levying the disability protection fund, and I was pretty competent. But I took part in a meeting chaired by a leader, and when he heard my boss say that I used my feet to do my work, he criticized my boss saying that this kind of work involved daily contact with enterprises and institutions, and that someone who typed with her feet would affect the image of our workplace and I should be replaced immediately. Isn't this discrimination against me as a disabled person, and not recognizing my abilities?

Zhang Yongxia

I live in Urumqi, Xinjiang. The average wage in Xinjiang in 2013 was 1500-2000 yuan. The current wage for disabled people in work is 1800-1500 yuan (without the 'five insurances'²). The average income is low, but the cost of living in Urumqi is not low at all. For example, the average price of a house is 7000 yuan per square metre. Rents are around 3000-1000 yuan per unit [per month]. An ordinary resident's living expenses are 600-800 yuan per month at the lowest. From what I understand from friends around me, and disabled people in work, most severely disabled people (above and including 2nd grade) depend on the minimum living subsidy of 366 yuan given by the Urumqi municipal government plus help given by family and friends or some social support. Most of those with a mild disability look for jobs by themselves, doing some simple handicrafts or working in a charity. But the total income is low and the work isn't stable. Some people drive a disabled people's vehicle as a taxi service, some run small shops. Most blind people do massage. In Xinjiang there are very few people who do online work like I do.

There is no accessible transport to speak of. There is no way that a wheelchair can get onto any of our local public buses. In the last two years the new BRT buses have been designed with a ramp for wheelchairs. But the design is no good: each time it has to be pulled out manually. Some ramps are very stiff and it's very hard to move them. It's also common for taxis to refuse wheelchairs. The cost of petrol is high and all taxis have gas tanks, so if a wheelchair is put in the trunk there is no way to shut it. But public transport regulations explicitly forbid vehicles leaving their trunks open. This year when I was in Beijing, there were dozens of situations when taxis refused to take me. The facilities at Urumqi International Airport are good, but there are no vehicles that can raise a wheelchair up. If the plane is far from the departure lounge and you have to go up stairs to board the plane, the only way is to be carried up. Furthermore, our local airport doesn't provide a small wheelchair for disabled passengers to enter the cabin. This year I flew from Urumqi to Beijing, and a passenger who I didn't know carried me to my seat. You don't often see wheelchair users on the streets of Urumqi because there are obstacles everywhere. It's difficult to go out so disabled people tend to stay at home. The less you go out the more the tactile pavements are obstructed, the more the toilets for disabled people are locked up or used for storage. It becomes more and more of a problem and so it's a vicious circle. 'Accessibility' has just become a slogan or something that is just for show.

² The 'five insurances' include old-age insurance, medical care insurance, unemployment insurance, industrial injury insurance and maternity insurance. <http://baike.baidu.com/view/1053906.htm?fr=aladdin>

Feng Rundi (the parent of a child with an intellectual disability)

The biggest problem our child (including her classmates) has in life and in study is being cut off. There are two few technical training organizations, either public or private. Our child finishes school at 15.00. After she gets home she is alone at home. We parents only get home from work at about 18.30. Her father works far away and gets home even later. The last few years we are rarely together because we've been trying to improve our family's financial situation. There are only three months in the year when we are together. We often get back very late. We would like to give our child art and piano lessons but haven't found a suitable teacher. Also, there is limited publicity and advocacy by the state and society about the CRPD. In Beijing the whole social environment is deficient as regards equality, inclusivity and accessibility for people with intellectual disabilities. Our child can't go out on her own to places she wants to go to like ordinary people do. (Parents are afraid something will happen and that children will try to solve problems by themselves and come to harm).

As the government develops its national strength, it should take vigorous steps to promote the CRPD. Material conditions are gradually improving, but ideology must come first. First, an equal environment must be created for disabled people on a spiritual level and to make our society rethink what 'disability' (残障 canzhang) is. We could all become disabled. Disabled people are a part of society like everyone else. They share the same world as everyone, like everyone they also create a beautiful future, enjoy society's riches. They shouldn't be stigmatized, be the target of ridicule, be discriminated against. The orderly provision of facilities comes second.

Zhang Wei

I come from the countryside in Xiangtan, Hunan province. It's already 16 years since my symptoms appeared when I was 13 years old. Parkinson's disease changed me into a disabled person. To be a disabled person it's necessary to acknowledge your defects. The prerequisite is a new recognition of who you are - a new acceptance of yourself, a new readiness to start out on a journey. This is especially the case when, for various reasons, you become disabled in later life. Objectively speaking, the disability has already appeared, it can't be changed. However much you try to escape or accept it in your heart, the disability will be there.

China has more than two million people with Parkinson's. In the early stages, the patient will take some medicine and still be able to live a normal life. They shouldn't be called disabled. But some invalids (myself included) are exactly the opposite. They don't want to admit the reality and are afraid of the grave future consequences of this illness. The natural choice is to give up their previous lives and ideals. I now think they are also disabled. After I was diagnosed when I was a teenager with Parkinson's I gave up my studies (I had good grades). I cut myself off for 10 years, from the age of 17 to 26. That was a relatively golden period of my illness, but it was wasted. In other words, disability is more frightening from the psychological point of view. When I think about it now, I was really stupid.

Su Chengkun

After I'd finished reading the CRPD, I understood the difference between 'canji' (残疾 'disabled and sick') and 'canzhang' (残障 'disabled and obstructed'). We long to be seen as independent individuals, not as a powerless community, not a burden on society, not enjoying 'special consideration'. We rely on our own two hands and our brains to make a contribution to this society.

There are state-run schools for special education. Perhaps it appears that we are receiving proper respect and care in our education. But where is the heart in this? When I graduated from high school, my parents thought of sending me to a special education college. I didn't want to go at all. I wanted to be treated the same as normal people. Going to an ordinary college I would face many serious physical challenges and life would be very difficult, but I would feel happy. I think that a happy spirit is more important than any kind of welfare.

We ourselves, our parents, our teachers, even our country, consciously or unconsciously force the ideas of 'weak' or 'the need to be looked after' onto us. What we actually need is equality and the opportunity to be part of society!

Wang Yurong

I live in a remote rural area. Communications and transport are not good and of course there is a low economic level. My family's situation has never been very good. My sight problems are not congenital. When I was small I was undernourished and had a high fever which caused a perforation of the cornea. Because of a lack of information we didn't know that I needed a cornea transplant. Our family's financial situation was so bad that treatment was delayed and in the end the optic nerve withered away and treatment was of no use. At that time disability prevention and emergency treatment were not universal.

Because we live in the countryside, there are limited channels of communication and there isn't enough publicity about special education. So people don't know that there are schools set up for children with special needs. Family members asked people all over the place about schools for me and only then found a school that would take me.

I remember, from kindergarten to third grade, my classmates excluded me because they were afraid my eye illness would infect them. They called me *xiazi* [瞎子 - this is a pejorative term used for blind people] to my face. The teacher had me sit next to the worst student in the class and did not care if I could see the words on the blackboard clearly. To keep me safe the teacher never let me take part in

outside activities with the ordinary students. When the students had gym classes or went on outings, the teacher would lock me in the classroom by myself until my classmates returned for the next class. As far as I was concerned, it was a very long wait. When I was in fourth grade I had a good teacher, who was serious and had a sense of responsibility - the teacher was in charge of my fourth and fifth grade classes. It was he who changed my fate. When he knew my situation he did his best to write the words large, and he allowed me to go close to the blackboard. He also let me to do activities together with my other classmates. From this action I derived consolation and inspiration. So far, my studies and my marks have advanced significantly.

Before learning about disability rights, I thought that it was excusable that my classmates and teacher excluded me, ignored me and locked me up in the classroom to keep me safe. But after I read the CRPD pamphlet, I felt that this was all discrimination against us disabled people and that there was a lack of understanding about disabled people. It violated Article 5 of the CRPD: equality and non-discrimination. And Article 8 says: raise awareness. They failed to treat me fairly and make things convenient for me according to my individual needs, and they also failed to act according to the inclusivity target of providing education for all without discrimination. There was a violation of Article 24 of the CRPD: Effective support measures appropriate to individual circumstances are provided in an environment that is most conducive to the development of learning and social skills.

Guo Yilin

We live in a county to the south of Beijing, and as far as the whole of Beijing goes, welfare for disabled people can only be said to be so-so. We only get the basic guarantees of life. The life of disabled people is only just OK. Below I want to talk about three aspects: education, life, and employment:

1. Education:

I don't think that as disabled people we fully enjoy the right to education in the places where we live. It's not what is stated in this article in the CRPD: 'Persons with disabilities receive the support required, within the general education system, to facilitate their effective education'. Our special education schools are not very different from how they were when they started up 10 years ago. The government doesn't pay much attention to them. Up till now there are still no state-run technical schools for disabled people, so many capable people do not have good results because there are no supporting policies.

2. Life:

Our lives at present have only basic guarantees. It's very difficult to find accessible public facilities or community service stations for disabled people that are mentioned in the document. These are only talked about on TV, but their use in actual life is pretty limited. It makes me feel that when it comes to basic welfare there's a big gap between the propaganda and actual practice. A lot of disabled people's organisations just exist to do this propaganda work!

3. Employment:

This year there are seven million new graduates. This huge number will definitely make it harder for us to find work. We mostly depend on government quotas for employment when looking for work, but if you choose this method, then it means you lose the right to enter society. From my point of view, this dependency system is a system in which the employers just do what the government asks them to do. Every month you are given a few hundred yuan, every day you are made to stay at home with nothing to do. Seen like this, it's equivalent to the enterprise giving us charity, it doesn't in any real sense give us the right to work. This appears to be a universal phenomenon amongst the people around me.

Let the reasons for this dependency phenomenon emerge. Society does not have the right understanding about disabled people. And also there is not enough government investment in employment for disabled people! There is a lack of knowledge, and if there are no real vocational skills, then employment is just a slogan.

What does real equality mean? Equality is equal participation in social activities and everyone of the same level having rights. But to do this (as regards disabled people) is really very difficult because you have to take risks, and on top of that there is everybody's mistaken concept of disability. So it is difficult to achieve it. Let me give the simplest example. When people are asked to vote for the Party district committee, we [disabled people] are rarely given ballot papers. I understand this is because we are not asked to take part in social activities and when there are family gatherings, a disabled person is hidden away in an inner room and not allowed to see people. If it's like this in families, how much more will it be like this in society?

I've just looked at the document [the CRPD pamphlet] very carefully, but I think many of the descriptions are based on the CRPD and this convention does not have much validity in law. Its implementation can only rely on people's compassion and social responsibility. The quality of citizens is going up steadily, but if there is nothing legal to support it, the CRPD will just be seen as a beautiful vase.

Gan Lu

I am very interested in accessibility, equality and raising awareness and this is also an important part of my work. In ordinary life and work, I have discovered that the biggest difficulty is physical inconvenience. It's not that I have a lack of ability, but that the people around me don't understand. Ordinary people's knowledge of disabled people is: disabled people are weak, disabled people can't do anything or only do something specially designated; disabled people are a vulnerable group who need compassion. Moreover, the general environment makes disabled people themselves believe that they are weak and in need of sympathy and help. Just because some physical impairment makes them weak, does it mean that they can't do anything well at all? If my legs are not good, I can be an accountant or do programming and other kinds of work where I don't have to run around. If I can't see, I can still speak and sing. I could go and be a radio presenter. Why do I have to go and do massage? If I can't hear, I can paint pictures or be an athlete.

Actually every disabled person can develop his own likes and things he is good at as long as he is given the right education and guidance. Why, if your eyes aren't good you wear spectacles, or if your legs aren't good you have a walking stick. So couldn't things be made more physically convenient with the use of certain tools? Are you considered disabled if you wear glasses? Are you considered disabled if your legs aren't good? It all stems from the fact that the general public doesn't know enough about disabled people. Because people don't know enough about disabled people, there will be even more discrimination and prejudice. If the general environment is like this, then it will make even disabled people, and their families, think of themselves as being weak and this will create a feeling of inferiority. There will be more conflict, so that they even refuse to have contact with society, or else there will only be small groups of disabled people formed. Only if disabled people are encouraged to go out more and have more contact with society, more contact with ordinary people, integrate socially, will the general public have a greater understanding of disabled people and their needs.

Zhang Chen

I was born in Ezhou, a small city neighboring Wuhan. Right now, I'm working as an accountant in the welfare factory attached to Ezhou Steel Company. There was quite a struggle getting this job. The first round of the employment process was a written exam. I wasn't allowed to take the exam due to discrimination. Since my family has been working for Ezhou Steel for generations, I eventually got a chance to take the test. Although I scored the highest, my only option for employment was to go to the welfare factory, and become a worker counting products. Also, they wouldn't publicly display my test score the way they did for other test takers. Before that, I had sent out a lot of resumes, but never heard back from anyone. I had also taken the civil service exam, and called every employer who had a suitable position for me. But they all told me, "you can apply for the job, but there's no way for you to pass the interview stage." Faced with a situation like this, I felt quite helpless. I had always known the difficulties in employment for disabled people, and the discrimination we face. If you haven't been in a situation like this you can never understand how it feels.

Liu Yan

I had lived in Beijing for almost five years when I was hurt in a traffic accident.

I think the ultimate equality we are pursuing is not just the welfare allowance granted by society, but obtaining a suitable job, and reaching the same level of achievement as non-disabled people. True equality and non-discrimination means we live with dignity, the way everyone else does. We have to get this dignity through our own efforts. Only when this true equality is rooted in our own heart, can we start to change other people's attitudes.

There's a very strange phenomenon in China. There are as many as 84 million disabled people – and this number doesn't even include old people. This is a population bigger than the entire population of many countries. But we rarely see disabled people on the streets, in malls, parks or other public

spaces. I think on one hand this is the result of the non-accessible environment, and on the other, it's also because disabled people and their families are embarrassed at being stared at in public.

Yu Mingyue

I'm from Weihai, Shandong, currently working in the customer service department of a house decoration company in Beijing. I've attended several job fairs designated for disabled people, and learned that the positions for disabled people usually are very low paid, and you would have to have at least an associate degree to apply for most of them. However, as far as I know, many disabled people have rather limited education and professional job training, so they only qualify for physical labor or telephone sales jobs. The job market that's open to disabled people is still very limited. There's not much job training available either.

Some higher education institutions are loosening their policies and are willing to recruit disabled students with exceptional performance. But the campuses are not equipped with accessible facilities, which makes people with severe disabilities reluctant to apply. According to the second national sample survey on disabled people in China in 2006, the percentage of disabled people with university degrees among all disabled people in China was only 1.1%, and among disabled people 15 years old or above, 43.29% of them were illiterate.

Sun Yue

I live in Tieling, Liaoning. I have Osteogenesis Imperfecta, which is also called brittle bone disease. I often broke my bones when I was young, so, since I was a child, I started to use a wheelchair. When I came to school age, schools refused to accept me, because they suspected that I had intellectual disabilities and that it would drag down the class performance. The principal suggested sending me to a special school for children with intellectual disabilities.

But it wasn't a school designed for children with physical disabilities. My mother fought for my rights to go to a regular school. I started school as an auditing student. Later I got into middle school with exceptional grades. At first, my homeroom teacher thought of me as a burden. So I thought, I had to change her view through my performance. When I proved that I could get the highest grades in class, she labeled me as a model of "someone with a disabled body but strong willpower", which added complicated layers to my identity. Looking back at this period today, I think that my experience was a typical example of teachers lacking understanding of disabled students. Even though they want to help, they don't really know how to do it properly, to create an equal and dignified environment for these students and really help them grow.

When I was getting ready to take the senior high school entrance exam, the Department of Education refused to let me take the exam because they thought compulsory education had ended for me and, as a disabled person, I had no right to go to high school and university. My mother fought again for my entry into high school. The school that accepted me had no accessible facilities at all. My mother carried me on her back every day to go to school. Her love and persistence allowed her to climb tens of thousands of steps. And I didn't disappoint her. My college entrance examination scores were very good. However again the Department of Education blocked me from

applying to universities. Their reason was: disabled students cannot go to university. Even the school recruitment office was turned down by the Department of Education. My mother, in desperation, carried me to the office to plead to allow me to apply. I finally had a chance. But after that, many universities rejected me due to my disability. I was lucky to receive help from the Overseas Students Association, and successfully entered Dalian University, majoring in Chinese Literature and Psychology.

At Dalian University, the school built a ramp and an accessible bathroom just for my dorm building. They also arranged other students from my dorm or my class to help out. All of these arrangements allowed me to complete my studies successfully. I'm more grateful for the fact that Dalian University rejected all of the media interviews and didn't give me any special "awards" that relate to my disability. At that school, I was equal with other students, with dignity and freedom.

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