

# NMA FUNDED / BUER CONSULTANTS PROJECTS

# "Project for the Holistic Habilitation of Children with Cerebral Palsy"

Mid-term evaluation November 2010

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# **EXECUTIVE SUMMARY**

In May 2010, the Chief Representative for Buer Consultants, Sindre Fosse, invited Mr Michael John Walmsley of Ming Chuan Educational Consultancy to put forward a bid for the mid-term evaluation of the NMA funded project "Holistic Habilitation for Children with Cerebral Palsy". In following correspondences, the terms of reference for the evaluation were agreed, as well as the members of the evaluation team. Consequently, the mid-term evaluation took place between 1st and 15th November, 2010. The evaluation team members who carried out the evaluation were Michael Walmsley (UK), Elizabeth Griswold (USA) and Xu Bing (Chinese).

The Holistic Habilitation for Children with Cerebral Palsy Project has its administrative centre in Beijing and covers three different provinces; that of Hebei, Si Chuan and Yunnan Province. The project was started in 2009 and is set to end in 2013. At the end of that 5 year period, the expectation is that the goal of developing an holistic habilitation model within the CDPF network will have been met. The overall purpose of the project is therefore to establish a more effective and locally based habilitation system for children with Cerebral Palsy in China. The project has two areas of focus:

- ✓ Develop a model for habilitation of CP children in China, and;
- Build a foundation for the education of professionals within habilitation by working with the hospital and educational system.

The executive organization of the project is the Social Services Guidance Center (SSGC), under the China Disabled Peoples Federation (CDPF), which is responsible for the overall management of the project and its implementation. The role of Buer Consultants is to represent NMA's interests and therefore carry out close follow-up and interaction with the implementing partners.

The majority of the funding comes from the Norwegian state through NORAD, which is supplemented by a share from NMA. In total the NMA matching fund is 45%. The local partners provide matching funds of at least 30%. The annual budgets from 2009 to 2010 were:

Year	Total (RMB)	N.	NMA		Local Partner	
		Total (RMB)	% of total	Total (RMB)	% of total	
2009	Y2,981,000	Y1,665,000	56%	Y1,316,000	44%	
2010	Y2,649,100	Y1,250,000	47%	Y1,399,100	53%	
2011	Y3,065,000	Y1,250,000	41%	Y1,815,000	59%	

#### **Conclusions and Recommendations**

There is a great need for a concerted effort to meet the needs of cerebral palsy children in China. To this end, the evaluation team heartily commends the efforts of NMA, Buer Consultants and the China Disabled People's Federation. The evaluation team truly believes that NMA through Buer Consultants are uniquely placed to bridge the gap between the NGOs and the government ministries involved in CP work in China. If they can facilitate the different parties to come together, co-ordinate and strategize, there would be a much greater chance of creating a national system for the holistic treatment of CP in China.

It is the **conclusion** of this evaluation, that whereas the project plan succeeded in defining the problem of cerebral palsy in China and the need for a system, it is weak on seven major issues:

- I. **System:** No work done on identify the sequential steps needed to establish the system and the time frame needed for each of those steps;
- II. Networking: Lack of networking amongst non government organizations (NGOs) already working with CP children in China, many of whom have more than decade of experience in therapy, training and management of CP projects;
- III. **Project Manager**: The chosen Project Manager has neither the time, skills or temperament for the role:
- IV. Financial Systems: No clear procedures for developing detailed budgets and financial reports;
- V. **Qualified & Experience Staff**: Real lack of experienced and qualified therapists and teachers, especially in the rehabilitation stations;
- VI. **Trained Experts**: Lack of experts from the needed disciplines of PT, OT, ST and Special Education, to provide training and to work as a coordinated team to do the assessments, and:
- VII. **Conductive Education:** Introduction without the experts to effectively implement it and without considering whether it really is the best approach to therapy for CP children in China.

In ligh	nt of these conclusions, the <b>recommendations</b> of this evaluation are as follows:
	Carry out a <b>feasibility study</b> to fully understand the resources available within China to provide the capacity building necessary for the fulfillment of the project goal and to determine the best approach to therapy (be it conductive education or otherwise);
	<b>Network</b> across China, with NGOs and government ministries in addition to the CDPF, namely the Civil Affairs Ministry, the Education Ministry and possibly the Foreign Affairs Ministry. The evaluation team truly believes that NMA through Buer Consultants are uniquely placed to bridge the gap between the NGOs and the government ministries involved in CP work in China;
	<b>Facilitate</b> the different parties within China who are involved with CP rehabilitation, to come together, co-ordinate and strategize. If the project can facilitate the different parties to come together (government and NGO), co-ordinate and strategize, there would be a much greater chance of creating a national system for the holistic treatment of CP in China;
	<b>Strategic Planning</b> to gain a far deeper understanding of the system which needs to be implemented and a practical, stage by stage approach to building up the capacity of the system, both in terms of training and resources and therefore develop a more realistic time frame;
	<b>Focus</b> most (if not all) of the resources in one province and first develop the system on a smaller scale. Once that is functioning well, expand to other provinces. From the evaluation team's perspective, the best choice for this would be Si Chuan Province, since they currently have the best resources and longest established rehabilitation centres.
	Re-organize the Leading Group so that it acts more like a board of directors representing all of the stakeholders i.e. CDPF officials and NMA representatives. Seek to expand this leading group to include other relevant parties involved in CP work in China who could become stakeholders e.g. members of NGOs, Civil Affairs Ministry, Education Ministry, etc. The Leading Group would look at the overall design and direction of the project, but would not be responsible for the day to day management and other project management issues.
	Through the newly formed Leading Group, appoint a <b>Project Manager</b> who has the project management skills and experience necessary for the job, but who also had a high degree of integrity, passion and commitment;
	Allow the Project Manager the freedom to create a <b>Dedicated Project Team</b> . This team could be made up of Buer Staff, CDPF staff and others who have the skills and experience necessary to implement and manage the project.
	Training and capacity building needs to take place on all levels i.e. leadership and management training to the leaders, plus occupational therapy, physio therapy, speech therapy and special education to all of the rehabilitation workers. The CDPF leaders need to expand their vision and leadership skills. To that extent, the trips to Taiwan, Hong Kong and Norway have been an excellent start to achieving that goal. However, the project has a good opportunity to input further into the government officials lives and expose them to concepts such as servant leadership. In addition to the higher government officials, the city and county leaders would also benefit greatly from leadership and project management training. For the resource centres and rehabilitation stations, there is an obvious need for training in occupational therapy, physio therapy, speech therapy and special education.
	The project needs to have a well defined <b>training schedule and curriculum</b> . Moreover, it will need to have a pool of trainers who can provide the necessary training (preferably trainers already within China and Asia) and places for the trainees to go to gain practical experience under the supervision of experienced and mature therapists.

Although there are many challenges which the project team need to urgently address, this should by no means be a reason to stop the project. After all, the project has only been running for a year and a half. However, the issues DO need to be addressed and drastic measures taken, otherwise precious time, effort and money will be wasted.

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# INTRODUCTION

In May 2010, the Chief Representative for Buer Consultants, Sindre Fosse, invited Mr Michael John Walmsley of Ming Chuan Educational Consultancy to put forward a bid for the mid-term evaluation of the NMA funded project "Holistic Habilitation for Children with Cerebral Palsy". In following correspondences, the terms of reference for the evaluation were agreed, as well as the members of the evaluation team. Consequently, the evaluation date was set for the first 2 weeks of November (1st to 15th November 2010). The evaluation team members who carried out the evaluation are listed below and their resumes can be found in the appendix:

No.	Name	Responsibilities for Evaluation	Nationality	Sex	Qualifications	Background Experience	Current Work
1	Michael Walmsley	Evaluation Team Leader & Consultant on Project Management	British	Male	Civil Engineering (BEng) Water Engineering (MSc Eng)	Civil and Water Engineering Projects, Project Management, Community Development Projects, English Teaching	Managing Director of Ming Chuan Educational Consultancy / Project Management & Education Consultant
2	Elizabeth Griswold	Consultant on Special Education and Physio-therapy	American	Female	Doctorate of Physical Therapy, Master of Physical Therapy with Honors, BS Zoology	Physical Therapy Trainer & Pediatric Physical Therapist, responsible for training Chinese physical therapists and working with physically disabled children in school and orphanage settings	Physical Therapy Trainer, Jian Hua Foundation, China (February 2008- present) -Responsible for training Chinese physical therapists and working with physically disabled children in school and orphanage settings
3	Xu Bing	Consultant on Special Education and Projects Management	Chinese	Female	Major in English, Bachelors in English (BA), Masters in Applied Linguistics (MA)		English to undergraduates at Zhengzhou University

**Table 1: Details of the Evaluation Team Members** 

# TERMS OF REFERENCE

The terms of reference drafted by Buer Consultants and NMA, requested that the evaluation team focus their efforts on the following aspects:

# 1. Project Design and Structures

- Has the Beijing CDPF leadership a good grasp of the objective, goals and plans as agreed in CDPF/Buer agreement and how do they communicate them to provincial and county level?
- What other support has Beijing CDPF given to the Provincial DPF station (besides training)?
- Does the CDPF in Beijing recognize the different level of development at the rehabilitation stations in the three provinces and do they provide appropriate training tailored to the needs of each?
- In what form are communications conducted between the rehab/assessment centers and the rehab stations (phone call, emailing, and visit)? How often are project reports submitted to the CDPF in Beijing, with copy sent to Buer Consult office?
- How does Buer Consult follow up its partners at national, provincial and country level? How is the communication between Buer Consult and its partner (regularity and perception by both parties)
- Will the project be able to achieve its objectives within the 5-year project period?

#### 2. Financial management

- What has been Beijing CDPF budget for each of the province given the different level of development in CP?
- Are the financial routines in the project (at all levels) according to NMA and national standards? How are financial resources managed at the resource centers and the rehabilitation stations?
- To what degree does Buer Consult have insight to the financial management of its project partners? What is their capacity in following up in this respect?

#### 3. The Concept of Habilitation

• This project is given the name Holistic Habilitation. What is the level of understanding for the word holistic, and what is the awareness level in the project for seeing the "whole" child? Furthermore, do the rehab personnel, and the personnel at the rehab centers, see the value of this approach?

# 4. The Habilitation Model – Development and Status

- What is the level of knowledge in terms of knowing what they are supposed to do in the project, and what they are supposed to receive? This refers to all levels: provincial, resource centers, and rehabilitation stations.
- What are changes experienced by the staff in the project, during the first two years?
- What has each of the rehab centers and stations done to reach out to more CP children who are not under the Buer/CDPF project?

#### 5. Assessment of the Rehabilitation Centers:

• Each child should receive an assessment from a team consisting of at least a doctor, a PT, an OT, and if possible a speech therapist. This assessment is going to give each child a plan for further rehabilitation and a training plan for the child to have at home, and at the local rehab station. Has this plan been communicated to the local rehab staff personnel, and to the parents?

- How is the dynamics in the assessment teams? Are they functioning well and do they give the appropriate guidance to the rehabilitation stations?
- Distance traveled to the rural communities has always been a challenge for those rehab staff in Yunnan Province. What have the rehab/assessment centers provided to the staff of the rehab stations in reaching out to those families who are located too far and might be too poor to travel for the weekly visit to the rehab centers as required?

#### 6. Rehabilitation Stations:

- What has been the assessment system conducted in each rehab station given its importance in CP cases? How regular, how detailed is the follow-up entailed after each case is assessed
- Have the parents and the local rehab staff understood the training and the importance of following this plan? Do they use what they have learnt and do they do it right? Do they see the value of this approach?
- Does each rehab center have access to the nearest professional help/support such as PT, OT, ST and conductive education in order for the HH system to not only succeed management-wise, but also the technical aspect of the project. If the answer is "no", what can be done to improve the professional efficiency of the staff?

# 7. Education – Increased Emphasis

- There has been a focus on education in the project. This to secure that the Children with CP also can get the right to education. In many cases with CP, the mental capacity of the child is 100% functional. The focus in this project has been on including the children into normal school, when this is possible.
- What has been done to increase the level of CP children getting into school, and has there been established any new alternative education facilities in any of the eight centers? What are the reasons for the achievements and what are the reasons why some have not achieved much in this aspect?
- What has been done in communicating the needs for integrating the CP children into the jurisdiction of the Education department, to be able to secure their education? Concerning this issue we would also like to know what the relationship between the local CDPF training stations and the local governments is in terms of advocating for the CP children's rights?

#### 8. Overall Expectations for the Evaluation

The overall expectation for this evaluation is that it will help NMA, Buer Consultants and the implementing partners, to see

- how the project is evolving;
- whether the structure is working, and;
- whether the communication lines are effective (especially in consideration of the large distances and numerous government institutions involved).

In this way it is hoped there can be a better understanding of how to follow up the project in the near future, learn more about its strengths and weaknesses, determine the best practices for promoting the education of CP children in their local society and find ways to improve the cooperation between the rehabilitation stations and the local education department.

# **Project Summary**

The following section provides a summary of the project. The information in this section was mostly taken from the original project report produced by NMA namely the "Holistic Habilitation for Children with Cerebral Palsy, Project Document 2009-2013". Further information was taken from the Mid-Term and Final Evaluation reports of the Sichuan Community Based Rehabilitation Project for Children with Cerebral Palsy, which was a previous project funded by NMA and implemented between 2003 and 2008.

# 1. Background Information on CP in China

According to the China Disabled Persons' Federation (CDPF), "there are 83 million people with various categories of disabilities in China" (CDPF 2008). Thus, the disabled population of China is roughly equal to the entire population of Germany (United Nations Statistics Division 2008). A review of key Chinese documents related to the disabled, such as The Outline of the Work for Persons with Disabilities during the 11th Five-year Development Program Period (CDPF 2006) and the Statistical Communique on Development of the Work for Persons with Disabilities in 2006 (CDPF 2006) revealed descriptions of progress for persons with disabilities such as blindness and deafness, but not a single mention of Cerebral Palsy. Various estimates suggest that there are about 1.78 million children with Cerebral Palsy under the age of 12 years old in China, with an annual growth of 40,000~50,000 children. CP is one of the most important diseases causing children to become seriously disabled. Given the lack of national level statistics on and specific plans for children with CP, it can only be assumed that these children are lost somewhere in between the health care system, the education system, and the disabled persons' community, caught between the vague categories of "physically disabled" and "intellectually disabled" (CDPF 2006). The main challenges in China concerning CP are therefore related to the following aspects:

- Lack of visionary management,
- Lack of standardization of Physiotherapy (PT) and Occupational Therapy (OT) curriculum;
- Lack of knowledge on basic habilitation, and;
- Lack of knowledge among parents.

To date, the approach to dealing with CP is therefore expensive and fragmented, the CP children have close to no possibilities of receiving any education and attitudes towards disabled people are still a cultural problem and a problem within the existing institutions.

#### 2. Project Background

The Norwegian Mission Alliance has been working with disabled people in China for the last 15 years. The first project funded by NMA which related to disabled people in China was the *Sichuan Community Based Rehabilitation Project for Children with Cerebral Palsy*, which was a five-year project implemented between 2003 and 2008, as a joint venture between NMA and the Sichuan DPF. This first project was designed to improve the access of children with cerebral palsy to rehabilitation and education using a community rehabilitation/education format based in two locations within Sichuan Province; Chengdu and Panzhihua. The conclusions from the evaluations of that project were that although the project had made a good start at meeting the needs of children with cerebral palsy (CP) in Sichuan, the rehabilitation training generally lacked a clear structure and plan and needed more specific training in the various rehabilitation skills of Occupational Therapy (OT), Physio Therapy (PT), Speech Therapy (ST) and Special Education (Sp Ed). In other words, there was a need to develop a more holistic approach to dealing with CP. It was also cited that many of the approaches used in the assessment were from a medical model point of view rather than from a community rehabilitation point of view. Generally though, the awareness campaigns for

cerebral palsy media campaigns had been successful and had increased the awareness of the local community towards CP. The recommendations from the evaluation of this first project can be summarized as follows:

Meed for training and expert support, specifically:

- Develop a systematic training approach to strengthen the rehabilitation personnel's skills in fundamental and key areas;
- Encourage some personnel to become specialized in Physical Therapy (PT), Occupational Therapy (OT), Speech Therapy (ST) and Special Education, BUT make sure that there is greater integration between these disciplines;
- Develop and train staff in the use of a community based rehabilitation evaluation process;
- Improve the training material and make it more appropriate to the level of the recipients, and;
- Increase the knowledge of child psychology, so that the local therapy workers can address the psychological issues of the CP children and provide counseling.
- Meed to network and cooperate, specifically:
  - Develop the relationship between Holy Love (a local and well established NGO doing similar work in Chengdu and other places in China) and the project and work in cooperation with them to develop a training plan for the development of educational specialists;
  - CDPF to get the support and work in cooperation with the other relevant government departments, i.e. Education Department and Health Department;

The current project "Holistic Habilitation for Children with Cerebral Palsy" is therefore an attempt to build on the experience which was gained from the previous project and to change the focus from solely supporting a few community-based rehabilitation stations, to working for the development of a more holistic habilitation system including education, healthcare and community-based services.

#### 3. Project Location

The project is located in three different provinces in China; that of Hebei, Si Chuan and Yunnan Province and has its administrative centre in Beijing (for greater details of the locations, refer to the Site Visits section of this report).

#### 4. Project Duration

The habilitation project covers a 5 year period, starting from 2009 and ending in 2013. At the end of this period, the expectation is that the goal of developing an holistic habilitation model within the CDPF network will have been met.

#### 5. Overall Project Goal

The purpose of the project is to establish a more effective and locally based habilitation system for children with Cerebral Palsy in China. The project therefore has two areas of focus:

Develop a model for habilitation of CP children in China, and;

Build a foundation for the education of professionals within habilitation by working with the hospital and educational system.

## 6. Specific Objectives, Subgoals and Indicators

The following is a summary of the main objectives and subgoals for the project:

No.	Goal	Subgoals	Indicators
1	national curriculum for Physio Therapy (PT) and Occupational	• Establishment of a committee consisting of members from the International Federation of Physio Therapy and Occupational Therapy and the leaders from the relevant educational institutions in China • Agreements are worked out with universities that will function as pilot users for the new curriculum	<ul><li>approved by relevant government bodies</li><li>The curriculum is put into use by at</li></ul>
2	habilitation of CP children that is suitable for China. Establish the use of such a model in Beijing,	on national level and on provincial level in Yunnan and Sichuan  • Qualified assessment centers with multi professional teams in Beijing, Chengdu, and Kunming are established  • Increase the knowledge and understanding about effective	<ul> <li>and China</li> <li>Course - people trained, concepts change, building of a new model</li> <li>Assessment teams are established with Doctor, PT, OT and Special</li> </ul>

Table 2: Summary of the Project Goals and Indicators

# 7. Target Groups and Intervention Strategies

The main target groups are:

Leaders in the health care system;

Health professionals at hospitals;

Educational authorities, and;

Rehabilitation personnel within the CDPF.

A secondary target group is: Universities and the students who are studying Physio Therapy (PT) and Occupational Therapy (OT). And the main beneficiaries of the project are children with CP and their families. The intervention strategies of the project are to work with the Chinese state apparatus (i.e. the China Disabled People's Federation and other relevant government departments) and with the Chinese universities for the development of curriculum and training future experts. The project also seeks opportunities to facilitate cross border and knowledge exchanges by arranging mutual visits between Chinese and Norwegian experts and thus provide a foundation for developing training courses and capacity building of the CDPF network.

#### 8. Summary of Project Activities

The following is a summary of the project activities for the project as defined in the initial project proposal: Exchange visit for core leaders in the CDPF system and invitation of central and relevant persons to Norway to experience the different methods of organization and execution of tasks in the Norwegian healthcare and welfare system; Development of a standardized curriculum for the education of physiotherapists and occupational therapists, primarily through workshop based discussions; Work with the hospital based rehabilitation system to develop multidisciplinary assessment teams at the centers in Chengdu and Kunming: Training in Beijing for 100 persons working in the nationwide CDPF system (the plan being to select 3-4 persons from each province to participate in 3 months of training in Beijing); Training of habilitation staff in Yunnan and Sichuan; Develop alternative models for special education in cooperation with the local education bureau, by developing training courses for teachers in order to educate and familiarize them with the issues and teaching methods relating to children with CP, and;  $\Box$ Training for parents of children with CP, including basic knowledge of CP and child development, as well as information on the children's disability rights.

#### 9. Project Management

#### a) Role of the Local Partner

The Social Services Guidance Center (SSGC), under the China Disabled Peoples Federation (CDPF), is the executive organization of the project and therefore is responsible for the overall management of the project and its implementation. Therefore, there is a leading group made up of SSGC / CDPF government officials and an appointed project manager for the project. In summary, the project manager and leading group have the responsibility for the following:

- Development of the overall project plan;
- Implementation of the project plan in accordance with the project agreement;
- Development and management of the budget;
- Orafting and submission of annual reports;
- Organization of personnel training and academic exchanges;
- Implementation and directing of professional work;
- Provision of technical support for the area of the project;
- Coordination of the DPF in the project area to ensure that they organize and implement the project activities to a good standard.

The responsibility for the implementation of the project activities at the provincial level is divided between project teams in the three project areas; Beijing, Kunming and Chengdu. Leading groups should also be established at the provincial levels, with the leader in charge of the local government as the group leader and the leaders of relevant departments of public health, civil affairs and CDPF as members. These leading groups should therefore define the duties of the various members, hold regular meetings, make a coordination plan for solving problems and set up a project office in the provincial CDPF or the municipal CDPF, to be responsible for the affairs for project implementation.

# b) Role of NMA & Buer Consultants

The role of Buer Consultants is to represent NMA's interests and therefore carry out close follow-up and interaction with the implementing partners.

# 10. Funding and Finances

The majority of the funding comes from the Norwegian state through NORAD, which is supplemented by a share from NMA. In total the NMA matching fund is 45%. The local partners should provide matching funds of at least 30%.

# **EVALUATION METHODS**

In order to evaluate the project, three methods were used:

- Review of all received project documentation, namely:
  - Holistic Habilitation for Children with Cerebral Palsy, Project Document 2009-2013;
  - 2011 Draft from Partner:
  - Annual Agreement 2010;
  - Annual\_Report\_2009\_HH\_ny;
  - Application 2011 BN rev 4;
  - Application HH 2010;
  - Rev\_09\_and\_financial\_report\_year\_end\_ny, and;
  - Additional reports at each of the sites visited.

Participator	y Assessment	Activities,	and

Observations and Interviews during site visits.

# **EVALUATION SCHEDULE**

The site visits took place between 1 and 12th November 2010 according to the following schedule:

Date	Day	Location	Activity
1 Nov 2010	Monday	Beijing	Initial meeting, planning, review of project documents
2 Nov 2010	Tuesday	Beijing	Participatory assessment with project staff & travel to Handan City
3 Nov 2010	Wednesday	Wei Xian, Hebei Province	Travel to Wei County and visit site. Evening, return to Beijing
4 Nov 2010	Thursday	Yong Shui Xian, Hebei Province	Travel to Langfang City and then visit Yong Qing County site. Return to Langfang City in the evening.
5 Nov 2010	Friday	Gu An, Hebei Province	Travel to Gu An County and visit site. Return to Beijing in the afternoon.
6 Nov 2010	Saturday	Dependent on Team Members	Rest
7 Nov 2010	Sunday	Dependent on Team Members	Rest and then travel to Chengdu in the evening
8 Nov 2010	Monday	Chengdu	Morning: Visit the Chengdu Rehabilitation Resource Centre and meet with government officials. Afternoon: Visit Pi County County Rehabilitation Station. Return to Chengdu in the evening.
9 Nov 2010	Tuesday	Chengdu	Morning: Visit Xin Jin County Rehabilitation Station. Afternoon: Travel to Pu Jiang County in the evening. Stay night in Pu Jiang County
10 Nov 2010	Wednesday	Chengdu / Kunming	Morning: Visit Pu Jiang County Rehabilitation Station. Afternoon: Travel back to Chengdu and go to airport. Fly to Kunming in the evening. Arrive in Kunming and stay the night.
11 Nov 2010	Thursday	Kunming	Morning: Visit Eshan County Rehabilitation Station in Yu Xi Prefecture. Return to Kunming in the afternoon.
12 Nov 2010	Friday	Kunming	Morning: Visit the Xi Shan District Rehabilitation Station in Kunming City. Afternoon, go to Buer Office for feedback session with Buer Consultants Project staff. Evening stay in Kunming.
13 Nov 2010	Saturday	Kunming	Morning: Evaluation team review all evaluation notes, make initial summary, conclusions + recommendations. Divide up work on report. Afternoon: Beth and Xu Bing to travel back to home destinations
14 Nov 2010	Sunday	Kunming	Rest
15 Nov 2010	Monday	Kunming	All Day: Evaluation and feedback with Buer Staff (Mike only)
16 Nov 2010	Tuesday	Kunming	Mike return home
30 Nov 2010	Tuesday		Submission of Draft Evaluation Report
10 Dec 2010	Friday		Submission of Final Draft of Evaluation Report and Video

Table 3: Schedule for the Evaluation Site Visits and Report Submission

# **Site Visits**

The following section provides information regarding the site visits made during the evaluation.

# 1. Beijing Social Service Guidance Centre (SSGC)

The Beijing Social Service Guidance Centre is based at Bo Ai Hospital in the Feng Tai District of Beijing, located about 10 minutes by taxi from the Beijing South Train Station. The SSGC is a branch of the China Disabled People's Federation and is the national centre for therapy and training. It is also the location for the Project Leading Group and the CP assessment teams which service Hebei Province. Below are some maps showing the location of Feng Tai District and Bo Ai Hospital:

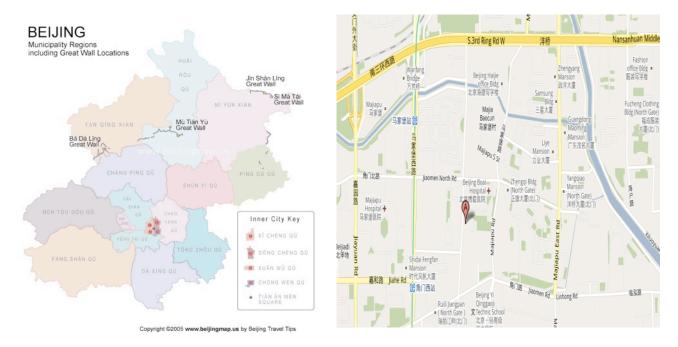


Figure 1: Location Maps for Bo Ai Hospital and SSGC, Beijing

During the evaluation, the first day and a half were spent at the SSGC centre, but the vast majority of the time was spent in meetings with the project leading group. The evaluation team were not given the opportunity to meet the assessment team for Hebei Province, who were supposedly based at the hospital. Apart from a power point presentation from Mrs Cao, the mapping activity and some financial records, no further information was gained during the time in Beijing.

#### 2. Hebei Province

Hebei Province is in the northern part of China and surrounds the cities of both Beijing and Tianjin. It covers an area of 78,200 sq mi (202,700 sq km) and its capital is the city of Shijiazhuang, where the Hebei Disabled People's Federation have their base. Hebei Province consists of a total of 11 prefectures, of which two are part of the project scope, namely; Han Dan and Langfang. Figure 2 shows a map of Hebei Province, giving the location of the two prefectures.

Two of the project Rehabilitation Stations are located in Langfang Prefecture, namely; Yong Qing County and Gu An County. The third Rehabilitation Station is located in Han Dan Prefecture, namely; Wei County.

No	Name	Hanzi	Pinyin
1	Shijiazhuang	石家庄市	Shíjiāzhuāng Shì
2	Baoding	保定市	Băoding Shì
3	Cangzhou	沧州市	Cāngzhōu Shì
4	Chengde	承德市	Chéngdé Shì
5	<u>Handan</u>	邯郸市	Hándān Shì
6	<u>Hengshui</u>	衡水市	Héngshǔi Shì
7	Langfang	廊坊市	Lángfang Shì
8	Qinhuangdao	秦皇岛市	Qínhuángdǎo Shì
9	Tangshan	唐山市	Tángshān Shì
10	Xingtai	邢台市	Xíngtái Shì
11	Zhangjiakou	张家口市	Zhāngjiākŏu Shì



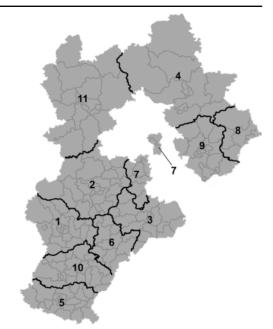


Figure 2: Map of Hebei Province

# a) Wei County Rehabilitation Station

Wei County (魏县) is located in the southern part of Hebei Province and is part of the prefecture of Han Dan. Its population is about 810,000 and covers an area of approximately 862 km². From Beijing, it take 3 hours by fast train to Han Dan City and then another 1 hour by car to reach the

Metropolitan Area

15
13
19
14
10
31
6
12
16
17
18
9

Figure 3: Map of Han Dan Prefecture (Wei County is No.18)

county centre. The rehabilitation station opened on 30th June, 2009.

#### Staff:

During the site visit, the evaluation team were told that there were 10 staff working at the rehabilitation station. However, there was no explanation regarding their respective responsibilities. It appeared that none of the staff were qualified and the doctor who assessed the children, was from a local hospital (Wei Cheng Dan Hospital) and not part of the regular staff. His name was Dr Shi and he had studied western and Chinese medicine. It was reported that Dr Shi

did the evaluations, therapy plans, and wrote the goals. Another staff member was Han Dan Ming, who was reported as being the therapist for the centre. Claire Zhang (a visiting therapist / volunteer from Hong Kong) had been to the station one time before the evaluation. Following the evaluation, it was discovered through other sources, that prior to the evaluation no work had been carried out at the station because the station did not actually have any full time personnel. The CDPF had simply asked the parents and children to come to the station on the day of the evaluation and as soon as the evaluation team had left, all of the families and children were sent home.

#### Family support:

Staff at the station told the evaluation team members that they opened the station every week to provide training for the parents. However, when the evaluation team questioned the parents, it was discovered that they had only come to the station a total of three times since the starting date of the project. Indeed, all of the assessment forms had only been completed just one week before the evaluation.

#### Training and Support:

A couple of the station personnel had received training once or twice, for short periods of time. There was an obvious lack of skills in therapy amongst the staff and during the site visit, the only therapy which was taking place was being provided by the visiting therapists from Hong Kong (Claire Zhang) and Tianjin (Dr Shi). Dr. Shi had studied therapy by himself and had participated in two or three training sessions in Hong Kong given by Claire Zhang. There had also been a two day training in Yunnan and a two day training in Chengdu regarding management. In addition, there had been a two week training in Beijing and a week long training in Shi Jia Zhuang. However, the quality and content of the training is unknown.

# Facilities and Equipment:

There appeared to be two stations in Wei County; one solely for the project and the other in a local clinic (see photos below). Both rehabilitation stations contained the basic equipment for CP children provided by the project (wooden tables, wooden stools, rolling stools, standers, standing frames, hand hold attachments, and elbow/knee immobilizers), but the degree of use and access by the parents and CP children was difficult to determine.





**Photo 1: Wei County Rehab Station 1** 

**Photo 2: Wei County Rehab Station 2 (in clinic)** 

#### Assessment Team:

The nearest Physio Therapist (PT) to support the Wei County Rehabilitation Station was in the city of Shijiazhuang. The only other PT was Claire Zhang from Hong Kong, but she generally only comes to the site to provide assessment and training about twice a year. There are no special education teachers, or specialists in other fields who regularly visit the rehabilitation station. The station did have an evaluation form with a section for a plan and therapy goals, but there was no daily record to prove that the children visited regularly.

#### Finance:

There was a budget provided for Wei County Rehab Station, but it contained no details of actual expenditure within different categories. From the records, it was observed that two of the staff received training for a period of more than 60 days in Zhengzhou, for which they received RMB10 per day in allowances. However, there was no trace of train tickets or hotel receipts for that training. Moreover, the staff at the station never mentioned that they had attended such a long period of training in Zhengzhou. In addition, there did not seemed to be a correlation between their expenses and the budget and by far the greatest expenditure (by evidence of the receipts), was that of meals in restaurants.

#### Education, Advocacy and Other Issues:

Members of the evaluation team were informed that there was another similar project in the same county with greater investment, but apparently no connection or overlap with the project rehabilitation station. All prior assessments had been performed by Claire Zhang and a Dr Huang Wei. It was also reported that a six story therapy building was going to be constructed in the town centre.

## b) Yong Qing County Rehabilitation Station

Yong Qing County (永清县) is located in Langfang Prefecture, within Hebei Province and is only an couple of hours by car from the Bo Ai Hospital in Beijing. It has a population of about 370,000 and covers an area of approximately 478 km². Below is map of Langfang Prefecture showing the location of Yong Qing County (no.6):

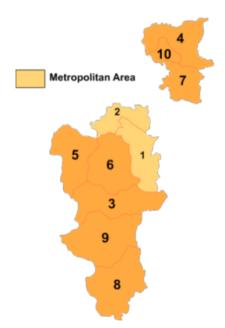


Figure 4: Map of Langfang Prefecture, showing the location of Yong Qing County (No. 6) and Gu An County (No. 5)

# Staff:

There was one part time staff member at the station, Yang Jing Huan. However, neither qualified nor had the time to do therapy work because of her other responsibilities. There was one massage therapist called Hou Jie who had begun working at the center in May 2010. She visited the station once a week on Wednesdays, but for the rest of the time was based at a local children's clinic (Wei Sheng Bu Children's Massage Centre).

# Family support:

There were a total of 15 children taking part in the project for this station. Some of children came every week and according to the parents, the equipment was available for them to use whenever they wanted. Some of the families lived far away from the station and so their travel times were as much as two or three hours one way. Thirteen of the families had been to the SSGC, Bo Ai Hospital in Beijing to receive assessment and training. Whenever the families went to the station, they were able to see how the therapists trained the children, as well as make friends with one another and share their experiences. It was reported that one child had been accepted by a mainstream kindergarten and that the child

had made a great deal of improvement. The families generally spoke well of the station staff and had a more positive attitude towards their children and life. Moreover, the children also seemed to be making a lot of progress as a result of the project facilities and training. It was reported that each time the parents visited the station, they received instruction from a therapy worker. Much of the treatment that was observed was massage, stretching, and basic exercises.

# Training and Support:

The rehabilitation workers at the Yong Qing station had visited the rehabilitation station in Pi Xian, Chengdu and received training there. It was also reported that the therapists who support the station and who are based in the local hospital had also been to Beijing and received training for a total of one or two weeks. The part time massage therapist, Hou Jie, had participated in a two week training in Beijing. Yang Jing Huan had been to Shi Jia Zhuang for a one week training on Cerebral Palsy. In summary, there was an obvious need for more professional training and for full time staff.

# **Equipment and Facilities:**

The station was reported to have opened during the previous year and made available to the local parents and children. The basic equipment supplied by the project was evidently in use (rolling stools, walkers, benches, wooden tables, prone standers, standing frames, wheelchairs, hand holds for wooden tables, elbow and knee immobilizers, therapy mats). The station was said to be open Monday to Friday and the children were able to come during that time. However, they would only receive training on Wednesdays. Moreover, not all of the children went each week. The station was supposedly serving 15 children, but some apparently lived too far away to attend each week. Some of the children had received therapy braces for their feet from Beijing's Bo Ai Hospital.

#### Assessment Team:

Claire Zhang, the Physio Therapist volunteer from Hong Kong, and Doctor Guo from Beijing, had been to the station three to four times in 2010 to do assessments. The specialists had provided some suggestions to parents and had kept records of the children's development, but were not able to attend the station on a more regular basis. The evaluation / assessment forms were supplied by Beijing's Bo Ai Hospital.

#### Finance:

The same problems were evident at Yong Qing, as in the Wei County Station, in that there was no detailed budget for the project. Therefore, the categories for the expenses consisted of the same general items listed in the budget and without any detailed explanation of how exactly the money had been spent. Therefore it was very difficult to ascertain how the money had actually been spent. In addition, the budget for the project did not match the categories found in the station's account book. The system of documenting receipts was very formal and each receipt had the signature of two people to verify its legitimacy.

## Education, Advocacy and Other Issues:

One parent complained that her child had not been accepted by the local mainstream school, even though her child was very intelligent and had good movement. It was reported that another child had been able to attend a local kindergarten on a part-time basis. As far as promoting and advocating the rights and needs of CP children were concerned, the local DPF had organized a special day's activity on Children's Day (1st June). However, this type of work had not been done on a regular basis. In 2009, members of the local DPF had travelled to a total of 5 counties to carry out the baseline study to determine the incidence of CP children within the county. However, in 2010 the CDPF had also asked the local DPF to do a baseline study of all disabled people in the county and so there was an overlap of the project work on CP and the government's national plan on people with disability. Again, this sort of issue is related to the finances and the inability of the project to separate it expenses from the local governments.

#### c) Gu An Rehabilitation Station

Gu An County (固安县) is located in the prefecture of Langfang. It has a population of about 390,000 and covers a total area of approximately 697km<sup>2</sup>. For details of its location, refer to Figure 4 and the map of Langfang Prefecture (Gu An County is number 5 on the map).

#### Staff:

There were two staff members; Zhao Xing Yan and Zhu Gui Fen. Both had studied medicine and their jobs included being responsible for children's body checkups. There was one doctor from the

local Women and Children's Hospital who helped out with the rehabilitation work at the station, but they did not have relevant qualifications to do therapy work.

#### Family support:

Generally, the CP children and parents attended the station on Saturdays for about 2 hours and the children were divided into two groups; pre-school children in the mornings and school age children in the afternoons. Some came once a month, whilst others came once every two weeks. The therapy workers did exercises with the children when they came in, but most were only working on one aspect of the child's therapy needs, e.g. walking. Fifteen of the parents and children had been to Beijing to receive training from CPDF. However, it appeared that neither the children or the parents were familiar with the equipment at the station and during the evaluation, most sat at the sides of the room waiting and watching. The parents hadn't received any training that had focused particularly on their needs.

# Training and Support:

Zhao Xing Yan had participated in a one week training about Cerebral Palsy in Shi Jia Zhuang and a ten day training in Han Zhou concerning conductive education, which was given by Hong Kong's Claire Zhang. Zhu Gui Fen had attended a ten day training in Beijing regarding Cerebral Palsy.

## **Equipment and Facilities:**

The station had also received the basic equipment from the project (wooden tables, standing frames, standers, rolling stools, elbow and knee immobilizers, OT peg boards and ring boards, three sided stairs, finger separators, parallel bars, hand holds for tables). By and large, the station seemed to be better equipped than the other two centres in Hebei Province (see Photos below). Some children had also received therapy braces for their feet.





Photos 3 & 4: Gu An Rehabilitation Station Equipment

#### Assessment Team:

The children had reportedly received an assessment both from Doctor Pang (a doctor from Beijing) and Dr Claire Zhang (the PT volunteer from Hong Kong). They had evidently come once or twice a year. Other reports stated that the children had gone to Beijing's Bo Ai Hospital for their evaluations, writing of therapy plans, and therapy goals and had stayed there for a total of 20 days. Evaluation forms were supplied by the Bei jing Bo Ai Hospital.

#### Finance:

As with the other two centres, the categories listed in the budget and expenditure were very general and vague and it was unclear how the majority of the money had been spent. Some categories also seemed to overlap one another. The receipts for meals was much greater than any other expense. The local government officials and staff members did not appear to understand the importance of having a detailed budget and matching expenditure.

## Education, Advocacy and Other Issues:

One child had attended a special education school in Lang Fang city.

#### 3. Si Chuan Province

Si Chuan Province (四川省) has a population of approximately 86,730,000 (figure from 2002) and is located in the upper Yangtze River (Chang Jiang) valley in the southwestern part of China. It is bordered by Qinghai, Gansu, Shaanxi, Guizhou, and Yunnan Provinces, Chongqing municipality, and the Tibet Autonomous Region. It has an area of 188,000 sq mi (487,000 sq km) and encompasses the central depression called the Sichuan (or Red) Basin. Its capital is Chengdu city (no. 9 on the map) and it is one of the most densely populated and ethnically diverse provinces in China.



Figure 5: Map of Si Chuan Province

# a) Chengdu DPF Resource Centre

The Chengdu (成都) DPF Resource Centre is located within the city of Chengdu and is owned and operated by the Chengdu Disabled People's Federation. As far as the project is concerned, the centre should be the base of the training and assessment teams and the main support for the rehabilitations stations in the outlying counties. The main focus of activities should therefore be training and capacity building and this *did* seem to be the case. Below is a list of the activities which the project has supported:

- Leadership Training: Three leaders from the Chengdu DFP and Provincial Education Bureau went on a vision trip to Norway and later several county level leaders from the DFP went to Taiwan for a similar purpose.
- Assessment Team: An assessment team was established at the city level and included workers from different fields based at the resource centre. The team make assessments twice a year and provide training and guidance for the staff working at county level.
- Specialist Training: Members of the resource centre attended about 6 training sessions at locations outside of the province. They also invited some specialists to the centre to provide training. The workers at the center also shared their experiences of training and expertise with one another.
- **Observation and Support:** Members of the resource centre had visited the county rehabilitation stations and observed the teachers' classes.
- **Promotion of CP Rights:** Staff from the centre had used different forms of media and methods to spread information during the year, e.g. radio, outside promotional events, etc.

Generally, the Resource Centre was very well equipped, appeared to be well organized, well managed and well used by the local community. There was a buzz and life to the centre which was absent in the site located in Hebei Province and Yunnan Province.

## b) Pi County Rehabilitation Station

Pi County (郭县) is located in the rural outskirts of Chengdu City. It has a population of about 490,000 and covers an area of approximately 438 km². It takes about an hour to travel by car from the Resource Centre in central Chengdu to the county station. It was reported that the station was established in June 2009, but other reports indicated that it had opened in August 2010. Conductive education had been introduced to the centre in September 2010 and before that, students were receiving one-to-one PT and OT treatment.

## Staff:

The station had a total of 19 members of staff, including; 8 rehabilitation therapists, 5 special education teachers, 4 assistants and presumably 2

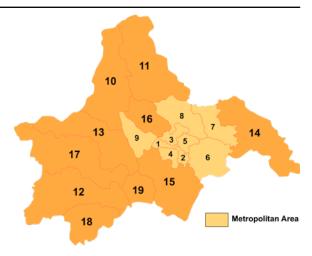


Figure 6: Map of Chengdu City and outlying counties and districts (Pi County no. 16, Xin Jin County no. 19 and Pu Jiang County no. 18)

other staff members. Most of the staff had medical or education backgrounds and covered the disciplines of PT, OT, ST and Special Education. They also had a Korean doctor, Korean physical therapist for adults and a Canadian occupational therapist.

## Family Support:

There were two classes for CP children, divided according to the abilities of the children. The primary focus was on the children aged between 0-7 years old. Children were able to come to the station every day free of charge and there was also a free bus service provided by the station. The parents were also able to receive training every week and the families stated that they felt supported and optimistic about their future. The station had began to use a conductive approach to therapy one to two months prior to the evaluation. With regard to attendance, some children came daily and others came weekly. Some participated in the conductive education class and were getting therapy through activities within that class, whilst other children came for the one-to-one therapy training. The therapists did exercises with the children according to their therapy plans and goals. Some parents did say that they were not able to bring their children every week and others reported that they did not follow through with the therapy at home.

#### Training and Support:

Staff from the station had attended training on rehabilitation, special education and the conductive approach to therapy about 6 times in the last year. The station leaders had also invited specialists to give training at the station on language, music, diagnostics, OT and listening. They had also received some training on the assessment of the children using PT, OT, ST and intelligent assessment methods. One of the PTs had been to Han Zhou to study conductive education and upon returning had trained the other staff members. The PTs and OTs had formally studied therapy and the ST had studied speech therapy in Chengdu for one month. The station had received a lot of support and donations from Korea. The director of the station was in fact Korean, who was a qualified Physio Therapist. There was also an Occupational Therapist from Canada who help out at the station but who was not present on the day of the evaluation. The therapists also felt their therapy skills were still lacking and needed more professional training. The therapists were also still unsure how to help the older children who went to the station.

#### **Equipment and Facilities:**

The station was very well equipped and had advanced and professional equipment for rehabilitation, integrated sensory, toys, etc. They had also received the equipment from the CDPF as supplied by the project. There were some very well developed facilities for older children and adults with disabilities, such as a fully functioning bakery, printing press and arts and crafts classes. (see photos below). There was even a shop at the side of the station which sold the products of the station. Cheng Du therapists reportedly visited the station on a monthly basis, to check on the progress of the children and help the therapists at the station.

#### Assessment Team:

Some of the assessment forms were from Korea and some were from Chengdu. They included the Gross Motor Function and PEDI as standardized tests for assessment. The short term goals were set for 3-6 months and the long term goals were set for one year. Generally, the therapists visited from Chengdu to do the assessments, as well as write up the therapy plans and goals.

#### Finance:

As with all the other stations, the financial records were too general and vague. There was no explanation for how the project money had been spent and the staff had no idea whether the expenses for meals or other categories were over the budget or not. The budget and financial reports were in exactly the same format as those sent by CDPF in Beijing.



Photo 5: Bakery at Pi County Rehab Station

Photo 6: Pi Xian Art and Craft Classes

# Education, Advocacy and Other Issues:

Two children were attending mainstream school and there was a plan to set up a special education school for children with different kinds of disabilities.

As far as the promotion of CP children and their rights was concerned, the local TV station had made a documentary about CP children and a local newspaper had written a column to introduce the subject of CP. The station had also organized an outing to the zoo for the CP children as well as printing some information leaflets to raise people's awareness about the issues of cerebral palsy. They had also provided training for the workers at township level and worked with different government departments to inform them of their work and the support that they needed.

#### c) Xin Jin County Rehabilitation Station

Xin Jin County (新津县) is the second of the project rehabilitation stations in Chengdu City prefecture and is located in the rural outskirts of Chengdu City (see Figure 6 for the location map). It has a population of about 290,000 and covers an area of approximately 330 km². It takes about an hour to travel by car from the Resource Centre in central Chengdu to the county station.





Photos 7 & 8: Xin Jin County Rehab Station; outside the station (left) and equipment (right)

## Staff:

There was one qualified rehabilitation worker based at the station, Zhu laoshi(朱老师). She had a background in medicine and was the therapy worker who carried out the therapy plans with the children and gave the parents their instructions. A second person at the station was Doctor Huang (黄金红), who had studied clinical medicine and did acupuncture for the children when it was needed. The third person at the station was Sui Laoshi, who had studied a major which focused on helping disabled people to gain work opportunities. She was mainly in charge of helping the children if they needed equipment or other help. Lastly, there was a therapist from Cheng Du, who visited the station about one to two times a month to give training.

# Family Support:

The station provided training for families 3 times during 2009 and 2010. Between July 7th and 8th 2009, the DPF at city level provided one-to-one training for the parents. However, the parents stated that they were still not receiving enough support and basically, the rehabilitation worker simply helped the children's physical needs and did not provide any help in speech therapy or cognition. The equipment was not being used very well and the parents seemed to have a very pessimistic attitude. Some of the children came to the station daily, others weekly. On the whole, the parents were doing the exercises, whereas the therapy worker was giving instructions alongside them. It was reported that there were 5 children in the conductive education classes and that 12 children came on a daily basis. The therapists tended to perform the same exercises with the children each time they came and did not add any variety to their treatment methods. They also tended to do the same exercise for each child, even though the problems were different. The children seemed to come in the morning for one-to-one therapy and then in the afternoon for conductive education classes.

#### Training and Support:

Several training sessions were conducted on management, cerebral palsy and conductive education. These training sessions were held in Chengdu, Hangzhou and Hong Kong. In particular, Sui Laoshi had attended a therapy training in Chengdu for one month to learn about therapy for children with Cerebral Palsy. Doctor Huang had received some training from therapists who had come from

Chengdu, but apart from that, had very little therapy training. Another staff member had attended a 15 day training in Hong Kong on the subject of conductive education. The therapy workers were also free to call or email the Chengdu therapists with questions and ask them to visit whenever help is needed. The Chengdu therapists came monthly to help out at the station. However, the station did not have a speech therapist and had very little occupational therapy. Generally, the staff had received very limited professional training.

#### **Equipment and Facilities:**

The station had received the equipment from the CDPF as supplied by the project, but it appeared that it wasn't getting much use. The equipment included; therapy mats, bolsters, standers, therapy chairs, therapy balls, wedges, parallel bars, peg boards, rolling stools, wooden benches with straps and conductive education wooden tables.

#### Assessment Team:

A team from Chengdu DPF came to the county to do the assessments, consisting of PTs and OTs. The assessment included the GMFM, which is a standardized gross motor function test, as well as tests on balance, range of motion, muscle tone, head/trunk control, hand/eye coordination, and fine/gross motor sections. The station had records of the children's visits, but generally the same activities seemed to be repetitions of previous activities, even though the records show that the children had long and short term goals.

#### Finance:

There was no separate accounting book for the project and judging from the receipts, the majority of the expenses were for meals. There was no explanation or details of how the project money was spent.

## Education, Advocacy and Other Issues:

It was reported that there was another British funded project for inclusive education nearby, which had been running for the last four years. This aspect seemed to have made it easier for the CP children to be accepted in local schools and to date, seven children had been accepted in these local schools. The station had organized promotional activities during national festivals in order to spread information about the project and CP. The station staff and local DPF had also organized a trip for 30 families to go to Chengdu zoo. On Children's Day, Mid-festival and National Day they had organized some entertainment activities.

#### d) Pu Jiang County Rehabilitation Station

Pu Jiang County (蒲江县) is the location for the third project rehabilitation station in Chengdu city prefecture and is located in the rural outskirts of Chengdu City (see figure 6 for the location map). It has a population of about 260,000 and covers an area of approximately 583 km². It takes about a couple of hours to travel by car from the Resource Centre in central Chengdu to the county station. The station opened in August 2009 and conductive education was started in March 2010.

#### Staff:

There were two full time staff employed at the station (Xia Lan and Qiu Wei), who each taught classes in physio therapy and conductive education. Xia Lan (夏兰) graduated the previous year from a Chinese medicine program where she studied some Chinese therapy techniques such as acupuncture and stretching. Qiu Wei had an education background and had studied some

occupational therapy in Chengdu. The Chengdu PTs and OTs came two times every month to do assessments, write up therapy plans and goals.

# Family Support:

It was reported that the staff from the rehabilitation station visited the families and trained the parents. They also provided three day's training at the station, as well as a two day's worth of guidance within the homes of the children. In addition, the staff had organized some outings for the children and parents, had provided the parents with CDs and books and provided some financial support to the poorer families. The families were also able to get a free lunch whenever they brought their children to the station. The station had records for family training plans and some of the children had received therapy braces for their feet from the DPF.

#### Training and Support:

Several training sessions were conducted on project management and other technical aspects. Xia Lan had participated in a one month training in Chengdu, a ten day Bobath training in Jia Mu Si, and had also gone to Hong Kong for a ten day conductive education training. Qiu Wei had NOT attended any formal training outside of the Chengdu training center. The therapist and teacher received training every Friday, were free to call or email the Chengdu therapists with questions and could request them to visit whenever they needed help. However, the station did not have a speech therapist and generally it was clear that the therapy workers were in need of more professional training.

# **Equipment & Facilities:**

The station was equipped with the same project funded equipment as the other stations and generally the facilities and equipment were all in a very good condition. The equipment consisted of stairs, therapy mats, wedges, stepper machine, conductive education wooden tables and benches, rolling stools, hand holds for tables, elbow and knee immobilizers, therapy balls, standers, bolsters, peg boards, walkers, standing frames, therapy chairs, trampoline, parallel bars, partial weight bearing supported walking system, wheelchairs and weight machines.





Photo 9: Pu Jiang Rehab Station Equipment

Photo 10: Problem Line Activity in Pu Jiang

#### Assessment Team:

The team from Chengdu DPF came to the county to do the assessments, which included the Gross Motor Function Measure, information about the child's current problems and how to assess it.

#### Finance:

The record of expenses was quite detailed, although it still did not satisfy the requirements of the project and there were no receipts for any of the expenses. The accountant could not find the receipts, even though there were over RMB 40,000 worth expenses recorded in their books. Neither could they provide a satisfactory answer as to how they had spent the money.

#### Education, Advocacy and Other Issues:

The station had organized activities during national festivals to disseminate information about the project and about cerebral palsy. They used a variety of media for this promotional work and they had also notified the different government departments about their work.

# Activity: Problem Line

During meetings with the Pu Jiang Rehabilitation staff, Chengdu DPF and county government, the evaluation team facilitated a problem line activity to determine the main challenges for the project from the project implementors perspective. The Chengdu DPF and station workers entered into the activity with a great deal of enthusiasm and there was a high degree of discussion and participation. There also seemed to be a great willingness to share information and discuss hard issues with one another. However, the Project Leader, Mrs Cao and the Project Accountant, Mrs Sun, both walked out of the meeting at this point and did not contribute. In summary, the Chengdu PDF and station staff identified several key challenges, namely:

Parents' attitudes;

Education;

Whole-life rehabilitation system;

Qualified and stable staff;

Cooperation among government departments;

Funding:

Resource network, and;

Social attitude.

Out of the above eight commonly identified challenges, the two which they felt were the most urgent and pressing were that of "developing and implementing a whole life rehabilitation system" and "resource networking".

#### 4. Yunnan Province

Yunnan Province has a population of about 43,330,000 (2002 figures) and is located in southern China. It is bordered by Vietnam, Laos, and Myanmar, Sichuan and Guizhou provinces, and Guangxi and Tibet autonomous regions. It has an area of 168,400 sq mi (436,200 sq km), and its capital is Kunming (no. 1 on the map in Figure 7). Kunming's population is one of China's most ethnically mixed, comprising more than 20 nationalities. Yunnan has a total number of 16 prefectures, eight of which are city level and the remaining eight are classed as autonomous prefectures.

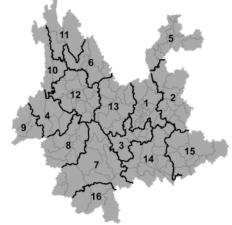


Figure 7: Map of Yunnan Province and the Sixteen Prefectures

#### E Shan Rehabilitation Station a)

E Shan Yi Autonomous County (峨山彝族自治县) is located in the city prefecture of YuXi (玉溪市) -Figure 7, no 3 on the map. The location of E Shan in relation to Yu Xi City Prefecture is shown in Figure 8. From Kunming central, it takes about 2 hours by car to reach the rehabilitation station in E Shan County. The station was set up in August, 2009.

## Staff:

It was reported that there were a total of 10 rehabilitation workers within the county and township. However, most of them did not appear to be qualified and generally worked within the township and only occasionally visited the families to provide support to the parents. There was one therapy worker called Shi Hong Ying who had an education background and one rehabilitation doctor called Dr Yin, who worked 30 minutes away at the Yu Xi Shi Di Xia People's Hospital. The latter, Figure 8: Map of Yuxi City reportedly came to the station when she was needed.



Prefecture and E Shan location

## Family Support:

The project sent 9 families to the city hospital in order for the children to receive rehabilitation training, get an assessment and provide training for the parents. Generally though, treating a child as a whole person was promoted by telling the parents to let the children do things on their own. The therapy worker felt that although the parents had received training, they were not able to do therapy to the level which was needed for their children. In total, there were about 13 to 15 children who came to the station as a part of the project. The children that needed therapy braces for their feet received them free of charge. The PTs went to the children's homes or schools about once a month, but the main focus seemed to be for the parents to learn how to do therapy at home.

## Training and Support:

A one week training was held for the Xi Shan and E Shan county doctors and rehabilitation staff, so that they could gain an understanding about CP. However, the training was not very appropriate for them and they still didn't have any practical skills to help the families. Moreover, whenever there was a training, the local DPF sent the doctors to the training courses, rather than the rehabilitation staff. More specifically, Shi Hong Ying had participated in 3 therapy training sessions in Kunming, Chengjiang, and Hualei for children with Cerebral Palsy. Each training lasted one or two weeks.

#### **Equipment and Facilities:**

The equipment at the station was the same as the other stations and appeared to be in good condition. However, the families did not often visit the station and there was no equipment at township level. The equipment was as follows: Walkers, wooden tables, standers, parallel bars, balance board, hand holds for tables, wedge for stretching ankles, wedges, therapy mats, wheelchairs, therapy chairs, standing frames, elbow and knee immobilizers, adaptive spoons, bolsters, wooden benches with straps, therapy balls, tunnel and finger separators.

#### Assessment Team:

The rehabilitation doctor, Dr Yin, from the People's Hospital had been doing the evaluations and writing the therapy plans and goals. The long term goals were set for one month and the short term goals were set for 2 weeks according to the hospital therapists. Moreover, the records documenting the children's visits indicated that phone calls had been made, but there was nothing about the children's exercises or activities. The therapy worker had a simple evaluation form, but the more detailed evaluation forms came from the hospital. The evaluation forms included the GMFCS, types of cerebral palsy and the main challenges for the child.

#### Finance:

As with the other stations, the categories documenting the expenditure were all too generalized and the main expenses appeared to be for training, family support, propaganda and the baseline study.

# Education, Advocacy and Other Issues:

The local DPF and station had organized two promotional events within E Shan County during the time when the local traditional festivals were held. They also used other forms of media for the dissemination of information about the project and CP knowledge. Some of the children are in normal schools. Sometimes the PTs are able to talk with the teachers about the children's therapy needs in school. Generally, the parents are not able to do therapy at home or perform the exercises appropriately and some of the children live far away so it is difficult for them to come more than once a month.

#### b) Xi Shan District Rehabilitation Station

Xi Shan District is located in the city prefecture of Kunming (refer to Figure 9) and has a population of about 850,000 and covers an area of approximately 791 km<sup>2</sup>. The rehabilitation station is currently located within a private hospital, the Guang Fu Community Hospital, which has its own professional equipment and provides physical therapy for both adults and children.

## Staff:

The hospital also had a number of trained staff. The children supported by the project, came to stay in the hospital for one month, along with their parents. During this time, the rehabilitation doctors provided medical treatment and training for the parents. They also set up medical and treatment records. In addition to the trained hospital staff, there were a total number of 11 rehabilitation staff working at community level. However, these community rehabilitation workers were not qualified and most just had a high school leaving certificate.

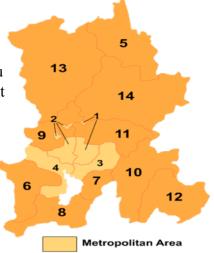


Figure 9: Map of Kunming City Prefecture and location of Xi Shan District (no. 4).

On the other hand, they had been receiving training since 2004. The role of these local workers was to visit the families of the CP children about once a week and provide guidance on physical and cognitive training. There were five physio therapists who worked at the hospital, one of whom (Li Wang Xiang - 李旺祥) was trained at the Hong Kong Polytechnic University and had a Masters degree in physical therapy. He did not work directly with the project, but could be a good resource for the project therapists.

#### Family Support:

Fifteen children had received treatment at the hospital for one month and this was funded by the local government. The rehabilitation staff visited the families and some of the families had also received some basic rehabilitation equipment and CDs. The therapists reported that they went to

each child's house once a week, played with the child, trained the parents and documented the progress the child was making. There was no conductive education. The therapists at the hospital said that the children came Monday through Friday for one hour of therapy and that the parents were free to stay and do more therapy with their child if they wished.

# Training and Support:

Several training sessions were held for the rehabilitation staff at a community level and this training was being provided even before the project started. One of the staff had received training in conductive education. Generally, the therapy workers need more professional training.

#### **Equipment and Facilities:**

The equipment at the station was a mixture of the hospital's equipment and the equipment funded by the project. The equipment at the station consisted of standers, standing frames, rolling stools, wooden tables, wooden benches, therapy balls, therapy mats and walkers.

#### Assessment Team:

The evaluation team did not see regular treatment records or therapy goals. The therapy plan was very general and simply stated information like the need for physical therapy, a foot brace and parent training. It was reported that a doctor (Ms. Ao), came from the Kunming Xi Shan District Fu Hai Guang Fu Health Center to do the assessments. However, the evaluation team did not have the opportunity to meet her during the site visit. The assessments were reportedly done at the hospital and consisted of GMFCS, identification of the type of Cerebral Palsy, medical history, hand function, developmental milestone evaluation form, range of motion, muscle tone assessment, reflex assessment and simple identification of general problem areas.

#### Finance:

There was only a brief financial report, and the evaluation team were not able to view the receipts because the receipts were reportedly at the Kunming District DPF office. Therefore, the evaluation team had way of verifying the financial data and seeing how the money had been spent.

# Education, Advocacy and Other Issues:

It was reportedly still very hard for the CP children to get admission to local schools, even though some of the children had proved to be very intelligent.

# **Evaluation Findings**

The following section details the **findings of the evaluation**, incorporating information gained through the review of project documents, some participatory assessment activities and observations and interviews during the site visit. The findings are presented in the following order: General Findings, Project Personnel, Project Management, Finances, Therapy Methods and Skill Levels of Therapists, Education and Advocacy Work.

# 1. General Findings

The project consists of a total of two resource centers and eight rehabilitation stations, all of which were visited during the evaluation. Moreover, during the site visits, the evaluation team met with nearly eighty parents of CP children, conducted around 40 interviews with family members, doctors, teachers and rehab staff. During the site visits, member of the team collectively listened to and/or read 10 progress reports from the CDPF, Chengdu, and other districts, counties and rehabilitation stations and viewed the various documents, files, records and materials related to the project which were supplied by the implementing partner. The following table summarizes the locations of the project sites, the institutions involved and the observed functions of each institution:

Provincial / Autonomous City Level	Prefecture and City Level	County or District	Governing Institution	Location for activity	Function / Activity
Beijing City		Feng Tai District	China Disabled People's Federation (CDPF), Social Service Guidance Centre (SSGC), China Research and Rehabilitation Centre (CRRC)	Bo Ai Hospital	Location for the     Implementing Partner     Leading Group     National Training centre     for therapy and     assessment teams
	Handan City / Prefecture	Wei County			Therapy & special education for CP children,
Hebei Province	Langfang Prefecture	Yong Qing County	Hebei Province and County Disabled People's Federation	Rehabilitation Station	training of parents and activity centre for CP children
		Gu An County	reopie 3 redefation		cinidicii
Si Chuan	Chengdu City		Si Chuan & Chengdu Disabled People's	Chengdu Rehabilitation Resource Centre	Location for the Provincial Level Implementing Partner Management Team, Assessment & Training teams.
Province		Pi County	Federation		Therapy & special
		Pu Jiang County		Rehabilitation Station	education for CP children, training of parents and
		Xin Jin County			activity centre for CP children
Yunnan Province	Yuxi Prefecture	E Shan County	Yunnan & Kunming	Rehabilitation	Therapy & special education for CP children,
	Kunming City	Xi Shan District	Disabled People's Federation	Station	training of parents and activity centre for CP children

Table 5: Summary of the Project Locations, Institutions and Functions

# 2. Project Personnel

The following section gives details of the various personnel of the implementing partner, who are involved in the project:

# **BEIJING SSGC / CDPF PERSONNEL**

Name, Institution, Position and Role	Photo	Name, Position and Role	Photo
Mr Shi, Director of the SSGC in Beijing, Executive member of the Project Leading Group	2007	Mrs Cao, Vice Director in the SSGC, Beijing. Project Manager responsible for the overall management and implementation of the project	
Mrs Sun, Project Accountant		Claire Zhang, Volunteer Physio Therapist from Hong Kong.	

# **HEBEI DPF PERSONNEL**

Name, Institution, Position and Role	Photo	Name, Position and Role	Photo				
Director of Gu An County Rehabilitation Station	· · · · · · · · · · · · · · · · · · ·	Zhu Gui Fen, Doctor from local hospital (exact role in project unknown)	朱柱孝				
Zheng Lan Zhong, Director of Lang Fang City Disabled People's Federation	郑 兰 忠	Teacher Zhao, Teacher at the Gu An County Rehabilitation Station					
Accountant for Yong Qing County Rehabilitation Station							

# SICHUAN DPF PERSONNEL

Name, Institution, Position and Role			Photo	
Huang Quan Rong, Director of the Chengdu Rehabilitation Resource Centre		Jiang Hua Yin, Vice Director of the Chengdu Disabled People's Federation	蒋 华 莹	
Teacher Shao, Therapist for the Chengdu Disabled People's Federation		Teacher Yang, Therapist for the Chengdu Disabled People's Federation		
Feng Li Shi Zhang, Director of Pi County Disabled People's Federation		Yu Fu Li Shi Zhang, Vice Director of Pi County Disabled People's Federation		
Korean Doctor, Principle of Pi County Rehabilitation Station		Yang Bing, Vice Director of Pu Jiang County Disabled People's Federation	杨彬	
Chen Li, Vice Director of Pu Jiang County Rehabilitation Station	陈莉	Wu Jia Xiang, County Government official in charge of disabled people's work.	1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	

Name, Institution, Position and Role	Photo	Name, Position and Role	Photo
Director of Xin Jin County Disabled People's Federation		Leaders of Xin Jin County Government	
Personnel and Teachers at Xin Jin County Rehabilitation Station			

# YUNNAN DPF PERSONNEL

Y UNNAN DEF FERSONNEL				
Name, Institution, Position and Role	Photo	Name, Position and Role	Photo	
Ma Ze Rong, Yunnan Disabled People's Federation Leader		Yuan Yuan, Yunnan Disabled People's Federation Assistant		
Vice Director of the E Shan County Rehabilitation Station		Leader at the E Shan County Rehabilitation Station		

Table 6: Details of Personnel Involved in the Project and Met During the Evaluation

## 3. Project Management

On the second day of the evaluation during the time allotted with the Project Leading Group at the SSGC centre in Beijing, a number of participatory assessment activities were planned in order to gain information about the project management issues of the project, namely:

bbo	te centre in beiging, a number of participatory assessment activities were planned in order to
gain	information about the project management issues of the project, namely:
	Project Mapping Activity - to determine the activities of the project, the distribution of project
	funds to the various project sites, the history of the project and the hopes for the future;
	Organisational Structure Activity - to determine the number of organisations involved in the
	project, the key personnel, the relationships between the organisations and the perceived
	roles, responsibility and lines of authority;
	The Bus Activity - to determine styles of leadership and main management issues faced by the
	project, to determine the clarity of the project goals in relation to the implementing partner,
	to determine any conflicts of interest with the funding partners NMA and to determine the
	motivation of the implementing partners.
	Problem and Opportunity Line Activities - to determine the main challenges and
	opportunities facing the project from the point of view of both the implementing partners and
	the Buer Project staff.

Unfortunately, most of the members of the leading group (especially the project leader, Mrs Cao), proved unwilling to participate in the activities. The only activity which was carried out was the mapping activity (see Table 7 and Figure 10) and even then, most of the information was provided by the Buer project team and Claire Zhang, the volunteer physiotherapist visiting from Hong Kong. Therefore, most of the findings and discussions concerning project management are from observations during the site visits. One observation of particular note, was that the members of the leading group were all fully engaged in work other than the project and their ability to devote their time and energy to the project was very limited. In addition, the leadership style of the Project Manager was very dictatorial, in that all orders seemed to start and end with her with very little room for the sharing of ideas and information.

Location	PERCEIVED NEEDS FOR EACH LOCATION			
	Training	Staff	Equipment	Family Support
Beijing CDPF				
Shi Jia Zhuang DPF (Hebei Province)				
Wei Xian Rehab Station	$\sqrt{\sqrt{N}}$	√√	√	√√
Yong Qing Rehab Station	<b>VVV</b>	√√	V	√√
Gu An Rehab Station	$\sqrt{\sqrt{1}}$	√√	V	√√
Chengdu DPF, Chengdu Resource Center (Si Chuan Province)	V			
Pi Xian Rehab Station	V	0	√	√
Xin Jin Rehab Station	√	√	√	√
Pu Jiang Rehab Station	V	√	V	√
Kunming DPF, Kunming Resource Center (Yun Nan Province)				
E Shan Rehab Station	$\sqrt{}$	√√	√	√√
Xi Shan Rehab station	V	√√	V	√

Table 7: Results of Mapping Activity for Perceived Needs of Project from SSGC Perspective

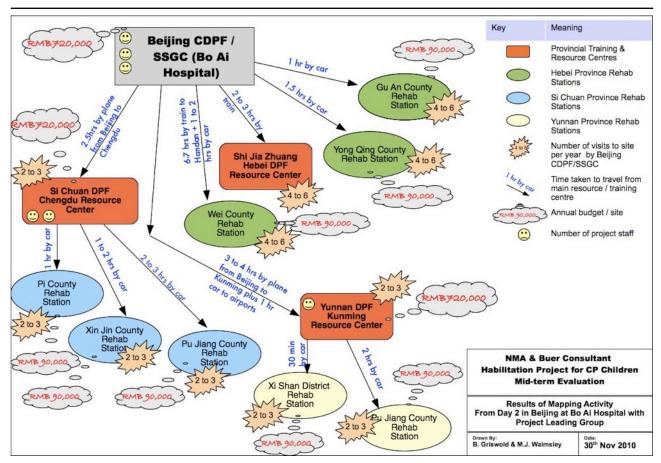


Figure 10: Results of Mapping Activity

#### 4. Finances

There were four main problems with the financial records and management of finances, namely:

- No detailed explanations or records of actual expenditure;
- No detailed budget matching the activities described in the planning reports;
- Inconsistencies in the recorded data, and;
- Unreliable auditing.

Generally, the finances were not very well documented and there were **no detailed explanations** of how the money was spent. In two of the county rehabilitation stations, there was no separation of the project expenses and the financial records from the other departments of the DPF. Moreover, the categories for the expenses did not match the ones in the budgets and some categories overlapped. For example, the category entitled "transportation" included the transportation of specialists, officials and staff for ALL activities and so it was impossible to see how much the transportation costs were for an individual training. In most cases, the accountants at the rehabilitation stations had no idea what the budget was for the project and therefore had no idea how to make a financial report detailing the expenses according to the budget category.

Within the project documentation provided during the evaluation, there was no evidence of a **detailed budget matching the activities** described in the planning reports. All of the budgets submitted by the implementing partner and consequently approved by NMA, contained general categories of activities, but no break down of how that budget was derived. Table 8 below, is the approved budget for 2010, but there was no other information about how the figures were derived and no detailed accounts for expenditure to see how the money was really spent.

Item	Activity	Total	NMA	Local
A.	Leadership Development			
1	Taiwan Study Tour (14 people)	Y186,300	Y160,000	Y26,300
2	Convene Assessment Seminar	Y35,900	Y20,000	Y15,900
В	Resource Center Establishment			
1	Skilled Personnel Training	Y66,900		Y66,900
2	Resource Centre	Y55,300	Y55,300	
3	Disabled Children's Rehabilitation	Y160,000	Y90,000	Y70,000
4	County Rehabilitation Station Skills Guidance / Training	Y146,000	Y96,000	Y50,000
5	County / District Rehabilitation Station Training	Y130,000	Y80,000	Y50,000
C	CP children Community Rehab. Pilot Scheme			
1	In 8 project counties / districts establish rehab stations	Y240,000	Y160,000	Y80,000
2	Basic equipment and training for the Rehab Guidance Stations	Y400,000	Y240,000	Y160,000
3	Training and Development	Y120,000	Y80,000	Y40,000
4	Assessment and Planning for 120 CP children	Y600,000		Y600,000
5	Activities for Families of CP Children	Y320,000	Y160,000	Y160,000
D	Project Management Activities			
1	County / District Project Work Inspection / Examination and Development	Y123,100	Y63,100	Y60,000
2	Baseline Survey	Y65,600	Y45,600	Y20,000
	TOTAL	Y2,649,100	Y1,250,000	Y1,399,100

**Table 8: Example Budget From Project** 

There were many **inconsistencies and gaps** in the records. For example, there was a record of an allowance for staff to attend a 60-day training in another city, but there was NO evidence of train tickets, bus tickets or receipts for hotel bills. Moreover, staff had stated during interviews that the maximum duration of any training which they had attended was 20 days. In addition, most of the receipts found in the county rehabilitation station's accounting records were for meals at restaurants. In fact, these receipts accounted for a staggering 50% of the overall expenses. Xi Shan District rehabilitation station in Kunming was working in cooperation with a local hospital. They had their own financial report, but could not provide any receipts because they had already handed them to the DPF at city level.

As far as **auditing** was concerned, some of the stations and centers had invited independent auditors to audit the expenses, but their reports did not seem very reliable. For example, in the Chengdu Resource Centre auditing report, it was stated that the counties had separate accounting books for the project, but this was contradictory to the findings of this evaluation team. The annual budgets as reported in documents from Buer Consultants were as follows:

Year	Total	NN	NMA		Partner
		Total (RMB)	% of total	Total (RMB)	% of total
2009	Y2,981,000	Y1,665,000	56%	Y1,316,000	44%
2010	Y2,649,100	Y1,250,000	47%	Y1,399,100	53%
2011	Y3,065,000	Y1,250,000	41%	Y1,815,000	59%

Table 9: Summary of Project Budget for 2009 to 2011

#### 5. Therapy Methods and Skill Levels Of Therapists

From the evaluation teams perspective, it appeared that the Beijing's CDPF was pushing conductive education to be the only approach to therapy. The rationale for using this particular approach to therapy was uncertain, but there was a definite sense that as far as the CDPF were concerned (especially from Mrs Cao), all of the rehabilitation stations and resource centres needed to be using this method, to the exclusion of all others. The result of this action seemed to be a greater emphasis on classroom activities and repetitive actions by the children. This caused the evaluation team members to ask the question, "What is the project goal?". In other words, "Is the goal of the project to have Rehabilitation Stations as a centre for conductive education, or as a place where parent can go to receive training on therapy tailored to meet the needs of their particular child?".

In terms of the skill levels and experience of the rehabilitation staff, it was very clear that the Chengdu Resource Centre and surrounding Rehabilitation Stations in Si Chuan were by far the best. Not surprisingly, the level of local government support was also the highest for this region, both in terms of financial input for the equipping of buildings, but also politically. Incidentally, the resource centre and rehabilitation stations in Si Chuan had also received a high level of input from expatriate professionals living in and around this region, either on a full time or part time basis. In direct contrast, it was evident that all three stations in Hebei Province needed more support from the central government, lacked qualified staff and the regular input from a professional assessment team. The attitudes of the staff, officials and parents in Hebei Province towards CP treatment, did seem to have changed since the inception of the project, but there was still very little understanding about the value of rehabilitation work, or indeed even how to carry out an effective therapy plan. Moreover, the little rehabilitation work which was being carried out in Hebei Province seemed to be more focused on the physical needs of the children, rather than their holistic needs (i.e. educational, emotional and psychological needs). The level of support, skills and experience of the rehabilitation stations in Yunnan Province lay somewhere in between Si Chuan and Hebei Province, but were still generally lacking any comprehensive plan and method to provide the holistic support which the project was advocating.

#### 6. Education and Advocacy Work

None of the project sites were really focusing on the educational needs of the CP children and generally, the main focus was on physical therapy. Moreover, only a few of the sites seemed to be having any success at getting the CP children into normal schools.

Generally, all of the provincial and county DPFs were making an effort for the advocacy of cerebral palsy children's rights and the promotion of their needs in the community. Most of the sites had carried out promotional activities, especially during the holiday seasons.

### **Discussion**

The following section presents some discussions on the various challenges faced by the project:

#### 1. Project Management

There are a number of project management issues which need to be addressed in order to make the project more effective and able to fulfill its vision. Those areas are as follows:

**Feasibility Study** - baseline study of resources and CP incidence, systems analysis;

**Project Planning** - SMART goals, planned activities, scheduling, detailed budgets, staffing;

Project Manager - commitment, communication, skills, experience, and integrity.

#### a) Feasibility Study

The initial proposal for the project was very well written and researched. It is clear that a great deal of thought and effort went into developing the proposal and that the person who initiated the project was very passionate about cerebral palsy and the needs of CP children in China. The proposal also went a long way to defining the overall problem and needs of CP children in China. However, it failed to properly research what the existing resources were within China concerning CP treatment and more or less ignored the many non government organizations (NGOs). Indeed, many of these NGOs have well established projects that have been in existence for more than a decade and who have teams of well trained local therapists ready to visit other less developed projects to provide Ironically, the evaluation teams for both the existing NMA funded CP project and previous one in Chengdu, were all made up from people working in the NGO projects and those people are still working in China in their various project locations in Chengdu, Xining, Xiamen, Tianjin, Zhengzhou, etc. Moreover, there is already an existing network of NGOs who exchange resources and attend an annual conference for the purpose of networking and training. Much of this work is sanctioned and backed by the Ministry of Civil Affairs and indeed, the conference held in October 2010 was actually hosted by the Civil Affairs Ministry in Beijing. There's also an additional network of expatriate medical workers across China and Asia who meet on an annual basis for continued professional development training; once every other year in China for China based medical workers and the other year in Chiangmai, Thailand. There is an additional organization called Asia Education Resource Consortium who support homeschooling parents across Asia. Part of their remit is Special Needs and they have a pool of specialists available, especially in the field of special education. Ironically, to the best of the evaluation team's knowledge, none of those special needs projects are working with the CDPF. Moreover, there seems to be no communication or sharing of resources between the Civil Affairs Ministry and the CDPF.

The purpose of a feasibility study is to assess in detail, both the problems and the resources available to deal with the problems and thus determine whether the project is feasible. Such a study would also help determine the timeline needed for the fulfillment of the project goals. The project proposal identified the need for a baseline survey to determine the extent of CP incidence in China, but it failed to take the next couple of steps, which were to assess the resources available and the best way of utilizing those resources to fulfill the project goal. It maintained a dangerously narrow field of vision and focused solely on the work and resources of the CDPF.

Part of the feasibility study could also have been to **define the system** which was needed to establish a national level of holistic treatment for CP children in China. This is important, because it defines the framework for the project and without it, it is hard to know what specifically needs to

be done. From conversations with the project staff and observations during the evaluation, the following diagram (Figure 11) could be used to define the system (the arrows represent the possible flow of resources):

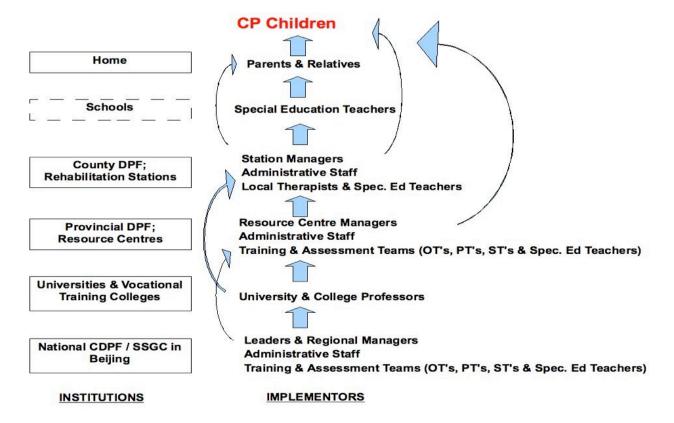


Figure 11: Possible System Needed for CP Habilitation in China

The system is basically designed to provide a service, of whom the main beneficiaries are the CP children and partly consists of the institutions and personnel needed to provide the service, i.e. the infrastructure. Another important factor in establishing the system, is the order in which it is set up. In other words, there is a critical order in the way it should be developed, otherwise the system won't work. To illustrate, consider the following:

- I. For the CP children to be getting the needed therapy in the home, their parents need training;
- II. In order for the schools to be taking on CP children and for the parents to receive training, there needs to be a sufficient number of trained and experienced therapists and special education teachers at the county and township levels (i.e. in the Rehabilitation Stations);
- III. In order for their to be a sufficient number of trained and experienced therapists at the Rehabilitation Stations, there needs to be an established provincial training centre with qualified and experienced OTs, PTs, STs and Special Education teachers working from a practical and universally accepted curriculum and training schedule;
- IV. In order for their to be qualified and experienced OTs, PTs, STs and Special Education teachers working from a practical and universally accepted curriculum and training schedule, there needs to be universities and vocational colleges who offer courses in those subjects;
- V. In order for there to be universities and vocational colleges who offer courses in those subjects PLUS an acceptance by local schools to receive CP children, then there needs to be government approval and financial backing.
- VI. In order for there to be government approval and financial backing, there needs to be a change in government policy which is agreed by all of the relevant government departments, i.e. Civil Affairs Ministry, Education Ministry and the China Disabled People's Federation.

The bottom line is that the system needs to be built up gradually in accordance with the resources available. This is capacity building. Right now (the time of the evaluation), even though there are buildings in place and people in them, the system is dysfunctional. Why? Because the system essentially relies on there being a sufficient number of skilled and committed personnel and there is a distinct lack of those at all of the required levels. To highlight this issue, below is a table which attempts to define the current levels of achievement measured against those goals. It is a "guestimate" based on observation NOT on hard empirical data, so it is neither definitive nor accurate, but will hopefully illustrate why the project is struggling to achieve its goal:

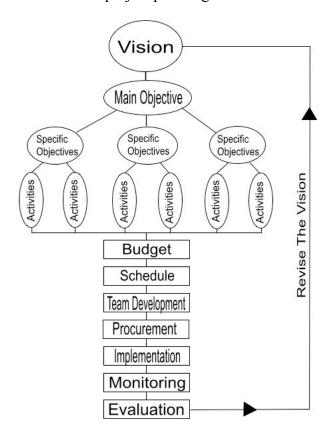
Item	Goal / End Point of Project	Achiev- ement Level (1 - 10)	Reasoning
1	All of the institutions are established (buildings constructed, equipment bought, etc).	8	Generally, the Chinese government are very good at creating the physical infrastructure needed for institutions. Providing buildings and equipment is not a problem and all of the project sites are functional in this sense. However, speech therapy and special education equipment are generally lacking.
2	The management systems are in place (established and defined roles and responsibilities of all personnel, planning procedures, budgeting, accounting, monitoring, evaluation, etc) PLUS good and dedicated leadership	5	Again, one of the Chinese government's strengths is the well established systems for implementing government policy. There are officials and elected bodies established from national to village level. However, the style of management is dictatorial. Power and control is maintained by the top leaders and information and decision making is generally one way, i.e. top to bottom. Thus the system is hugely inefficient and bureaucratic. It is a difficult system to work with, both for those on the inside and on the outside. As far as the project is concerned, the other major challenge is that the leadership is not dedicated full time to the project and lacks the skills needed for the task.
3	The curriculum for OT, PT, ST and Special Education Teachers are all standardized, being taught in the universities and colleges and being practiced in the hospitals, resource centres, rehabilitation stations, schools and homes.	1	The number of Chinese experts with experience of doing all forms of therapy within China is minimal. The majority of people in China with the expertise and experience of doing therapy with CP children, are mostly expatriates working in non-government funded projects, some of which have been operating in China for more than 10 years. However, there is very little connection between them and the government institutions responsible for training therapists and indeed, the CDPF. Hence, the development of a workable national training program for therapists in China is negligible compared to the needs.
4	There are sufficient numbers of trained personnel (specialized and administrative) in all of the institutions, and the skill levels of the personnel matches their required tasks.	1	Since there is no national level program established for the training of doctors in therapy and vocational workers for PT, OT, ST and special education, it should not be a surprise that the number of trained personnel for this type of work is way below the needs of the country. Moreover, even if a training program were quickly established, you would first want those graduates to spend a number of years working under experienced therapists in well established projects / therapy stations. This factor also increase the time scale of the project goal to have a national model for therapy.
5	There are established and sufficient sources of funding to pay for all of the costs involved in providing the services and maintaining the system (fees to parents, taxation, donations, etc).	5	The Chinese government DO have a system of taxation specifically to fund projects and institutions working with the disabled. The system is such that every company needs to pay roughly RMB200-300 per employee of the company every year. This money should then go towards the needs of disabled people in China. Chengdu Provincial government seemed to be using that money for its designated purpose. Hebei Province is some way behind. As far as charities are concerned, they do exist in China, but their legal status is dubious. Therefore, there is no well defined system for Chinese people to donate money for this kind of work.

**Table 10: List of Goals Needed to Achieve the Project** 

#### b) Project Planning

By and large, the project goals were not SMART enough i.e. Specific, Measurable, Achievable, Realistic and Timed. The project proposal identified the need to establish a system for the holistic treatment of CP within China, but it did not define in detail what that system was and the specific goals and activities which would be needed to create the system and make it functional. Once the system is clearly defined, strategies need to be put into place to determine the best course of action and the overall timeframe needed. From this, the project goals can be determined with much greater realism. From the project goals, specific project activities can be defined, from the project activities, a schedule and personnel requirements and finally a detailed budget to match. Figure 12 shows a diagram illustrating the process which could be used for project planning.

When the evaluation team questioned the government partners as to how the budget was derived, they could not give a response. In fact, they had difficulty understanding the concept. It thus transpired, that the way in which the local government produce budgets and receive funding is very different from the way in which a project or private business operates. For the local partner, budgets are set by central government, in that a lump sum is allocated to them. They then have to spend that money and produce receipts. There is little accountability and no concept having to base a budget on a detailed plan. Table 10 below is an example from a planning proposal for the project and this was the only type of information available to the evaluation team to show how the budget was derived. In the example below, there is no information saying exactly what the activities are, i.e. How is



**Figure 12: Project Planning Process** 

rehabilitation going to be carried out? Where is it going to be carried out and when? How many times a year? Who is doing the rehabilitation work? Are there outside experts needed? How much are their fees? How many staff are involved? If the had to travel, where did they travel to? If they stayed the night, how many nights, where and how much?

Description	Indicators	Means of	NMA	Local Partner
		Verification		
Continue to work with Hebei, Yunnan,	Hebei, Yunnan and	Interviews with	20,000	20,000
Chengdu health, education consultation and	Chengdu 8 project	the leadership of		(Transportation,
cooperation department, to carry out a holistic	counties / areas to carry	the project area		accommodation)
rehabilitation of children with CP, to carry out	out rehabilitation services			·
appropriate community-based rehabilitation	for children with cerebral			
training, training of community rehabilitation	palsy, 240 to benefit poor			
personnel and parents of disabled children,	children and families with			
training demonstration window	cerebral palsy			

Table 11: Example from Project Plan & Budget 2011

Below is an excerpt from a budget for a community development project in rural China to show the sort of detail that should be expected from a project proposal. Note also, that this budget was the produced after the goals, activities, staffing requirements and schedules had been derived.

Item	Description	Unit	Quantity	Rate	Cost	
<u>A</u>	Direct Costs					
1	Salaries					
	Staffing costs for the QX Training Team for the duration of the project (18 months). Calculations					
	for the number of man/days for each of the staff / team members, is	detailed on	the sheet			
	"Staff Allocation".					
1.1	Training & Development Activities: Total man-days = 278	sum			29,775.49	
1.2	Relational Activities: Total man-days = 70	sum			7,865.71	
1.3	Project Management Activities: Total man-days = 73	sum			8,560.13	
1.4	Reporting, Monitoring & Evaluation: Total man-days = 29	sum			3,783.59	
		Subtotal			49,984.92	
2	Administration Costs					
2.1	Printing costs for reports, etc	sum			500.00	
2.2	Stationary (pens, ink for printers, etc)	sum			300.00	
	Subtotal				50,784.92	
<u>B</u>	<b>Training &amp; Development Activites</b>					
1	Venue Hire					
	For training sessions and PRA activities for the duration of the proje	ct @ 40RM	B per day			
	Training Sessions: 18 in total	no.	18	40.00		
1.2	PRA Sessions: 3 in total	no.	3	40.00	120.00	
2	Refreshments					
	For Trainees & Trainers during the sessions @ 25 RMB per session					
	Training Sessions: 18 in total	no.	18	25.00		
l	PRA Sessions: 3 in total	no.	3	25.00	75.00	
3	Travel Expenses					
3.1	Travel to and from venue for staff based in QX City for entire team:					
	local transport @ 50RMB each					
	3.1.1 Training Sessions	no.	18	100.00	· /	
	3.1.2 PRA Sessions	no.	3	100.00	300.00	
3.2	Travel to and from venue for staff / associates based in Tianjin, using	g public tra	nsport:			
	3.2.1 Training Sessions	no.	18	74.00	1,332.00	
	3.2.2 PRA Sessions	no.	3	74.00	222.00	
3.3	Accommodation in QX City for JHF Leadership based in Tianjin:					
	3.3.1 Training Sessions	no.	18	50.00	900.00	
	3.3.2 PRA Sessions	no.	3	50.00	150.00	
	Subtotal				6,069.00	

Table 12: Example of Detailed Budget from a Rural Community Development Project

#### c) Project Manager

The last issue concerning the project management is the choice of project manager. The project manager is the key to the success or failure of a project. It is up to NMA, Buer Consultants and their implementing partner how they manage the project and who to appoint as the project manager, but they should first agree upon the role of the project manager and qualities that would be required of the person to fulfill that role. It would also be advisable to seek someone who has the project management skills and experience necessary for the job, as well as having a high degree of integrity, passion and commitment. One of the main problems for this project is that the person who was appointed as project manager, has neither the time, skills or temperament for the role.

#### **Conductive Education** 2.

Conductive Education is an education system created for children with motor disorders such as Cerebral Palsy. Its basic principle is to see the child as a whole being and promote function. Moreover, there is an emphasis on holistic intervention and a focus on every aspect of a child's development. Therefore, therapy and education are combined together. Conductive education also seeks to make children active participants and not just recipients of treatment. In fact, there is an emphasis on active participation rather than just receiving passive exercises for the purpose of This type of learning is carried out in a group classroom setting, where influencing function. teachers and students work together to create an environment for learning. Conductive education also seeks to give the child an opportunity to practice a particular skill in many different situations so that the skill can be reinforced. The idea is to turn any given part of a child's day into a learning situation, but at the same time have the child practice functional skills throughout the day. Conductive education also includes an interdisciplinary group of trained professionals responsible for planning and carrying out the program. However, there are pros and cons to conductive education and these are listed as follows:

> **Pros** Cons

- Improves a child's willingness to participate Limits the ability to focus on a child's and helps them work towards independence with daily living skills;
- Encourages a child to depend less on their parents or teacher;
- Encourages teachers to look at a child more child's physical limitations and education, and;
- Provides opportunities for social interaction and communication with other children and teachers.

- individual needs:
- Gives up the ability to really address specific PT, OT and ST needs because it is done in a group setting and every child is doing the same movement, therefore;
- holistically, seeking to combine improving a Movements are simpler and less individualized, and;
  - Creates a formula for treatment, even though every child is different and has specific needs.

There have been a few controlled studies comparing conductive education to traditional therapy approaches, but none of these studies have been able to show that conductive education is superior in any way to other methods. Moreover, there have never been studies to look at the long term successes or failures of the method or its cost effectiveness.

In terms of the project, the evaluation team see that there are two main problems which the project faces by focusing on conductive education as an approach to meeting the therapy and educational needs of the children:

Insufficient trained professionals with a lack of interdisciplinary coordination, and;
Constrictive nature of the Chinese Education system.

Conductive education is typically carried out by **trained professionals**. This means that trained PT, OT, ST, and special education teachers are all a part of the process. If the teachers are not well trained, then it is very difficult to ensure that the child's individual needs will be met. At present, the project has a serious lack of trained professionals and even those that do have the training, are **not** working in coordination with one another.

The Chinese education system can be very constricting in nature and therefore has a tendency towards rigid methods of teaching and training, with a particular emphasis on rote learning and repetition. Moreover, the education system and culture generally do not encourage innovation or creativity. Hence, when a certain methodology or approach has been introduced and accepted by the establishment, there can be a narrowing of vision and a refusal to accept any other methods and approaches to solving a problem. This is beginning to be the case through the introduction of Conductive Education through the CDPF. In terms of what the CP child will face in a normal Chinese school, classes are generally very large (average of 60 children in one class) and therefore the role of the teacher is more of a lecturer and provider of information, rather than an educator. There is also huge pressure on the teachers and students alike to perform, both because of the high school leaving certificate and the fact that the teacher's pay is linked to the grades of the students. Hence, right now a child with special needs is very unlikely to receive the attention they need in a normal Chinese classroom.

#### 3. Goal Setting and Assessment in Therapy

The goal of therapy is to achieve the maximum amount of movement, function, independence, and quality in an individual child's life. A therapist's goal is therefore to help the child's movement become as normal as possible so the child can achieve their best function, that is:

- Help them work on activities that are similar to actual functions carried out in daily life, and;
- Engage in activities that add personal meaning and purpose to their lives.

If a child is unable to obtain a full normal level of function, the goal of physical therapy is therefore be to help the child carry out daily life activities as independently as possible, decrease their limitations, and prevent further disability. In summary, teaching function is a very important aspect of therapy and education. Functional goals are therefore goals that work toward a child's ability to perform a functional task and include measurable activities that assist the child in being able to accomplish the goal as a result of physical therapy.

At present, the project has no standard form of documentation for the rehabilitation stations and resource centres and no standard way to set goals for the children.

In order to work toward the goal of treating a child holistically, each child's goals and therapy plan needs to focus on function. Within the project rehabilitation stations, some of the goals that are being set, are focused on function whilst others are just focused on performing an exercise without documenting what they hope to achieve. Therefore, if the staff were trained how to document and use a functional plan and goal, then it would be easier to work on function with the children. Generally, there are very few rehabilitation staff members who are working full time for the project. Therefore, there is no one person who is consistently and daily working towards the goals of the project.

### **CONCLUSIONS**

There is a great need for a concerted effort to meet the needs of cerebral palsy children in China. To this end, the evaluation team heartily commend the efforts of NMA, Buer Consultants and the China Disabled People's Federation. As a result of the project, there is now a greater awareness of the need for children with cerebral palsy to receive therapy and education and there is also a greater awareness that a child needs to be treated as a whole being. Moreover, in some of the project sites, an understanding of the importance of a child's function and independence is beginning to emerge. There are also individual sites which are doing very good work, particularly in Sichuan Province, where therapists are regularly traveling from the Resource Centre to the rehabilitation stations to provide training to the therapy workers, parents and children.

However, there are many issues facing this project and although these issues should not be used as a reason to stop the project, they do need to be addressed and drastic measures taken, otherwise precious time, effort and money will be wasted.

It is therefore the conclusion of this evaluation team, that whereas the project plan succeeded in defining the problem of cerebral palsy in China and the need for a system, it is weak on seven major issues:

- I. **System and Planning:** No work was done on identifying the sequential steps needed to establish the system and the time frame needed for each of those steps;
- II. **Networking:** Lack of networking amongst non government organizations (NGOs) already working with CP children in China, many of whom have more than decade of experience in therapy, training and management of CP projects;
- III. **Project Manager**: The chosen Project Manager has neither the time, skills or temperament for the role;
- IV. **Financial Systems:** No clear procedures for developing detailed budgets and financial reports;
- V. Qualified & Experience Staff: Real lack of experienced and qualified therapists and teachers, especially in the rehabilitation stations;
- VI. **Trained Experts**: Lack of experts from the needed disciplines of PT, OT, ST and Special Education, to provide training and to work as a coordinated team to do the assessments, and;
- VII. **Conductive Education:** Introduction without the experts to effectively implement it and without considering whether it really is the best approach to therapy for CP children in China.

#### RECOMMENDATIONS

work in China;

In lig	ght of the above conclusions, it the recommendations of this evaluation that the project take the
follo	wing measures:
	Carry out a feasibility study to fully understand the resources available within China to
	provide the capacity building necessary for the fulfillment of the project goal and to determine
	the best approach to therapy (be it conductive education or otherwise);
	Network across China, with NGOs and government ministries in addition to the CDPF,
	namely the Civil Affairs Ministry, the Education Ministry and possibly the Foreign Affairs
	Ministry. The evaluation team truly believes that NMA through Buer Consultants are uniquely
	placed to bridge the gap between the NGOs and the government ministries involved in CP

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## **Responses to the Terms of Reference**

The following section provides conclusions in response to the questions within the terms of reference:

Item	Criteria / Question	Conclusion
1	Project design and structures	
	Has the Beijing CDPF leadership a good grasp of the objective, goals and plans as agreed in CDPF/Buer agreement and how do they communicate them to provincial and county level?	<ul> <li>It seems that the Beijing CDPF leadership has some grasp of the goals and plans of the project, BUT are more focused on the technical aspects rather than how to set up a system to change the current situation. In particular, they seem to be concentrating on bringing conductive education to the therapy stations, which does have a part in addressing the child as a whole person.</li> <li>As for communication, the evaluation team saw a lot of documents issued by different levels government which should have communicated the project goals. Moreover, it appeared that the Beijing CDPF leadership also went visit the sites once or twice a year.</li> </ul>
	What other support has Beijing CDPF given to the Provincial DPF station (besides training)?	Beijing CDPF have partly understood the needs of the stations and has purchased one set of equipment for each station. The stations in Hebei province brought the children in the project to Bo Ai Hospital for evaluations, treatment plans, therapy goals, and orthotics. The Beijing CDPF makes visits to Yunnan and Sichuan 2-3 times/year and the Hebei sites 4-6 times/year. Typically Director Cao and Sun Xiao Ming are the ones visiting the different sites.
	Does the CDPF in Beijing recognize the different level of development at the rehabilitation stations in the three provinces (even between the rehab stations within each individual province)?	The Beijing CDPF did seem to recognize that there were some real differences in the level of development of the rehabilitation stations. In fact, there is a stark difference between the stations in Hebei Province and those in Si Chuan province.
	Do they provide appropriate training tailored to the needs of each?	There is still a need for more training at each rehab station and although the teachers at each station have received different training and have different backgrounds, the individual needs of the teachers at each station are very different. Perhaps the greatest training need is for professional therapy training. The most amount of training and support was taking place in Si Chuan Province. However, by and large, the level and amount of training has been way below the needs of the project.
	In what form are communications conducted between the rehab/ assessment centers and the rehab stations (phone call, emailing, and visit)? How often are project reports submitted to the CDPF in Beijing, with copy sent to Buer Consult office?	The main forms of communication are emails, phone calls and site visits. In Chengdu, the assessment center sends their staff to the stations on a regular basis, or invites the station staff to the resource centre to receive training. In other provinces, it appears that there is no coherent and permanent assessment team that works together making visits to the sites.
	How does Buer Consult follow up its partners at national, provincial and country level? How is the communication between Buer Consult and its partner (regularity and perception by both parties)	Buer Staff mostly seem to visit the sites and provided management training for them twice or three times a year. Other than that, communication is by phone and e-mail.

Item	Criteria / Question	Conclusion
	Will the project be able to achieve its objectives within the 5-year project period?	No. The objectives are much too high and the problem too large for the project to achieve its goal within the given period and needs more of a foundational system to accomplish its objectives. The government partners were also in agreement about this issue and felt that the project goals was more of a vision for the future, rather than an immediately achievable goal.
2	Financial management	
	What has been Beijing CDPF budget for each of the provinces given the different level of development in CP?	It seems that Beijing allocate different amounts of money to different provinces. From the expense records for 2009, it appeared that about 20% of the budget went to the Beijing CDPF. Hebei Province received the most financial support from NMA, at RMB 278,414, whereas Yunnan Province received the least financial support, at RMB226,742. The money allocated to the different counties was also different, in that one county only received a RMB 50,000 from NMA, whereas another county received RMB 90,000. There does not appear to be a clear rationale for this distribution, especially considering that each station was roughly the same size and was dealing with the same number of children.
	Are the financial routines in the project (at all levels) according to NMA and national standards? How are financial resources managed at the resource centers and the rehabilitation stations?	<ul> <li>Two of the counties did not have accounting books which were separate from the project and all of the expenses were mixed in with the other departments of the DPF.</li> <li>The categories for the recorded expenses did not match the ones recorded in the budget and some of the categories overlapped with one another.</li> <li>There was no explanation or details for how the money was spent. For example, one category entitled "transportation" included the transportation costs of specialists, officials, and staff for all of the activities and it was therefore difficult to see how much individual activities cost.</li> <li>The accountants often did not know what the budget was or how it was derived. They therefore had no idea how to make a financial report for the expenses in accordance with the budget.</li> <li>Some of the counties, like Wei county, did not have equivalent receipts for the expenses. For example, there was an allowance for staff attending a 60-day training in another city, but there was no record of train or bus tickets and no receipts for the hotels. Moreover, the staff had stated that the longest training they had attended was 20 days.</li> <li>Most of the receipts in all of the county stations were for meals and accounted for about 50% of the total expenditure of the project.</li> </ul>

Item	Criteria / Question	Conclusion
	To what degree does Buer Consult have insight to the financial management of its project partners? What is their capacity in following up in this respect?	<ul> <li>No detailed budgets were produced by the local partner based on a detailed plan. The budgets submitted by the local partner were vague and not based on any real cost estimates. However, Buer Consultants accepted the budgets on face value and overly trusted the local partner. Therefore, blame for miss-spent funds has to lie partly with Buer Consults.</li> <li>In China, the account books with the receipts reflects the real expenses and insights into the financial management. Moreover, the way that Chinese government departments develop budgets and account for expenditure is very different from private funded projects or businesses. The Chinese government departments are simply allocated a budget by central government and then are obligated to spend it. They do not have the mind set or skills to develop a budget based on predicted and planned activities. Moreover, government departments need to spend their budgets, otherwise they receive less the following year. This should go some way to explaining the poorly managed finances of the project.</li> </ul>
3	The concept of habilitation	interiors of the project.
	This project is given the name Holistic Habilitation. What is the level of understanding for the word holistic, and what is the awareness level in the project for seeing the "whole" child? Furthermore, do the rehab personnel, and the personnel at the rehab centers, see the value of this approach?	It seemed that local government implementors are still far from understanding the concept of holistic rehabilitation, since most of the therapy and focus was on the physical needs of the children i.e. PT work. Some of the rehab stations had invited doctors from hospitals or cooperated with hospitals to provide training. However, with the exception perhaps of the Chengdu Resource Centre and Pi County Station, none of the assessment and training team specialists were working as one united and coherent team. This was especially true in Kunming, where there was a strong reliance on the medical treatment provided by doctors.
4	The habilitation model –development and status	
	What is the level of knowledge in terms of knowing what they are supposed to do in the project, and what they are supposed to receive? This refers to all levels: provincial, resource centers, and rehabilitation stations.	Each level is aware that they should receive training, equipment for the rehabilitation stations; and rehab stations should receive support from resource centers and provincial levels. There is a broad general understanding of what each level is to do in the project but there is not necessarily a detailed understanding of what they are supposed to do. In that sense, it seemed that the project implementors are still not very clear about their responsibilities and the objectives of the project. Moreover, the provincial or resource centers were not able to provide sufficient support to the rehab stations and did not have a clear picture about how to achieve the goals nor what they needed to improve the situation.
	What are the changes experienced by the staff in the project, during the first two years?	The staff had received some training and there is a greater understanding of the need for children with cerebral palsy to receive therapy and education. Also there is more awareness of the importance of training parents and including them in the process of habilitating their children.
	What has each of the rehab centers and stations done to reach out to more CP children who are not under the Buer/CDPF project?	Some stations had extended their services to CP children outside of the project, particularly; Pu Jiang county. The stations in Yunnan Province had also visited other families with CP children and provided them with some guidance.

Item	Criteria / Question	Conclusion
5	Assessment of the Rehabilitation	
	Centers:	
	least a doctor, a PT, an OT, and if possible a speech therapist. This	Most of the assessment team members that we met seemed to do their assessments individually and not as a team. To that end, there did not seemed to be a complete assessment team functioning in any of the provinces.  • In Hebei and Yunnan Provinces, there was no assessment team. There were some specialists, such as PTs, OTs and STs, who had visited the stations, but the visits were sporadic and on an individual basis, i.e. they were not working in a co-ordinated and unified way. Therefore the children had not received regular assessment. In some of the counties within Hebei Province, the parents and children had stayed in the Bo Ai hospital to receive assessment from the hospital doctors. The normal practice was for the parents to accompany their children during the assessments. Assessment forms were provided and filled out and to an extent, parents were then able to follow the instructions and train their children at home.  • In Chengdu, the assessment team came from the DPF and consisted of a PT and OT, who would go together to do assessments. Even though they worked more as a coordinated team and there was greater functionality, it was still for form an ideal madel assessment town.
	Distance traveled to the rural communities has always been a challenge for those rehab staff in Yunnan Province. What have the rehab/assessment centers provided to the staff of the rehab stations in reaching out to those families who are located too far and might be too poor to travel for the weekly visit to the rehab centers as required?	<ul> <li>still far from an ideal model assessment team.</li> <li>It was reported that there are therapist's that go to the children's homes weekly to do therapy in the homes and to give parents instruction on how to help their children.</li> <li>The other places occasionally provide a teacher to go to the children's homes but there is no system in place to help with these families. Most of the time if a family was not able to come weekly the therapist would just see them monthly.</li> <li>In Xi Shan district, the staff were reported to regularly visit the homes of the CP children.</li> <li>It was also reported that there was a rehab station at township level, but that there was no equipment.</li> </ul>
6	Rehabilitation Stations:	to wiship level, out that there was no equipment.
	What has been the assessment system conducted in each rehab station given its importance in CP cases? How regular, how detailed is the follow-up entailed after each case is assessed	The assessments were done differently in each place and there did not seem to be a fixed scheduled which was regularly followed. The teachers said that evaluations would occur every year and that the goals were set for varying lengths of time. The assessment forms also differed greatly between the different stations and different provinces, so there was not a standard assessment form or a standard way of assessing the children. There was also no standard way of documenting the plan, goals, and daily treatment.
	Have the parents and the local rehab staff understood the training and the importance of following this plan? Do they use what they have learnt and do they do it right? Do they see the value of this approach?	Some of the therapists had the ability to carry out the plans they had been given but did not know how to change the plan, add to it, or solve new problems that arose. Some of the therapists had a very limited knowledge of how to carry out the therapy plan. Some of the parents seemed to be very active in trying to carry out the plan they had been given at home while others did not have time or said they did not have the right equipment.

Item	Criteria / Question	Conclusion
	Does each rehab center have access to the nearest professional help/support such as PT, OT, ST and conductive education in order for the HH system to not only succeed management-wise, but also the technical aspect of the project. If the answer is "no", what can be done to improve the professional efficiency of the staff?	<ul> <li>As far as conductive education is concerned, it does not seem that there are any professionals that can be consulted other than Hong Kong's Claire Zhang. There needs to be more training to improve the efficiency of the staff and more full time staff devoted to the project.</li> <li>In Sichuan there was good access to professional PT and OT support.</li> <li>In Hebei, while the Bo Ai Hospital is close by, the professionals there do not go out to the rehab stations.</li> <li>In Yunnan, there are some professional therapists in the area but it is difficult to determine whether the project therapist often communicate with them about the children's situations.</li> <li>There is a great need to build up a full-time professional assessment team, including PT, OT, ST. Spec Ed. Moreover, overseas Chinese doctors and specialists or foreigners with Chinese mandarin, could be invited to cary out assessments and provide training at the training centre. If this were the case, then the curriculum would need to be developed very early on. Training would have to be provided for the different levels and skills of the therapists, i.e. one for a professional assessment team and another more basic curriculum for rehabilitation staff working in the county stations. Therefore, the local staff could become specialists in different fields or / and staff could provide basic services for the families at the county level.</li> <li>The staff need systematic and practical training for long periods of time, under the guidance of specialists and working with children at the training centre. In this way, the training would not only provide some theoretical knowledge relating to different fields, but would also provide the opportunity to gain practical experience, much like an internship. The curriculum and experience from this training could then form the basis of the teaching materials and textbooks of a national curriculum for PT, OT, ST and Special Education courses.</li> </ul>
7	Education – increased emphasis	
	There has been a focus on education in the project. This to secure that the Children with CP also can get the right to education. In many cases with CP, the mental capacity of the child is 100% functional. The focus in this project has been on including the children into normal school, when this is possible.	In Xin Jing county, the CP children were able to enter into normal school. Another similar project nearby run by a British organization could have influenced this situation. In other counties, there were still many obstacles in the way of the parents and children to enter into normal school. The reason why most of the CP children could not enter main stream schools is complicated. Some of the reasons are to do with the political system and the fact that the different government departments lack effective communication

Item	Criteria / Question	Conclusion
	What has been done to increase the level of CP children getting into school, and has there been established any new alternative education facilities in any of the eight centers? What are the reasons for the achievements and what are the reasons why some have not achieved much in this aspect?	channels and do not cooperate with one another. Therefore the DPF needs to become more effective at communicating with the education department about the situation of CP children and become better advocates. Another major reason, is that teachers in the schools are under a great of pressure to maintain the academic performance of their school and are therefore fearful that a CP child would reduce that level. The number of children in a standard Chinese classroom is also very high (60 and above) and therefore, the teacher cannot devote the time needed to meet the CP child's special educational needs. Moreover, the teacher lacks the training to do so. Generally, the attitude of schools and parents towards disabled children needs to dramatically change, since there is a deep prejudice against them. A lot more ground work needs to be done in order to turn this situation around.
	What has been done in communicating the needs for integrating the CP children into the jurisdiction of the Education department, to be able to secure their education? Concerning this issue we would also like to know what the relationship between the local CDPF training stations and the local governments is in terms of advocating for the CP children's rights?	<ul> <li>Some propaganda and promotional activities were carried out on special days and national festival, in order to disseminate information about CP, but not about their civil rights. The officials in some of the counties, particularly those near to Chengdu, also tried to communicate with different government departments.</li> <li>In E Shan there is a good relationship with the center and the education department so it is easier for these children to enter normal schools. There needs to be cooperation between the national and local DPF and the education department. The centers have organized some activities to make the community more aware of what Cerebral Palsy is and what the needs children with CP have.</li> </ul>

APPENDIX I: EVALUATION	TEAM MEMBER'S RESUMES

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#### **EDUCATION**

#### **Doctorate of Physical Therapy**

The University of St. Augustine for Health Sciences St. Augustine, FL January 2002 **Master of Physical Therapy with Honors** 

The University of St. Augustine for Health Sciences St. Augustine, FL September 2001 **BS Zoology** Auburn University Auburn, AL June 1999

#### EMPLOYMENT AND PROFESSIONAL EXPERIENCE

Physical Therapy Trainer, Jian Hua Foundation, China (February 2008-present)

-Responsible for training Chinese physical therapists and working with physically disabled children in school and orphanage settings

*Pediatric Physical Therapist*, Child and Family Development, Inc., Charlotte, NC (October 2005-January 2008)

-Responsible for evaluation and treatment of pediatric patients in a private clinic setting working with multiple diagnoses including Cerebral Palsy, Down's Syndrome, Autism, Developmental Delay, Spina Bifida, and orthopedic injuries. Responsible for training physical therapy students on their clinical internships and working with other disciplines with case collaboration and co-treatments.

*Physical Therapist*, Jian Hua Foundation, China (June 2005-Ocotober 2005)

-Responsible for training Chinese physical therapists and working with physically disabled children in school and orphanage settings

*Physical Therapist*, Cleveland Regional Rehab, Cleveland Regional Medical Center, Cleveland Pines, Crawley Memorial Hospital, Shelby City School System (March 2002-June 2005)

-Responsible for evaluation and treatment of patients primarily in an outpatient clinic and the school system with some weekend and as needed coverage at an acute care hospital, swing bed hospital, and skilled nursing facility

#### **TRAINING EXPERIENCE:**

Beth gave trainings for the following places:

- The First Northwestern China Rehabilitation Seminar April 2009 Xining Orphanage
- Qinghai, China
- The Ministry of Civil Affairs of the People's Republic of China training center June 2009
- Beijing, China
- The Annual National Special Education and Therapy Conference August 2009 Xining
- Orphanage Qinghai, China
- Twice a month training for Jian Hua and Qing Xian therapy center therapists Qing Xian,
- China February 2008- present

#### **CONTINUING EDUCATION**

- Evaluation and Treatment of Children with Cerebral Palsy April 2009 Qing Xian, China
- Cerebral Palsy Seminar December 2008 Zhu Hai, China
- Facilitation with Neurodevelopmental Treatment October 2007 Maryland (MD), USA
- Pediatric Vestibular Rehabilitation July 2007 Georgia, USA
- Treating Gait Dysfunction in Children with Cerebral Palsy March 2007 MD, USA
- Taping to Improve Alignment, Strength, and Function in Children July 2006 MD, USA
- Dynamic Bracing Workshop April 2006 North Carolina (NC), USA
- Neurodevelopmental Treatment Handling February 2005 NC, USA
- How to Jump Start Learning for Children with Sensory Dysfunction July 2004 NC, USA
- Clinical Instructor Credentialing Program April 2004 NC, USA
- Introduction to Neurodevelopmental Treatment February 2004 Ohio, USA
- Fall Risk Assessment and Conditioning Program September 2002 NC, USA

#### LICENSES AND CERTIFICATION

- 1. North Carolina Physical Therapy License
- 2. Manual Therapy Certification The University of St. Augustine for Health Sciences

#### SPECIAL NEEDS VOLUNTEER ACTIVITIES

Special Olympics Volunteer Spring games Shelby, NC 2002-2005

## **RESUME- XU BING**

### **Personal Details:**

Name Xu Bing Date of Birth: 7th December 1975

NationalityChineseSex:FemaleMarital StatusMarriedChildren:None

**Profession:** Linguistics, Teaching and Project Management

### **Contact Details:**

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### **Education and Qualifications:**

Dates		Educational Institution	Qualification
From	To		
2002	2004	Sheffield University, Sheffield City, UK	Masters in Applied Linguistics (MA)
1997	2000	Zhengzhou University, Zhengzhou City, Henan Province, PR China	Bachelors in English (BA)
1993	1995	Zhengzhou Normal College, Zhengzhou City, Henan Province, PR China.	Major in English

## **Career Summary:**

Career	Sullill	nary:			
Dates		Company /	Position and Responsibilities		
From	To	Organization			
Oct 2008	to date	Gift Special Needs Children's Parents' Club project, Zhengzhou	<ul> <li>Project Manager:</li> <li>Establishing and developing relationships with parents, related government departments, relevant resources, etc;</li> <li>Organizing various kinds of activities for parents and children;</li> <li>Building up a team and motivating team members to work efficiently;</li> <li>Administration and management, such as writing project proposals, reporting, making budgets and setting out aims and objectives;</li> <li>Interpreting for foreign specialists on conferences, training and workshops, and;</li> <li>Publicity through media and different channels.</li> </ul>		

May 2010	to date	Zhengzhou University of Light Industry, Zhengzhou City, Henan Province, PR China	English Lecturer: Teaching English to undergraduates
June 2009		Seven Colored Flower Welfare Kindergarten / World Bank, Zhengzhou City, Henan Province, PR China	Internal Evaluator: Final Evaluation of the Seven-Colored Flower Welfare Kindergarten, a project funded by the World Bank.
April 2005	Aug 2007	Friends of China, Representative Office, Zhengzhou City, Henan Province, PR China	Office Manager & Assistant Chief Representative Office manager and chief representative for the representative office of Friends of China Foundation Ltd., responsibilities of which also included assisting in the development and management of special needs projects funded by FOC.
2004	2009	Friends of China, Representative Office, Zhengzhou City, Henan Province, PR China	<b>Volunteer:</b> Volunteer work supporting severely handicapped orphans and helping in the process of adoption.
July 1996	<b>July 2002</b>	Zhengzhou No.57 Secondary School	English Teacher: Teaching English to secondary school children
July 1995	July 1996	Zhengzhou No.44 Secondary School	English Teacher: Teaching English to secondary school children

### **Professional Profile:**

I am quick to grasp new ideas and concepts, as well as developing innovative and creative strategies. I am highly motivated and am always seeking to to improve my professional competence. Moreover, I am capable at leading and motivating teams, so that they can work more efficiently towards fulfilling their goals. Even under significant pressure, I have proved to possess a strong ability to perform effectively.

Family Name: WALMSLEY First Names: MICHAEL JOHN

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1 son

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#### **EDUCATION**

Dates		Subject	Institution	Qualification
From:	То:			
Feb 09	1 month	Teaching English as a Second Language	Trinity College London, course done through International Training Network. P.O. Box 6335, Christchurch, Dorset, BH23 9BN	Trinity College TESOL Certificate
Sept 2002	July 2005	Chinese Mandarin	New Century Language School, Zi Jin Shang Lu, He Xi Qu, Tianjin. PR China	Certified as Advanced Speaker
May 1999	Aug 1999	Nepali Language & Cultural Studies	Language & Orientation Program c/o UMN, PO Box 126, Kathmandu, Nepal.	Medium / High Pass
Oct 1998	April 1999	Community Development & Cross Cultural Studies	Selly Oak Colleges Crowther Hall, Selly Oak, Birmingham. United Kingdom	Certificate Pass
March 1998		Engineering in Emergencies	Register of Engineers in Disaster Relief (RedR 1-7, Gt. George Street, London. SW1P 3AA	) Certificate Pass
Oct 1992	Oct 1993	Water Resources Technology & Management	University of Birmingham, School of Civil Engineering, Edgbaston, Birmingham. United Kingdom.	Masters Degree (MSc Eng)
Oct 1988	July 1991	Civil Engineering	University of Birmingham, School of Civil Engineering, Edgbaston, Birmingham. United Kingdom.	Bachelors Degree II (i) (B.Eng)
Sep 1986	July 1988	Advanced Level Certificates	Chesham High School, White Hill, Chesham, Bucks. United Kingdom.	3 "A" Levels
Sep 1982	July 1986	Ordinary Level Certificates	Chesham High School, White Hill, Chesham, Bucks. United Kingdom.	7 "O" Levels

#### **LANGUAGES SPOKEN**

LANGUAGES OF OREN			
Language	Competency		
English	Mother Tongue		
Italian	Spoken (good), Written (very good), Understanding (very good), Reading (very good)		
Chinese Mandarin	Spoken (Good), Written (Good), Understanding (Good), Reading (Good)		
Nepali	Spoken (fair), Written (fair), Understanding (good), Reading (fair)		

### **WORK EXPERIENCE**

Dates		Organization	Position	Responsibilities
From	То			
June 2007	To date	Ming Chuan Educational Consultancy, 12-5-301, Zhuo Da Me Gui Yuan, Hua An Xi Lu, Qiao Xi Qu, Shi Jia Zhuang City, PR China www.mingchuanconsultancy.com		Overall management of Ming Chuan Educational Consultancy Ltd (a wholly foreign owned enterprise located in the city of Shi Jia Zhuang, China), development of the overall business, facilitator for business and project management training seminars and evaluation of overseas funded development projects.
Sept 2005	June 2007 Oct 07 July 2006	Jian Hua Foundation 9/F, Mongkok Harbour Centre, 638, Shanghai Street, Kowloon, Hong Kong. PR China.	Projects Coordinator PAMEC Member Associate Care Working Group Member	Part of Tianjin Leadership Team; mainly responsible for coordinating a community development project in Qing Xian, Hebei Province.  Member of JHF's Project Approval, Monitoring and Evaluation Committee; directly responsible for 4 JHF projects.  Member of JHF's associate care working group: responsible for various aspects of expatriate member care in Tianjin.
May 2	007	Personal	Team Leader	Organize part of the British Trampoline National Squad to take part in a joint training camp with China's Number 2 team in Tianjin, PR China.
May 2	007	Xincon Consultants, Kunming, Yunnan, China	Evaluation Team Leader	Heading up a team for the evaluation of the Zhao Tong Community Development Program, in Zhao Yang Prefecture, Yunnan, China.
March	2007	Xincon Consultants, Kunming, Yunnan, China	Evaluation Team Leader	Heading up a team for the evaluation of the Yuan Yang Environmental Development Program, in Yuan Yang Prefecture, Yunnan, China.
November 2006		Evergreen Family Friendship Services, Kairos Agricultural Development Program, Yangqu, Shanxi, China	Evaluation Team Leader	
Februa	ary 2006	Xincon Consultants, Kunming, Yunnan, China	Evaluation Team Leader	Heading up a team for the evaluation of the Liang Shan Health & Development Project, in Liang Shan Prefecture, Si Chuan, China.
Sept 2002	Aug 2005	Jian Hua Foundation 9/F, Mongkok Harbour Centre, 638, Shanghai Street, Kowloon, Hong Kong. PR China.	Associate Consultant	Studying Chinese: Based in Tianjin. Good Language Acquisition  Advising on community development projects and project quality control.
Oct 2001	1 mth	World Concern c/o Forest Dept of TAR, Ling Guo Bei Lu 25, Lhasa Tibet, PR China.	Consultant Engineer / Trainer	Short-term assignment (1 month): Consultant for Water Supply Projects and Trainer for Technicians working for the Qomolongma Nature Preserve. Rural water supply design and construction.
Aug 2001	Aug 2002#	Okhaldhunga Hospital c/o UMN PO Box 126, Kathmandu, Nepal.	Resident Engineer	Survey & Physical Mapping of Hospital, Assessment, Design and Construction supervision of hospital water supply system improvements. # Intermittent; 7 months in UK on leave
July 2001	Aug 2001	Council for Technical & Educational Vocational Training c/o UMN PO Box 126, Kathmandu, Nepal.	Advisory Engineer	Production of a teaching manual on the subject of Water Supply for Rural Communities
April 2001	1 mth	World Concern c/o Forest Dept of TAR, Ling Guo Bei Lu 25, Lhasa Tibet, PR China.	Consultant Engineer / Trainer	Short-term assignment (1 month): Consultant for Water Supply Projects and Trainer for Technicians working for the Qomolongma Nature Preserve. Rural water supply design and construction.

1999	Mar 2001	Program & Karnali Technical School. c/o UMN PO Box 126, Kathmandu, Nepal.	· ·	Teaching at the technical school to technician level students in the subjects of water supply and sanitation and general construction.  Advisor for Community Development Program with respect to water supply and sanitation projects (& other construction projects) for 16 villages in the Karnali District of Nepal (Jumla).
Mar 1998	Aug 1998	,	Construction Worker	General construction work for local builders
Jan 1997	Jan 1998		Assistant Engineer	Design and construction of sewage and sewage sludge treatment works, both in preliminary and final design phases: Motney Hill Sewage Treatment Works (Southern Water) Millbrook Sewage Treatment Works (Southern Water) Camberley Sewage Treatment Works (Thames Water) Almond Valley & Seafield Tender Design (East of Scotland Water)
Oct 1995	Jan 1997		Resident Engineer	Survey and Physical Mapping of Hospital. Design Proposals, Funding Applications, Final Design & Drawings and Construction Supervision for a water supply & sanitation project. Design & Construction of Workshop.
Oct 1993	July 1995	Montgomery Watson Ltd Terriers House, 201 Amersham Road, High Wycombe. Bucks. HP13 5AJ. United Kingdom	Graduate Engineer	Preliminary Engineering Design for 4 sewage sludge treatment works (Strathclyde Sewerage) Assessment of Sludge Dryers for use in Strathclyde Sewage Sludge Disposal Scheme. Ormesby Water Treatment Works: hydraulic design for new filters.
Aug 1993		United Kingdom	Post Graduate Researcher	Research into the enzymatic hydrolysis of cellulose acetate at low pH, using anaerobic, mesophilic digestion.
Oct 1991	Dec 1991	, ,	Graduate Engineer	Process design of biological & chemical wastewater treatment plants.  Translator for Italian / English operating manuals.

### <u>Interests</u>

Sport:	Cycling & Touring: Cycled over Alps and Appenines and toured in other countries.		
	Trampolining: Used to Compete for University, Club Captain for 2 years, Advanced Coaching. Also		
	coached in Tianjin, China.		
	Gymnastics: used to compete when younger and more at University. Club Captain for 2 years at		
	University.		
	Karate: purple belt.		
	Running & Weight Training.		
Music:	Play Guitar and Piano. Like classical and contemporary music.		
Reading:	A wide variety of material.		
Other:	Cooking, eating and a nice glass of Barolo.		

# **APPENDIX II: INTRODUCTION TO CEREBRAL PALSY**

#### 1. Introduction to Cerebral Palsy <sup>1</sup>

Cerebral Palsy(CP) is a non progressive condition that results from damage to the immature brain leading to posture and movement dysfunction. Cerebral describes the two halves of the brain. Palsy describes any disorder that impairs control of body movement. In Cerebral Palsy the areas of the brain affected are those associated with the motor systems, resulting in impairments in movement control. These impairments are caused not by muscle or nerve problems but by damage or faulty development of the motor areas of the brain disrupting the brain's control of movement and posture leading to poor coordination, poor balance, and abnormal movement patterns. Cerebral palsy is caused by damage to the brain, which normally occurs before, during or soon after birth. Known possible causes of cerebral palsy include:

- Infection in early pregnancy;
- A difficult or premature birth;
- Bleeding in the baby's brain, and;
- Abnormal brain development in the baby.

Although cerebral palsy appears to involve the muscles, it is caused by damage to the part of the brain that controls these muscles, called the cerebrum. The cerebrum is also responsible for other important brain functions, such as communication skills, memory and the ability to learn. This is why some children with cerebral palsy also have learning and communication difficulties. Damage to the cerebrum can also cause problems with vision and hearing.

In the past, doctors believed that the **damage to the brain** occurred during birth as a result of the baby being temporarily deprived of oxygen (asphyxia). Asphyxia can sometimes occur during a difficult or complicated birth. However, a major research project carried out in the 1980s showed that asphyxia was only responsible for an estimated 5-10% of cases of cerebral palsy. Most cases occurred as a result of damage to the brain that happened before the child was born. The adult brain is fairly adaptable and can recover from quite serious damage. But the brains of children, especially during the first six months of development, are particularly vulnerable. Any damage that occurs during this time can have serious and lifelong consequences. Researchers believe there are three ways the brain can be damaged before birth:

- i) Periventricular Leukomalacia (PVL), which is damage of the white matter of the brain, and can be caused by:
  - an infection caught by the mother, such as rubella (German measles);
  - the mother having abnormally low blood pressure;
  - premature birth, especially if a child is born at six months of age or earlier, and;
  - the mother using cocaine during her pregnancy.
- ii) Abnormal Development of the Brain, which could be caused by:
  - mutations (alterations) in the genes that help the brain to develop;
  - infection such as herpes, toxoplasmosis (an infection caused by a parasite) and cytomegalovirus (a herpes-type virus that most people have immunity to), and;
  - trauma or injury to the unborn baby's head.
- iii) Intracranial Haemorrhage, which is bleeding in the brain and can be dangerous because the brain can be deprived of blood, which can kill tissue and the blood itself can damage brain tissue. Intracranial haemorrhage normally occurs in unborn babies when they have a stroke. Strokes can be caused by:
  - pre-existing weaknesses or abnormalities in the baby's blood vessels
  - the mother having high blood pressure (hypertension)
  - an infection during pregnancy, particularly pelvic inflammatory disease

A few cases of cerebral palsy are caused by damage to the brain that occurs after birth. The damage normally occurs during the first few months of a baby's life, before the brain develops its ability to withstand and adapt to a moderate degree of damage. Damage can be caused by an infection of the brain, such as meningitis, or as the result of a traumatic head injury.

The **symptoms** of cerebral palsy normally become apparent during the first three years of a child's life. They may be slower in achieving important developmental goals, such as learning to crawl, walk or speak. Children with cerebral palsy also tend to have problems with their muscle tone (the unconscious ability to contract or relax muscles as needed). The child may have:

- Hypertonia: increased muscle tone, which can make them appear stiff or rigid;
- Hypotonia: decreased muscle tone, which makes them appear floppy.

In some cases, the child may experience an early period of hypotonia for the first two or three months of their life, before progressing to hypertonia. Children with cerebral palsy also tend to favor one side of the body over the other, which can make their posture appear unusual. There are a **number of types of Cerebral Palsy:** 

- **Spastic Hemiplegia** where a child has little movement due to decreased range of motion, increased muscle tone, muscle co-contraction, and muscle tightness. The muscle stiffness (spasticity) on one side of their body can effect their hand, arm or leg on one side and give problems speaking. However, their intelligence should not be affected by the condition;
- **Spastic Diplegia** muscle stiffness in their legs, but also involves weakness and lack of muscle control leading to problems with balance and can impair ambulation. Communication skills and intelligence should be unaffected;
- Ataxic Cerebral Palsy where a child has poor grading of movement, intermittent muscle tone, inadequate postural control, and may have intention tremors. Generally, their balance and depth perception will be affected and they are therefore uncoordinated and have problems with activities that require precise movement. However, communication skills and intelligence should be unaffected;
- Athetoid or dyskinetic cerebral palsy where a child has quick jerky movements, abnormal involuntary movements of the limbs, poor postural control, and difficulty grading and timing movement; Generally, they have increased and decreased muscle tone, which results in the problems of maintaining posture, their speech is affected since they have difficulty controlling their tongue and vocal cords and they also have problems with eating and drooling. Intelligence is not normally affected;
- **Spastic quadriplegia** most severe type of cerebral palsy, caused by extensive damage to the brain, resulting in high degree of stiffness in all limbs and may be unable to walk. At the same time, the neck muscles will be very loose and they may have problems supporting their head. They will find speaking difficult, and may have moderate to severe learning difficulties. Frequent epileptic seizures are common in children living with spastic quadriplegia;
- **Hypotonic/Flaccid Cerebral Palsy** where a child has low muscle tone, poor head and trunk control, difficulty initiating movement, poor posture, and floppy movements, and;
- **Mixed Cerebral Palsy** where a child has a combination of two of the above types, most common being a combination of spastic and athetoid.

A child's degree of severity can vary and the degree of body involvement can also vary. A child's involvement can be divided into four categories: hemiplegia where one side is affected, diplegia where the lower body is affected, triplegia where three limbs are affected, and quadriplegia where all four limbs and trunk are affected.

#### 2. Approaches to Treating Cerebral Palsy <sup>1</sup>

Cerebral palsy is not a progressive condition. This means it will not get worse as the child gets older. However, it can put a great deal of strain on the body, which can cause problems in later life. There is no cure for cerebral palsy, but a range of treatments can help relieve symptoms and increase a child's sense of independence and self-esteem. In western nations, the treatment of cerebral palsy children will usually include a team made up of many different health professionals, namely:

- a pediatrician;
- a health visitor;
- a social worker;
- a physiotherapist, who improves a person's range of movement and coordination
- a speech and language therapist;
- an occupational therapist, who helps with the skills and abilities needed for daily activities, such as washing or dressing;
- an incontinence advisor, and;
- an educational psychologist, who specializes in helping people with learning difficulties.

An individual care plan would be drawn up to address any needs or problems that the child has. The plan is continually reassessed as the child gets older and their needs and situation change. The parents / relatives and the child would also be assigned a key worker, who would be the first point of contact with the various support services available. While the child is young, the key worker is likely to be a health visitor. As the child gets older and their needs become more complex, it is likely the key worker will be a social worker. In the UK and the USA, there is no single treatment plan for a child with cerebral palsy. Instead, there is a wide range of treatments, which are all designed to help the child achieve as much independence as possible. Some of these treatments are outlined below:

- Physiotherapy (PT) is the assessment and treatment of gross motor function, developmental tasks, body awareness, large muscle strength, flexibility, posture, mobility and ambulation, endurance, joint range of motion, motor planning, manipulation skills, balance, and coordination. Physiotherapy is normally started as soon as the child has been diagnosed with cerebral palsy. It is one of the most important ways of helping the child to manage their condition. The overall goal of physiotherapy is to help a child gain the most function and independence with his or her movement.
- Speech Therapy (ST) is the treatment of a delay in speech development including articulation, fluency, resonance or expression. Speech pathology services often include treatment for children with communication disorders and with feeding or swallowing dysfunctions. If their communication difficulties are severe, the therapist may be able to teach them an alternative method of communication, such as sign language. Special equipment to help the child communicate may also be available, such as a computer connected to a voice synthesizer.
- Occupational Therapy (OT) is the assessment and treatment of small muscle strength, body awareness, upper body range of motion, developmental milestones, fine motor and handwriting difficulties, flexibility, positioning for functional skills, such as doing homework or work for a job, self-care skills such as eating and dressing, sensory integration / sensory processing disorders, play skills, visual motor skills, visual perceptual skills, and splinting. In summary, occupational therapy is designed to improve the child's posture and to make the

- most of what mobility they already have. Occupational therapy can be extremely useful in boosting the child's self-esteem and independence, especially as they get older.
- Medicines: If the child's muscles are particularly stiff and overactive, it can cause them
  frustration and pain. If the child experiences these problems, they may require medication to
  help relax their muscles.
- Treating feeding and drooling problems: Children who have problems controlling their mouth will often have problems swallowing food, as well as difficulty controlling their production of saliva. Both of these problems can be potentially serious and require treatment. If the child has problems swallowing their food (dysphagia), there is a risk that small pieces of food could enter their breathing tubes and lungs. This can damage the lungs and trigger an infection (pneumonia).
- Orthopaedic surgery: Orthopaedic surgery is designed to correct problems with bones and joints. It may be recommended if the child's cerebral palsy is causing them pain when they walk or move around. It can also improve their posture and mobility skills, which may improve their confidence and self-esteem. During surgery, the surgeon will lengthen any muscles and tendons that are too short and are causing problems. Surgical procedures are normally staggered over your child's life, taking into account their likely physical development. The recovery time from this type of surgery is relatively quick. Most children will have fully recovered a week after each surgical procedure.
- Selective dorsal rhizotomy (SDR): Selective dorsal rhizotomy (SDR) is a surgical procedure that is normally only recommended when other treatments for muscle stiffness and overactivity have been tried and failed. During the operation, the surgeon will locate the nerves in the spinal column that are causing the muscle stiffness and remove them. Children who have surgery will require extensive physiotherapy, lasting three to nine months, to 'relearn' basic motor skills such as walking. This type of surgery has caused complications in some children. Indeed, in the past, a lot of this type of surgery was performed in the US, but because of the complications that is no longer the case. This type of surgery is frequently done in China, but should not be considered to be the best form of treatment.

### 3. Complications of Cerebral Palsy <sup>1</sup>

Before the 1950s, it was rare for children with cerebral palsy to survive into adulthood. Because of advances in treatment, this is no longer the case. However, during the transition into adulthood, children with cerebral palsy may experience complications, some of which are outlined below:

- **Post-impairment syndrome:** Most adults with cerebral palsy experience post-impairment syndrome. This condition is the result of a combination of factors caused by the stresses that cerebral palsy places on the body, including fatigue (people with cerebral palsy use five times as much energy to walk or move about than able-bodied people), muscle weakness, pain, arthritis (caused by the increased pressure that the condition puts on the bones and joints) and repetitive strain injury. Further physiotherapy and equipment that can assist walking, such as a wheelchair or walking frame, may help relieve some of these symptoms;
- **Body organ problems:** Most adults with cerebral palsy will experience premature ageing of their body organ systems (such as heart, veins and arteries) by the time they reach 40. This is partly because of the strain that the condition puts on the body.
- **Depression:** The daily challenges of living with a chronic condition such as cerebral palsy can cause stress and anxiety, which in turn can trigger conditions such as depression. Cognitive behavioural therapy (CBT) has been shown to be effective in helping people fight

their depression and cope better with their condition. Cognitive behavioural therapy is based on the principle that the way we feel is partly dependent on the way we think about things. People who trained themselves to react differently to their condition, using relaxation techniques and maintaining a positive attitude, reported that their levels of pain, stress and depression went down. Making contact with other people living with cerebral palsy may help.

Reference: 1. Information taken from the United Kingdom National Health Service Website on Cerebral Palsy and additional input from Evaluation Team member and physio therapist, Elizabeth Griswold.

### **APPENDIX III: INTRODUCTION TO CONDUCTIVE EDUCATION**

**Conductive Education**, is an educational system that has been specifically developed for children and adults who have motor disorders of neurological origin such as cerebral palsy. It is based on the premise that a person who has a motor disorder may not only have a medical condition requiring treatment, but may often have a major problem in learning that requires special education. The key principles of conductive education are as follows:

- **i.** The child is a Unified Whole: Practitioners of conductive education prefer a treatment that considers the individual as a unified whole and provides an overall, holistic intervention. Holistic means that everything in life, the total functioning of the individual, personal development and social organization, is seen as interdependent, interconnected, multi-leveled, interacting and cohesive;
- **ii.** Targets the Whole Personality: Conductive education attempts to build up the impaired children's personalities gradually in a manner appropriate to their age and therefore the CP child is an active participant in the learning process. CE is conceived of as a partnership between educator and learners to create circumstances for learning- it is an all day learning process;
- **iii. Activity and Intention:** Restoring the interrupted learning process is not possible without the active participation of the individual, and that consequently passive exercises or patterns cannot change or improve the functional stage of the individual.
- **iv. Continuity and consistency:** Continuity is considered necessary to reinforce a new skill. An opportunity to use the same skill for many different tasks is also considered essential. The system has to provide possibilities for children to practice emerging skills not only in specific learning situations but in the many inter-connecting, in-between situations of which life consists;
- v. Inter-Disciplinary: The group of professionals who are responsible for the program should have training based on the same philosophy and relevant practice. Instead of a multidisciplinary approach, there is an interdisciplinary model where a single specially trained group of professionals are responsible for the planning and implementation of the whole process.

The Conductive Education system consists of many interrelated facets. While the elements of this system can be identified and analyzed, these elements cannot be used separately from each other. Conductive educators believe that conductive education works only as a unified system, not as a composite or amalgamation. Conductive Education as a system has six significant components:

The Group;

The Facilitation;

The Daily Routine;

The Rhythmic Intention;

The Task Series, and;

The Conductor.

Conductive education has been assessed in only a few controlled studies which have focussed mainly on progress in motor skills, and the method has been compared to traditional physiotherapy. These studies have failed to demonstrate the superiority of conductive education. There has been no scientific examination of long-term success or cost effectiveness. A review that included less well-designed studies concluded that the research literature did not provide conclusive evidence either in support of or against conductive education, and that the limited number of studies and their poor quality made purely evidence-based decision-making about conductive education impossible.