

# **Sichuan Community Based Rehabilitation Project for Children with Cerebral Palsy: Mid-Term Evaluation**

## **Overview of Report:**

This report is divided into nine major sections. These sections are: Overview, Summary, Background, Purposes, Methodology, Findings, Recommendations for Future, Concluding Comments, Conclusions and Recommendations, and Appendixes. The summary section provides a quick glance at the background, conclusions, and recommendations of the evaluation. The background section is divided into two sections: an Overview of The Project Proposal and a Current Project Background. The Overview of The Project Proposal provides information regarding the background and structure of The Project as initially proposed. The Current Project Background provides background information of the project as it is currently. The other sections provide more detail and specifics of the evaluation process, findings, and recommendations. The “Findings” and “Recommendations for Future” sections address the specific questions contained in the “Terms of Reference.”

## **Summary:**

### *Background:*

The Sichuan Community Based Rehabilitation Project for Children with Cerebral Palsy (The Project) was evaluated by a panel of three experts to determine the strengths and weaknesses of the project at the midpoint of a five year joint venture with the Norwegian Missionary Alliance (NMA)/Xincon AS and Sichuan Disabled Persons Federation (DPF). The team was composed of Christopher A. Zaino, PT, PhD (Team coordinator); Cindy Pearson, MA.Ed; and Jian An Li, MD (The Team). The Team had expertise in rehabilitation, special education and experience with the rehabilitation and education situation in China. Visits were made to 13 of the 16 rehabilitation centers and rehabilitation stations; resource partners (Chengdu No. 1 People’s Hospital and Holy Love special school); and interviews conducted with rehabilitation personnel, teaching personnel, management personnel at the provincial and local levels of the DPF and parent interviews.

The specific conclusions and recommendations are elaborated in the body of the report. However, in brief, the conclusion and recommendations for The Project are:

### *Conclusions:*

- ✧ The Project is a good start at meeting the needs of children with cerebral palsy (CP) in Sichuan
- ✧ The Project has started the training of the rehabilitation personnel, but has lacked a clear structure and plan for the rehabilitation training that has resulted in needs for more specific training in a variety of rehabilitation skills.
- ✧ There is a lack of rehabilitation evaluations by the rehabilitation staff. The evaluations are done in hospitals and done from a medical model point of view as compared to a community rehabilitation point of view.
- ✧ There has been the development of some liaisons between the DPF and local schools such that approximately 35 children are receiving some education.

- ✧ The ability of the rehabilitation personnel to address the educational needs of the children with cerebral palsy needs further development.
- ✧ The development of cognitive training is stronger in Chengdu, possibly due to a stronger information connection with the Holy Love School located in Chengdu.
- ✧ Some of the staff are affiliated with the community health centers and have divided loyalties between The Project and the Health Department that hired them.
- ✧ Nearly all of the personnel in Panzhihua were part-time employees with The Project and part-time with the Health department. This did not allow them to focus on the development of the rehabilitation skills needed to guide the children and parents in community rehabilitation.
- ✧ Awareness of cerebral palsy media campaigns have been used and have impacted on the awareness of the local community citizens.
- ✧ The parent handbooks look relatively detailed, but may be too complex for most parents to fully be comfortable with. Therefore, many parents have not really utilized the parent handbook well.

*Recommendations:*

- ✧ Increase Expert support for rehabilitation
- ✧ Continue to develop a systematic training approach that will strengthen the rehabilitation personnel's skills in fundamental and key areas.
- ✧ Develop and train in the use of a community based rehabilitation evaluation process.
- ✧ Target key personnel for further training to allow them to become stronger in the rehabilitation skills necessary. Allow these personnel to be more involved in supporting the other rehabilitation personnel.
- ✧ Encourage some personnel to become specialized in physical therapy/occupational therapy, speech therapy, or special education.
- ✧ Continue to develop the relationship between Holy Love and The Project.
- ✧ With Holy Love, develop a training plan for the development of educational specialists over the next 2.5 years.

**Background:**

*Overview of The Project Proposal:*

The Sichuan Community Based Rehabilitation Project for Children with Cerebral Palsy is a five-year joint project with NMA and the DPF of Sichuan, China. Following a preliminary inquiry in spring 2003, it was decided that NMA and China DPF would jointly apply for support to an urban rehabilitation project in Sichuan Province. Xincon AS of Kunming, Yunnan China manages The Project since NMA does not have a representative office in China. This Project is designed to improve the access of children with cerebral palsy to rehabilitation and education using a community rehabilitation/education format. The Project selected two locations in Sichuan – Chengdu and Panzhihua. The DPF in these two cities have former experience with rehabilitation of children with CP and had done thorough preparatory work that showed that there is a great need for a program that can address the needs of these children and their parents. The DPF in both of these cities have worked with the managing of the local aspects of The Project.

### Chengdu:

Chengdu is the province capital of Sichuan and is a central city of southwest China. The city has a long history and is rich on culture. Chengdu city is divided in to 7 districts, and administers 4 municipalities and 8 counties. Totally this area consists of 12,300 square meters. With its 11 million inhabitants Chengdu is one of Chinas largest cities.

Chengdu is an industry and merchant city with 1,300 large industrial enterprises and at least 200,000 wholesale dealers. Also large farming areas give a large contribution to Chengdu's total income.

In Chengdu city, local district centers are being build with the purpose is to provide integrated services for the local community. These centers have medical clinics, maternal and child health centers, libraries, meeting rooms, computer and training sites, job centers, and other community support services. The centers are often located near an existing or new park. It was planned to use these community centers as a basis for the community rehabilitation centers.

### Panzhihua:

Panzhihua, the city furthest south in Sichuan province, is located close to Yunnan province in a mountainous region at the foot of the Tibet plateau. The city is mineral rich and has a strong iron and steel industry. Panzhihua also has the Ertan Hydroelectric Power station (the largest hydroelectric power plant in China). In addition to the steel and hydroelectric industries, Panzhihua also has an all year around warm climate good for fruit and vegetable farming.

The city administration is divided into five districts, East District, West District, Renhe District, Miyi County and Yanbian County. Totally there are 1.11 million people living in Panzhihua. Out of the total population 620,000 lives in the city. 90% of the population in Panzhihua comes from other places in China. Roughly 140,000 are of minority group whose origin is Panzhihua area.

The DPF has a close and good relationship with the city's health officials. Primary health services have recently been reorganized to provide a community clinic in each neighborhood. The clinics provide medical service, simple forms of training, rehabilitation, and medicine sales. There are also a few beds for patients that need medical observation. The plan was to use these community clinics and DPF's own offices as a base for the community rehabilitation center personnel and center locations.

### Focuses of The Project:

1. To meet a service need for children with physical and mental disabilities.
  - a) Previously there were minimal to no services available for these children's needs
2. To support and focus on the equal rights of all people by focusing on the rights of children with disabilities.
  - a) As members of society
  - b) To an education
  - c) Against being discriminated against
3. To provide more timely and comprehensive information regarding the condition of CP to the parents and families of children with CP.
4. To provide opportunities for parents to network together to allow them to support each other.

5. To develop improved competence in rehabilitation personnel to address the needs of these children with CP

#### Financial Sources:

The financial resources were to come from three sources. These were NMA, Local governmental authorities, and those receiving services. The plan was for NMA to take the largest financial burden and the families receiving services to take the smallest financial burden initially.

#### Goals:

The main goal of The Project is for it to become a model for all of China to emulate. An important step in achieving the goals listed below is when rehabilitation and education is provided for these children with CP.

The primary, overriding goals are:

1. Promote the awareness of the current status and needs of children with CP
2. Promote the rights and opportunities of persons with disabilities as outlined in the UN's Standard Rules of the Equalization of Opportunities for Person's with Disabilities

The Project goals and secondary goals are:

1. To provide appropriate rehabilitation and education programs for children with CP in a manner that will allow these programs to be self-supporting and self-sufficient in the future.
2. To improve the overall competence of the rehabilitation and education of children with CP.
3. To empower the parents of children with disabilities to become organized in an appropriate manner in order to obtain the necessary support from the authorities and support systems for their children with disabilities.
4. To develop the hospital and rehabilitation personnel skills related to physical rehabilitation of children with CP.
5. To develop and distribute informational material for parents and the community to promote the awareness of CP

#### Initial Project Strategies:

- ✧ Establish two service and information centers, one in each target city.
- ✧ Recruit and train 16 rehabilitation staff members.
- ✧ To utilize Holy Love Special Education School in Chengdu as project consultants.
- ✧ To develop training videos and other resources.
- ✧ Establish community rehabilitation centers in conjunction with the already existing district community health centers.
- ✧ Conduct training in basic rehabilitation and pedagogic methods to support rehabilitation and education of the children with disabilities.
- ✧ Offer appropriate rehabilitation and education programs for children with CP.
- ✧ Offer appropriate parent training for parents of children with CP.
- ✧ Equip the community rehabilitation centers with appropriate equipment – rehabilitation and educational.

- ✧ Arrange provincial level conferences and seminars open to participants from 21 cities and districts.

### Roles of Project Partners

The project shall mainly be administrated and implemented by the provincial DPF. They will coordinate the work together with their local DPF branches in Chengdu and Panzhihua. NMA will arrange and recruit expertise from different special fields during the project cycle. The representative from NMA will also be a member of the control group for the project established at the project start. The control group met once quarterly initially to ensure that project developed according to the plans and budget guidelines. NMA also contributes to the project's application, budgeting and communications process with the partner in Norway.

### *Current Project Background:*

The rehabilitation staff of the community rehabilitation centers are mainly graduates from the Health Department schools. This is a two-year vocational degree at the level of high school. There are also others that have graduated with medical backgrounds. However, many are new graduates that have not taken the examinations to qualify for practice of medicine.

The training for the rehabilitation staff consists of three months of training with the Chengdu No. 1 People's Hospital, training in special education with Holy Love or other educational specialists, some with six month training at China Rehabilitation Research Center in Beijing, and/or on the job training. The manual for the three month training discusses: the theory of rehabilitation for children, Differential diagnosis of children with CP, Evaluation of children with CP, Rehabilitation of children with CP – overall theory, Occupational therapy of children with CP, speech therapy; movement therapy – motor function training, early intervention for children at high risk, cognitive training, caregiving within the home for children with CP, individual educational plan (IEP) for children with CP, setting goals and implementing speech therapy for children with CP, setting goals and implementation of activities of daily living (ADLs) training of for children with CP, and use of functional training for children with CP.

Additionally, there are regular (about once a month) experience exchanges that allow the staff to share their work experiences, what they have learned, and the challenges that they face. These are useful in developing the staff skills in rehabilitation.

### **Purpose:**

The purpose of this evaluation is to assist those involved in the operation/management of The Project in improving the services provided by The Project so that children with CP can be positively affected through the rehabilitation provision. This was done by determining the strengths and weaknesses of The Project and then to make recommendations that will allow The Project to become an even stronger model of community rehabilitation within Sichuan and China as a whole. The intended audience of this report is Xincon AS staff so that they can encourage the continued development of The Project; NMA so that they can see how their support of the project has led to positive outcomes and continues to impact the children with CP; DPF of Sichuan, Chengdu, and Panzhihua so that they can continue to develop a successful rehabilitation program for children with CP; and the rehabilitation personnel (indirectly) so that they can

understand the strengths and weaknesses of their interactions with the children with CP and the families of these children.

The specific objectives covered in this evaluation are outlined in the Terms of Reference (see appendix). The main objectives are related to determining the relevance of The Project, the design of The Project, the management of The Project (from rehabilitation and training points of view), the accomplishments of The Project, the efficiency and effectiveness of The Project, the sustainability of The Project, and to provide reasonable recommendations that will allow The Project to meet its goals.

Since the expertise of the team was in rehabilitation and special education, this team did not address the aspects of management, budget, and accounting. There have been audits of the accounting that apparently have not discovered any inappropriate accounting practices. Please refer to these for evaluation of the accounting procedures. After discussion with Birgitte Gilje Eikrem of Xincon AS, it was determined that if the management process needs further evaluation, that this could be done separately since the previous audits did not seem to identify any inappropriate accounting practices. However, management from a rehabilitation point of view will be discussed.

### **Methodology:**

The evaluation of the project was done via:

- ✧ Discussions/presentations by DPF at all levels,
- ✧ Visits to the rehabilitation centers and stations,
- ✧ Interviews with family members and rehabilitation staff,
- ✧ Observation and questions and answer interactions with the rehabilitation staff as they worked with children with CP
  - Although not a goal of the evaluation, The Team did provide instruction to the rehabilitation personnel to assist them in correct rehabilitation practice following the question and answers evaluation of their current skills
- ✧ Visits to the resource partner sites (Chengdu No. 1 People's Hospital and Holy Love special school)
- ✧ Random chart reviews and paper work evaluations

### ***Findings:***

This section is based directly on the objectives of the Terms of Reference document. The subheadings (*italics*) and questions (underlined) are from that document.

### ***Relevance:***

This section will address the questions: 1.) Does The Project meet actual needs? and 2.) Are the needs of children with CP and their families being met? In summary, The Project is meeting a great need in China as a whole and specifically in Sichuan. If the focus is shifted to a true community rehabilitation approach, the needs of the children and their families will be better met.

### Does The Project meet actual needs?

The Project is very relevant. The needs are well documented in the “Project Document 2004-2008, BN: 0463.” The Team is in agreement with the statements made in that document related to the under service of children with disabilities in general and of children with CP in specific. The need for the education of these children with disabilities is a great need all over China. With the “2015” educational initiative from the Chinese government, the needs of all children to be educated are being promoted.

Additionally, the rehabilitation needs of these children are also great. There are some hospital based rehabilitation programs available in China and Sichuan; however, these are using a model that takes the children out of their naturally occurring home and school environments to work on skills in an intensive rehabilitation approach.

It is known that community based rehabilitation is the model that is being promoted world wide due to the benefits of working with a child in his naturally occurring environments. Community based rehabilitation is when the child is treated in his own community (minimizes travel) and rehabilitation interventions are often done in the home or school environment. Community based rehabilitation also focuses on training the family. Teaching the family how to work with the child on goals that are of concern to the family and child allows for the quickest development of important daily living skills. This occurs due to the increased opportunities to practice the tasks during the entire day. This is a focus of The Project, but has not been carried out well. This is probably related to the association of the rehabilitation staff and some rehabilitation stations with community health departments or hospitals.

The use of small groups also promotes the improved learning of motor skills and encourages cognitive development. When a child is in a small group, they learn the motor tasks by observing the other children in the group. They learn quicker from observing a peer model of movement as compared to an adult model. An additional benefit of small groups is that it is more cost effective for the center and the family. The center could generate more revenue using a small group format and the financial burden on the family is also reduced.

### Are the needs of children with CP and their families being met?

The children with CP and their families are receiving services that they did not before. Therefore, their needs are being addressed at least partially. This is an initial step in the longer process of developing fully functioning community rehabilitation and educational services. There is a continued need to develop the staff skills and to refine the approach to the service provisions. As these services are improved and refined, the needs of the children with CP and their families will be more fully met.

Unfortunately, The Project is not using a real community based approach to rehabilitation or a strong use of small groups. Also, the rehabilitation staff skills need further refinement and improvement. Recommendations for resolving these issues will be addressed in the Recommendations sections.

### *Project Design:*

This section will address the following questions: 1.) Are the service models based on the indigenous conditions of the two project cities? 2.) Is The Project adapted to local and national

government plans? and 3.) Is The Project adapted to social, economic and cultural contexts of the area?

In summary, the service model considers the local and national government plans and is adapted to the social, economic and cultural contexts of the areas. However, the training of the parents needs to be more functional based and family centered in the rehabilitation provision.

Are the services models based on the indigenous conditions of the two project cities?

The Project is run differently in the two cities. In general, The Project in Chengdu sees children five times a week for rehabilitation and home visits are done about one time a week. In Panzhihua, the children are being seen for rehabilitation one time a week and home visits made one time a week. The schedule of visits is adjusted as there is a need or in the parent's interest. The home visits for Panzhihua rehabilitation stations are a problem at times due to the large distances that need to be covered. This is partially due to the difficulty of obtaining and maintaining possession of appropriate rehabilitation station locations. Also, the travel in Panzhihua is not as convenient as is Chengdu. This is due to the mountainous terrain and lack of good roads to some locations.

The project is run using a very strong medical model of rehabilitation in both cities, but even more so in Chengdu. Actually, they are in essence duplicating the existing limited services that are available in Chengdu. Having children come for rehabilitation for five times a week is missing the strengths of the community based approach to develop the parents' training and to have the rehabilitation occur in the naturally occurring environment more. However, the parents' are being trained more than they would be in the hospital based rehabilitation in both cities. Additionally, Chengdu has some strong relationships with the local schools and many of the children are being educated in local regular education classes or special education classes. However, the daily rehabilitation services are competing slightly with the educational services that are being provided by others. To adjust for this, Chengdu does see many of these children later in the day – after they are dismissed from their classes.

One strong educational-rehabilitation model was at the Chengdu JinJiang special education center found in the He Ping elementary school. At this school, the principal was interested in meeting the educational needs of the children with disabilities. There is a rehabilitation station located in the special education center. Some of the children are in the special education classes and then are brought to the rehabilitation station for rehabilitation interventions. A better approach would be to support the teaching staff and the children's rehabilitation needs within the regular education classroom as much as is possible. This will promote the children's ability to access education by supporting the teaching staff with the needed techniques to support the children with disabilities' needs and addresses the physical impairments that are directly interfering with the educational opportunities.

Is The Project adapted to local and national government plans?

The projects are attempting to meet the local and national governmental plans of educating all children by 2015, but there needs to be more support of the educational aspect of The Project. The Project is also trying to interact with the Health Department by using some of their staff as rehabilitation workers and using space within the Community Health Department centers. However, these interactions are mainly in personnel use and provision of space for the



rehabilitation station use. The Project rehabilitation stations are fully independent of the Community Health Department Centers. Nevertheless, the work in Panzhihua appears to have more support and cooperation of the local governmental entities.

A fuller cooperation between these entities could be pursued such that the rehabilitation stations focus on community based rehabilitation and educational programs and allow the Community Health department Centers and hospitals to address the medical and intensive rehabilitation needs (for example: following surgery, making of orthosis, and the like). Also, the rehabilitation stations of The Project can work with educational programs to support the teaching staff in how to assist these children in being able to access the educational process. This could include adapting activities to fit the physical abilities of the child with CP and adapting the facilities to remove or minimize environmental barriers.

#### Is the project adapted to social, economic and cultural contexts of the area?

The Project is adapted to the social, economic and cultural contexts in at least three ways. First, The Project is using a more medical model of rehabilitation. This is partially due to the experiences of the resources supports from the Chengdu No. 1 People's Hospital and the use of the Community Health Department Centers' staff. But it is also due to the culture of rehabilitation happening at a center and not at the home. However, for reasons mentioned above, this model needs to be slowly modified to a true community based model of rehabilitation.

Second, The Project is considering the economic contexts of the families by providing free services. However, this ignores that many families – especially in Chengdu – can assist with the financial support of the rehabilitation stations. In order to fully implement a procedure that encourages appropriate payments for rehabilitation services there needs to be a clear policy for the determination of the financial strength of the families and then a sliding scale of payment as appropriate. This is not currently being used, but would allow the project to be more fully adapted to the economic context of the families. Additionally, the support of The Project to the families in the area of making their own equipment as needed (provision of plans and suggestions to the families) allows the family to meet the equipment needs within a cost effective manner.

Lastly, The Project is addressing the needs of children with CP within the cultural context of the area by promoting a general awareness of the CP condition in the communities. The Project has developed a parent training handbook and VCD's that address the general condition of CP and the rehabilitation needs of these children. There is also a broad use of different media to promote the needs of children with CP via printed, television, and public bulletin boards. Additional, The Project is encouraging parent networking. This combats the general situation of parents of children with disabilities being isolated. As the parents meet together, they can develop a sense of importance of themselves and their children with disabilities. Thus, this meets a cultural need of the target group in a culturally sensitive manner.

#### *Process and Management:*

This section addresses several questions related to the management of The Project. As discussed in the Purpose section of this report, the management of The Project from a purely managerial point of view is not addressed. We will be solely addressing the rehabilitation, educational, and training management here.

In summary, there are some good resource partners that add to The Project, however, the Holy Love Foundation is under utilized. The equipment needs are adequate, but there is a need for more toys. Xincon AS has been a good partner in the project, adding important managerial and other support to The Project. Lastly, there is a need to coordinate between governmental departments to improve the overall effectiveness of The Project.

Is The Project organized and administered in an efficient and effective manner at the different organizational levels?

In China, there are three departments that are all responsible for meeting the needs of children with disabilities. They are the Ministry of Civil Affairs, Health Department, and Disabled Persons Federation. For the most efficient provision of services for children with disabilities, these three departments need to coordinate activities. There is some interaction with the Department of Health, but this is not a real cooperation between the departments. In addition, Panzhihua does have a small leading group that is made up of persons from the DPF, the health Department and another department. This is a step towards more cooperation between departments. However, more interaction between departments would allow them to do what they do best and for The Project to do what it is designed to do. The Health department can be responsible for the surgical, medical, and orthotic services and The Project for community rehabilitation. Additionally, the Ministry of Civil Affairs – especially the Children Welfare Institutes – could interact with The Project in some ways. One important way is with the training. They can coordinate some joint training that can address the needs of all the staff in joint training. The training has sought some joint interaction in that some of the training is open to persons from 21 different cities. This is a good support for the work of rehabilitation in general.

What is the system for monitoring, coordination and communication between the different areas/organizational levels of The Project like?

The Project at the provincial and city levels all have a good organizational chart outlining the overall structure of the managerial organizations. The provincial level did make several visits (not told how many) to the local rehabilitation stations and local DPF offices. Both the cities report that there is good communication between the provincial and city levels.

What added value does Xincon AS bring to The Project in addition to the financial contribution?

The DPF at all levels commented on the support that was received from Xincon AS staff. This included the excellent managerial support from Mr. Wang in the areas of dealing with the details of the funding, budgeting, and good overall coordination. In addition, Xincon AS has attended yearly discussions of The Project and visits regularly, about every two months, to meet with the project office, hold workshops and trainings, and get updated on appropriate issues. They also visit the stations to meet with the children, parents and rehabilitation workers. Additionally, the Xincon AS staff has come to many community awareness functions that have been a great encouragement of The Project in general.

During this evaluation process, the Xincon AS staff were very helpful. They gave guidance to the process of the evaluation to allow the evaluation to achieve its goals without deterring the process. They were also useful in directing unneeded local personnel to other

physical locations in a way that was appropriate culturally and allowed us to meet the objectives of the particular visit. They supported us in all steps of the process and encouraged the team to discuss what was needed to allow efficient planning, and implementation of the evaluation. Most important, they assisted with the arrangements with the local DPF personnel so that what we could do what was needed and not let the DPF's proposed plans interfere with what was needed for the evaluation at that point in the evaluation. It was a real pleasure to work with the Xincon AS staff at all levels and they are providing a good support for The Project at many levels.

How does The Project deal with deviations between expected results and actual results? If deviation has been found, have the deviations been used as a basis for learning? How can the project increase the learning processes?

One of the areas of difficulty mentioned was the contradictions between the parents' expectations for rehabilitation and the actual rehabilitation results. Many parents want their child to walk. The parents are happy with what they have seen so far in rehabilitation, but they are not satisfied with the fact that their child is still not walking normally. The rehabilitation staff have discussed this with the parents and now parents have more confidence in The Project's rehabilitation services and continue to increase their participation with The Project.

Are the necessary resources available in The Project?

From a staffing and equipment point of view, the resources are adequate for the current needs. There are only 160 children being seen by 32 rehabilitation workers. Even though the staff in Chengdu is doing more treatment per week, they are also full time and there should be a gradual shift to more community based practice and less of a reliance on coming into the rehabilitation stations for so many times per week. Thus, from that point of view, the staffing is adequate.

The rehabilitation stations are equipped well in terms of general equipment. However, there are items that are not needed often – if at all. These include the slanted boards that fit between the parallel bars. The problem is that this is not a natural environment and training walking in that environment will not generalize to the normal walking environment outside the station. In addition, there is a hand function exercises that is very specific to finger strengthening. However, without proper training, it is unlikely that it will be used well. Additionally, this specific equipment would be necessary only in very special situations. It is understandable that this standard equipment would be purchased initially since the resource personnel were coming from a medical model and that the new staff did not have the experience to know what to buy.

Equipment that is lacking is just a variety of age level, cognitive level and physical ability appropriate toys. Work with children needs to be play oriented and requires the use of a variety of toys. Also some toys that encourage group activities can be purchased. This can be used in small group activities and individual therapy sessions. These toys are also important for cognitive development. Additionally, there is a need for some more assistive devices for walking. This can include walkers, canes and crutches.

There is a need for more written resources available to the rehabilitation workers, especially in the area of education. Many of the staff are interested in reading more books and articles about how to teach the children but the resources are not readily available.

Related to personnel, there is a need for some more expert personnel to oversee the running of the rehabilitation stations. This can include the use of local expert personnel. The availability of these personnel is greater in Chengdu with the local hospitals and the universities present. Some key personnel from Huaxi Medical College of Sichuan University were introduced to the DPF personnel when in Chengdu. The other possibility is to train a few personnel in each city to become specialized with one of the therapy or educational focuses to allow them to become an “expert” support person for The Project. This training will be discussed more in recommendations.

#### Assess the role of resource partners?

The resource partners are the Chengdu No. 1 People’s Hospital and Holy Love Foundation. Additionally, there has been educational support from the Chinese Rehabilitation Research Center (CRRC) for six-month internships in Beijing. These resource partners add to The Project. However, there are some concerns.

First of all, the Chengdu No. 1 People’s Hospital has a medical model focus and this affects their ability to train the community rehabilitation station staff. They are promoting a medical model of care and have not assisted The Project in developing a rehabilitation based evaluation. Currently all therapy evaluations in Chengdu are being done by the Chengdu No. 1 People’s Hospital and then the goals are being discussed with the family and rehabilitation station staff. This is not a truly family centered approach to rehabilitation. Panzhihua is also having the children evaluated by medical staff and then having the goals developed by those professionals.

There is a similar problem with CRRC training being done within the CRRC in Beijing. This is different from the situation at the rehabilitation stations. The current approach by the CRRC is to have the children come to Beijing for three months and provide intensive – full day – rehabilitation for the children. They do provide some parent training, but it is different from the idea of community rehabilitation. It is possible to gain experience and understanding of rehabilitation at the CRRC, but the rehabilitation at the rehabilitation stations will need to be adjusted to be community based. This would not be difficult if the community based approach to rehabilitation is fully understood by the rehabilitation staff, but currently it is not well understood.

The Holy Love Foundation is a strong resource partner. In Chengdu, where the information interaction between Holy Love and the rehabilitation station staff is stronger, the educational aspect of The Project is much stronger. In general, the approach of the Holy Love Foundation is appropriate for community-based rehabilitation. They have a strong special education experience that can greatly enhance the educational aspect of The Project. Possibly due to a lack of contact with the Holy Love Foundation, the educational aspect of Panzhihua needs much more development. However, both Chengdu and Panzhihua have a number of children that are attending local schools.

#### *Accomplishments:*

This section addresses what The Project has been able to achieve to date. This includes the rehabilitation services provided, the training that has taken place and the quality of that training. In summary, there is progress on all the goals of The Project, however, there needs to be

a better plan for the training to develop a community rehabilitation focus and stronger clinical decision making skills in the staff. A better-developed standard of re-evaluation will improve the long term care of the children. Lastly, there is good support by the community as evidenced by a number of volunteers that have assisted and the governmental support at the various levels of the community.

Has The Project reached its goals for the period?

The Project has made good gains on promoting awareness of CP in the general community with a large variety of media presentations. This has assisted in more children with disabilities being able to have improved access to education as a right. The Project has helped to organize the parents into support networks. This has been useful, but the parents are not strongly committed to this yet. This will take some time to develop.

Related to informational material for the parents, there has been the development of VCD's, but we were not able to view these fully. We did see some clips in the rehabilitation stations and they appeared well done, but it was not enough to truly determine the appropriateness and content of the VCD's. Related to the printed matter, there is a parent handbook that is strong in the variety of topics that are covered and appears to be written by persons with a good level of understanding of CP. It does a good job of describing what CP is and the basic characteristics of the condition. It does not promote the active aspect of rehabilitation enough and is not being used by many parents. There may be a need to incorporate the use of the booklet in to the rehabilitation interventions – so as to guide the parents in its use and encourage the parents' referral to the book.

Related to the educational aspect of The Project, there are many strengths and weaknesses. The Holy Love Foundation is a strong, but under utilized resource partner. Many of the rehabilitation workers have had less than a month of training in special education methodology and practices and therefore are unable to train parents in how to teach their children. Many children are attending educational programs at various levels – kindergarten, primary school, and special education. In addition, many rehabilitation stations have small group activities that are helping to improve social and cognitive function in these children with CP. Some small group activities are only on the weekends and others are during the regular rehabilitation sessions. Parents are interested in working on educational goals at home and the rehabilitation staff are interested in developing the training of cognitive abilities. However, many staff members do not feel confident in this area and lack the immediate support to assist in this. Chengdu's educational services are better since they have The Holy Love Foundation in the vicinity. Overall, the educational aspect is lacking, but there are gains being made in this area as compared to the situation prior to the start of The Project.

Related to rehabilitation skill development, there are several areas of the training that is quite lacking. There have been some initial gains that have assisted the development of rehabilitation skills in these staff. However, the lack of a true rehabilitation model of care and specifically a community based rehabilitation approach has influenced the training. The training has focused on muscle tone and passive components too much. Additionally, the skill of the workers demonstrates that a significant amount of the topics have not been well learned. These include basic functional anatomy, biomechanics, clinical management, goal writing, and rehabilitation plan development.

Lastly, the rehabilitation and education programs for children with CP need further development in several areas to better offer quality care. The recommendations suggested later in the report should make significant gains in this quality. However, there needs to be a shift in the work load and the number of children managed in order to be able to achieve sustainability of the program from a financial perspective. On the other hand, the use of the experience exchange conferences are a great mechanism to support the training of the staff to allow them all to have the skills needed to maintain quality care. An important aspect of the program that is needed to assist in becoming self-sufficient in quality of care is the development of some of the staff with more expert training in a more narrow focus of rehabilitation or special education and then using these internal “resource” personnel to develop the quality of all the staff.

How are the rehabilitation and special education services provided for the children with CP and their families at the rehabilitation stations in regard to their needs?

There are strong points of the overall program. There are many children that are receiving rehabilitation and education programs that did not have that care previously. The rehabilitation staff is attempting to work with the parents. However, the programs need to develop a more family focus in that the needs of the family are given priority and the rehabilitation plan is based on the needs and concerns of the families. This was modeled for various members of the rehabilitation staff several times during the evaluation process. Also, the care for the children needs to be more play and activity based in general. Some staff and some rehabilitation stations did a better job with this, but all still lack a real understanding of how to play with the child during therapy interventions.

Assess the professional level of the rehabilitation workers at the stations and the centers.

Considering that many of the staff are two-year health care graduates, the level of the staff is not surprising. However, there are some college medical graduates that also do not have a strong handle on how to really develop an appropriate function based rehabilitation intervention plan. The development of the staff skills requires a systematic plan of appropriate course work that builds upon itself so that the skills learned become more and more advanced. This would also include some more advanced trained personnel that can assist with practical training. Training for rehabilitation cannot only include knowledge training, but needs to include practical training. The work at CRRC does assist with this, but some practical training within the local context of the rehabilitation station is also important.

Considering all factors, probably the number one deficit is that the staff lack is the ability to write a clear, measurable, objective goal that can really guide the entire rehabilitation process – including therapy and education. This is a very crucial step in the development of a good rehabilitation intervention plan. The other skill that is lacking is good clinical decision making. However, part of the problem with this clinical decision making skill is a lack of a good foundation in functional anatomy and biomechanics. Additionally, the rehabilitation staff do not have the skill to develop a systematic plan for the education training of the children with CP, particularly when the child is older or his cognitive impairments are more severe. The staff also do not know the sequence of educational skills that need to be taught to the child.

Assess the training provided by parents/caregivers in the rehabilitation program.

The training provided by the parents/caregivers was observed in only a few cases. However, discussion of the home exercise programs given to the parents by the rehabilitation staff was done. The focus of the home exercise programs was a repeat of the type of programs done in the rehabilitation stations. They included a lot of specific activities that were not function based and were not a guiding of how the parent can work with the child during daily activities to support improvements in function. But, there was some focus on activities of daily living during the home programs development. This is good, but the focus of the home exercise programs should be more related to functional activities, encouraging practice during normally occurring activities of daily living. Additionally, the use of positioning is an important aspect of parent programs to encourage the long duration, gentle stretching of tight muscles. Research shows that a muscle needs to be stretched for a total of 6 hours a day to effect a change in the muscle length. These 6 hours of stretching can include stretching that occurs during active movements, functional activities and positional stretching (at home) done throughout the day. This cannot be done only in the rehabilitation stations.

As mentioned above, many of the parents did not know how to set up or work with their child educationally at home. Some of the children with normal intelligence were working through elementary school books with their parents at home. Older or more cognitively severe children's parents did not know what to do with them other than work on some of their daily living skills. In general, parents did not have a balanced view of how therapy and education needs to go hand in hand. There was an over emphasis on therapy and an under emphasis on education.

Assess the internal evaluation, the children's dossiers and training plans in the rehabilitation program.

Some of this is discussed above. The internal therapy evaluation is mostly done by a medical professional outside of the rehabilitation station. Thus, the evaluation is a medical evaluation that does not focus on the functional abilities and needs of the child. In Chengdu the educational aspect of the evaluation is being overseen by Holy Love Foundation with a gradual shift to the rehabilitation workers conducting the evaluation. There is a quite comprehensive daily living skills checklist developed in Taiwan and used by Holy Love Foundation that is useful, but may be a little too complicated. As the rehabilitation focus shifts to a family focused rehabilitation with more emphasis on functional skills, the evaluation can be modified to meet the needs of the rehabilitation personnel more.

From an educational standpoint, the evaluations were quite basic and lacked the necessary components for assessing non-verbal communication skills, visual skills, and/or listening skills – skills which are often lacking in children with CP. The evaluation focused on skills like colors, shapes, position, addition, big/small, verbal language – including facial expressions and verbal expression with simple sentences, activities of daily living including self care and eating.

The records of each child were quite comprehensive. They included evaluations and records from the hospital, updated evaluation, records of when the rehabilitation worker visited the child's home, what goals were taught and the parent's signature.

A strong point of the evaluation process in general was that there was a videotape of each evaluation. A weak point was that there were goals placed on the cumulative evaluation that were not incorporated into the three-month evaluation. Therefore, it is easy for those goals to be overlooked in the long run. Even though there appeared to be a schedule for the evaluations (every six months), the evaluations did not clearly focus on the goals being addressed and were not comprehensive. Progress also needs to be clearly documented at least weekly.

Is the information material provided by The Project appropriate for families with CP and the general public?

As discussed above, the informational material for the parents appear appropriate. The book is quite detailed and may need further discussion with the parents to determine the reasons why the book is not being utilized more by the parents in both Chengdu and Panzhihua. The VCDs used may need to be loaned to the parents to allow them to view the content when not distracted by the children. Another solution is to have a separate place to show the VCDs. The VCDs were seen showing in the rehabilitation room during the treatments with the children. This is distracting to the children and the parents. The other informational material for the general public that was seen appears to be appropriate.

There are a few rehabilitation workers who have taken the initiative to put together some of their own informational material to give to parents. This shows a lot of investment in the project by them and a desire to meet the needs of the parents.

Assess the role of the volunteer services in The Project and the parent associations.

The use of volunteers is a great way to build the child's tolerance to people other than himself. Volunteers also help to build community support for the project and become ambassadors for the disabled. The Project's volunteers are being used in a variety of ways during community outings and in the clinic. Some volunteers are being used to assist the staff in dealing with fussy children so that they will not interfere with other children's rehabilitation. However, the volunteers can be used to add support to the rehabilitation by assisting with small group activities, talking with parents when their children are in therapy, playing with the children before and after therapy and being an encouragement for the family and child. It would benefit the centers to have the volunteers actually be an integral part of the therapy sessions.

The parents associations are developing. In one center the parents commented that they were not only seeing each other while at the center but also outside the center and helping each other watch their children when needed. One parent has developed a website for other parents. However, there are still many parents, especially those newer to the program, who are not as involved as they could be. It will take time for the parents to be really involved. There may need to be further evaluation on the approach used to determine how the parents association needs to function to meet the parents' needs. More suggestions will be given in the recommendations section.

Assess the cooperation between The Project and the government.

There is good cooperation between the government and The Project. The level of matching funds was greater than initially expected. The government agencies in both cities appear to be supporting The Project. Many of the local community representatives came out to



the rehabilitation stations during the evaluation team visits. This is a sign of their support. Additionally, the health department of Panzhihua also loaned out their staff to The Project – even though the salary was paid by the Project.

*Efficiency/Effectiveness/Coherence:*

This section discusses how effective The Project is and how it might become more efficient and effective. It also looks at how well The Project coheres to the objectives of The Project. In summary, The Project is making good gains in these areas. However, there is a need to increase the workload of the staff to be able to achieve sustainability in the future. This can be done via increased small group activities to promote rehabilitation. Also, the use of the parents more to promote appropriate practice of functional activities at home will allow more children to be adequately serviced by only seeing each child one or two times a week.

Are the resources used in an effective and efficient way?

The use of the financial funding was not evaluated during this evaluation. The equipment is being used and is appropriate – except for the exceptions mentioned earlier. There are a lot of personnel resources that are being used, but there needs to be a shift to improving The Project staff skills so that they do not need to rely on outside staff as much. Therefore, there needs to be a stronger focus on training and support to decrease the need for outside staff to do regular evaluations and rehabilitation plan development. One area of resource misuse is in rehabilitation staff resources. The number of visits that the child receives is not dictated by the child's needs as much as it is by the desire of the family. Therefore, there are children in Panzhihua that are receiving once a week therapy interventions and some that are receiving five times a week therapy interventions. Currently, there is time available to do that, but later, this practice will mean that some other children are not receiving the services that might otherwise be available. Currently, it appears that most – if not all – of the children in Chengdu are receiving rehabilitation five times a week. This limits the resources available for other children with needs. This is important since there are many children that have needs that are not receiving rehabilitation services.

The travel to the families' home is important for working on functional goals in the context of the child's natural environment. But, do the visits need to be done weekly? Some families will need that assistance, but extensive use of home visits requires a significant amount of personnel resources. There needs to be a clear plan for the use of the family visits to ensure that they are positively affecting the care of the children without reducing the personnel resources for other children. Therefore, family visits are important, but need to be used appropriately and with a clear goal in mind.

The rehabilitation workers are also resources for those in the community and schools. As more and more children are attending local kindergartens, elementary schools, or special schools; the rehabilitation workers need to have training and skills to equip them to help the local teachers plan and make adaptations for children with disabilities in the classroom. In time the local teachers will also be able to be a resource for other schools who have students with disabilities and a network can be formed amongst the local teachers.

Would other measures achieve the same results with the same or less resources?

The use of small group rehabilitation for some sessions will improve the efficiency in an effective manner. These children can receive the necessary rehabilitation intervention within the group setting – which assists the children to learn social and motor skills at the same time.

The use of a function based rehabilitation evaluation would greatly improve the utilization of the personnel resources in that outside personnel would not be needed to do the initial evaluations. This would help The Project to reach the “evaluation by staff” goal.

To what extent is The Project achieving its objectives and producing the desired results?

The Project is making good gains in meeting its objectives, but the training of the staff is an area that needs to be improved. This will be discussed more in the recommendations for the future section. The training of the rehabilitation staff is a very crucial aspect of this Project. Only when the training is effectively targeting the necessary skills in a systematic manner can the objectives of The Project be fully achieved.

Related to the information bulletin boards, this is a cost effective manner to promote information to the general public and for parents. However, some of the bulletin boards used very plain notices that may not be readily read by the general public. Some extra expenses to produce more attractive notices may increase the effectiveness of these notices. Additionally, the cost does not necessarily have to be great. This should be further evaluated. The other media resources used seem to be appropriate. Local newspapers are being used to promote public awareness through various columns and essays.

Assess the coherence between The Project’s objectives and activities.

There is coherence between The Project’s objectives and activities. The methods used to achieve public awareness of CP are using public media or visible public displays. The methods of the training has some areas that need refinement, however, the essential concept of the training is appropriate for the development of the rehabilitation staff skills. The only problem in this area is an under utilization of the Holy Love Foundation – which could assist in the development of the educational aspect of The Project. The encouragement of the parents and the development of the parent associations are well directed at empowering the parents. However, the exact needs of the parents and how to best meet those needs do need further consideration. The rehabilitation workers need to better understand the parents and what they are dealing with so they can help them set reasonable goals for the future. If this does not happen, many parents will lose hope because their child “isn’t able to walk.”

*Sustainability:*

This section addresses the sustainability from a professional and financial point of view only. Administrative sustainability is not addressed. There are issues of sustainability that need to be addressed to ensure that The Project is sustainable by the end of the funding period. Specifically, the professional sustainability will require the development of more expertise in the rehabilitation staff. This should include the development of some staff with one particular focus – education, physical therapy/occupational therapy, or speech. These specialized staff can be supportive staff for the other staff when needs arise. A positive factor related to the professional sustainability is the experience exchanges. These are a useful way for the staff to promote the

overall development of other staff. Therefore, this format of training is useful and should be considered.

Related to financial sustainability, there is some support from the government in both cities. This will assist with the financial sustainability. However, in order to achieve financial independence there will eventually be a need to go to a fee for services based approach. This can use a sliding scale to provide additional support for those that are financially unable to pay for the entire costs. A shift to a small group and community based rehabilitation approach, where the family is utilized more to do training at the home will allow more children to be treated and will minimize the cost of the rehabilitation for each family while maintaining a good level of financial support for the centers and stations.

### **Recommendations for the future:**

This section will address some suggestions that we feel will improve the overall quality of The Project. We all feel that The Project is a worthy project that is meeting some very important needs for children with CP within these communities. With attention to the recommendations, The Project will become a much more successful project and a model for the entire country to follow. The initial two items discussed are those raised by the Terms of Reference objectives. The others are recommendations from The Team. The recommendations from The Team are listed in outline format. After each major outline, there is a short paragraph that explains the issues in a little more detail.

#### *How can the target group be extended/Is it possible to include children with other disabilities?*

There are many children with disabilities that have rehabilitation needs. Extending the target group to other disabilities is useful. However, it is important to continue to follow children that are relatively similar. This could include the treatment of children with Down Syndrome, children with mental retardation, children with spina bifida (myelomeningocele), and even children with muscular dystrophy. The latter two would be a greater challenge, but could be done. However, children with disabilities that are very different should be avoided. For example, children with autism are very different and require an entirely different approach. We understand that Chengdu is looking into starting a program with children with autism. Since this will require a completely different method of treating those children, the rehabilitation workers would need completely different training and skill sets. This would definitely not be recommended as an addition to the rehabilitation work in This Project.

#### *How can the experience gained through The Project be spread to new areas and new groups?*

As The Project develops, the staff in The Project can have others that are interested in developing a similar program to do practical rotations in the rehabilitation stations. Also a detailed plan for the implementing of the project can be developed to guide others in knowing how to avoid the mistakes made here. An essential component is a clear plan for the implementation of the training program and topics. However, these other programs will need to have the support of the government, equipment and locations or the finances to acquire those items, and support of local experts to guide the training. Lastly, the emphasis on a functional based approach with appropriate parent education from the start will be greatly beneficial for the development of an appropriate community based rehabilitation program.

## *Recommendations from The Team*

### I. Increase Expert support

#### A. Special education and rehabilitation resource personnel

1. Use of local experts to support the work of the current rehabilitation personnel.
2. Short-term training to support clinical decision making processes
3. Practical experiences within the health station setting, therefore not needed to have the personnel travel to outside locations
4. Develop some of the leaders within the group of rehabilitation station personnel – allowing them to become “experts” in a particular area (specializing in education, physical therapy/occupational therapy, or speech) and then supporting the training and work of the other rehabilitation staff.
5. Utilize Holy Love Foundation more for training and problem solving in education.

#### B. Use of other resources available, for example

1. Hong Kong Society for Rehabilitation’s WHO collaborating Center ([www.rehabsociety.org.hk/who.html](http://www.rehabsociety.org.hk/who.html))
2. Child Rehabilitation website run by Beijing Welfare Institute and Hong Kong Society for Rehabilitation’s WHO collaborating center ([www.childrehab.org.cn](http://www.childrehab.org.cn))
3. Chinese Association of Rehabilitation Medicine ([www.carm.org.cn](http://www.carm.org.cn))

The staff lacks the necessary experience and training to truly function independently. They are being asked to do multiple rehabilitation and educational tasks – many of which are new to them – and they currently do not have the resource personnel to assist them in their development. Therefore, they need to seek resource personnel that are in the vicinity that can help as needed (or on a regular basis like once a month) with more difficult cases and questions. These resource persons should be in the vicinity so that the interaction can be ongoing. These can include personnel from Huaxi Medical College Hospital and The Holy Love Foundation. Both of these facilities have personnel that have more advanced skills that can really assist in the development of rehabilitation personnel skills. Additionally, they both seem to have a desire to assist in the development of The Project.

Secondly, there can be short-term training courses that bring people into the rehabilitation stations. In doing this, you can train within the current situation of the rehabilitation station. There is less risk of the rehabilitation staff coming back and saying: “We cannot do what they did at their place because we do not have the same equipment.” The training would fit the exact need of the rehabilitation stations and encourage the staff in their work.

A main focus of this training needs to be in guiding the rehabilitation staff to use what they have already learned. This is achieved by guiding the rehabilitation staff in the clinical decision making process. A particular child can be used and the evaluation, rehabilitation intervention plan and progress walked through with the rehabilitation staff. The clinical decisions that need to be made at each stage can be discussed as a group.

Third, if some of the stronger staff are given specialized training in one area (education, physical therapy/occupational therapy, or speech), they can then become the “experts” for the other staff. This will allow the staff to support their colleagues and to train new staff as needed. This could include them traveling among the different rehabilitation stations in that city, helping to guide the evaluation process and developing appropriate goals/interventions. This will increase the sustainability of the professional staff. There will be turn over in the staff, this turn over needs to be prepared for.

This opportunity to specialize can also be expanded to include all staff so that all the staff do not have to try to do everything. It is a challenging task for one person to fully consider all the educational, physical, and speech needs of a child. However, some children will have more needs in one particular area.

Lastly, the staff can seek out outside resources including books, website information, and the like. Through this process, information regarding short-term training will be learned about and the continued education of the staff will be achieved. Of course, staff going to outside training should then bring that experience back to the other staff so that all can learn and grow through that training. The experience exchange is one good forum for that exchange.

## II. Training Needs

- A. Develop a complete training scheme for the entire training period
  1. Emphasize basic foundational courses and clinical decision making aspects
  2. Emphasize play as a part of rehabilitation interventions and as a goal of rehabilitation interventions.
  3. Emphasize the need of children to transition to adulthood.
- B. Develop a training plan/strategy for the education aspect of the rehabilitation using The Holy Love Foundation as a resource
  1. Focused training in weekly segments
  2. Other training once monthly
  3. Other special education experts to work alongside the rehabilitation personnel to support their development in educational issues.

There are some major issues with the staff’s current level of training. There are many basic anatomy questions that the staff could not clearly answer. Therefore, there are a number of topics that needs to be including and strengthened in the training. These include: basic muscular and skeletal anatomy, functional anatomy, gait, rehabilitation based evaluations, use of clinical decision making – HOAC II is a useful tool (Rothstein JM, Echternach JL, Riddle DL. The hypothesis-oriented algorithm for clinicians II (HOAC II): A guide for patient management. *Physical Therapy*, 2003; 83:455-470.), the disablement model, monitoring of progress (David KS. Monitoring progress for improved outcomes. *Physical & Occupational Therapy in Pediatrics*. 1996; 16:47-76), motor learning, play and play in therapy, family focused interventions, goal writing and rehabilitation interventions – can include the Canadian Occupational Performance Measure (COPM), life span approach to therapy, systems theory of

rehabilitation, transition to adulthood planning, orthotic prescription and use, surgical management in CP and related rehabilitation, use of medications in CP.... This is not a comprehensive list, but does cover some of the basic topics. Most important is for the staff to have practical, hands on training in these topics. Rehabilitation is not just knowledge, but also has a lot to do with how you interact with the family and the child during the intervention.

The level of skills of the rehabilitation staff is low in the overall educational aspect of the rehabilitation. There needs to be a more support in this area. A three year training plan in the area of education needs to be developed so that the training is focused and directed at the needs of the individuals. This may include specialized weekly training for two “education experts” in each city. In turn, they can hold bi-weekly trainings with the rehabilitation workers and also spend time in the centers helping them implement what they have been trained in.

Rehabilitation workers need further training in a number of areas. They need to understand cognitive processes and know how to write specific long term and short term educational goals that suit each individual child’s needs. Children with higher intellectual functioning may be able to follow the local kindergarten or elementary school curriculum but the teachers still need to know how to make basic adaptations for the child. Children with lower intellectual functioning need to be taught functional academic skills that will allow them to be as independent as possible in society. They may include using money, reading characters of items in the grocery store and how to use the telephone. Another important area of training is that of communication and how students with little or no verbal communication communicate with those around them. The Holy Love Foundation, located in Chengdu, has strong skills in each of these areas. Their teachers have a high skill level and they value training. Additionally they have many resources that can be of value to the Project. Additionally, training needs to be given to allow the rehabilitation staff to understand the child and what he feels his needs are. Understanding that what the child feels are his own needs is not a cultural thing. This recommendation is made because of a number of responses by older children in the centers who lack motivation to study or do their therapy at home. Clearly they were depressed and not really caring what they did as they felt it would not make a difference anyway. Rehabilitation workers need to know how to identify this response and how to motivate children to want to learn and do therapy at home. The individual child’s desires and needs, when taken in consideration, could make a difference in their progress.

### III. Evaluation process that targets the needs of rehabilitation

#### A. Rehabilitation personnel use evaluation

#### B. Family and management use evaluation

1. Can incorporate functional outcome measures to represent the child’s progress to the family and management.

The current evaluation is a medical based evaluation that covers a lot of topics that are not necessarily important for the development and implementation of a

rehabilitation intervention. The rehabilitation evaluation should focus on functional skills – including posture control, mobility in crawling, standing, bed, transitions between postures and others; some impairment issues like range of motion, muscle tone, and muscle strength; have a history, objective, assessment, and plan.

A simpler evaluation can be used to share the finding and progress with the family and management staff. This should have some functional outcomes measures associated with it. An example is the Wee FIM or the Pediatric Evaluation of Disabilities (PEDI) assessment. This evaluation form does not need to have all the information that is needed by the rehabilitation staff for rehabilitation intervention planning and clinical decision-making.

This evaluation process and goal development/rehabilitation intervention planning needs to be done by the rehabilitation personnel in conjunction with the family in a family centered approach to rehabilitation. The goals need to be goals that are important to the family and not just what the rehabilitation staff/medial doctors want to work on. They need to be functional and measurable. This can be guided by the use of the COPM – this measure guides the staff in determining what issues are important to the family.

#### IV. Emphasis on Sustainability

- A. Consider a sliding scale of rehabilitation fees to be paid by the parents
- B. Develop different levels of rehabilitation intervention intensities
- C. Use of small groups as an intervention format
- D. Development of guidelines that indicate the expected work load levels
- E. Development of the professional skills to provide sustainability of The Project

Currently, The Project is not sustainable. The professional skills development is important to the long-term sustainability of The Project, but has been discussed above. Currently, the fee for service aspect has been terminated. The fee for service will encourage the families to maximize the use of each rehabilitation session and will encourage more interaction with the child at home also. However, the family focused basis of the interventions need to be continually developed.

Additionally, the use of different levels of rehabilitation intervention intensities will allow children to get the level of services that they need without over utilizing or under utilizing the services. The level of services needed will vary with the various conditions of the child. For example, a child that is at a stage of development that is starting to see the emergence of some important functional skills will benefit from a short duration of more intensive rehabilitation. When the children are in a more stable developmental stage, they may do well with therapy sessions once a week, twice a month or even once a month. These decisions need to be made on the basis of the current condition of the child and his development/needs.

Small groups are a useful tool for rehabilitation interventions. The child will learn motor skills better from a peer model of movement than he will from an adult model. Therefore, small group rehabilitation allows the child to learn motor skills better than when he is only with adults. The child will also benefit from the social interactions. The

cost per session would be reduced for this type of therapy intervention, but the increased number of children would actually increase the revenue. Thus, small groups are a good way to improve the financial sustainability of The Project while decreasing the families' financial burden and providing quality therapy. However, good small group therapy does require some skill and training.

- V. Consider some level of stratification of rehabilitation stations
  - A. Highly skilled rehabilitation center
  - B. Less skilled rehabilitation stations

The levels of needs of the children are not the same. Some children are more complex and challenging. If there is a stratification of the rehabilitation stations, children that are more complex and challenging can go to that/those rehabilitation centers. The more simple cases can go to the other rehabilitation stations. The problem with this is that the family may need to travel farther to get to the rehabilitation center. This partially defeats part of the purpose of community rehabilitation - community based and community located. However, one solution is that the child goes to the rehabilitation center for a relatively short period of time to better determine his needs and then he returns to the rehabilitation stations with the necessary documentation to guide the rehabilitation station personnel in the best method of proceeding with the rehabilitation intervention and with a list of family/rehabilitation personnel generated goals.

#### VI. Parent Support Networks

- A. Choose head parents from each center and give them specific training in
  1. Grief and acceptance process associated with having a child with disabilities.
  2. Empower parents to push for their children's rights

As stated above the parent associations are in the developing stages. In order to enhance the development of the parent associations each center needs to have a lead parent who is able to network the rest of the parents in that center. The head parent could be a great resource to other parents, as well as, to new parents whose children are just beginning to attend the center. These head parents would need further training from experts. In the past there have been trainers from Hong Kong who came to give parent training. A plan would need to be developed to provide head parents on going training in how to help parents accept that their child has a disability and assisting them as they go through the normal stages of grief. The head parents can then pass this on to the parents in their center.

As parents become more of a support for each other they can also help each other in the process of helping one another access the local system for education and other needs of the child.



- VII. Develop the ability of the children to access education by building up a support network
- A. Find a model teacher that is willing to assist parents and staff knowing how to access education
    - 1. The fourth grade teacher in Chengdu Jinjiang educational center (the one that has an “Uncle” accompanying a fourth grader everyday).
  - B. Regular meetings to support the children with disabilities accessing education.

When a child with a disability enters a school system there is so much preparation work that needs to be done. The teacher needs to understand the disability and know what adaptations and modifications the child needs. The local students need to be educated in the disability and the disabled child’s strengths. All this needs to be done by someone who understands how to link the parents, teacher, students, and rehabilitation worker together.

Making a teacher a model for other teachers could greatly enhance the effectiveness of students’ educational experiences in the local schools. This teacher could then meet with other teachers who have children with disability in their classrooms once a semester to talk about how they are making adaptations and how to encourage this child in his studies. At other times she could be a resource for these teachers when they need to problem solve. Further training through Holy Love Foundation in basic accommodations and adaptations would be beneficial for this teacher. There is a fourth grade teacher of one of the children that attends a center in Chengdu who seems to be willing to work with the family to educate their child according to his needs and she seems to have a willingness to understand students with cerebral palsy. This teacher may be a good model to start with.

- VIII. Do daily charting of educational goals
- A. Use a chart that can be quickly recorded on

Daily charting can help improve the efficiency with which goals are assessed and provide accountability for meeting these goals. There are a number of methods of charting but training in task analysis, prompting systems, and skill sequencing will help a teacher decide which chart method is most suitable for each child. Holy Love or an educational specialist would be able to provide this kind of training. Additionally, daily charts will keep the focus of the therapy sessions, both at home and in the centers/stations, on the aim of achieving the long term and short term goals that have been written for that child. Daily charts will also minimize documentation time and the increase the compliance with the recording.

- IX. Train specialists in adaptations at school and assistive devices

There are many adaptations that can improve the ability of children to access education and general functional activities. When a child cannot correct their functional skills, appropriate adaptations and assistive devices will greatly enhance the ability of the child to access education and improve their activities of daily living. However, this

is an area that needs special training in order for the appropriate use of the assistive devices and adaptations. Also, the training will allow the rehabilitation staff to have a greater awareness of what options are available.

In addition to devices and adaptations made to help with physical limitations, the rehabilitation workers need to be trained in various assistive techniques that will help children who are either non verbal or language delayed. These communication techniques will greatly enhance the child's ability to progress in the rehabilitation process and language development.

- X. Training in Educational options
  - A. Inclusion
  - B. Special education class in a general school
  - C. Special education school
  - D. 1/2 day schools set up by the centers
  - E. Specialist in the center to teach the children
  - F. Training of parents to teach the child at home

There are many options for children with disabilities to receive an education. For most children the optimal learning environment is a classroom with other children. This would support the approach for them to be included within the current local school systems. However, as mentioned above, there would have to be support for the teaching staff and the child's rehabilitation needs within the class as much as is possible. Again, this will promote the child's ability to access education by supporting the teaching staff with techniques needed to work with the child with disabilities and addresses the physical impairments that are directly interfering with the educational opportunities.

For children with a more severe cognitive disability partial inclusion may consist of being in a special education classroom within a local school and being included in the regular education classroom for various classes and activities. The third option would support more cognitively severe children attending a school that is designed just for disabled students.

One of the limitations is that local schools are not willing to accept children who are not able to walk or cannot take care of themselves in the area of toileting and eating. Therefore, another option may be to set up 1/2 day schools in the centers/stations so that children can get their basic educational needs met at the center by teachers who are trained in special education. A variation of this could include a rehabilitation worker at each rehabilitation center/station that is trained in special education. When a child comes in for therapy, they can also have small group or one on one academic training for 1-2 hours. The specialist could also train the parents in how to teach their child at home. Most of the parents are willing to help their child at home but lack the necessary materials and skills to know how to help their child or know how to set appropriate goals for them.

No matter what the situation is, the approach of therapy and education paired together has to be incorporated into every child's individual plan.

**Concluding Comments:**

Overall, there are many aspects of The Project that are encouraging. There is a lot of enthusiasm for the project, the majority of the parents feel their child has made progress, the government has been supportive, and the overall goals of the project are aimed at the needs of the community. However, there are areas that need to be addressed. With careful attention to these needs, this Project will become a successful model for all of China. The more important aspect of The Project is the need to carefully and systematically train the rehabilitation personnel. There is especially a great need in the area of the educational aspect of The Project. Please see this report as a guide to assist in the successful progression towards this worthy goal.

Thank you for allowing us to participate in this important Project. We humbly submit this mid-term evaluation in the hopes that you will be able to continue to the great work started.

Sincerely,

Christopher A. Zaino, PT, PhD (Team Coordinator)  
Cindy Pearson, MA.Ed.  
Jianan Li, MD

## APPENDIX

## Terms of Reference

Evaluation of Sichuan Community based rehabilitation project for Children with Cerebral Palsy (CP)  
(22 April 2006)

### 1. Background

**Sichuan community based rehabilitation project for children with CP was established as a result of a recommendation from a feasibility study done in spring of 2003.**

**In Sichuan Norwegian Mission Alliance (NMA) is working together with Sichuan China Disabled Peoples Federation (S-DPF), Chengdu-DPF and Panzhihua-DPF on this project. The program has set up two “Management and Service Centers” and 14 “Community Service and Guiding Stations” in the two cities of Chengdu and Panzhihua. Today these centers and stations provide rehabilitation services for approximately 100 CP children.**

**Along with the Norwegian counterparts general practice of midterm evaluation it is therefore in spring 2006 initiated an evaluation of this project.**

### 2. Objectives

#### 2.1 Overarching objective

**Gather information on the status of the project. If necessary use this information to adjust the project in order to provide a good development and to ensure that the long term and the short term goals/objectives will be met/achieved.**

#### 2.2 Goal for the evaluation

**Identify the strength and weaknesses of the project. To give clear recommendation on measures of improvements of the project plans, implementation, organization and structure in order to improve the progress of meeting the short term and long term goals.**

#### 2.3 Specific objectives

##### 2.3.1 Relevance

- **Is there a need for the project?**
- **Are needs of the CP children and their family met?**

##### 2.3.2 Project design

- **Assess the two different community based service models according to the different conditions of the two cities.**
- **Is the project adapted to the local and national government’s plans?**
- **Is the project adapted to the social, economic and cultural context?**

##### 2.3.3 Process and management

- **Is the project organized and administered in an efficient and effective manner at the different organizational level?**
- **How is the system for monitoring, coordination and communication between different areas/organization levels of the project?**
- **Does Xincon as give any value to the project?**
- **How does the project deal with deviations between expected results and actual results? Has the deviation been a basis for learning? How can the project increase the learning processes?**
- **Are the necessary resources available in the project?**
- **Assess the role of the resource partners, Chengdu No 1 people's hospitals rehabilitation center and Holy Love foundation.**
- **Are the routines of financial control in place?**
- **Are there any unexpected processes as a result of the project?**

#### 2.3.4 Accomplishments

- **How are the rehabilitation and special education services provided for the CP children and their families at the station in regards to their needs?**
- **Assess the professional level of the rehabilitation workers at the stations and the centers.**
- **Assess the training provided by parents/caregivers in the rehabilitation program.**
- **Assess the internal evaluation, the children's dossiers and training plans in the rehabilitation program.**
- **Is the Information material provided by the project appropriate for families with CP and the general public in the different local communities of Chengdu and Panzhihua.**
- **Assess the role of the volunteer's service in the project and the parents associations.**
- **Are there any unexpected results?**

#### 2.3.5 Efficiency

- **Are the resources used in an effective and efficient way?**
- **Would other measures achieve the same result with the same or less resources?**

#### 2.3.6 Sustainability

- **Has the project already achieved or will the progress of the project eventually lead to professional, administrative and financial sustainability?**

### 3. Methodology

**The methodology includes both how to collect data, analyze and make conclusions. The following aspects will be evaluated: Planning, execution and participation**

**The framework for the evaluation team will be Term of Reference. The evaluation team will clarify the Terms of Reference, methodology and how the evaluation shall be carried out together with Project office and Xincon as.**

**The evaluations team should have access to the project document, project plans, reports and internal evaluations. It is expected for the team members to study all relevant documents prior to the evaluation.**

**In order to establish a common understanding of the aspect under evaluation, it is important to describe the project, its context, its stakeholders, their roles and responsibilities, and how they have worked together to achieve the project goals.**

#### **4. Team**

**General criteria should be:**

- **Credibility- they should be accepted and respected by central parties**
- **Professionalism – the team should have a combination of relevant special expertise, professional evaluation competence and knowledge of the country/culture**
- **Independence- consultants must not have special relations to the project subject to evaluation.**
- **Suitability – consultants must have capacity and will to understand and communicate their findings and conclusions with persons from other cultures**
- **Gender balance – all teams should consist of both men and women**

#### **5. Economic framework**

**The approved economic framework for the evaluation is USD 5000, this should cover allowances, travel costs, communication, office expenses.**

#### **6. Time framework**

**The fieldwork of the project will be done in April 2006. Draft report handed in mid May 2006 and final report in beginning of June 2006.**

#### **7. Expected products and follow-up**

**The evaluation will be done in cooperation with Xincon as and project personnel in Sichuan. Before end payment a written report in English and in accordance with terms of reference, will be handed in. A draft of the evaluation shall be presented to Xincon as with possibility to give a comment before finalizing the report. If there should be some principal disagreements with the conclusions in**

**the final report, Xincon as and Project office reserves the right to include comments to the areas that they disagree with in the report. The report will included recommendation and conclusion. Additional products and activities expected are:**

- **A written summary report for the project office in Sichuan prepared by Xincon as**
- **The evaluation team gives a brief presentation of the main findings from the field work to key personnel persons and relevant parties before departing the area.**
- **A seminar arranged by Xincon as to share the conclusion with the project representatives in Sichuan.**
- **Establishment of a commission who is responsible for formulating a follow-up plan regarding the possible recommendations presented in the evaluation report.**