

Norwegian Mission Alliance: The China Polio Project

Results and Lessons Learned

November 2008

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Foreword

We would like to thank the Acting Director and staff at the New Hope Center for their hospitality and willingness to answer all our questions when the evaluation team visited Pizhou for one week in October 2008.

We would also like to thank Qingsong Wang for organising the evaluation for us and supporting the team while in Pizhou and Nanjing. Thanks also to Lie Xue for excellent translation for those of us who can't understand Chinese and to advice and support from AnAn Wu from Amity Foundation.

The following report is a team effort. Dr. Li Jianan has written the chapter on physical rehabilitation (3.1.). Cheng Yiji prepared the chapter on education in Chinese, which was later translated to English (3.2.). Sheila Purves wrote the chapters on social integration (3.3.), models for rehabilitation (3.4.) and the contextual chapter (2.2). Stein-Erik Kruse was responsible for the remaining chapters and for trying to prepare a coherent report – without changing the style and substance as presented by individual authors.

Table of Content

Foreword	2
Table of Content.....	3
Acronyms	4
CHAPTER 1: INTRODUCTION	1
1.1. Background	1
1.2. Purpose and Objectives	1
1.3. Methods.....	2
1.4. Limitations	2
CHAPTER 2: THE CHINA POLIO PROJECT	3
2.1. Overview of Project	3
2.2. Context	5
CHAPTER 3: FINDINGS AND OBSERVATIONS.....	10
3.1. Physical Rehabilitation.....	10
3.2. Educational Potential.....	13
3.3. Social Integration	15
3.4. Models for Rehabilitation.....	17
3.5. Micro Finance	21
3.6. Advocacy for Disabled People’s Rights.....	22
3.7. Future sustainability	22
CHAPTER 4: CONCLUSIONS AND LESSONS LEARNED.....	26
4.1. Conclusions	26
4.2. Recommendations	28
4.3. Lessons Learned.....	30
Annex 1: Terms of Reference	34
Annex 2: People Met.....	38
Annex 3: References	40
Annex 4: Models for Rehabilitation.....	41
Annex 5: Case Studies.....	44

Acronyms

ADL	Activities of Daily Living (a functional measure of basic skills: dressing, toileting, eating, bathing, etc.)
AFO	Ankle Foot Orthosis
CBR	Community based rehabilitation
CDPF	China Disabled Person's Federation
CeBR	Center based rehabilitation
KAFO	Knee Ankle Foot Orthosis
LCH	Lao Chu Hui
NHC	New Hope Center
NMA	Norwegian Mission Alliance
NMU	Nanjing Medical University (formerly Nanjing Medical College)
PHB	Public Health Bureau
PRC	People's Republic of China
RC	Red Cross

CHAPTER 1: INTRODUCTION

1.1. Background

There was a nationwide outbreak of polio in China during 1989-90 affecting Pi and Shuyang Counties in Jiangsu Province. A survey carried out in 1992 identified 545 children with disability due to polio sequela¹ out of a population of 1.5 million. The total number of cases in 1996 had increased to 762. In Shuyang County, also with a population of 1.5 million, 250 cases were identified. A survey showed that that 42% had one limb affected by polio, 47% have two limbs and 11% had three or more limbs affected.

The Government with support from WHO conducted several immunisation campaigns and a surveillance system was put in place in order to prevent new polio outbreaks, but less attention was given to treatment and rehabilitation of children and youth with polio.

Norwegian Mission Alliance was well known for its polio work in Taiwan and started collaborating with Amity Foundation in China in 1992 supporting polio victims in Huaiyin. In 1993, Amity requested NMA to support the children affected by polio in Pizhou and Shuyang Counties.

Following a pilot period (1993-1996), there have been two phases in the project – one from 1997 to 2001 and the next from 2002 to 2006. The project has been funded by the Norwegian Mission Alliance for 15 years and with support by Norad for 10 years. Total funds allocated to the polio project have been approx. 25 mill CNY (or 22 mill NOK). Significant external technical support and equipment should be added to this amount. Funding from Norad came to an end in 2006, but NMA has continued supporting the project with its own funds.

1.2. Purpose and Objectives

According to Terms of Reference¹, the overall purpose of the evaluation is to summarise and assess the major achievements of the polio project, identify important lessons learned and provide recommendations for future activities. The objectives are to document and assess the relevance of objectives and models used for rehabilitation, results achieved, efficiency of project management and use of funds and prospects for future institutional and financial sustainability.

The evaluation should seek to answer the following broad questions²:

- To what extent has the *physical rehabilitation* of children and youth been successful and adequate?
- To what extent has the target group (polio affected children and youth) improved and achieved their *educational potential*?
- Has *microfinance* been successful in supporting families in the rehabilitation of children and youth?
- To what extent have children and youth been successfully *integrated into the society*?
- How has this project worked in relation to *disabled people's rights*?

¹ See Annex 1: Terms of Reference

² For more detailed questions see Annex 4.

- To what extent has the project introduced and consolidated *new models and approaches for rehabilitation* of polio patients and how efficient and relevant have they been?
- To what extent has the project *built competence and capacity in the field of rehabilitation medicine* focusing on new concepts of polio rehabilitation?
- Has the project been able to establish an *effective and sustainable project organization*?

1.3. Methods

The evaluation has used three main methods for collecting information. It started with a review of project documents and plans, previous studies and evaluations and other relevant reports.³ The main part of the evaluation was carried out during an eight day visit to Pizhou Country and the New Hope Center (NHC) in October 2008. Interviews were conducted with NHC management and staff, government and NGO partners and not least with youth that had been benefited from the project, their families, teachers and employers. Finally, a small survey was carried out of their physical status and need for further surgeries. The various team members prepared contributions to various thematic areas, the draft report was compiled by the team leader and shared with NMA and NHC and finalised based on their comments.

1.4. Limitations

There are threats to the reliability and validity of findings in such an evaluation. The findings should be treated with caution as:

- The findings and conclusions are based on a limited sample of cases, and there will be variations that the evaluation did not cover – impact may be higher or lower among other beneficiaries.
- The analysis of impact builds on the situation at present, but impact is often the result of complex processes that require a longer time to be properly assessed and understood in the full.
- The evaluation was completed in a short period of time, and with team members from various professions and geographic locations. The advantages were that this brought different competencies and experiences to the study, but the disadvantages were that the basis for value judgement may not be uniform.

In other words, we may not have been able to present a complete picture, but hopefully an important part of it.

³ See Annex 3: References

CHAPTER 2: THE CHINA POLIO PROJECT

2.1. Overview of Project

The goals and objectives for the two phases of the project are:

Phase 1

According to the project document for the first phase, the overall goal was to improve participation in family and community life, education or work of children and young people in China, who had been disabled. The project objective was to establish models for developing local resources for comprehensive integrated rehabilitation and education for about 800 children in Pi County and 300 children/youth in Shuyang County.

Project objectives and activities:

- (a) Improve physical mobility and daily life skills:
 - Subsidize surgeries, orthoses and adaptive equipment
 - Train children and their families in rehabilitation and use of orthoses
 - Equip orthotic shops, train local orthotists, and improve orthotic material
 - Train local personnel to provide needed services and run a case management system
- (b) Increase school and working opportunities:
 - Integrate most children into village schools
 - Bring the most severe cases who cannot access village schools into a center based integrated rehabilitation programme.
 - Encourage village school inclusion of disabled students and train teachers
 - Offer disabled students remedial training
 - Organise vocational training
- (c) Improve the economic capacity of involved families to gradually take over payment for orthoses and wheelchairs:
 - Improve family health through development of clean water resources
 - Establish community development projects
- (d) Promote the models of comprehensive polio rehabilitation for wider use in China.

Phase 2

The goals and objectives for phase two are not dramatically different, but there is more emphasis on education, consolidation and sustaining established practices and strengthen organisational capacities. The long-term goal is now to bring the integrated and complete concepts about rehabilitation to the local people and to professionals. The ten year objective goal (1997-2006) is to improve participation in family and community life, education or work of children and young people in China, who have been disabled.

The five year goal for 2002-6 was to establish a sustainable model for providing comprehensive, integrated rehabilitation and education for 650 youth from Pi County, who are disabled primarily by polio.

Project objectives

- Improve the capacity of the polio cases and their families to sustain individual rehabilitation outcomes while achieving their educational and vocational potential.
- Assist the target group to complete their corrective surgeries, especially those that need to be done after skeletal maturity, with the necessary rehabilitation and educational tutoring during convalescence.
- Assist the target group to complete the nine-years mandatory education program.
- Investigate and prepare a comprehensive plan for Senior Middle School and Vocational Training Middle School attendance.
- Investigate and prepare a comprehensive plan for pre-vocational and short-course vocational training programs in 2003-4.
- Produce good-quality orthoses on site in NHC with repair services and also provide wheelchairs, cycles, and adaptive equipment, in as cost-effective manner as possible.
- Provide effective rehabilitation services for polio cases from Pi Zhou City (formerly as Pi County) and other nearby counties.
- Develop NHC Board's capacity to effectively oversee the project and develop administrative, professional, and financial sustainability.
- Improve the administration and management of the project, especially in ongoing project evaluation and program planning, use of report information for internal quality control, fundraising, training of department leaders to take responsibility in management and team building, and running a cost-effective micro credit program.

There were two sub projects in two different counties:

The Pi Zhou Project

The Pi Zhou project was initiated and supported by the local government and Red Cross. A surgeon was sent for specialized training; and surgeries were started. The local government donated land and money for the first building phase of New Hope Center. Various hospitals were involved in providing surgeries, rehabilitation, coordinate orthoses, and direct follow-up in townships.

The New Hope Center combined a dormitory-based, integrated education and rehabilitation center for 90 cases with severe polio and a mobile team and CBR approach for 560 cases. The strategy included provision of an environment for severely involved children to access barrier-free primary school integrated with rehabilitation; a place for project administration; a home base for mobile team and CBR follow-up of cases for all of Pi County; site for the orthotic lab; site for intensive rehabilitation training of polio cases; short summer camps for short courses in crafts, arts, life skills for children, a resource for demonstration to society of the human potential of these children; a base for outside specialists to work and stay; and a point for other areas to learn how to do functional-outcome based services for children with polio.

Training of NHC staff on project management, community based rehabilitation and social work professions was provided by the Amity staff. Other training in medical field such as PT, OT, orthotics has been provided directly by NMA staff and consultants.

The training has been based on certain key concepts illustrating the characteristics of the rehabilitation model:

Rehabilitation model

- Functional based outcome criteria when deciding which surgeries to perform for an individual.
- Introducing scoliosis surgery methods for polio cases.
- Using orthotics and adaptive equipment to support weak extremities, in order to improve mobility in patterns that will be safe to use over the lifespan.
- Using physical rehabilitation methods and functional training for each case to achieve mobility.
- Using a case management approach, coordinating surgeries with rehabilitation and orthotics, as well as integrating new mobility skills into family and school settings.
- Providing rehabilitation and orthotic services within both CeBR and CBR models, so that case management work followed through each case as necessary at the school and home levels.
- Subsidizing school tuition as well as subsidizing orthotics, surgeries, and rehabilitation to supplement what families could pay for their children during the growth years.
- Setting up transparent administrative routines to support a result-oriented functional outcome project.

The Shuyang County CBR project

The Shuyang County Polio Project began in 1994. One County Hospital nurse was trained initially in rehabilitation with on-site follow-up training. Cases were followed four times a year at County Hospital for rehabilitation, orthotics, adaptive equipment, and education. In addition, project staff made home visits to those cases with difficulties.

A marked change in the Shuyang Project occurred in 1998 and most of the activities came to a halt. The project document for phase 2 states that NMA staff made repeated, specific project recommendations to correct the situation, but at the end decided to terminate the project after phase one.

2.2. Context**Socio-economic Situation**

The 2007 government statistics for China, Jiangsu Province, Xu Zhou (the city which administers Pi Zhou) and Pi Zhou (a county-level city), demonstrate that Jiangsu is quite well-off as a province. While rural areas of Xu Zhou and Pi Zhou are poorer compared with the average in Jiangsu Province; they are still higher than national average. Pizhou also has less poverty than other counties under the administration of Xu Zhou.

Figure 1: Economic Information (2007) www.stats.gov.cn

	Population	Per Capita GDP	Average annual /capita net income (Yuan)	
		Yuan (US\$)	Rural	Urban
PR of China	1,321,290,000	35,000 (4300)	4140	13786
Jiangsu Province	76,245,000	35,000 (4300)	6561	16378
Xu Zhou City	8,711,200	N/A	5534	16366
Pi Zhou	1,462,800	N/A	5770*	15746

*Rural per capita annual net income in China, rose to CNY 5,770, an increase of 13.4% over last year.

There is no summary of the present situation of the young people targeted by the Polio Project. Since these young people are just starting out, and many still live with their families it is difficult to judge, but most of them appear to be satisfied. For those getting only Yuan 300-400/month they still need family support, but the individuals earning Yuan 1000/month (which was many of those interviewed) they are within the rural average, although since they wish to live in the city, they will need to increase their earnings in order to start families. The annual social economic development report (Statistics Bureau) shows the national poverty level is divided into two categories: annual income less than Yuan 785 (US\$95) and

between Yuan 785 and 1,067 (US\$130). According to a poverty report in Jiangsu, the province uses a higher level to define poverty. The number of people whose annual income is lower than Yuan 2,500 (US\$305) is 3,586,000, with 83.6% of them located in the northern area of Jiangsu. See Figure 2 for more details regarding poverty in Xu Zhou.

Figure 2. Poverty Level of Xuzhou (2007)

	Less than 2500 Yuan		Countryside		Percentage of all population	
	No. of Families	Population	No. of Families	Population	Family (%)	Population (%)
Xu Zhou All	324,762	1,002,679	1,840,800	695,8000	17.64	14.41
Feng Xian	62,649	210,800	255,300	971,500	24.54	21.70
Pei Xian	39,210	120,573	250,200	979,100	15.67	12.31
Tong Shan	45,464	104,763	280,800	1,007,000	16.19	10.40
Sui Ning	71,353	232,989	284,600	1,139,800	25.07	20.44
Xin Yi	37,859	103,885	210,500	799,500	17.99	12.99
Pi Zhou	47,851	178,124	37,300	1,411,300	12.83	12.62

Educational statistics in Pi Zhou are excellent. Percentage of children who enter school in 2007, is 100% with all proceeding to middle school, with the nine-year, free education law. There are three vocational high schools with 8,564 students, an increase of 21.5% over last year. The two special education schools together have 2,375 students in 2007, an increase of 210% over the previous year, which probably demonstrates the increased awareness of the rights of all children to attend school, even those with disability. The Polio Project target group also attained almost 100% schooling earlier than the county as a whole.

Situation of People with Disability in People's Republic of China

The National Co-ordination Committee of Disability is made up of representatives of 32 different ministries and executives of the China Disabled Persons Federation. The aim is to co-ordinate their approaches for helping people with disabilities, draft policies, regulations and laws, and ultimately to ensure a certain level of mainstreaming. However, this inter-sectoral co-ordination is not so easy to operationalize at the front-line, unless there are very clear government endorsed targets or projects. For example, a poverty alleviation project to repair homes or provide micro-credit, may neglect disabled people as they are seen as the responsibility of CDPF.

The Ministry of Public Health has regulations that third level hospitals (in Pi Zhou there will be several of these) must have comprehensive rehabilitation medicine departments. In reality, these departments, in a city such as Pi Zhou, will be limited to fairly passive therapies aimed at pain relief and movement, and are not yet comprehensive in nature. Most patients after stroke, fractures, or with spinal cord injury or a child born with cerebral palsy or a muscle disease will need to go a Xu Zhou or Nanjing to get basic rehabilitation services. Access to medical rehabilitation is changing rapidly as more rehabilitation therapists are graduated. Recent changes in the health sector promote comprehensive community health centres, which in bigger cities may include rehabilitation for some categories of disabilities.

The Ministry of Civil Affairs is responsible for child welfare institutes (orphanages, where many children abandoned are disabled), social welfare institutes (for older orphans, elderly persons without families and people with mental illness) and centers for disabled soldiers. They are also responsible for allowances for those in poverty and dire need. Each province has at least one factory /assembling plant for artificial limbs and orthoses under the Civil Affairs although this is changing in major cities as hospitals develop their own departments and the private sector is growing.

The Ministry of Education is responsible for special schools and they have over the last 15 years, piloted different approaches on the continuum from special school to inclusive education (special classes in regular schools, some integrated classes, etc.). Any district with more than 400,000 population must have a special school.

Other Ministries with roles include Police and Security, Finance and Planning. Any community-based rehabilitation project needs to ensure their endorsement, as well as that of the local government at each level.

The China Disabled Persons Federation (CDPF) was formalized as an independent organization (a government related NGO) in 1988. It was preceded by the China Welfare Fund for the Handicapped formed in the early 80s. It was founded by Mr. Deng Pufang, (himself a wheelchair user), son of the then President of PR China, Mr. Deng Xiaoping. It is a national organization, with a structure exactly matching a government ministry, with offices at provincial, city, district, county levels and more recently at street (communities in cities) and townships (rural areas). Local governments fund offices (buildings) and staff, which normally should include many staff with disability. Operational funds come from a variety of sources including fines collected from companies that do not fulfil the employment quota for disabled people in their workforce. CDPF directs their work through five-year plans that are integrated into the national government five-year development plans. They have been instrumental in the passing of the various laws and regulations listed below.

2006 National Sample Survey of People with Disabilities

The first sample survey of people with disability in China was carried out in 1987, finding 5% of the population with a permanent disability. Continuing to use strict disability criteria, on the basis of the second sample survey in 2006, it is estimated that 82.96 million persons have disabilities (seven categories), being 6.34% of the population.

Figure 3: Information about Disability in China www.cdpf.org.cn

	Population of PWD (millions)	% total population	Ave Annual Income (hsehd)		Poverty level (% below) (Annual /capita income)	
			rural	urban	<683 Yuan	684-944Yuan
PR China	82.96	6.35	2260	4864	12.95%	7.96%
Jiangsu	4.79	6.4	N/A		N/A	
Xu Zhou	0.58	6.34	N/A		N/A	
Pi Zhou **	0.104	6.4	N/A		N/A	

** verbal estimate from Pi Zhou DPF official

Figure 4: Classification of Disabilities in China & Pi Zhou

Type of Disabilities	National pop'n	%	Pi Zhou (estimate)*	
Visual	12.33 m	15 %	15,545	15 %
Hearing	20.04 m	24 %	25,273	24 %
Speech	1.27 m	2 %	1,600	2 %
Physical	24.12 m	29 %	30,410	30 %
Intellectual	5.54 m	7 %	6,987	67 %
Mental Illness	6.14 m	7 %	7,741	7 %
Multiple	13.52 m	16 %	17,051	16 %
Total	82.96 m		104,607	

* Pi Zhou was not a sample county in the 2006 survey, and these estimates appear to be directly taken from the national figures.

According to the sample survey, of children with disability (age 6-14 years), only 63 % were receiving schooling. Among all disabled people, only 36 % had received medical services and relief (required surgeries), while only 8 % had received rehabilitation training and services and 7.31% had received support appliances and services. The Pi Zhou Polio Project is exceptional in all these areas.

Some Relevant Laws, Regulations and National Policies

1991: The Law of the People's Republic of China on the Protection of Disabled Persons

1993: Persons with Disabilities Education Act

2007: Regulations on Employment of Persons with Disabilities

2008: UN Convention on the Rights of Persons with Disabilities (ratified)

2002: Setting of the national policy goal: "Access to basic rehabilitation services for all who need them by 2015". This goal has strongly promoted community-based rehabilitation (CBR) efforts, especially in urban districts. In 2008-09, CDPF is pushing rural areas to develop pilot CBR projects. Governments at all levels have been asked to provide funding on a per capita/population basis, with the advised level being based on the economic development of the region. Thus, when (not if) the Pi Zhou DPF develops rural CBR, they should have some small funding from the city government.

Additional efforts underway to support people with disability include: revision of the 1991 Law, reduction & exemption of the impoverished disabled persons from agricultural taxes (even after rural reform); continue to exempt import taxes on disability-related products, grant preferential legal services and financial support, etc.

NGOs and Private Groups working with People with Disability

The development of civil society has been supported by the Central Government to some extent in recent years, but it has had its ups and downs. In other fields, people's organizations for environmental action, child health, workers legal rights, occupational health, migrant rights, etc. have been established, but the list is constantly changing as they break up or reform. In the disability area, particularly common are small organizations set up by parents and/or professionals to provide services for their children with autism, cerebral palsy and mental handicap. Others include well-established and long-lived groups such as Amity in Nanjing, HANDA (working with ex-leprosy patients) in Guangzhou, and Holy Love in Chengdu.

NGOs have difficulty getting legal status particularly as non-profit organizations and many register as businesses. However, it depends on the individual city or provincial government if

they get tax-free status. All NGOs are expected to register under an approved umbrella organization such as CDPF, Civil Affairs, Red Cross, Women's Federation, etc. This organization then takes responsibility for government relations.

In spite of this, there are many small organizations managing very well and over the long-term. There are many NGOs set up with external donations. One major concern is building management capacity and accountability in these often family-based organizations.

The Changing Disability Context in China

The situation is changing rapidly along with the social and economic situation of the country. The families and local staff of the Pi Zhou Polio Project commented in different ways that the recent focus of the government to develop the rural areas has led to very much improved roads, public transport, water, sanitation facilities, schools and loan facilities, etc. This year, a further rural reform concerning land ownership is occurring that will allow farmers to pool their land for greater returns. Health reform is ensuring that rural residents can access basic health care, and in Jiangsu Province there is almost universal participation of rural residents in the new rural co-operative medical system.

These improvements in quality of life and increased access to information are helping families with disabled members to provide more space for growth and reach out to services available. In addition, in 2008, three big events have turned the attention of the country on to the significance of rehabilitation and the abilities of people with disabilities. These are the Olympics and sports rehabilitation, the Paralympics and amazing abilities, and the Wenchuan Earthquake in Sichuan, with more than 370,000 people injured and up to 10,000 left with permanent disabilities of varying degrees.

CHAPTER 3: FINDINGS AND OBSERVATIONS

3.1. Physical Rehabilitation

The polio rehabilitation project was established in 1993 when the children were aged five to six years old. In 2008, there were 648 people (350 males and 298 females) from the original target group. Average age is 20 years.

Rehabilitation treatment

Surgery: Plastic surgeries on extremities were performed on 488 patients (830 operations), including joint plasticity, tendon lengthening, transfer and release. The spinal surgery was performed in 98 cases and spinal revision in six cases.

Rehabilitation training: Rehabilitation interventions included muscle strength training, joint motion training, gait training, ADL training, pre and post operation training and psychological intervention.

Orthotics: Orthosis for lower limbs were 2756 pieces for 455 patients. Spinal braces were 232 pieces and corrective shoes 153 pairs. Orthosis maintenance for 362 patients has been provided in 2008. In addition, 49 patients with Knee-ankle-foot orthosis (KAFO) and 27 ankle-foot orthosis (AFO) and 108 pairs of corrective shoes have been produced in 2008. Assistive devices: The distribution of 2193 Crutches and 296 wheelchairs 296 was done during ten years.

Table 1. Application of orthosis

	Male	Females	Sum
Two leg KAFO	96	78	174
Left KAFO	67	76	139
Right KAFO	64	44	108
Left AFO	15	8	23
Right AFO	5	6	11
Sum	247	212	455

Rehabilitation efficacy

Physical function: Significant improvement of physical functions have been demonstrated in all patients. The most important achievement is the recovery of ambulation capacity in 95.8% of patients. All patients with one leg involvement resumed their independent walking. Majority (269 cases) of the 296 patients with paraplegia and quadriplegia regained walking capacity. Wheelchair dependence was seen in 27 patients with most severe paralysis on three or four limbs.

Application of orthosis: Dependence on orthoses for walking has been dramatically reduced. Among 455 patients with orthoses at entrance of the project, 106 patients (23%) reduced their dependence on orthoses, including 65% with both leg KAFO now requiring only single leg KAFO, 20 % with single KAFO to AFO, and 21 % with AFO to no orthosis.

One hundred sixty two patients (36%) do not use orthosis any more due to improvement of physical functions, including 71 % with both leg KAFO, 70 % with single KAFO and 21 % with AFO. Few of them had symptoms. Only eighty seven cases (41%) are still keeping the application of orthosis, including 187 patients remaining the same orthosis (127 % with both leg KAFO, 47 % with single KAFO, 13 % with AFO).

Table 2. Change of dependence on orthosis after project

	Baseline	Final evaluation
No orthosis	193	425
Two leg KAFO	174	127
Single leg KAFO	247	83
Single leg AFO	34	13

Activity of Daily Living (ADL): ADL includes eating, grooming, dressing, toileting, bladder and bowel control. All patients were dependent before the project. Up to today, 621 patients (96%) have resumed independent life and reasonable good quality of living. Twenty seven patients (4%) are partially dependent in ADL due to severe disability (wheelchair dependent). Significant improvement of ADL is attributed to rehabilitation interventions and body development. This dramatic improvement of actual physical function in ADL is much greater than their physiological function. We suggest that the adaptation from childhood through long term rehabilitation intervention may be the mechanism. For example, many patients with muscle strength less than grade two may walk freely without any orthosis and crutches.

Relationship between improvement of physical function and employment: Among the 648 patients, 344 have been employed and 271 are in schools, including 105 in universities and colleges, 120 in high school, 40 in technical school and six in secondary school. Unemployed are 33 including wheelchair dependent 9, paraplegia 8 and single leg paralysis 6. It is clear that physical limitation is one of the major causes of unemployment but not the only cause. Psychological problem should be taken into consideration. Some of the unemployed patients have potential to be employed by adaptive devices and training.

Achievement in sports: In the 13th Para-Olympic Games in Beijing, seven athletes from the New Hope Center obtained six gold medals, two silver medals and one bronze medal in table tennis. In addition, two people joined wheelchair tennis game and one person was in the team of Chinese wheelchair basketball. These achievements in disabled sports demonstrate the value of physical improvement as a result of systematic rehabilitation and point to the great potential in physical function. Participation in disabled sport may also benefit patients self esteem and social involvement. Some disabled athletes have obtained good rewards also financially in money and opportunities for further university studies.

Comparison of institutional and community based rehabilitation: The comparative data for efficacy of different types of rehabilitation are insufficient. From the sampling investigation, majority of the most severe cases were in the New Hope Center for institutional rehabilitation. Presence of severe patients in communities was moderate. Therefore, there is no solid basis for making direct comparison between institutional and community based rehabilitation. It is true that the New Hope Center played an important role for severely disabled polio victims. It is also true that an institutional rehabilitation center is essential for guidance and supervision for rehabilitation of people in the community.

Capacity building for medical rehabilitation

The new site for New Hope Center was completed in 2008. The new center has a rehabilitation building with 4500 m², and departments of PT, OT, ST, functional evaluation, orthosis workshop and sports for the disabled. Routine rehabilitation equipment has been installed, which are basically sufficient for long term rehabilitation service. Rehabilitation workers include one physiotherapist, eight rehabilitation therapists and three workers in orthosis. Clinical administration has been on the right track and software for long term

medical rehabilitation has been established. The orthosis workshop has capability to make KAFO, AFO, back brace, etc.

Cerebral palsy rehabilitation has been a new direction for NHC with reasonable good quality and parent satisfaction. It has recruited 97 CP children in treatment, partially funded by a new province-wide initiative of Disabled Persons Federation. Whether DPF continues in following years to select NHC as its training site is open.

Limitations

The physical infrastructure at the new site is still under construction. Equipment for rehabilitation therapy needs to be upgraded. There is no rehabilitation ward and no sufficient environment for patient education.

Medical professional leadership should also be upgraded. The team of rehabilitation service is not sufficiently mature, including low level of education. Administration and documentation of medical rehabilitation should also be improved. The capacity building of clinical rehabilitation is essential for future development of medical rehabilitation.

The follow up have been organized, but not comprehensive enough to draw a solid conclusion on treatment efficacy in order to prepare a scientific report for international scientific journals.

Case Report

Sha Xueli, female, 20 years, suffered from polio 20 years ago with paraplegia and creeper. She was on two leg KAFO when she was five years. She changed to a single leg KAFO five years ago and discarded crutches after two years. She walks now independently with single leg KAFO and no crutches even though her quadriceps is still paralyzed. She has full independence of daily living activities and has successfully opened a handicraft workshop with 80 employees. This girl is a good example for reduction of her orthosis application. She is also a good example for self employment.



Du Fuwei, male, 20 years suffered from polio for 20 years. He crawled and only started to walk with two leg KAFO and two crutches when he was five years old. He was admitted to the New Hope Center at the age of eight and then returned home. He attempted to change to single crutches and single KAFO, but a new deformity occurred after two years. He had to return to two leg KAFO and two crutches. However, he has been able to walk independently with one leg KAFO and without crutches for five years as muscle strength increase to grade four on right leg, even though muscle strength of his left leg still less than grade 2. He is fully independent in daily living activities. He has also opened a small business with income more than average level of the local residents. He has a girl friend and plan to be married this year.



Wang Haipeng, male, 21 years, quadriplegia from polio. He has been walking on two leg KAFO with two crutches. He received two operations on lower limbs and also spinal operation for scoliosis. He completed primary school in the New Hope Center. His two legs are completely paralyzed. His left hand grasp power is normal, but upper arm is paralyzed.

His right hand is weak, but upper arm is normal. He has been unemployed for 2 years. His daily living activity is limited to bathing only. He has been depressed for long time. During the evaluation, he happened to meet a classmate who is a three-wheel taxi driver. After 10 minutes driving, he was able to drive the car by himself. He was smiling and willing to start as a three-wheel taxi driver. This case demonstrates that unemployment to some extent is also due to lack of vocational counseling and training as well as motivation.



Before driving training



After training

3.2. Educational Potential

Education and level of education of a disabled person is an essential factor for successful integration into society. Based on the local situation, New Hope Center cooperated with the local education departments and schools to make such integration into education possible. According to the statistics, 90% of primary schools and middle schools in the county have now students with polio.

Up to 2008, 99.7% of the 648 children with polio have received education. Of them, five have graduated from universities, and 105 are now studying in universities. Of the target group, 12 graduated from high schools, 120 are now studying in high schools. 43 have found jobs after graduation from vocational schools and 40 are now studying in vocational schools. Of the 648 children with polio, 50% have received middle level and high level education. This figure is very close to the level of ordinary children in the area.

New Hope Center became an educational resource center for the children with polio in local community schools. The placement of children with polio to study in local community schools was a key to success. However, such placement required good supporting system. This is a challenge which needs to be addressed in also other part of China where children with disabilities are being integrated. The support from NHC came in different forms:

- (a) Training teachers in community schools about polio and issues related to disabilities. NHC invited professionals in special education to give lectures on psychological characteristics of children with disabilities and appropriate education methods.
- (b) Modifying school facilities in order to create a barrier-free environment. Many community schools in China have still barriers so it is difficult for students with disabilities to enter, for instance Chinese squat type toilets, many stairs and sidesteps. NHC provided schools with “seat toilets” and modified sidesteps into slopes, and equipped the schools with rehabilitation equipment and helped children with daily transportation to schools.
- (c) Regular training courses for parents teaching them to support and train their own children.

- (d) Regular visits to community schools and homes providing help and offer education scholarships for the poor.

Inclusive education

Inclusive education has benefited both polio children and schools. The community schools selected motivated teachers to teach classes with polio children. At the same time, with the investment from NHC, the schools modified canteens, dormitories, equipped classrooms with ramps, corridor with handrails etc. The schools also established support group for polio children helping with practical and pedagogical issues.

Inclusive education has also provided ordinary students with the opportunity to learn from children with disabilities. It has created a win-win situation. Teachers can see disabled children study along side their able-bodied peers. After classes, the teachers and classmates would help polio children with difficulties. Between classes, children with disabilities played games and table tennis together with ordinary children. On the way to and from school, able-bodied students helped children with their bags and pushed their wheelchairs. At home, disabled children played together with children in the neighbourhood. CBR field workers offered polio children with guidance and support.

Vocational education and work

At present, the 43 people who graduated from vocational training have jobs. 40 are still studying in vocational schools and most of them are in practical training. The vocational schools helped students with polio to choose a career most suitable to him or her. Most students with polio preferred professions to do with clothing, computers and electronics. After graduation in these professions, they went to jobs in factories, or set up their own businesses.

The 43 young people who have jobs, are now working in factories in Changzhou, Nanjing, Zhenjiang and Shanghai. For those who set up their own small business, teachers offered technical support and guidance in business planning. For example, Chen Hai Gang from Che Fu Shan Township, when he graduated from vocational school, set up a mobile phone business to sell and repair mobile phones.

Sports and culture

The New Hope Center also organized various interests groups and training programmes in music, art, calligraphy, paper-cutting, bonsai, computer, and sports like wheelchair table tennis, wheelchair rugby, weight-lifting, shooting, etc. The wheelchair table tennis team has participated in several competitions at provincial, national and international levels and has received some 200 medals. Eight members from the NHC team were selected to the national sports team and won six gold medals, two silver medals and one bronze medal in the 2008 Beijing Paralympics. Two in the national wheelchair tennis team and one in wheelchair basketball team achieved also very good results. The NHC Chinese Music Band, consisting of 32 children with polio, gave about 100 performances inside and outside the province over the last 6 years. The art works of calligraphy, painting and paper-cutting of they were presented in many exhibitions at the provincial and national levels and won about 60 medals.

3.3. Social Integration

Through a small series of interviews, we considered the extent of social integration of the youth and from the other side, the changes in social attitudes and community environment.

We interviewed four young adults about their daily life and a group discussion was held with 14 others. All these 18 young people had attended at least to middle school, with most working and a couple still studying. We also interviewed the parents of two university students in their own homes in the villages (the students were away) and one family, where the young couple (both with polio), had married and had a four-month baby, and were living with the husbands family (father, grandmother and others).

The work consisted of: family-owned shops selling small daily necessities, private business (e.g, mobile phones, jade carving), contract work for handicraft & jewelry items, sewing in a factory (with other disabled workers but in open employment), working in open employment, and at least one young lady who was the middle-person to organize 80 non-disabled women to take on contract work at their homes.

One young man interviewed was studying at a public health school (pharmacy studies) and another, who graduated from middle school, was studying jade carving on a part-time basis. Two families were proud that their son/daughter was studying at university⁴.

Achievements

It is quite clear that in spite of some special challenges, these young people have daily lives very similar to their peers. They go to work or school in the mornings, dressing in very typical and smart clothing (brand name running shoes, jeans, etc), with hairstyles like their peers. They have found different ways of transportation, they use mobile phones frequently, they claim their phone books are full of friends without disability, they go out to eat in restaurants, are thinking about how to improve their lives in the future and most of them seemed to be focused on themselves. The group interview demonstrated a range of characters, voices and personalities.

Although their finances are not plentiful, not one of the young people we spoke with complained about lack of money, perhaps because of family support. They control their own spending and saving. The young women with more severe disabilities, who are using wheelchairs, said they got about RMB 300-400/month (about US\$50) working in a clothing factory in a county 40km from Pizhou. Others made between 800-1000/month. None of them claimed to give money back to their families, but hoped to later and most stated their families give them money. This is the usual case for all young people in China these days. Those still in college received support from family, NHC scholarships and some loans.

Important challenges described by all the young people were to do with decreased mobility and physical barriers, but their confidence levels are generally high and they were comfortable asking for help. One young man said the only barrier he faced was he could not lift heavy objects by himself. This type of example was commonly voiced, rather than complaints about other people's attitudes.

⁴ Questions and details of the interviews may be found in Annex 5.

Only one person stated that hospital staff had bad attitudes towards her, but she was not able to come up with any specific example. One spoke of being initially rejected at public health school, but accepted after intervention from a family friend. The first week as a student in this college was difficult, but once the other students and teachers got to know him they have only offered help. He says he feels confident (after the first week) to ask them for help and to say when he doesn't need their help.

The integrated rehabilitation model of the project, with family-like spirit, seems to have instilled in these young people, a high level of self-confidence and self-esteem. They know how to make good use of their own self in order to change other people's attitudes. The story of how the two young persons with polio persevered in the face of parental displeasure to get married and have a baby, demonstrates this confidence, striving for self-determination and basically an optimistic outlook.

The educational opportunities as well as the opportunities to learn leisure activities (handicrafts, music, sports) and community skills during holidays with psychosocial support to get over the hard times (from the NHC and the community workers) probably gave them some advantages over their peers from the rural villages which helped towards balancing the physical issues. Their teachers (and project staff) assumed they would be able to find work and the assumptions are perhaps self-fulfilling to some extent from the young people's perspective.

The project has affected change and acceptance in social attitudes and accommodation through a non-confrontational approach. Although in many countries there is an aggressive assertion of rights, the silent and implicit strategy is certainly valid and perhaps even receives greater long-term acceptance in Chinese society. Those who come into contact with the young graduates of the polio project, after an initial uncomfortableness, seem to have instinctively understood that they are fine young people with the same hopes and desires as those without physical disabilities. They certainly dress and act the same way and are visible in all locations of the community.

The project staff has made use of the community resources: health care, schools, work opportunities, as well as using the national directives such as the Education Law and the "work quota regulations", to support their work. In addition and more explicitly, programmes such as sports for the disabled, arts and music troupe and "abilympics" (skills contests) are national strategies for awareness and promotion of the abilities of people with disability, and Pizhou has both led and joined these activities very successfully. They have raised the profile of the young people, given them social skills and opened doors to travel and new experiences in their own and other provinces.

From the family perspective, the Polio Project gave their child a life. They very much appreciate the NHC work and the ongoing relationships, but they don't have a sense that NHC owes them anything; that is the NHC has not created a dependency attitude either for them or their children. They also do not see themselves as resource persons however in their own communities. This needs to be investigated further to see if there are parents or family members who could become future community workers for other children with disability.

Limitations

The young people (perhaps as all young people) are adapting themselves to the physical and social demands of their communities, instead of asserting their rights, for example for barrier-

free schools, toilets on the same floor as their classrooms. They don't want to stand out or bother people. Even when the public health college rejected one young man, his family found someone to intervene for them rather than make a public issue of the unfairness. In today's understanding of the world, the physical and social environment should be changed equally or more: "rather than fit the square peg into the round hole, why not accept different shapes"; can our schools and communities accept diversity and difference? This is a recent western concept that is not well accepted in China and indeed creates difficulties for all children with differences.

The project was able to affect change in schools, vocational schools, and communities for this large group of children with polio disabilities. However, the opportunity to use it as a springboard for community rehabilitation strategies to help other children with disability has not been grasped by the local or national Disabled Persons Federation. The community network has not been maintained since 2006, the vocational schools (and probably primary and middle schools), that opened their doors, are not considering accepting the children with cerebral palsy or other more complex conditions. It is unfortunate that the Disabled Persons Federation, who has responsibility for programmes to improve the lives of all disabled people did not build on (not necessarily to take up the polio project itself) the structures of this project at an earlier stage. This is to some extent due to the general level of development of the rehabilitation work in past years, where they focus on achieving targets. In the last 5-10 years, there is a strong national strategy promoting community based rehabilitation however, and surely this project is one excellent model, and with its strong core (institution), a very acceptable model in China.

3.4. Models for Rehabilitation

According to the project document, two holistic models for physical and social rehabilitation of persons with disabilities were followed:

- (a) The first model was an *adapted community based rehabilitation (CBR) model* – taking rehabilitation and other services as close to the grass roots as possible and using as many local personnel and resources as possible without excluding use of external personnel and resources when needed to achieve functional results for individual children.
- (b) The second model was an *institutional model* (New Hope Center), providing integrated education and rehabilitation in an accessible environment serving the more severely disabled children.

The community based approach to rehabilitation was organised as follows: children were brought to county (Pi) and city (Zhen Jiang) level for surgeries, initial provision of orthotics and exercise prescription was done by experts from Norway (Taiwan) and Nanjing; with external financing and local official endorsement; and training of local county staff to monitor follow-up

Community services were then set up using township and village doctors to make home visits, supervise exercises, repair orthotics, follow-up surgeries, directed and monitored from county-level. CBR front-line work was strengthened in 1997 by hiring eleven full-time local (village/community) staff responsible to ensure that every child was seen weekly. This organized and closely monitored input was seen as a significant aspect, which impacted on the outcomes for the children. The special characteristics of the model were:

- A community-based rehabilitation model, but with very strong direction from centre (Pizhou New Hope Centre) and external expertise and all financing from outside
- Functional-outcome based, integrated team methods for polio cases.
- Principles of case management of disabled children and youth.
- Adaptation to local situation and needs, using a strong institutional core.
- Model for training specific CBR skills with regular upgrading.
- Integrated surgeries and rehabilitation exercise, orthoses and assistive devices.
- Children ensured an education through provision of advocacy and real support for environment modifications, transportation, accessible dormitories and whatever else was required to maintain a child in school.
- Gradual decrease of direction and supervision of the children as they grew older with decisions for further schooling, work opportunities and adult life being made by the family and individuals concerned (except for those on the national paralympic team).
- Transparent administrative routines.

The Norwegian partner and experts have several time raised questions about the institutional approach arguing that small children should stay with their parents if at all possible, grow up and go to school in their own family and local community⁵. Chinese counterparts have defended the need for a Center because:

- Severely disabled children are not able to go to school, families are not able to bring them there and most normal schools have too many barriers for disabled children.
- A center gives the project higher visibility and status among parents and government authorities.
- Institutions are common in China and seen as necessary for a rehabilitation project.
- A center with strong expertise and capacity for providing technical, managerial support and training to community workers is required – also for a CBR programme.
- The center has enabled and supported most of the sports and cultural activities.

The evaluation team had various opinions as regards institutional versus community based models. There was general agreement that effective rehabilitation requires a central model with technical expertise and administrative capacity for coordinating the work, offer training and carry out supervision. The most severely disabled will also need institutional care. The team also acknowledged that New Hope Center provided a necessary place for children from the community to stay a short period of time for receiving intensive rehabilitation training pre and post surgeries.

However, members of the team argued that the polio project had followed primarily an institutional model with a community component – and not the other way around. In an institutional model most resources tend to gravitate to and be absorbed by the Center creating a model which is not sustainable and replicable in other settings.

NMA could have advocated more strongly for the benefits of community models – or at least not terminated the CBR project in Shuyang County after phase 1. It should also be mentioned that the team visited families with severely disabled children who had lived at home with their families, brought regularly to the nearest community school by their siblings and now studying at universities. A CBR model seems to work also for the most severe cases if parents are prepared and motivated and given sufficient support.

⁵ A summary of the international debate about institutional versus community based approaches can be found in Annex 4.

A study of rehabilitation model

A research project was carried out in 2004 comparing the educational achievements and psychological outcomes on children exposed to different rehabilitation strategies in Pi County (Xu Jian Cheng and Wang Ming Bin, 2004).

The study covered 500 randomly selected children. A total of 427 questionnaires were collected from three different groups: An experimental group with 212 polio children and a group of 215 ordinary children as comparison. The experimental group was divided in two - those who lived and studied in New Hope Center (the institutional group) and the community group of those who lived at home and studied in local community schools.

Some of the findings were:

- (a) Average results from an intelligence test showed that the community experimental group performed better than for the comparative group. After one year, however, the marginal difference disappeared. The institutional group achieved more or less the same results.
- (b) In terms of perseverance and boldness, the study showed that there was no significant difference among the groups in first grade. In second grade, average scores for the community experimental group were much higher than the “normal” group and the institutional group somewhat higher than its comparative group suggesting that the polio children were more perseverant to carry things to the end.
- (c) The mental health condition of students in the institutional group was found to be problematic:
 - Several children showed special behaviour, like being too pedantic, checking things over and over again without trusting themselves, repeatedly washing hands, counting numbers and touching things, etc.
 - Feeling inferior and dispirited.
 - Showing certain anxious reactions, feeling insecure, frightened without any reason, restless and distracted.
 - Being hostile, getting easily worried, loosing temper and argue with others.
 - Having stubbornly biased reaction, always feeling that someone or other want to take advantage over them, and that the most people cannot be trusted.

The study argued and concluded that since the polio children in the community group did not receive the special care as the institutional group did and their achievement and development were equally good or sometimes better, polio children should be integrated into their community to the extent possible. New Hope Center should consequently improve and strengthen its community based rehabilitation work.

Issues of costs and cost effectiveness

Evaluations of social development projects often ignore assessments of costs. This is unfortunate, because a model for rehabilitation might be technically sound and highly effective, but too costly and not sustainable. Implementation may require an external donor because it cannot be sustained with local resources. Cost issues are complex and only some will be discussed here.

During the period 1993 to 2008, New Hope Center received significant external support. The following table shows that NMA has been the single most important donor (in particular between 1993 and 2006 with support from Norad) while less than 8 % has come from local sources.

The total investment over 15 years has been 24,5 mill CNY (approx 22 mill NOK). The costs of external personnel and equipment (surgeries and equipment for scoliosis, visits of Norwegian doctors, visits and follow up from physiotherapist and orthosis experts from Taiwan) are not included in this figure and could add another 3-5 million CNY. If we estimate total cost to 28 million CNY for a target group of 750 children – the cost per child per year is approx. 373 000 CNY or approx. 37 000 CNY (33000 NOK) per year. The figures are not exact and hide also differences between children living in New Hope Center and those staying with their families, but illustrate the very high level of funding and cost.

Year	NMA through Amity	NMA transfer	Pizhou Gov. and society
1993	78,059.60		3,000.00
1994	104,038.00		103,000.00
1995	477,193.00		100,000.00
1996	2,044,650.00		50,000.00
1997	1,834,895.00		50,000.00
1998	2,120,482.00		35,000.00
1999	2,015,000.00		41,781.08
2000	1,596,200.00		43,725.28
2001	2,015,999.13		89,021.50
2002	2,443,233.53		216,630.23
2003	2,736,926.00		273,172.90
2004	1,400,000.00		182,900.83
2005	1,680,202.90		231,959.25
2006	1,201,265.61		217,710.68
2007	182,180.56	444,299.46	135,016.61
2008		267,130.71	68,729.70
Total	21,930,325.53	711,430.17	1,839,648.06

Currency: CNY (1 CNY in average 0.89 NOK)

Resources have been spent well and prudently. There has been no extravagance, but on the other hand costly operations have been carried out because they were required for effective medical rehabilitation.

We are not able to assess if this has been an appropriate level of investment. It has certainly created results for the target group and their families. However, there are several thorny questions: Has the total cost of the project been too high? Is the model too expensive in a Chinese context and as such not a model for the country – because it cannot be replicated and sustained with local resources? The next set of questions is to what extent there would have been alternative ways of implementing the model creating similar or even better results?

The total investment is high and higher than local governments in China will spend on a similar project. Allocations from the National Federation of the Disabled to the new CP children will be much lower – maybe one third or fourth of what the New Hope Center have been able to spend on polio children.

Could the same amount of resources have brought more or better results by using alternative approaches/models, like:

- Gradually reducing number of children living in the NHC and rotating the children living in the NHC by only the medical needs.
- Shift balance from an institutional towards more and less costly community based approaches.
- More partnering and cost-sharing with other organisations.

New Hope Center may have followed the best course, but could have raised and discussed questions of costs more systematically. However, since sufficient funds always were available from the donor, it was probably not seen as necessary.

3.5. Micro Finance

The micro credit programme started in 1998 and has all the time been managed by an independent organisation - Lao Chu Hui (LCH). The amount of capital from the start was CNY 100,000 gradually increased to CNY 830,000. Interest on loans was not charged until 2004. Annual interest rate was then set to 6% covering all expenses in managing the programme. New Hope Center became responsible for monitoring implementation and visited regularly villages and towns two or three times a year. Such expenses were covered by NHC.

Loans were and are only given to the target group and their families. The entire capital was all loaned to 178 clients in 2004 and all repaid April 2008 year and then loaned out again. Almost all loans are meant to parents helping them to generate more income and cover extra expenses for school fees, transport, etc. Most of the loans have been used for activities like: chicken and pig raising, planting and greenhouses, workshops, brick making, etc. Total amount per family used to be CNY 3000, but it is now increased to CNY 5000.

The micro credit programme has been very successfully implemented. There have hardly been any defaulters among the families with a repayment rate nearly 100%. In other words, the original capital is still intact.

Previous evaluations have shown economic benefits for families. A family in Chen-shan village within Pi County, with a polio girl named Ku Fang is a typical example. They loaned 3,000 and rented a piece of land and planted watermelons and peanuts. The family got a net income about CNY 2,000, which was about 2.5 time of their annual income before. Another case is a family in Shan-Lin village, with a polio girl name Wang Jing loaned CNY 3000 and bought pigs and raised pigs. Her net income is CNY 4300.

A previous evaluation found that the micro credit programme had helped 70% of 167 families of children with polio to rise above the poverty line of annual income of CNY 1200 per capita, as defined by the Pi County government. The importance of the micro credit programme has probably been reduced since the economic situation in the County and among the families has improved, but it is important to keep in mind that poor families in rural areas have no collateral and few alternative ways of getting access to credit.

NMA has decided to terminate the credit programme in 2010 – and all clients have been told to pay back their loans. The original capital will be given to the new Hope Center for supporting future operation of the Center.

The need for loans to families has been reduced, but most of the children are now young adults. Some of them are in higher education and an increasing number are trying and will try to establish themselves as entrepreneurs. In other words, they are in need of scholarships, seed money and small loans for setting up businesses. All or a part of the original capital should be made available for loans – not any longer to parents, but to the young people – helping them in the next step forward. . In other words, NMA should reconsider its decision.

3.6. Advocacy for Disabled People's Rights

The question is to what extent the project has promoted and advocated for disabled people's rights? This is a complex question that needs to be understood in the right context. Central to rights based approach to development is the protection and realization of human rights – including the rights of the disabled. It uses established and accepted standards as a common framework for assessing and guiding all development initiatives. Protecting and fulfilling human rights obligations is seen as the way to achieve development.

A rights based approach may lead to different outcomes than other development models because it entails another view of action. Rather than pursuing an action merely as part of a project, such as providing services for polio children, a rights based approach will also make demands on national and local governments. It translates people's needs into rights and recognizes the human rights of disabled people without necessarily ignoring people's physical needs. This approach also changes the situation of the beneficiary group from passive aid recipient to rights-holders, empowered to hold responsible actors accountable.

What could a rights based approach have meant for the polio project? Relevant activities would have been establishing parent groups supporting and advocating for the rights of their children, negotiating with the local government to provide more support to the disabled, using China's laws and regulations to make sure that disabled children are educated, not discriminated and gradually prepared for a handing over of responsibility to the Government, etc.

To what extent has the project followed and taken into account a rights based perspective? First of all – such a perspective was not well known when the project started. It is neither mentioned in the project document. The emphasis has been on providing services to a group of children in need of help and secondly to develop and promote a comprehensive model of medical and social rehabilitation – and primarily the first. Several informants have also mentioned that there is no scope for advocacy organisations (based on the western model) in China. In other words, it would not have been possible for the New Hope Center to be a more vocal representative for the disabled. Other more simple reasons for a low advocacy profile could be that they were too busy getting the job done or they did not find an advocate at higher level who wanted to promote them (Amity keeps generally a low profile and CDPF or local Provincial DPF was not developed enough to see the unique lessons of the project and how they could be distilled for their work).

On the other hand, the Center has proven that it is possible to rehabilitate even severely disabled children. Children are able to walk, go to normal schools, drive motor bikes, start small businesses, marry and have children which represent indirect and effective model building and possibly advocacy. New Hope Center is also well respected by the Government and sometimes used as an example for assisting other groups of disabled. The Center could have used its connections and status to leverage more support and advocate for other changes, but this has not happened.

3.7. Future sustainability

The question about future sustainability has several dimensions. The first is to what extent New Hope Center will be able to continue its activities in the future without financial support from the Norwegian donor. It is important to keep in mind that the funding from NMA dropped significantly between 2006 and 2007 (from 1.2 mill CNY to 626 500 CNY).

However, Norwegian support continued at a low level in 2008 and may stop completely from 2009 – according to existing plans.

Another important development is that NHC has taken up work among a new target group – children affected by cerebral palsy. An annual amount per child is provided from the Government through the Provincial Disabled Persons Federation. The total number of children is approximately 90, of which 4-5 at present have autism.

A fundamental question is to what extent the polio project should be sustained – a question which is different from whether the New Hope Center should continue as before – only with a new target group. One line of argument is that the polio project started in 1993 and is gradually coming to a successful end after 15 years. The original problem is basically solved! A large number of children have been physically rehabilitated, offered education and vocational training and an increasing number are successfully employed. The target group will over the next years need intermittent medical checkups, some scholarships for further education and vocational training and others advice and credit when entering the job market and a reference point or an organization representing their interests.

This means that the project is almost over. As such, it is a model case – one of the few development projects that have come to an end because objectives are achieved. It does not need to be sustained in the form of a large center as long as a minimum level of follow up is secured. The fact that there is a physical infrastructure in place is from this perspective irrelevant and should be discussed separately from a continuation of the polio project. It is also irrelevant that a number of adults are attached to and would like to continue a meaningful and life long involvement with children that are not any longer children and will need them less and less over the next few years.

It is important to make effective use of existing staff and infrastructure and also provide support to other groups of disabled, but the existence of staff and infrastructure do not justify a continuation of the project. We suggest preparing a plan for gradual phasing out of the polio project based on a careful assessment of what follow up is needed. The continued use, funding and organization of the New Hope Center should be discussed separately.

Current project organisation

When the New Hope Center was fully operational approximately 100 children stayed at the Center supported by 40-50 staff. At the moment NHC has 23 staff⁶ and plans to recruit more in order to assist the CP children. The New Hope Center is registered as a non-profit entity under the Civil Affairs Bureau. It has a separate Board. For two years there has been an acting Director (since the first and only Director became ill).

There are several problems and weaknesses in the current project organization that need to be resolved urgently:

- There has been no Board for two years and consequently no board meetings - in a period where the Center has been through its most important transition.
- The Acting Director was appointed by the previous Director without approval of the Board. There are no plans for starting a recruitment process – partly because there is no one to initiate and organize such a process.

⁶ 12 in rehabilitation, 2 in brace workshop, 3 in finance/management, 2 in supply, 2 CP teachers and 2 care givers.

- There are different and to some extent conflicting perceptions about project ownership – but also about ownership of buildings and equipment. Pizhou Red Cross claims that the New Hope Center is a project under Red Cross and that Red Cross is the legal owner of land, buildings and equipment while NHC management maintains that the ownership is with the New Hope Center as an independent legal body.
- There are also different views on long-term direction and strategy. Red Cross is ready to appoint and reestablish a new Board and develop a disability center under Red Cross while the current leadership would like to be an independent NGO led by a Board with representatives from various partners.

In other words, the situation is unclear. Issues of legal ownership are complex in China. We suggest that Norwegian Mission Alliance through Shincon assists New Hope Center to clarify its legal status and issues of ownership – if necessary with the use of a legal expert. The next step will be to identify and discuss future options and make decisions. There are several possible scenarios:

1. If Red Cross is found to be the legal owner of the New Hope Center – organization, buildings, equipment, etc. – it is their responsibility to reestablish the Board and prepare a medium and long-term plan for the Center – including the funding and appointment of a New Director.
2. If the New Hope Center is an independent legal entity (owned by its own Board), there are various options:
 - Maintain New Hope Center as an independent entity and establish a Board with representatives from stakeholders (like Red Cross, the national Disabled Persons Federation, etc.) and selected individuals.
 - Hand over the Center to Red Cross and formalize what was not clear in alternative 1 above
 - Hand over the Center to the national Disabled Persons Federation – the most logical owner given the target group and plans for establishing a rehabilitation center for disabled persons in Pizhou.
 - Discuss if Amity or a similar organization could take the responsibility for maintaining an independent Center – in order to keep the NGO character of the Center (since both Red Cross and the National Federation are semi- government entities)⁷.

The current situation is fragile and unsustainable. The New Hope Center goes through a well known process of transition from being a pioneer organisation led by a strong leader and founding father to become a permanent organization with more formalized structures and a new leader. The Center has not been able to go through such a transition on its own, and Norwegian Mission Alliance has either not seen the problem as their responsibility or not been willing or able to go into relatively complex and sensitive issues and provide necessary support.

The sustainability of competence and knowledge

Another important asset is the knowledge and technical competence that have been built up over 15 years. Knowledge of integrated rehabilitation, including a community support

⁷ Red Cross and CDPF are GO NGOs; they are not government ministries as such, but get their salary and some other funding from government; and would like to think they represent government. The problem with Red Cross taking it over is that CP and autism, mental handicap rehab is too far from their terms of reference (medical, relief, etc).

network that worked during the vital years when the kids were at community schools, has been missing in China and was introduced through the polio project. The New Hope Center is trying hard to get new skills and experience, based on their own strengths; and they are already doing much better than anyone else in Pi Zhou.

As part of the follow up, NMA could provide some financial support for research and documentation of the rehabilitation model and its effects. Based on such evidence, it would be possible to prepare a more systematic plan for dissemination through advocacy and publications, seminars and workshops and training opportunities.

CHAPTER 4: CONCLUSIONS AND LESSONS LEARNED

4.1. Conclusions

1. The polio project has been well implemented and followed its target group for fifteen years, has reached most of its objectives and should be considered a success.
2. The physical rehabilitation of children has been extensive and corrective surgeries have shown good results in combination with use of orthosis.
3. The project has helped polio children to enter normal schools and most have achieved very good academic results. Later a considerable number has completed or is in the process of completing vocational training and higher education.
4. Polio children have been assisted to take more active part in family and community life and events.
5. An increasing number have obtained jobs and started to earn an income helping them to become gradually independent of their families and the New Hope Center.
6. The polio project has achieved impressive results within sport and culture – not least demonstrated by the ten athletes from NHC taking part in the Paralympics in Beijing 2008 winning six gold medals and nine medals in total.
7. The micro finance programme has been well implemented and benefited a large number of families with polio children. The original capital has not been reduced and should be used for helping young people to enter the job market.
8. The most visible and measurable results can be found at the individual level – in the physical, educational and social improvements for a group of polio-affected children.
9. There have also been changes at community level in terms of increased awareness and reduced discrimination, and among teachers and in schools in terms of willingness to take in disabled children and facilitate “inclusive education” by removing physical and psychological school barriers. The evidence that this has happened and to what extent it has happened is not very systematic and much more anecdotal than for the results at individual level.
10. There is also limited knowledge of the extent to which improvements in schools and communities have been and will be transferred to and benefit other groups of disabled children, and to what extent changes among some teachers and in some schools will spread and be adopted by other schools, communities, counties or provinces.
11. The project has successfully introduced and established a holistic model of rehabilitation – combining corrective surgery, use of orthosis, basic education, vocational training, community support, sport and culture and employment within a combined institutional and community based approach.
12. As such the project has introduced a new and innovative model of rehabilitation in China. The project is also known beyond the Pi Zhou, but we have not been able to determine

how well it is known and how broadly or more importantly – to what extent the model has been disseminated to other parts of China.

13. The project had in the first phase as one of its objectives “to promote the models of comprehensive polio rehabilitation for wider use in China”, but it was not included in the plan for phase 2. Few activities have also been carried out to support the achievement of such an objective. The lack of effective dissemination of the project experience and model has been a major missed opportunity. It would also have required more and much better research and documentation as a basis for dissemination, advocacy and training. The project has mainly been successful as a local project benefiting a group of children and their families.
14. The project has exclusively focused on the targeted children and their families and not other individuals and groups in the community with similar or even larger problems and disabilities. We have not been made aware of problems and conflicts created by such an exclusive approach, but it could be seen as a weakness in the design or at least a limitation – given that a major investment benefited a relatively small target group in a poor environment for a long period of time.
15. The ideas and practices underpinning the concept of holistic rehabilitation are found relevant and also sustainable and replicable in China. The entire model – or complete “package” of institutional and community services supported from the New Hope Center on the other hand is neither sustainable nor replicable. It is too costly. Large amounts of external funds have been necessary to realize the model and achieve all the impressive results.
16. Funds have been spent efficiently and prudently, but there have been no analysis and discussion about issues of cost effectiveness – or to what extent the same or better results could have been achieved through alternative models and methods. Most counties will not have the necessary resources to support the combined model – or they may not be willing to spend so much resources.
17. The project has built competence and capacity in the field of rehabilitation, but over the last two years lost some of its previous strength and capacity, particularly in the education area. Current level of capacity and technical competence among staff is relative weak – judged as a medical rehabilitation center, but not as compared to other NGO centers.
18. The specialized scoliosis surgery carried out by Norwegian doctors was an extremely important additional component and contributed also to build technical capacity among doctors in local hospitals.
19. Promoting and advocating for disabled people’s rights was never an objective for the polio project. The main emphasis was on service delivery and model building – and mostly on the former. It was also mentioned that a strong advocacy profile – emphasizing that disabled people have rights and can also claim their rights based on Chinese laws and international conventions signed by China, is still a foreign idea and could be politically unacceptable at the local level. However, the mere existence of a polio project demonstrating potentials and abilities of disabled children and youth have had a significant “silent” advocacy effect.

20. The management and organisational basis for NHC is weak. There is no Board, only an Acting Director, conflicting views on ownership and future direction and not least – no plans to secure financial sustainability. Future level of expected funding provides only short term and also insufficient level of resources.
21. The main institutional problem is that the project is still a project with no organisational foundation. It is led and managed by a small group of committed individuals not being able to make a transition from being a project to an organisation.
22. The polio project is in the process of being successfully completed and does not need to be sustained. It is one of few examples of a development project coming to an end – because most objectives are achieved!
23. It is questionable if NHC has the managerial and technical capacity and sufficient financial resources to establish a new project for cerebral palsy children. The Center may be able to attract more people and money, but should first clarify and build a more solid organisational foundation.

4.2. Recommendations

We offer the following overall recommendations:

1. NMA should assist New Hope Center to:
 - Clarify issues of ownership and organisation
 - Prepare plans for management models (including role and composition of Board, appointment of Director, etc) and consult with partners.
 - Prepare financial plan and identify sources of funding
2. The Polio project should prepare a phasing out plan (3-5 years) with budgets covering:
 - Medical follow up and surgeries
 - Vocational training and educational scholarships
 - Job creation
 - Establish member organisation
 - Documentation and research of the polio project and experience
 - Dissemination of and training in the rehabilitation model
3. Future funding of the new cerebral palsy project should primarily come from sources in China.

Recommendations specifically for the polio project

(a) Social Rehabilitation

1. Identify young people for leadership training.
2. Employ 1-2 young people with polio to work in New Hope Center and consider employing those training in health professions in future; show confidence in such trainees and provide opportunities for those with more difficulties to find jobs.
3. Facilitate formation of self-help group for social activities that may grow into a group involved with advocacy or support activities or even to help others with different disabilities.

4. If a small resource centre is established, preferably by the young people themselves, it should set up a fund for purchase or loan application for special equipment and modifications, instead of relying on an external donor. This latter should be phased out.
5. NHC is already targeting a different target group of disabled children; they should be clear about this move and not try to continue long-term support of the young people with polio, but keep space for a small resource centre.
6. It is essential that the principles and lessons learned from the Polio Project are discussed, adapted and applied to the new target group of children. Continue to promote a comprehensive, holistic model, with a strong emphasis on play, education and social integration at all ages, where medical approaches (passive therapy, electrotherapy surgeries, assistive devices, orthotics, etc.) play a complementary and supportive role. It is not possible to turn the child, whether CP, polio, autistic or mentally handicapped, into a “normal” child. Look at the strengths of each child and help the child to develop to their full potential, while also making the environment more accessible.

Technical

7. Complete construction of the new site of New Hope Center with sufficient facilities and equipment for medical rehabilitation and teaching facility for patient education.
8. Emphasize capacity building of medical staff by sending staff to national training courses in rehabilitation medicine and recruiting new staff of therapists, teachers and nurses as well as administrative persons.
9. Open and strengthen new services for cerebral palsy rehabilitation and rehabilitation for other diseases with limb dysfunction.
10. Establish a polio rehabilitation service offering rehabilitation counseling, vocational counseling and training as well as regular follow up. The follow up should be once a year for all and two to four times for severe cases. It is also recommended to establish a federation of polio victims for organizing group activities for communication and information exchange.
11. Orthosis should be maintained each year and replaced every 1.5 years. This maintenance and replacement will last 30 to 40 years until patients lose capability of walking. It is expected for 300 pieces of orthosis for maintenance and 50 pairs of orthosis replacement.
12. Establish a fund for further operation and rehabilitation intervention since it is expected that 20 cases for further operation will be required over three to five years, including spinal revision and joint plastic operation.
13. Set up a research foundation and/or a scientific committee for polio research and support two to three research projects each year. The objectives of research should be: To address questions of therapeutic and administrative practices in both short term and long term.
Potential research projects:
 - Mechanism of muscle strength regaining and compensation in polio victims biomechanics and electrophysiology.
 - Optimization of orthosis for polio victims during physical development.
 - Optimization of rehabilitation model for polio rehabilitation: institutional and community based rehabilitation.
 - Prevention and treatment of post polio syndrome.
 - Relationship of employment and physical function.
 - Psychological-social status of polio victims.
 - Health economic study for long term rehabilitation in polio victims.

Education

14. Consider using their experience in education both in organizing a primary school and in supporting disabled children at community schools to set up a “school” situation for the children with cerebral palsy. At present in China, there are three situations for these children:
- The children are reasonably mild and, with lots of lobbying, they go to regular school: but they need good preparation: can they walk far enough, manage steps, hold a pen, pay attention to teacher, play and share with other children; NHC knows these issues and with some expertise in Occupational Therapy, should be able to “prepare” children for school, which is something not done in other rehab centres in China.
 - The children are quite severe and no school has the resources to accept them: they need some kind of education and NHC can do this either through working with a special education school, setting up their classes
 - There are a few examples of CBR programmes that send teachers or volunteers to the homes of very disabled children to help them to learn at least the basics; this would build on NHC experience in community support.

Community –based rehabilitation network

15. It is very timely, considering the national goal of “Access to rehabilitation for all by 2015” for NHC to resurrect the community service network and consider how to support the children with cerebral palsy and other disabilities using the NHC as a resource and training site. For example, of the 90 children they presently have, most may only stay for a few months, due to the expense of having a family member look after them. When the child returns home, there should be a follow-up plan, and a link with a nearby community worker or village doctor (or other interested person, such as a parent of a grown-up polio child) to stay in contact, encourage and help the child .

4.3. Lessons Learned

The polio project can offer several important lessons to inform and guide other similar projects. The following are such lessons, but should also be seen as success factors – what contributed to make the polio project a success and what the problems were.

- **An incremental approach - one road with several steps**

The point of departure for the polio project was centred on care and support for the whole person. It was based on a concept of rehabilitation with several steps – starting with medical rehabilitation, then education and vocational training, adding culture and sport and ending with job creation and preparing for living an independent life.

- **A combined community and institutional model**

The community based model was carried out under the guidance of the central rehabilitation staff mobilizing resources in the community such as local government, community schools, hospitals and relatives to help the people with disabilities. The model is featured by a core Center and a network of community based rehabilitation service in all towns and villages. The model with a core of institutional rehabilitation plus a network of community based rehabilitation service will be a practical way and worthwhile for exploration and use in other areas of China.

While much of the resources focused on helping the severely disabled and maintaining an institution, the balance of the target group lived and was served in their homes, communities

and regular schools. All children were regularly followed up at home and school and their families also knew where to get help, and received appropriate response. Eleven community workers were hired by the project and paid as full time staff for almost ten years. This is somewhat unique in community programmes in China, where the family is often expected to become the daily therapist, the teacher and the social worker finding their own resources.

In the Polio Project, while certainly most resources were focused on the child, the aim was to achieve a functional outcome that facilitated taking up age-appropriate roles (attend school, play and live with other kids, learn some community and job skills). It was understood that the family needed help to improve their environment and micro-credit was a good way to try to do this. It was also understood that the family and schools needed support and the employment of full-time community rehabilitation workers, who were closely supervised and mentored as part of the team approach, was a successful strategy.

- **A clear plan with short term tangible results and long term goals**

The polio project had a clear plan for what it wanted to achieve. The short term expected results were also achievable and could demonstrate immediate visible results – children were operated, could walk and move around. The more long term objectives could build on and support the first and basic physical rehabilitation.

- **Staff expectations of the young people with polio**

The young people were not treated as children by the staff. This is very different from other institutions (even regular middle schools) where adolescents are often expected to be spoon-fed and may have few opportunities to solve their own problems or face the reality of the world. The attitudes of staff and the spirit of the programme is admirable and should be a model for others. The young people stated they need NHC for orthotics replacements and meeting of old friends, and possibly to facilitate work opportunities. Not one young person said they wanted to continue to live at NHC or that they wanted an allowance. The staff had displayed an expectation that they would be able to manage in spite of the difficulties and the majority have accepted this.

- **Flexible and dynamic programme to meet changing needs**

The project has changed with the children's developmental needs from pre-school to adulthood, taking particular care to help the children over the transitions, from infant/toddler to primary school, to middle school, to higher education or vocational training and to supporting jobs. In addition, if the family is supported (via micro-credit) in this project it will improve the quality of life and the social attitudes.

In this project, there were no specialized services in Pi Zhou (medical rehabilitation, vocational schools) so the project had to, and did provide a “one-stop” service to some extent. However, in other locations in the present time, these services may be available, but someone needs to ensure that the children are referred and successfully transitioned.

In contrast, children growing up in orphanages in China (of whom 70-95% in any one orphanage are disabled children), are, these days, often provided with early stimulation and rehabilitation interventions from 0 – 8 years, with decreasing quality of services from 7- 14 years, and for those unable to adapt to everyday life, they will be transferred (‘abandoned’ a second time) to a social welfare institute (adult institution) between 14 – 18 years for the rest of their lives. While it is recognized by front-line orphanage staff that this lack of attention to

the adolescent years is a problem, change is very slow. The child welfare institutions in China could learn much from the Polio Project experience.

- **A local project with strong external technical support**

The polio project has always been a local project and managed by a local Director and staff. However, most funds have come from an external donor, but also significant technical support and advice – most importantly from NMA personnel with experience from a similar project in Taiwan. The physiotherapist project was clearly the brain behind the “model” and also preparation of the two five year plans. On the other hand, there were never any long-term adviser or expatriate Director attached to the project. Technical support was provided through short-term intermittent visits. There was never any doubt that the Director was responsible for implementation. As such there has been a constructive and complementary relationship between local personnel and expatriate consultants. The Norwegian doctors have played the same complementary roles, but provided more specialized technical inputs.

- **A strong leader**

Despite some formal links to other organisations and certain bureaucratic features, the polio project has remained a personalised NGO – managed and controlled by a respected and strong Director – able to maintain New Hope Center independent from unwanted influence. The Director has been the “*pater familias*” for an extended large family – protecting and looking after 750 children and in particular the hundred children living in the Center with personal care and commitment. This has obviously been a strength and also one important success factor, but also one of its weaknesses – in particular because a successor was never identified and a transition to a new phase never prepared.

- **Committed and Responsible Staff and Team**

A strong team approach, with group problem-solving as well sharing of successes is a hallmark of this project. While the leadership is clearly hierarchical, the job roles and delegation of duties are clear with the different staff being able to defend their work and decisions taken, and there are many occasions for sharing of information at regular meetings and follow-up visits. In this rural community, for a new intervention where previously there were no skills and few expectations other than getting the kids standing initially, this tightly controlled team approach has worked very well and the community workers (now no longer working on this project but who would be happy to take up a similar role in the future) and present staff (most of whom have worked there for some years) said they were satisfied and comfortable in this type of work environment.

- **A non-governmental organization (NGOs) is an effective project holder**

NGOs are relatively new in the Chinese context. In this project we see a successful outcome, given that the NGO had reasonably stable resources (financial and technical from an external source) and had government endorsement (Health Department, Red Cross, Disabled Persons Federation and Civil Affairs) through good relationships of the local project director. The local staff team was able to learn how to co-operate with an overseas and Chinese project donors, meet their expectations to some extent, while operating in a local administrative, political and economic environment, which entails frequent changes of leaders, targets, regulations and priorities.

- **Integration of surgical and rehabilitation training**

Before the project, most surgery in China was focusing on correction of deformities without rehabilitation training. Therefore, efficacy of surgeries was limited. With the implementation of this project, integration of surgery and rehabilitation training enhanced efficacy dramatically under the guidance of international and national experts, especially surgery of spinal scoliosis.

- **Dialectics of orthosis application**

At the initial stage of this project, the majority of victims were crawling. Hence, it was essential to fit orthosis for those children with severe paralysis of lower limbs. Application of the lower limb orthosis and spinal braces prevented and corrected deformity successfully. After physical development to adolescence and also the effect of rehabilitation intervention, the majority of gained improvement of muscle strength and joint stability associated with adaptation, and thus improving walking capacity dramatically. During the recent five years, many patients reduced their dependence on orthosis. Some patients even gave up the orthosis and resumed independent walking with or without crutches. It is worthwhile to explore mechanism of this adaptation or compensatory phenomenon for patients with paralyzed muscle as progress of physical development.

It is also important to be aware that the discarded orthoses may prevent future deformity and wear and tear on mal-aligned joints, so that as the young people become more stable in their own homes and communities, they need follow-up and medical advice to slow down general deterioration.

- **Value of scientific research**

Based on this successful long-term project, it is still difficult to draw any firm scientific conclusions mainly due to inadequate and limited quantitative data. It is still possible to compensate for such weaknesses in order to promote the model and project in other parts of China.

Annex 1: Terms of Reference

Evaluation of China Polio Project

Introduction

The project among polio affected children in Jiangsu Province started as a pilot project (1993-95). This pilot period was extended to 1996. The first 5-year project period was from 1997-2001. The second project period, 2002-2006 is coming to an end and Norwegian Mission Alliance (NMA) would like to carry out an evaluation. The project is located in Pi County and Shuyang County in Jiangsu Province. The New Hope Centre (NHC) is a rehabilitation centre serving as a base for the project. Amity Foundation is NMA's local partner, while Shincon, a Norwegian consultancy company, has represented NMA in China in the polio project in the second phase of the project.

The polio project has been one of the largest in NMA's history. The project has existed for 14 years. Since the support from Norway is coming to an end, it is important summarize and assess major achievement, collect and analyse experiences in order to facilitate learning for all parties involved. In other words, this is an end of project evaluation to be used by NMA in their work in China and elsewhere, and for the NHC in continuing the current rehabilitation work.

The long-term goal for the polio project is increased participation for children and youth disabled by polio in family and community life, giving them access to education and meaningful work. In the last project period, an additional goal was to establish a sustainable model for providing comprehensive and integrated rehabilitation, and education for the affected children/youth.

The evaluation will assess the outcomes of education and vocational training, micro credit loans, the technical aspects of the rehabilitation covering medical care and efficiency of rehabilitation equipment. The evaluation should primarily use qualitative methods to capture how the project and its benefits are perceived. Quantitative methods will also be used to document achievements, but NMA considers qualitative methods necessary in order to assess the model that has been used to rehabilitate children/youth with polio, and whether the rehabilitation have brought about positive and sustainable changes.

Purpose and objectives of the evaluation

The overall purpose of the evaluation is to summarise and assess the major achievements of the project and identify important lessons in order to inform and improve future planning.

The objectives are to assess the relevance of objectives and model(s) used for rehabilitation, results achieved, project organisation and management and institutional/financial sustainability.

Major Evaluation Questions

The evaluation should seek to answer the following questions:

1. To what extent has the target group (polio affected children and youth) improved and achieved their educational potential.
 - How many have taken part in the education program?
 - What is the educational level of the children/youth taking part in the project?
 - How many have taken part in vocational training?
 - How are their vocational skills?
 - How are these children/youth's social abilities?
 - What have been positive and negative aspects of the educational and vocational components?
2. Has microfinance been successful in the rehabilitation of the polio children/youth?
 - How many have got micro credit loans?
 - What kind of investments have they made?
 - Have the micro credit loans improved their socio-economic situations?
 - Have they had other effects?
3. To what extent has the physical rehabilitation of children and youth been successful and adequate?
 - Has correcting surgeries given good results? Which results? Should correcting surgeries continue?
 - What are the results for using various types of rehabilitation equipment?
 - Has the self-rehabilitation given good results? Which results?
4. To what extent have children and youth been successfully integrated into the society?
 - What has happened to the children/youth after ending their education and/or vocational training in terms of level of dependency on family/institutions and employment?
 - What is the children/youth's level of participation in family and community life?
 - How do the children/youth take part in family and community life?
 - Has there been any difference in attitudes and way of dealing with disabled people in the local communities, due to the project?
 - Is there evidence of impact beyond the local communities?
5. How has this project worked in relation to disabled people's rights?
 - What kind of advocacy work has been conducted?
 - Who has been the target group?
 - What has been the impact of such advocacy work?
6. To what extent has the project introduced and consolidated new models and approaches to rehabilitation of polio patients and how efficient and relevant have they been?
 - What characterize the models/approaches to rehabilitation?
 - Have the models/approaches been relevant in a Chinese context?
 - Are the approaches clear, consistent and according to international standards?
 - Have the models/approaches been innovative?
 - Have the model/approaches led to the achievement of the project's long- and short-term goals?

- Has the project has the expected impacts on the polio children/youth? Have there been any unexpected/undesirable effects?
- Are the models/approaches efficient in terms of cost/benefits? (Present a cost/benefit analysis) Could the same amount of resources bring more achievements by using alternative models/approaches?

7. To what extent has the project built competence and capacity in the field of rehabilitation medicine focusing on new concepts of polio rehabilitation?

- What have been the means and scope of capacity building?
- To what extent have models been replicated elsewhere?

8. Has the project been able to establish an effective and sustainable project organization?

- Are all components in the rehabilitation process well integrated (surgical, physical rehab, brace, special education, social work, microfinance)?
- Is the project organisation well established?
- Does the organisation have sufficient technical and managerial competence?
- Will the organisation be able to sustain all activities financially?

Evaluation team

The evaluation team will be selected from the following criteria's:

- Credibility – team members 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 and culture
- Independence – consultants must not have bindings to the project or the project workers 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 – the team should consist of both men and women
- The team should consist of both Chinese and foreign consultants

Knowledge about China, and development within the situation for disabled people in recent years, will be a good foundation for the evaluation.

The team will have the following members:

- Mr. Stein-Erik Kruse – team leader with responsible for the final product. Competence on qualitative methods, capacity building and organizational issues.
- Mrs. Sheila Purves. Competence on training and rehabilitation in Hong Kong.
- Dr. Li Jianan. Competence on medicine and rehabilitation.
- Mr. Cheng Yiji. Competence on education and special education.

Staff from Amity Foundation and NMA (Shincon) will be available for the evaluation team and provide necessary documents and information for the team.

Methodology

The evaluation will integrate qualitative and quantitative methods, in order to assess the integrated rehabilitation model. A field work will be conducted where the team will gather data for further processing.

The evaluation will use in-depth interviews with a sample of the project beneficiaries. In addition the evaluation should also provide a quantitative overview of outcomes concerning education, vocational skills, present situation of the youth that have ended the

programme, and the physical rehabilitation. It should also be presented stories of some of the project beneficiaries.

Fieldwork and Report

The team will be conducting the field work in week 41-42, 8-16th of October 2008. Prior to the field work, the team will communicate and finish a strategy for the field work, and decided how to analyse the data and outline of the report. The evaluation report will be finished in December 2008.

Expected Results

The expected result of the evaluation is a written report in English. It is also expected that the evaluation team gives a brief presentation of main findings from the field work to key personnel persons and relevant parties before departing the area

Annex 2: People Met

Time	Team of visitors	Who interviewed	Purpose
10 th afternoon	Mr. Cheng, Sheila, Qingsong Mr. Chen, Mr. Zhang Hushi (NHC)	Visited Pizhou vocational high school to talk with vice the principals: Mr. Liang, Mr. Peng, Mr. Yan	Polio students at the school and those who graduated from the school
	Stein-Erik, Espen, Sheila, Dr. Li, Hanne, Wu, Li Xue/ NHC: Ms. Guo, Mr. Zhang Hucai	Liu Erhu (man) – Electric bike garage Chen Haigang (man) – Mobile phone repair and sale Mao Pingping (woman) – Barber Cao Hailian (man) – Handicraft Sha Xueli (woman) – Handicraft	Social / employment or business
11 th morning-noon	Stein-Erik, Li Xue, Wu Anan, Qingsong,	Ms. Guo, Mr. Zhang, Mr. Chen (NHC)	Identity of NHC
	Sheila, Hanne	Some polio youth: 17 + 1 in afternoon	Social
	Mr. Cheng, Mr. Chen(NHC)	Teachers and principals from two Pizhou middle schools and one primary school	Education
	Dr. Li Jianan, Dr. Zhang Hucai(NHC) Dr. Chen (359 hospital)	Some polio youth	Physical evaluation
Afternoon	Stein-Erik, Wu Anan, Lixue, Qingsong	Mr. Li Guiqing (Chief secretary of Red Cross),	Identity of NHC, role of Red cross, Ownership of property and assets of NHC
	Sheila, Wu Anan, Ms Guo, Hanne, Dr. Li,	Young lady (20 years) with polio: her business which has 80 contract (part-time/temporary); assisted by cousin's wife.	Social
12 th morning – noon	Sheila, Hanne, Qingsong NHC: Ms. Guo, Mr. Zhang Huishi, Mr. Ren Wenquan(worker at brace shop)	Family of Guo Xingyuan(polio-boy) who won the silver medal, talk with his parents and see house for chicken raise related micro credit, dry food sale; a polio couple of Yang Lai(husband) with heir 4 month baby and Dong Haiqing (wife), parents of husband and grandma; family of Xue Pan(girl) at a medical college, talked with her parents.	Social
	Stein-Erik, Wu Anan, Cheng, Li Xue NHC: Chen, Zhang Hucai	Gao Yundong (man) – shop and electric bike garage with loan of CNY 5000, talked with him and his wife, his mother and grandma; Tang Lei(man) at Nanjing University, talked with his mother, loan of CNY 5,000 for chicken raise(300 hence); Wang Wenli (man) – working as a tailor at a textile factory in Kunshan city in Jiangsu, talked with his parents, loan of CNY 5000 for chicken raise;	Micro credit
Afternoon	Sheila, Wu Anan, Hanne, Li Xue, Qingsong; NHC: Ms. Guo	Liu He (man) – running a jade handicraft workshop not related Micro credit	Social
Morning afternoon	Dr. Li , Dr. Chen(359 hospital), Dr. Zhang(NHC)	Some polio youth (39 checked in total including some checked)	Physical evaluation

13 th afternoon	Stein-Erik, Sheila, Wu Anan, Li Xue, Qingsong	Director-general of Pizhou Disabled Persons' Federation(DPF)	Relation and cooperation between DPF and NHC
14 th am	Sheila, Dr. Li, Dr. Zhang, et.al. Sheila, Wu Anan	Visit CP rehab programme at old NHC Interview with two community rehab workers (1997-2006): Dr. Zhang (village doctor) and Ms Zhang (previously factory worker)	How they see their future (Model Building) Model Building

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Annex 4: Models for Rehabilitation

Two key international documents

The United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities⁸ (1993) set forth clearly, the need for general awareness-raising, appropriate medical care, rehabilitation and support services. Target areas recommended to be included in all national planning are: accessibility: education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion. The “Standard Rules” formed the platform for the initial discussions for the UN Convention on the Rights of Persons with Disabilities⁹, which was adopted in 2006, and which China ratified on 1 August 2008.

In order to achieve the goals of “equal opportunities and participation”, it is understood internationally, that countries should provide comprehensive rehabilitation services (medical, educational, social and vocational) which not only help clients to reach their potential, but also includes strategies to make changes to the physical and social (or attitudinal) environment, increasing accessibility and upholding the rights of people with disability.

Service Delivery Approaches

There are three main service delivery approaches described in provision of rehabilitation services, but no country uses only one: (1) specialized institution (2) outreach services from & by an institution and (3) community-based models. The mix of the models varies according to location and availability of manpower and resources, but also with the fact that different disabilities at different stages of the disability process require different services.

Certainly, in the last 40 years there has been a move towards more community-oriented and community-based approaches, as it is realized that while specialist care and expensive technology is best housed in institutions, the issues of cost, urban locations and selection criteria are primary concerns for access, while the issues of effectiveness and appropriateness in preparing clients to live in society are equally significant questions. In addition, it is agreed that programmes should facilitate self-help group formation, and make opportunities to mentor and develop participation, planning and leadership among people with disabilities themselves, particular for concerns about disability and rehabilitation. Certainly hand-over of some services and programmes particularly to do with the rights and responsibilities of disabled persons, to those persons is essential.

⁸ <http://www.un.org/esa/socdev/enable/dissre00.htm>

⁹ <http://www.un.org/disabilities/default.asp?id=259>

Community-based Rehabilitation (CBR)

The generally agreed characteristics of CBR delivery system are: services provided close to or in the homes of the clients, by local community staff (volunteers or paid), using low-cost and appropriate technology (appropriate to the target community, since it may range from urban & sophisticated to rural, poor, remote and/or under-developed). The community services are supported by a dynamic two-way referral system which is both vertical (special services) and horizontal (across sectors/needs), by supervisors/ mentors, and usually a resource or co-ordinating centre at higher level. CBR should meet the medical, educational, social and vocational needs of its clients and in the optimal situation, people with disabilities and their families are increasingly involved in planning, working, evaluating and leading the activities and indeed the programme.

There is agreement that CBR does require investment, usually from an external source, whether donor(s) or governments of different levels, and often requires external initiation, particularly where it is to become comprehensive. In an ideal situation, specialist institutions are seen as necessary referral centres, but not drawing financial support from the community services, thus distinguishing CBR from private, profit-making services (such as doctors clinics or private schools).

Models of Rehabilitation for People with Physical Disabilities

In general, the terms, medical model, educational model, social model and more recently the rights-based model are used to distinguish the strongest component of a rehabilitation programme. Hospitals and hospital-associated rehabilitation centers use the medical model focusing on correcting or providing compensation for impairments, thus using surgeries, physiotherapy modalities, orthotics and medications as the major interventions. The educational model may refer both to behavioural (psycho-educational) approaches; as well as ensuring children receive educational opportunities.

The social model does not negate the need for medical interventions, but focuses more on changes needed in the handicapping physical and social (attitudinal) environment; while the human rights model emphasizes that each and everyone person has rights and responsibilities, and no-one should be forced to adapt to the environment against their will. These latter two models are often combined and usually outreach to, are oriented to or are based in communities.

In China, rehabilitation centers and community-based programmes have emphasized correction of impairments and adaptation to the community, school or work environment. Parents want their children to walk and consider that using a wheelchair will make them lazy, and will continue to pay for medical rehabilitation to make them walk even well-past school entry age. Similarly, children with hearing impairment are taught oral language no matter what their impairment severity, waiting until 8 or 10 years old before giving in to sign language. And young adults want to get rid of their

crutches and look normal, even though they may fall frequently or walk more slowly than is useful.

In China, rehabilitation therapists and doctors have been insistent that parents and clients want medical solutions, but in recent five years, there is a growing awareness that we cannot “make” people “normal” and that adapting the environment, providing assistive devices, and ensuring more support from government and society are equally important. Together with teachers, administrators and parents, rehabilitation staff are beginning to realize that other goals are also important: “functioning and independence in self care activities, “coping at home” “going to school”, “improving quality of life of the individual”. CBR is not just about doing massage and exercises. However, we don’t see these changes in hospitals and medical rehab centers, where electrical modalities, exercise equipment, passive exercise, massage and acupuncture continue to predominate and use up parents financial resources.

Annex 5: Case Studies

Questions included

- How do you spend your day and how often do you go out of the house in a week?
- What daily activities do you need assistance for and will you ask for assistance when you need it? What are the major barriers you face in your daily life?
- Do you control your own money?
- Who do you spend time with in your leisure time?
- Are your financial resources enough for your daily needs? Do you contribute money to your families or do they help you?
- When you are sick with the flu (or other non-polio disability related problem), are you treated the same as other people by the health staff; do you feel discriminated in anyway?
- What do you do when you feel discrimination?
- Who has helped you the most in your life, supported growth of confidence & self-esteem?
- When do you feel sad and unhappy?
- Do you still need the NHC?

Discussions with young adults from Pizhou Polio Project

1. Mr. Xxx , 20 years (does not use crutches, but probably should have at least one to take some of the stress; one KAFO although both legs involved)

Came with his girlfriend (from Anhui Province, no physical disability; very quiet & holding a teddy bear; did not take part in the interview); he is very confident; says nothing can stop him. Family of girlfriend has no opinion about his disability and she now lives with him and his family in village. They work at family shop; he is in charge of cash. He has a younger brother and sister.

His only thing he has trouble with is if he has to lift/push heavy stuff; then he needs assistance. He uses an electric bicycle so transport not an issue. He controls all his own spending and when they go out, he makes the decisions. He has friends who do not have disability; he likes listening to music.

He is not able to say who is his biggest role model or who helped him the most; just says that he can manage and will be able to manage in the future. He does not consider himself disabled; but happy enough to come today to meet old friends.

2. Mr. Sxxx, 21 years (uses two crutches; both legs have KAFO; some trunk involvement)

Studying at Xuzhou Technical School; but first year of three year (zhong zhuan) held in Pizhou Public Health School. There are about 80 students in first year, consisting of

mainly girls studying nursing; he is studying pharmacy (will be able to sell medicine at end of course) with 20 in his class of whom only a few men.

He is in his first year in a three-year vocational study program. After two years, he will have one year internship and will become some sort of pharmacist or able to work selling medicines. It was his parents idea to choose this profession, since it was more likely that he would find work after graduation. Also, because it was a kind of work he was physically capable of doing. They themselves are middle school graduates. His father works as hired hand on a day-to-day basis, and also as a farmer together with his mother.

He was discriminated when he applied to be a student there. The college refused him at first try, but then an “uncle” with connections opened the door for him. It seems like it was necessary for him also to pay an extra amount/fee so that the school would admit him.

He was a little bit nervous about moving away from home to the school dormitory in town, because of the physical barriers. His room is on the second floor, the classroom on the third, and the toilets are only on the second and ground floor. In the beginning he had to put both crutches under one of his arms, while leaning on the banister when he used the stairway. Going up and down the stairs was hard work and did also cause some pain to his shoulder. But now, as he has gotten to know the other students well, he feels comfortable about asking them to help him carry the crutches, and he is not afraid of asking too often. They will initiate to help him too.

He was also nervous about starting school (just six weeks ago) for other personal reasons, but according to him, none that he would not have had even if he wasn't disabled. In the beginning he got some stares, and the teachers seemed to doubt his abilities. But now they treat him like everybody else. One small problems remains, he is a little bit homesick and is looking forward to graduate and find work near his childhood home. Also, washing clothes his quite painstaking, since he needs to lean against the sink and keep the balance.

He is very concerned about making his own living, and to not be a burden to his parents. He has two younger brothers. He also says that his parents have had a hard life. Now they support him with half of the necessary amount through his student years, the rest he gets through the NHC, and also a loan. He thinks he will try to give money to his parents in return, when he finish school and finds employment.

He has a positive outlook on the future. He is not very optimistic about finding a wife, or not that to find someone will be the biggest obstacle, but that her family will not support her choice out of concern for her future.

In leisure-time, he enjoys music. He is a singer, and describes himself as being at a 'ok' level. When asked if he has made any contributions to society he said he joined a

singing competition with very high-level contestants. Since it is not so often that a disabled person performs like this, the television interviewed him even though he did not win. He feels this is good to let people know about the abilities of people with disabilities [also perhaps he is saying that not only athletes can succeed].

3. Mr. Hxxxx; 22 years (using two crutches and one KAFO)

He graduated from middle –school and is now working three hours every morning in a group with other disabled people with aluminum (jewelry or some other kind of handicraft). The rest of the day he studies how to do jade carving, which he is really interested in, and hopes will be make him more money in the future. He only earns 600 RMB a month and he has to pay study fees for jade carving. It is hard to support him self on this amount, but he has managed to buy a three-wheel motorcycle so that he can get to work and around (and maybe also uses as a taxi) He lives with his parents and two younger brothers.

His history with NHC is quite interesting; he was living in another county and could only crawl until 1999; then someone told him about the project and he came to NHC. He got surgery in 1999 and again in 2001. He roomed with Mr. S in the hospital (359) for three months and they became friends; but he hasn't seen him since then. He was really happy for this opportunity today to meet with him and they have exchanged mobile phone numbers. Even though they both live in Pizhou at the moment they wouldn't normally meet, but it's really great to meet today, he says. He sees NHC as a way to bring them together occasionally.

He has a more positive view when it comes to marriage. He says it will happen when it's meant to happen. He describes himself as a person with strong mental health, and with a stable mood. He compares himself with his friend (Mr. S), and thinks that he is more optimistic about the future since he already is in the workforce, and supporting himself. He feels that there are many people who are willing to help him. Though he is not able to give any money to his parents, but he says that they are pleased, since they don't need to support him. "If you can give, that is good, but we understand if you can't."

He says his family was most important to support him, but having friends in society is very important. He hopes to be able to help other persons in the future in some way; although he says he doesn't contribute anything to society now or take part in community activities. And he thinks his condition might have had a positive effect since he might have been "a bad kid" if he hadn't been in this situation.

4. Group of 14 young people (with different levels of disability, living in different counties and having different work; all were working)

All in early 20's; finished school and working. Not clear if they lived at the New Hope Centre during their school days, but at least five of the group use wheelchairs (4

women, 1 man), and most of the rest are using 1-2 crutches; only one lady is not using crutches. All dressed appropriately for Pizhou City, with many of them very fashionable and wearing make-up; boys mainly in Chinese brand-name sports shoes.

Working Situation:

- Four-five started own enterprise in Pizhou City; just one month ago, mostly workers have physical disabilities; several without disability
- Five or six work in a factory which does sewing in another county; apparently about 20 workers almost all disabled; including those with hearing impairment; they said it's private); get RMB 300-400/month; live in staff quarters (all buildings accessible)
- Two women (one using two crutches; other one without) work in private business; accessible because all on one floor; make up to RMB1000/month; good boss and stable; has staff quarters

Living Situation

Most seem to live in staff quarters; some still live at home

Financial Situation

All have just enough to manage, but very difficult; none contribute to their family (parents') income. Admitted that their parents often give them a little to help out.

Parents and Siblings

Parents would like them to be self-sufficient, but did not have high expectations for them; just happy if they can find something to do. One severely disabled woman (using wheelchair) said that her older sister was married with a child; no-one else talked about siblings although all admitted having 1-2 young brothers/sisters; no-one admitted prejudice against sibling because a disabled member in family

Friends

Asked if the friends' telephone numbers on their mobile phones were able-bodied or disabled, they all replied both. One woman stated there was no difference. About one-third said they ate out in restaurants with their friends; while those using wheelchairs said they ate at home with their friends (perhaps for financial reasons)

Marriage and Child

Nobody claimed to have special boy/girl friend; agreed that it was generally better to get married but thought there were many barriers including meeting the right person, the person's family, their own financial situation and mobility issues (transportation so difficult to meet many people)

Hospital Visits

Majority said that they were not discriminated against when going to see a doctor or going to hospital. One young woman (using wheelchair) said she had problems, but

when asked for example only stated “examining bed too high” [which interviewer had already given as example of problems they might face]

Key Person in Your Life

Most stated their families, some included friends, two gave names of NHC staff

Barriers Facing You

Roads, transport, physical issues were volunteered. When probed about discrimination or prejudice, they did not feel this was major; said once people knew them it wasn't a problem. For example, if they were out and there were steps/stairs, they just asked the people nearby to help them by lifting their wheelchair: said they did not have any problems. They all seem to have good self-esteem and able to cope with discrimination.

When are you sad (cry?) or are angry (shout at people)?

- When I can't do something that I want to do
- I used to cry a lot when I was young and I saw others running around

Do you think about why you have these physical disabilities (and not someone else)?

- (fate or God); “it's just that way and I have to get on with it”
- laughed at idea that some places they say it's because their ancestors did something bad, although perhaps “min” involves this concept.

What expectations do you have of New Hope Centre in future? If NHC asked for your help to stop it closing down would you support it?

- Yes, if we could, but we don't have must ability (finance) to help [no awareness of their strength as a lobby group or self-help group]
- Orthotics; we need NHC for our orthotics; no-one else can do this for us
- Work.. jobs..

NHC is working with children with cerebral palsy and autism now... is that good? Do you support?

- Yes, definitely, we must support

Summary:

They seem to be a happy, friendly group, grateful for their jobs, support system and friends. They seem to adjust themselves to the situation in which they find themselves; but are confident enough to ask for help when needed, be seen in public, have friends and talk about themselves. As all young people, very focused on themselves and their own concerns; no discussion of their families and siblings; not much thought of future.

Two quite outspoken women and one man in this group; but all interested and involved in the discussion.

5. Ms Slx, 20 years old

While quite disabled (both legs involved and possibly trunk) she now manages with KAFO (long leg brace) on left leg, no brace on right leg (but knee muscles hardly contracting) and no crutches; has waddle gait but is fast, balanced and confident. Says she falls about once/week, usually at home, when she is not paying attention; no serious injuries. She lives with her brother (perhaps a cousin) and his wife since she has bad relations with her own parents (she says they want to control her too much and she doesn't agree with their ideas). She doesn't need a boyfriend yet, but she says she is confident. She sees herself as a regular person and says there is no need to keep referring to her disabilities.

She worked in different enterprises since graduating from middle school, including learning how to sew, but most recently she met a lady from Zhejiang who has contracted out handicraft & jewelry work to her. She has now 80 persons working for her to get these done (mainly her disabled friends don't want to do it because not enough money), so she has housewives, farmers. She has rented one small room in city to collect stuff, and where the women come for a few hours to work. She has set up "rules" for the contract work and she says she has learned two principles: must be honest with the workers and must be strict.

We went to visit her "room" which is open to the street, just like all the others on the block. Her sister-in-law is there and working hard. It is only three months since they started, but they seem quite confident. The Zhejiang boss lady also comes by (someone has contacted her to say that we are there).

Discussions with Families

Interview with mother and father of Mr. GXY in their home.

GXY got polio when he was just nine months. He had two older sisters who are healthy and one is married; both live away from home. GXY spent his early years crawling all over, always a very curious boy. The villagers avoided him or called him useless. In 1994, he was identified by the Polio Project Survey, and then received surgeries, braces, learned to stand up and attended primary school at NHC. He came home regularly. He attended Pizhou Middle School and later Senior High School, staying at the NHC dormitories. He learned to play table tennis and won a silver medal in the Paralympics. He will go to university in Nanjing to study physical education and counseling.

Attitudes

He is a very kind boy, who is always concerned for others. NHC gave him a big TV for his Paralympics performance, but he gave it back to the NHC for the children with cerebral palsy although his own parents only have a very small old TV. His parents and teacher are very proud of this act showing his appreciation of others' hardships.

The parents feel that “standing up” is the big issue that changed everyone and his own attitude. Before NHC project they felt unable to cope with it and just unlucky.

Environment

Parents have built a new home and started up a chicken/egg business using a loan from NHC micro credit. They are very confident of its success and have already built a new dry toilet with support from the township. They say that life is much better these days for everyone because of increased government attention to the rural areas, so better roads, health insurance, etc.

Awareness of Others with Disability

When asked about other disabled children or adults in their village they said they had advised one mother to take her CP child to NHC. They do not see themselves as having any special experience that they can offer other people with disability.

Interview with a newly married couple: Mr. YL and Ms DHQ (both with polio), with their new baby of 4 months; Mr. YL’s father and grandmother

Background

Mr. YL went to NHC; he uses crutches but also spends a lot of time in the wheelchair. His wife can walk without crutches in the home yard. They met working at a factory (open employment). They have set up a small shop to sell daily items in the village (part of the family home).

Attitudes

When they first told their family they wanted to marry, both families disagreed. Ms DHQ’s family said her boyfriend was too disabled and would burden her. His father said, if you are both disabled what will you do when you get old. Neighbours were also not supportive, but they persevered. The father describes crying when he first realized they would not listen to him. Now they have a baby boy, they are all happy and it’s shown the village what is possible.

Ms DHQ said that her doctor told her it would be ok to have the baby but they would arrange a Caesarian Section; in the end she gave birth at the township clinic because she went into labour too suddenly and the whole thing happened within a couple of hours.

They are optimistic and happy; although the father still worries.

Interview with parents of Ms XP

Background

A very poor family, in a home made of mud, where the roof leaks. The mother is looking after a newborn baby of one of her daughters. The other two kids are working. The youngest daughter gave up after middle school to work so that her older sister, Ms XP (with polio) could finish high school. She sends her money for her first year in

Shandong where she is attending medical school. The family makes RMB 2000-3000/year (US\$250) which is very, very poor in Jiangsu Province. They have to look after two old people (uncles in their 80's) and themselves. The farm land often floods, especially recently.

Attitudes

They did not ask for any help from NHC (although they gave XP a 1000 scholarship). She went without her wheelchair but has now asked for it even though it's broken. (NHC will send her a better one after this visit). They really appreciate NHC, are very proud of their daughter, but particularly the mother seems quite out of hope. The father is very calm and gives the impression of coping. The family has great hopes for XP when she finishes university, but she may still need to help to find a job.

From all three interviews, it is very clear that the families are not dependent on NHC and see it as a psychological and social support. I wonder if it had been a government organization if this would have been the same.