Rehabilitation and Education Promotion Project for Children with Cerebral Palsy Phase II (2014-2016)

Final Evaluation Report

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The children and their families are our ultimate beneficiaries, while also being our teachers and stimulating us to search out more solutions with them and for them. Thank YOU!

Note

The evaluation visit to each county was short and findings and issues raised are not comprehensive. Although there are many common successes and challenges, each county has its own characteristics, which were the focus of the visit. It is probable that experiences reported for one county are also found in the other counties, but were not directly observed or discussed. Thus, the evaluators would recommend: (1) to read the challenges and recommendations for all counties, since many points raised may be usefully discussed by all counties; (2) the issues raised, challenges and recommendations are used as starting points for discussion, to help local planners make strategic plans based on local priorities. The evaluators welcome future contact for discussion and debate.

Abbreviations

CP	Cerebral Palsy
China DPF	China Disabled Persons Federation
CBR	Community Based Rehabilitation
DPF	Disabled Persons Federation
NMA	Norwegian Missionary Alliance
SSGC	Social Service Guidance Centre, China Disabled Persons Federation

Executive Summary

The *Rehabilitation and Education Promotion Project for Children with Cerebral Palsy* was initiated in 2009 by the Norwegian Missionary Alliance with China Disabled Persons Federation (Social Service Guidance Centre) with the overall aim to develop holistic rehabilitation services in eight counties of China. After the first phase's external evaluation (2013), it was agreed to continue the project in five counties, focusing on consolidating the holistic approach and sustainability of the service platform. Specifically, the second phase should improve access to both professional rehabilitation therapies and educational opportunities, for all children with cerebral palsy, including those children with more severe disabilities.

This final evaluation of the second phase concludes that this is a very successful project bringing opportunities to many children with cerebral palsy and their families; capacity building for all stakeholders, & developing good practice for dissemination, policy development and future research.

It is noted that Phase II has emphasized the social and educational integration of the children, instead of only focusing on "fixing" the children's physical issues. All five counties demonstrate this balanced and holistic approach to services for both children and their families. Significantly, children with severe and complex disabilities have been included in most activities, and are no longer neglected due to lack of knowledge or skills. In addition, the respective resource centres have worked effectively to support the county project sites.

The project goals were achieved or surpassed in all counties, although the service characteristics vary. There has been a remarkable co-operation between the disability sectors (County Disabled Persons Federations) and the health and education services, demonstrating combining of resources and mainstreaming of services according to local conditions and resources. The project experiences have added to and promoted policy development, while the project counties have also used local and national policies to their full (especially early screening for delayed development and educational policies). Sustainability of the services is ensured through use of an inclusive developmental approach; that is inter-sectoral collaboration and mainstreaming of services.

Recommendations for the common challenges include to explore methods to: (1) maintain an effective and dynamic CBR service provision system, especially for children with more complex disabilities and for children living in remote areas through clear understanding and funding for resource centre role; (2) enrich the educational experiences of children and enable their progression to the child's maximum potential; (3) increase relevance and practical utility of expert's visits and the referral system by having clearer expectation of what is important to each child; (4) improve and extend the use of assistive technology as a way to increase a child's activity and participation levels in home, school and community; (5) develop appropriate services for adolescents as they become more independent and prepare for adulthood; (6) mentor family mutual support groups to move from social gatherings to more complex issues facing families; (7) explore and debate the balance and complementary roles between medical rehabilitation therapies (including surgical interventions) and a child's comprehensive developmental needs; (8) develop the role of Occupational Therapists to work with families, teachers and children in the areas of daily living skills, education, and community skills.

Detailed recommendations are made within the report for each county. In general, we suggest the three Sichuan counties should focus on capacity building of own staff, manage the balance between medical rehabilitation and the children's other needs, consider how to increase participation level of children in education, and start planning for adolescent services and preparation for adulthood. For Eshan County DPF, it is essential to strengthen links with the primary health networks for early identification of children with delayed development, and with the education sector to improve communication between teachers and rehabilitation workers. For Wei County, the key challenge is how to ensure that all children with cerebral palsy (and other disabilities) have access to rehabilitation and education services, through activating their CBR network. Eshan and Wei Counties both continue to need strong support from their resource centres and city and provincial level experts. The Sichuan counties are already more independent, but they need support to set up feasible and relevant quality service standards, based not only on output (they are achieving already) but with outcome indicators related to children's function and participation.

While the counties are facing challenges they are all optimistic about future development and quality improvement of services. The family members and children are fundamentally satisfied. Since their lives are changing, the young people will now expect and hope for more opportunities in their lives and will no doubt look for further service development in areas of assistive technology, livelihoods training and support. There are many new opportunities for exploration, pilot projects and research.

Rehabilitation and Education Promotion Project for Children with Cerebral Palsy Phase II (2014-2016)

Project Background

The *Rehabilitation and Education Promotion Project for Children with Cerebral Palsy (CP)* is supported by Norwegian Missionary Alliance as a follow up of the *Holistic Habilitation Project for Children with Cerebral Palsy*. It is the second phase of the project, extending the development support from 2009-2013 (Phase I) for a further three years, with the key hope to ensure sustainable programming for children with cerebral palsy.

The stated goal in the second phase project plan was "to promote the development of holistic habilitation concept for children with CP in the project pilots sites especially in the aspects of rehabilitation service and education", including

- Children with CP in project counties can access to professional rehabilitation services in local Disabled Persons Federation (DPF) rehabilitation centers;
- Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching, etc.;
- The experiences of the project are summarized and published in a proposal to relevant government departments for promotion.

In Phase II, five of the original eight project sites were selected to continue (Yunnan Province, Eshan County; Sichuan: Pi Xian, Pujiang and Xinjin Counties and Hebei, Wei Xian); with Yunnan Disabled Persons Rehabilitation Centre in Kunming, and Chengdu City Disabled Persons Rehabilitation Centre in Sichuan as resource centres for their respective counties. For Hebei Province, the China Rehabilitation Research Centre in Beijing took up the resource centre role for Wei Xian initially. The Hebei Provincial Centre for Persons with Disabilities has also been involved since the beginning in a supportive role, and is now fully acting as resource centre.

Strategies discussed and noted in various project documents include: (1) strengthening the resource centres and referral systems; (2) working with different government departments to get children access to both general health care & rehabilitation services, as well as, crucially, opportunities for education; (3) including children with severe impairments caused by cerebral palsy; (4) strengthening links with parents and supporting family activities; (5) promoting knowledge and awareness of children with cerebral palsy and their needs and abilities; (6) disseminating the lessons and approaches of the project and the project sites.

Changes to the project plan in Phase II included more flexible arrangements for each project site to focus on local priorities. Yunnan identified need to improve professional resources and the community rehabilitation workers' team (both ends of the spectrum). Sichuan identified access to education as the key goal, while Wei Xian in Hebei Province identified developing parents support as well as social activities [Reference: Project Document_vr003 (updated)].

Purpose & specific objectives of final evaluation

Based on the needs and suggestions of the Phase I evaluation (2013), Phase II focuses on three aspects: children's rehabilitation, educational opportunities, capacity building and public awareness.

Evaluation Objectives

1. To review the project outputs and outcomes referring to the project documents;
2. To summarize the impacts of the project in both positive and negative aspects;
3. To make recommendations for further development of the services for children with disabilities

The evaluation should include: 1) the efficiency and effectiveness of the project; 2) the project impacts to children and their families; and 3) the management of project sites.

Based on the findings, the evaluation should give recommendations to each project site and to the project partners for future development, expansion and dissemination.

Evaluation methods

The evaluation used a participatory framework, with strong attention to observation, discussions and interviews with stakeholders including children.

Prior to the onsite evaluation, the project management team sent the relevant background documents for review, including Phase I final evaluation, Phase II project proposal, and implementation plan, the mid-term evaluation report, some financial documents and the terms of reference of this evaluation.

According to the requested evaluation purpose and scope, the two evaluators met to design the activities and data collection instruments. Based on our request, the visits to each site were decided by the project management team according to the actual situation and local conditions.

The project management team (Ms Cai Yinghong and Ms Guo Jing of NMA; Ms Sun Shumei, SSGC) accompanied the evaluators throughout the two weeks. They facilitated the arrangements but did not affect the evaluation process. At the end of the visit to each site, the evaluators gave initial feedback to the local project officials and the project management team, which also raised discussion and clarified some issues.

1. **Schedule**

   The full evaluation was held over 13 days (Oct 8-20, 2016), visiting Yunnan, Sichuan and Hebei Provinces, five project counties and three cities which acted as the resource centres. (Appendix 1)

2. **Data collection**

   The data was collected in two ways: (1) first-hand information obtained from the evaluators' visits through interviews with concerned staff and officials, observation of activities, family visits and interviews with parents and children; and (2) second-hand information obtained information through indirect means, including listening to the work report and checking project files and activity records.

The evaluation process at each project site followed a similar sequence:

- Meeting to present oral and written project summary by key officials of each site, clarified through discussion
- Observation of service provision (usually therapists with children)
- Interviews with project management and front-line staff, based on questionnaire answers
- Interviews with school teachers, mainly based on questionnaire answers
- Interviews with children (if possible) and parents
- Review of records of project activities and services.

Questionnaires for managers and staff were sent out before the evaluation started. Two project sites returned these prior to the visits (Pujiang and Xinjin) and the other sites returned the completed questionnaires at the time of the evaluation visit.

The project arranged the specific families and children to visit, and also arranged to meet the requests of the two evaluators to visit children and families at home and in school, and to meet teachers. A convenience sample of staff with varying responsibilities were interviewed, and some children and family members were interviewed during observations of activities according to the evaluators' selection.

The questionnaires and interviews focused on changes brought about by the project. Some examples are: (1) During the past 2-3 years, has the way you work with the CP children and their families changed? (Questionnaire for project management at county and city / provincial level; and to front-line technical staff) (2) In recent 2-3 years, has your understanding of rehabilitation for CP children changed? (Questionnaire and interviews with project managers at the county (city) level) (3) You have received rehabilitation services for some time: what changes have you noticed in child's life, and are there any changes for the family? (Child and parent interviews).

Other questions to project staff included: What do you think are the main change(s) occurring because of this project and what are the reasons for this change? How do you feel about this project and please give an example of why you feel this way? The evaluators also asked about inter-sectoral communication and co-operation such as DPF staff with teachers as well as DPF officers with Education and Health officers.

3. Data analysis:

The notes from first-hand information were discussed and themes developed; and collated with an analysis of the second-hand information (done by Chinese evaluator). The overall impression of each project site was developed, and a listing of strengths and weaknesses made with reference to the analysis. Summary of numbers of questionnaires received are in Appendix 2 and part of the questionnaire and interview results can be found in Appendix 3 (Chinese only)

4. Limitations of the evaluation method:

Each visit was arranged appropriately and was conducive to understanding the key issues. All stakeholders were open to questions, and many different activities were observed and discussed frankly. The project files were all open to assessment. However, there were numerous limitations, including the brief duration of each visit, resulting in snapshot views of many activities. For example,

only two county schools were visited, and in only two counties, did we visit homes, while in the other three counties observation and interviews were done in the rehabilitation centres. The visits and were selected mainly by project staff for convenience, resulting however in potential bias and lack of understanding of the whole picture.

In view of the above, the following evaluation report represents only what the evaluators observed and identified in the short time available, and thus, is based on an incomplete understanding of all the complex factors involved. It is clear that some issues are not addressed, while others may be only partially explained by what was found during each short visit.

Findings

The findings for each county & its resource centre or expert support network are described below. These are followed by issues arising, challenges and the specific recommendations for the respective county. We follow a similar pattern in discussing respective resource centres. Finally the findings, challenges and recommendations regarding overall project management are made.

Eshan County, Yunnan Province 云南省峨山县

This county has achieved the project objectives and in doing so, has created a viable Community Based Rehabilitation (CBR) programme for children with cerebral palsy and their families. In a mountainous and poverty region, with a population of about 150,000, Eshan has established a fundamental holistic service model. The county currently has difficulty to hire professional rehabilitation staff so must continue to rely on the resource centre. However, if this is issue is solved, we are confident that the holistic concept and practical experience will influence services for all children with disabilities and even adults in coming years.

Findings according to expected project outcomes

1. **Outcome 1: Children with CP in project counties can access to professional rehabilitation services in local DPF rehabilitation centers**

   1.1. Children

   - 28 children from 5-18 years receive monthly visits from a rehabilitation worker to provide encouragement for the children, support for families, educational support and advice for families to overcome problems;
   - Some of these children attend the community rehab stations or county rehabilitation centre on an irregular basis/weekends because parents think the equipment can help them; while at the same time both child and parent(s) meet with others and get opporutnity for companionship and guidance;
   - All children are assessed by the provincial resource centre's professional staff once per six months in the county centre; children can be referred to the Resource Centre and get professional care, particularly required medical interventions such as Botox or orthotics.;
   - Children often take part in the County DPF activities or in community social activities. They are called in to participate in community social activities such as Children's Day every June 1st, and a Sports Day organized for the children and their parents, both to provide social opportunities and to raise the awareness of the media and the public.
   - Children know each other through group activities and there is much evidence that they make friends and support each other through social media/telephone.

   Issues to consider

   - Rehab workers do not have the expertise to solve some of the problems, such as appropriate recommendations for school children to maintain their physical abilities through sports, how to improve the child's independence through appropriate use of assistive devices or orthotics, etc.
   - The regular assessment by experts from the provincial resource centre is performed in a very short time and usually it is not carried out in the child's own home or school. The assessment focuses on body/structure issues; and does not target practical and functional goals (e.g. in 6 months this child can feed self or put on shoes, or walk as far as the shop).
   - With the extended project duration, some children are entering adolescence with accompanying, social, psychological and physical changes. Indeed, psychological problems of older children were mentioned in parent interviews and teacher's questionnaires. Although there is no concrete evidence that children face psychological issues at school, there is a cause for concern.

- Children with severe disabilities need early planning for the time when they leave school. There is an instance of one child who has finished primary school and now stays at home with only rehab workers visits).
- As children with cerebral palsy grow, they will also face more and new physical conditions (body/structure), which will require specialist medical management, new assistive devices and further rehabilitation training.

1.2. Family Members

- Family members participate voluntarily and as able in mutual support activities initiated and supported by the project, such as Children's Day, sports and social activities.
- Family members have good relationships with each other and support each other through telephone and «wechat»
- Four mothers stated in the interviews, that the most important aspect of the project, after helping their children, was the family mutual support activities: shared information, peer support, time to talk with each other; stating they have become more optomistic and positive about the lives of their children.

Issues to consider

- Eshan is a poor county. Who will initiate and fund parents assistance and social integration activities, which are stated by parents, as most appreciated? Small funds need to be allocated in annual budget or committed by local foundations.
- Families need help and support to plan for their child's future.

1.3. Service Providers

- County Rehabilitation Workers Team: this is a very stable team of ten workers, of whom 8 have been doing the work since the beginning of Phase I. Turnover and changes are within normal limits. Two staff are based at the County rehabilitation centre, in-charge of two allocated rooms with rehab training equipment, where they do assessment, training and parent guidance and organize activities for the children and parents. Each of the other 8 rehab workers are responsible for the children in their township. All these ten staff also have responsibilities for other people with disability, as well as tasks appointed by the local township.
- During the interviews, the rehab team notedEx that training in Occupational Therapy (OT), assistive devices and psychological areas were really important for changing their perspective: 'before we mainly used physiotherapy (PT) methods but these were difficult for us; now we can change many things in the child's life through OT and assistive devices; we understand the child's life process better'.
- Each worker is able to describe the children they are responsible for, and what they are doing. They visit monthly, and if the child is in school, they visit the home in the late afternoon or on weekends.
- They also visit those children who are severely disabled and follow the plan from the experts, but also talk with mother/grandparents. 'For this very severely disabled child (blind, cannot speak and cannot move) we gave her a wheelchair, and after feeding the child, Grandma can now take her outside for the sun'.

Issues to consider

- Since the community rehabilitation workers team is stable, it is important to plan continuous training to strengthen their work with disabled children, especially for the younger colleagues.
- Eshan County has no professional rehab resources and the provincial resource centre cannot necessarily give frequent or timely support; it is necessary to consider how the team members can develop their own technical expertise and then support each other (eg. One colleague may be interested in assistive devices; another learns more psychological skills, etc.).

2. Outcome 2: Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching

2.1. There are 28 CP children in this county. All children are receiving home visits by the rehabilitation team, and/or some kind of education. There is no special school in this county.

Receiving Education	Regular School	Regular Preschool	Home School	Completed primary school	Severe/multiple impairments
Yes	12	1	4		
Not at present				2	7

2.2. None of the children with CP attending school have dropped out, but two children completed primary school and now stay at home, due to the long distance from home and because they they need support for daily living skills they cannot live at the middle school by themselves.

2.3. Of the 11 questionnaires returned by teachers, none had received training on how to support children with disability. DPF staff and the child's rehab worker mostly communicate by telephone. To help the children, the teachers reported giving them more attention, reducing difficulty of learning requirements, and asking the other children to help, etc. A few teachers said they provide after school remedial services.

Issues to consider

- Some teachers (4/11 questionnaires) said they needed more technical training and support. Currently, DPF staff help is limited to understanding the dynamics of communication with disabled children.
- Most of the teachers are worried that these children have inferiority complex, but they do not provide concrete examples in the questionnaire.
- The teachers have a tendency to over-protect the child when he/she encounters problems, (by lowering requirements) rather than encourage and work with the child to find solutions; these may also be times when DPF staff should be consulted.
- Two teachers reported that the child in their class is often absent due to participation in rehabilitation training; which suggests that education is not considered a priority.

3. **Outcome 3: The experiences of the project are summarized and published in a proposal to relevant government departments for promotion**
   Eshan county's experiences of rehabilitation for children with cerebral palsy has been reported and is well understood by the city and provincial DPF levels as a successful CBR project. We are confident that the city and province are dissseminating this experience through their usual conferences and educational meetings.

Eshan County: Summary and Recommendations

Characteristics

Eshan County has developed a practical and viable model of community rehabilitation for children with cerebral palsy and their families, covering to a varied extent, four of the five components of the CBR Matrix[1] (The fifth component, livelihoods, was not in the scope of this project, although it will become necessary as the children grow).

The rehabilitation workers based at county and township levels are providing support to the children and families close to their homes (township rehab stations) or in their homes. The service network is complete and is common with other services of DPF and social welfare, which signifies the integration of the project activities into the regular work planning, and thus sustainability of key areas (eg. home visits, assistive devices, ensuring children go to school).

We note that many children with cerebral palsy enter school, even when they have difficluty walking. All staff believe that school is a priority goal for the children (as reported on questionnaires), and the children with severe disabilities are also visited at least monthly, some receiving teacher visits also.

Parent mutual-help activities are highly welcomed by parents of the CP children. Parent interviewed reported that they promote opportunties for mutual support, and better communication with DPF staff. The rehabilitation staff reported that with their more holistic approach in recent years, the biggest change is their relationships with parents.

A strong relationship has been established with the resource centre, with a consistent holistic approach from both sides and thus a common language.

Challenges

1. County DPF state that there are no children with cerebral palsy in 0-5 year category however, this seems unlikely. Some infants with various conditions may be receiving intervention in the cities, without notification to local DPF, which means on returning home, there could be a prolonged delay in getting support from DPF and community rehabilitation team.
2. Social integration activities for children and families require funds and time from the local DPF. These important activities should not be stopped due to lack of small funds at project end.

[1] World Health Organization (2010). "Community Based Rehabilitation: Community Based Inclusive Development".

3. In the children's documentation (case files), whether written by the Resource Centre experts or the community rehabilitation staff, there was little evidence of functional goals related to daily life activitities. This may influence the work and outcomes assessment of local staff
4. School teachers, in their questionnaires, have reflected some difficulties they face including: little communication from the child when home schooling, the child requires more specific rehabilitation services, the child cannot participate in physical education class, and he/she is not participating as actively in other areas as they could or should; as well as two children did not continue their education after primary school.
5. Eshan County has no local rehabilitation therapy resources. With the project closure, the provincial level has no funding to provide regular assessment & technical support. This requires urgent consideration by stakeholders at county, city and provincial levels. This county is one of many rural counties facing the problem of how to sustain rural CBR networks until their own local expertise and resources are established.

Recommendations

1. The early identification of developmental delay, potential cerebral palsy or other conditions should be made a priority by the maternal and child health network, with referral as early as possible to DPF. County DPF needs to review the situation with the local Health Bureau to make sure children are not falling through referral gaps, or being sent home from city hospitals without follow-up.
2. In CBR programmes, self help and mutual support groups are core activities to sustain the platform: DPF annual plans must include regular actvities and small budgets; funds and also organizational responsibility may be mobilized from local social organizations and volunteer groups (women's federation, etc). Over time, these mutual support groups may grow into self-sufficiency.
3. We recommend County DPF requests visiting experts to set specific functional goals for each child which can be realistically achieved within 3-6 months and with the aim to improve the child's daily life skills (whether eating, toileting, speed of walking, helping with housework, buying items for mother, etc). In this situation, each child's rehab worker and parent should be present at the assessment, to come to consensus. Assessment is best performed in the child's living environment.
4. Strengthen the relationship between DPF and Education officials and schools, and particularly between the rehab workers and the teachers, with the aim of exploring ways to solve problems facing both children and teachers. It is noted that issues are complex: introduction of educational assistive devices, increasing participation, and progressing children to higher grades, will need support from both provincial/city level DPF and special education experts.
5. Due to lack of local rehabilitation expertise, the county may consider further special training for individual community rehabilitation workers on areas such as: assistive devices, psychological support skills, education solutions for children with special needs, etc. Since Eshan County is poor, it is difficult to consider "service purchase agreements", but perhaps, through government programmes, experts in both rehabilitation and education can be invited, with the goal of improving the health and education of children with disabilities.

6. It is noted that Yuxi City has medical and basic rehabilitation resources. These should be strengthened and maybe used to support county level work in the future. The provincial level should also consider how to strengthen the city-level rehabilitation, so it may act as the resource centre.
7. Eshan County, in the future, will need to consider how to support their educated children with cerebral palsy to move successfully into adulthood, particularly for livelihoods training and support. This may be done through adult self-help groups focusing on livelihoods.

Conclusion

Eshan County may be proud of this excellent CBR practice model. The County DPF should consider which elements are most precious to them, and ensure that they continue, whether through mobilizing regular budget or project funding (from province, city, enterprises, community resources). The City DPF may consider both how to use the experience and approach to stimulate other counties community services, and how to provide the essential supervision (technical expertise) that Eshan needs on a regular basis.

Resource Centre for Eshan County
Yunnan Disabled Persons Rehabilitation Centre

Since 2009, with the ongoing support of this project, this provincial level centre has greatly developed its paediatric rehabilitation services currently working with more than 200 children annually. Today, they can act as an effective training and resource centre for the over 120 counties in Yunnan Province, demonstrating a professional and holistic approach.

Findings:
The paediatric rehabilitation training room was established in 2010, and was expanded to a department in 2012. They gradually expanded their therapy staff, increased the equipment and also services they offer, and the number of children they are seeing including seeing both children with cerebral palsy and those with intellectual disabilities. They report that they have weekly family trainings, as well as regular social and outside activities for the children often associated with traditional holidays and festivals. The centre has both a medical rehabilitation service and a social- educational division, using Conductive Education (CE). This permits children to get the specific services they need as they grow and develop.

This project has been instrumental in the centre's success, through supporting continuing education opportunities and increasing specialization of staff, and promoting both holistic understanding of children's rehabilitation as well as the differences between adult and child rehab services. It was noted that the opportunity to visit children in Eshan in their homes helped one of the senior therapists to understand the children better. In the provincial centre, several classrooms now house the CE programme (similar to preschool environment), reflecting the overall project trend from focusing only on physical issues to simultaneously facilitating all areas of a child's development. It is noted that the parents are now more skillful in letting their children move, participate, problem solve and make choices independently.

As a resource centre, the Yunnan Centre identified four key functions: (1) re-assessing all the children in the project and recommending therapy plans (every six months), (2) accepting the county's referrals (eg. a child needing an orthosis or assistive device, or spasticity assessment and intervention, or hip surveillance) and then providing follow-up to those children, (3) providing training opportunities to the Eshan rehabilitation workers and (4) giving advice for family training. It was noted that the Centre therapists are working on adapting their documentation to be more user-friendly for both the institutional situation and the community therapists, by using the ICF (International Classification of Functioning) terminology and framework. This is an excellent initiative and should be written up and shared after initial trial.

Challenges
For the provincial rehabilitation centre itself, we identify three main challenges related to professional issues:

1. Linkages and communication channels between the medical rehabilitation department and social-educational (CE) department are not clear. From a professional perspective, the approach should not be solely left to the choice of the parents because all children need opportunities to learn how to

integrate all aspects of development: intellectual, emotional, fine and gross motor skills etc. All children need specialist, individual assessment and holistic approach to both early intervention and preparation for preschool and school.
2. The prescription, training and use of assistive devices to support children where they lack skills is not well developed, although there is increased awareness of the needs.
3. The skills to cope with very severely disabled children, and again to use assistive technology and environmental adaptations appropriately remain under-developed.

In its role as a resource centre for less-developed rehabilitation services and CBR:
1. There is a tendency to focus on physical impairment of the child during the bi-annual assessment, which is probably reinforced by parents' hopes for "recovery".
2. The skills needed for activity and participation are still neglected in the assessments, with no functional (daily activity) goal setting, that are recorded.
3. Due to limited time during the assessment visit (1-2 days to assess 28 children), there is also little opportunity for assessing the child in the home or school environment, nor for interactive teaching with the community rehab workers team.
4. The assessment team did not include rehabilitation staff from city level, so that at the end of the project there remains no-one to carry on the support services.

Most significant challenge:
After the project completion, there will be no funding for the bi-annual monitoring and assessment visits, which seem to be significant motivators for the rehab workers and the ongoing support for children with CP. We appreciate that the Yunnan Centre will continue to offer training places to the Eshan County DPF. However, this may not be enough to sustain the workers enthusiasm, or help them meet the often complex, rehabilitation needs they face in the community environment.

Recommendations
Developing Expertise of the Provincial Centre:

1. Optimal assessment practice: the centre should form a plan to work towards comprehensive assessment for each & every child: (medical, PT (include correct mobility device), OT (include daily life and educational assistive technology), speech (communication & swallow), educational expert/educational psychologist; and if possible, a social worker); common goals must be set with priorities; children should be challenged to reach the goals, supported by assistive technology and environmental adaptations (physical and social environments).
2. Documentation: strengthen in particular, the practice of team-based goal setting & setting medium-term goals related to functional activities and participation; the achievement of daily life goals may be treated as indicators of change and progress (outcome indicators).This type of assessment and common documentation will help shape parents understanding of the holistic approach, as well as link up the medical and social/educational training departments; and to work within a child/family - centred approach.
3. Consider to send staff (including someone with assistive device/wheelchair interests) for training in how to work with and enable children with severe disabilities.

Resource Centre Role for Eshan CBR Project and other counties in Yunnan Province

From this project, we can see that the CBR approach helps children with disabilities get an education and helps parents to better understand their children's developmental needs. We recommend that the provincial resource centre:

1. Promote the lessons learned from this project with other counties by organizing peer visits and facilitated discussions between officials, rehab workers, and school teachers. These sharings do NOT have to be in formal classroom situations but can be field visits or integrated with other educational activities (eg. within the education sector, or among village doctors, etc).
2. To organize some opportunities for children, rehab workers and therapists to meet with each other, similar to the camp activity in Pujiang in 2015. This has value for all involved, and also for the parents themselves to learn how to let go and trust their children.
3. To set up a wechat (or other social media) network between rehab workers and Yunnan Centre with regular (eg. once/2 months) education talks or case discussions.
4. Fully use the rehabilitation therapy college of Kunming Medical University, where all the students of speech, OT and PT would greatly benefit from field visits and practice teaching, while Eshan can benefit, if the students do projects with practical outcomes (eg. posters to promote play for all children, including those with disabilities; designing a safe playground; proposing appropriate ways to include CP children in physical education classes, etc).

Overall, we believe that the Provincial Disabled Persons Federation with the Provincial Rehabilitation Centre should establish a CBR Resource Centre to actively support city DPFs and county DPFs community service platforms. This centre should be dedicated to supporting less-developed areas to ensure their children have access to some kind of support close to their homes. The provincial budget should include small funds for follow-up of staff, training on site (city or county level), demonstration of how to perform home visits, meeting with other sectors, etc.

Pi County (Pi Xian), Chengdu City, Sichuan 四川省成都市郫县

Pi Xian has a population of over 750,000 (2010). It is under the administration of Chengdu City to which is has excellent highway links (30 minutes by car or bus).

In the first phase of this project, Pi Xian built an integrated model of rehabilitation and education, using a preschool model, with referrals to the education sector for those able to transfer to school. The second phase (2014-16) has provided the platform for this project to be truly integrated into the everyday work of the Disabled Persons Federation, the Education Department and community health network. Key words to describe the importance of the second phase are: consolidation (meaning both improving the quality and scope of the services), and resource mobilization (developing relationships and projects with a variety of other partners, including inter-sectoral collaboration). These strategies have resulted in a sustainable, holistic service for children with cerebral palsy, as well as children with other disabilities, and their families.

Findings

1. **Outcome 1: Children with CP in project counties can access to professional rehabilitation services in local DPF rehabilitation centers**

   1.1. Children

   - Currently, there are 84 children with cerebral palsy (age 0-12) and all are receiving services, through different strategies:
     - DPF Pre-school Education & Rehabilitation Center (Preschool Centre): 19 children with CP (2-3 have intellectual disabilities);
     - Integrated regular classes: these children with different disabilities receive regular follow-up and support of the resource teachers, supported by special education experts when needed;
     - Home visits and schooling: County DPF staff organize for the local community rehabilitation coordinators to follow-up children who cannot go to school.
   - County DPF has set up a contractual arrangement with community family doctors to ensure that "all people can have home health visits" as required. Seventy-five children (aged 0-12) have health records; of these 36 children have medical rehabilitation needs and are getting basic services including regular physical examinations, rehabilitation and referral services;
   - Local maternal and child health network and community health center has established an early detection and referral relationship including the County DPF;
   - Pi Xian DPF Preschool Center has a physiotherapist and a teacher, providing a comprehensive range of rehabilitation training, and education including learning in groups (Conductive Education) and individual training; there is high parental satisfaction (interviews with parents);
   - The Preschool Centre offers free transport services to facilitate children and parents;
   - The Preschool Centre also prepares the children to enter primary school, with tailor-made training; DPF staff help to refer and link up with the target school.

   Issues to consider:

   - One evaluator met a child at the Pre-school Centre with sequelae of viral encephalitis (brain damage). The child was treated at both County and Chengdu City hospitals, but was not referred

to DPF. Only one year later the parents found out about the local rehabilitation services. This suggests that while the primary health care system is identifying children with high risk or congenital conditions, those children with acquired disabilities may be falling through the network. It requires education and promotion at all levels, with improved communication and data collecting system. The higher level hospitals must also take responsibility for more comprehensive discharge planning including referrals.

- Pre-school Centre follows the Conductive Education approach, and the thematic classes are documented. However, the individual child's specific requirements and goals are not recorded, so the child's progress is not clear.
- Since there is no professional medical rehabilitation service in this county, many children are referred to Chengdu, but the evaluators found no detailed referral records, showing purpose of referral, referral results, higher-level hospital's recommendations and follow up;
- There are plans to establish a County rehabilitation center, to provide for children with physical rehabilitation needs closer to home; however, it is critical to avoid over-emphasizing physical issues to the detriment of education and social participation. The scope of work of the new county rehabilitation centre needs to integrate institutional and community rehabilitation services and maintain the holistic approach.

1.2 Parents

- Parents understand clearly the DPF services and policies, and can select their preferred services, such as enrolling the child in the Preschool Centre, requesting home visits or applying for subsidies to take their child to a higher level city rehabilitation centre;
- Free transportation for parents to take their child to the Preschool Centre is a big incentive and convenience;
- DPF and the Preschool Centre frequently organize parent and child activities with a high level of participation;
- They also organize many parent training activities to increase awareness of cerebral palsy and disability issues; currently the DPF is preparing to establish a parent school, hoping to provide more systematic, training and support for parents.

Issues to consider:

- Parents can apply for DPF subsidies and referral to support rehabilitation training at hospitals in Chengdu City (such as Ba Yi Rehab Centre and # 416 Hospital's Rehab Centre). But there are no clear records of rationale and expectations such as specific goals of the referral in the child's files, nor can we find records of communication or recommendations from the expert referral centre, including no discharge plan. In the higher level centres, we find no clear idea of short/mid-term functional goal setting and how to continue to progress when child goes home. The problem arises of how to take advantage of the expertise of higher level rehabilitation centres and how to come to consensus of the referral goals, improve the effectiveness of referral services, and avoid wasting resources including the opportunity costs for parents?
- According to parents' feedback, they are concerned about the long-term care for severely disabled children. Examples included: buses are not accessible for wheelchairs, and this requires heavy lifting (especially as the child grows); wheelchairs are provided free, but often are not the correct size or are inappropriate for the child, but parents feel helpless about these problems. If

children and adults with severe disabilities are to participate in community activities (including education, work, and so forth) then the allocation of government resources for barrier-free facilities and assistive devices becomes critical.

- Regarding the plans for the new parents' school: since DPF is already providing parent education on a regular basis, it is important to consider the aims and strategies carefully so that more can be achieved. Parents are excellent resources for other parents and also good advocates for the needs of their growing children.
- Parents can be used to train parents, but should be guided to focus on daily activities and functional needs of child and family. A family mutual support group may help with respite care, discuss and introduce options for lifetime management and similar common concerns. They may also counsel families to let their children become more independent in making their own choices and decisions and requesting help rather than always expecting help.

1.3 Service Providers

- There are nine staff at the Preschool Centre of whom four are rehabilitation workers, 3 teachers and 2 child care workers (for 19 children), which is quite adequate. However, there is very high staff mobility, especially among the rehabilitation and teaching staff. The centre benefitted from this project's training, especially the Conductive Education (group-oriented) approach combined with individual training. This has been maintained, with the advice of an experienced physical therapist to maintain standards.
- County DPF leadership state that the holistic rehabilitation concept is now the foundation for all their work for all children with disabilities: there is good co-operation with other government sectors such as health and education sectors, and thus efficient and effective use of resources. To provide health services, DPF co-ordinates with the community health services , and for educational aspects, they co-ordinate with the special education school, which is responsible for home schooling as well as supporting the regular school resource teachers and rooms. Pi Xian DPF provides comprehensive and integrated rehabilitation services, including support for children transitioning to adulthood and needing career development services.
- Access to Health Care: Pi Xian DPF has established a stable cooperation with community health resources, based on national health polices, to ensure that all disabled children are provided with convenient free medical examinations on a regular basis. If a problem is identified, community (village) health workers or rehabilitation coordinator will contact hospital and DPF services. Mandatory newborn screening at community health centres, ensures that children with disabilities are immediately referred to DPF, who organize for community health staff (village doctor) or a community rehabilitation coordinator to provide guidance and support. Pi Xian DPF also arranges for the experts of Ba Yi Rehabilitation Centre (provincial level) or other experts to assess the children either at the provincial centre or in Pi Xian.

Issues to consider:

- Currently Pi Xian DPF has no rehabilitation center, and lacks manpower in medical rehabilitation, so they are discussing to set up a centre at a local hospital. DPF must be very clear about what they want from this hospital-based rehabilitation centre; and how to maintain a two-way referral system and complementary services with the present Preschool Centre. DPF may also require

that the hospital rehabilitation utilizes the same holistic concepts in planning medical rehabilitation care,

- Currently, staff of the Preschool Centre are less involved in supporting children in regular school, home rehabilitation or home school. This may be to do with time issues and also professional expertise, but both community rehabilitation coordinators and regular school teachers may need support on activity and participation issues. DPF may consider how to increase opportunities for communicating and sharing with communities and schools to ensure common goals and progression of each child to reach their potential.
- All children with disabilities need support and preparation as they become adolescents and then adults; and DPF staff may consider to use case management and life-long planning approaches.

2. Outcome 2: Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching

2.1. There are 84 children (age 0-12) with cerebral palsy of whom 52 have access to different forms of education.

Receiving Education	Regular School	Regular Preschool	Home School	Completed primary school	Severe/multiple impairments
Yes	25	10	17		
Not at present					32

2.2. The principal of the County Special Education School has been in his position for two years. He reports that they have just completed the first 3 years of a 6 year project plan to promote inclusive education; which is aligned with Chengdu City education policies and has support from Save the Children (UK) for several pilot sites. They now have 51 schools that have a resource classroom each with one teacher trained as resource teacher. The special education school supports the resource teacher.

2.3. In 2015, 17 children received regular home schooling (twice/month done by special education teacher and /or resource teacher). In 2016-2019, their aim is to increase this number to 22 children. There are criteria for home schooling, in that the child must be able to benefit from teaching.

2.4. If a child's home needs environmental adaptation, the budget can come from either education or DPF funds. But there are still some problems, as illustrated by at least one example (toilet access).

2.5. The budget for the resource rooms, teachers and home schooling is part of the respective school or Special Education School's regular budget. Recently, there is also budget to send teachers for overseas study tours (Taiwan, Canada) to learn more about inclusive and special education.

Issues to Consider

- A review of the children attending regular school could look for: areas of less participation and possible reasons, challenges facing teachers, whether children are being over-protected, whether the children's emotional, behavioral, social and intellectual skills are progressing as other children, etc.

- Assistive technology should be introduced to ensure children with difficulty writing or communicating can stay up academically with their peers, according to their abilities.
- DPF and Education experts may consider together how to prepare children for each stage in their educational life, from kindergarten to primary school, to middle school, to high school or other destination; and develop guidelines for the different staff to intervene as well as communicate with each other and with the families.
- Adolescence needs specific consideration including prevocational and livelihoods training
- Home schooling may be reviewed to identify problems for teachers and children; to consider if they can progress to regular school. Also some very severely disabled children are probably not getting home schooling from a teacher.

3. **Outcome 3: The experiences of the project are summarized and published in a proposal to relevant government departments for promotion**
   The three project counties under Chengdu City have all discussed their experiences with sister counties. The Chengdu DPF have invited PiXian to share in particular with Dujiangyan and Wenjiang Counties, including their work training parents, rehabilitation assessment, integration of rehabilitation and education, etc; as well as their expansion plans and vision for the future.

Pi County (Pi Xian): Summary and Recommendations

Characteristics

After the project's first phase development, which steered the partner towards the holistic approach, the second phase crucial contributions were to give the time and guidance to develop the following strategies: (1) varied educational opportunities, working together with the county Special Education School; (2) family support and children's social integration activities; (3) co-operation with community health care networks for early identification of children with potential disabilities as well as provision regular, free health checks for children with disabilities near their homes. (4) referral pathways to send their children for intensive, more professional rehabilitation at nearby Chengdu City rehabilitation centres (5) full use of supportive government regulations and programmes, as encouraged by the project management as well as mobilizing local resources and establishing partnerships with local/Chengdu expertise

Challenges

1. How to improve the consistency of the service provision? At present, for the individual children, there are no documented common functional goals, so that there may be little relationship between what happens in the group and in the individual sessions. Similarly in referring children to higher level rehabilitation services there is no documentation of the expectation (relevant to the individual child's daily life and expected goals) nor of the progress and recommendations when the child returns to the county.
2. How can the county offer medical rehabilitation care for the children with cerebral palsy without losing their holistic model of service? The county is setting up a new rehabilitation centre in partnership with a local community hospital, which will offer early stimulation and development

therapies for infants and young children. However, there is a danger that parents will take their children out of school for increasingly longer periods in the hope that medical therapy will allow them to walk.

3. What is the role of DPF in education of children with cerebral palsy? In the current situation, the education policies are very strong and the special education school plays a major role in supporting inclusive education and home schooling, but there is still a significant role for rehabilitation therapists to intervene in the physical and environmental approaches. This includes ensuring good seating (at a desk), developing communication abilities (use of special assistive devices as required for speech, writing, reading, etc), facilitate activities of school life, including issues such as eating lunch, toileting and washing, as well as increased participation in physical education classes and other classes which may present barriers.

Recommendations

1. Rehabilitation therapy services
    1.1. Strengthen the quality and consistency of services, whether in the DPF Preschool Centre, home visits, hospital or school through common goal setting for each child. The goals (3-6 monthly depending on the child's progress) must be related to daily life tasks within the child's living (school) environment. They should be documented and regularly reviewed by therapists and teachers, so that the child is challenged and progresses, and even within a group exercise session or classroom a child's individual needs are met. Regular team discussions on the child's progress, new goals and how to help the child reach them, especially with invited experts present to facilitate, are also a capacity-building opportunity for all staff working with the child.
    1.2. Make better use of mobility devices and assistive technology to support the child's progress and his ability to participate in age appropriate activities. Rehabilitation is not only about training a child but also about changing the environment or enabling the child to participate. Examples can range from using both a walking frame (within a classroom) and a tricycle to get to and from school; training writing and drawing ability using a special device on the pencil and/or using a tablet computer for assignments and examinations, etc.
    1.3. In planning to contract services from local hospitals, require that the holistic approach continues, balancing active rehabilitation therapies and medical/surgical interventions with the need for practising daily living skills and participation in educational and social activities to encourage all-round growth and development. This needs capacity building among the hospital staff to clarify their role in the child's lifelong plan, as well as educating parents. Again common goals will assist this process. It is all too easy for parents to believe that medical treatments are the most important.

2. Support inclusive education
    2.1. Develop strategies to help the child (and parents) prepare for school. Individualized checklists of common problems will help a child to progress each year.
    2.2. Inter-professional team meetings are helpful (resource and special education teacher, DPF and rehab staff, parents, etc).

2.3. County DPF should follow-up children in school to ensure (1) the child is participating to their potential; (2) help teachers solve equipment, technology, transport problems, and (3) the child has a plan for transition to middle school and beyond, or an alternative.

2.4. Regular review of the medium and long term goals for children receiving home therapy or home school (by County DPF and resource teachers as appropriate)

- For children getting home schooling from special education /resource teachers it is important to consider if and how they can enter regular school, possibly with use of assistive technology; so this will need discussion with DPF
- For children with severe disabilities, it is important to get expert advice on use of assistive technology to improve the quality of life of the child and family, even if school is not a possibility.

2.5. County Disabled Persons Federation should develop expertise in Assistive Technology and particularly technology for assisting communication, from fundamentals to high technology, so that a child can indicate his/her daily needs, converse, develop the imagination and intellect, write and read, etc.

Conclusion

Pi Xian has grasped the many opportunities provided by this project, for training and capacity building (including peer visits and support) for staff and partner staff (education, community doctors, etc), and developed close relationships with the project's responsible centre in Chengdu, stimulating the successful achievement of all expected project outcomes. This comprehensive service, includes a system for early identification, referral, preschool education with some therapy elements and transfer to primary school. There is also a platform for the children to transition to adult roles, with classrooms for crafts and also a bakery, although presently these are set up for young people with intellectual impairments. The stage is now set for improving the quality of services, with continuing capacity building, effective communication strategies among staff, introduction of appropriate assistive technology and considering the needs of adolescents. Community rehabilitation service network must not be neglected; it needs continuous support to maintain and develop, including the integration of parents resources.

Pujiang County, Chengdu City, Sichuan 四川省成都市浦江县

Pujiang County has a population of over 240,000 (2010) and is administered by Chengdu City, linked by highways, taking about a one hour bus ride. Pujiang DPF has achieved the project expectations and is moving forwards with confidence. The county has established an effective approach to helping all their children with cerebral palsy, making good use of the expertise and resources of education and health sectors, as well as social capital of the local communities. The programme has a reasonably stable platform and the county is actively planning to strengthen the depth and quality of their holistic rehabilitation approach.

Findings

1. **Outcome 1: Children with CP in project counties can access to professional rehabilitation services in local DPF rehabilitation centers**

   1.1. Children

   - Pujiang has 40 children with CP (0-18 years). According to project records 51 people with cerebral palsy (including some over age 18 years) are receiving services. All children are accessing services with 18 children attending the DPF Rehabilitation Centre, and others receiving home visits.
   - DPF Rehabilitation Centre provides training over 4.5 days each week including therapy in a group and individual basis. The group training focuses on cognitive development and fine motor (hand) function; while individual training tends to focus on gross motor exercise and guidance for parents. All of the other children (including those going to school) will come to the Centre twice each month for guidance and the rehabilitation staff will visit every child in their home at least once each semester.
   - All children have access to regular assessment from experts. Prior to 2015, this was carried out by experts of the Chengdu Education & Rehabilitation Centre (resource centre). After 2015, the resource centre coordinated other Chengdu experts to visit. The therapists report that the assessments by these experts is very important to develop each child's rehabilitation plan.
   - Each child's record and rehabilitation plan is very detailed; all have objectives for training of physical issues, but there are few objectives related to daily living skills. There were no records of referral recommendations to check, regarding children referred to higher level hospitals.
   - Children had received individualized orthotics, standing frame, and wheelchairs, etc. (funding from other projects).
   - Other than rehabilitation therapy, all children have access to regular experts visits, organized by the DPF Rehab Centre or rehabilitation community stations, as well as opportunities to participate in social integration activities.
   - Social activities for the children are rich and varied, including twice weekly integrated activities with a regular kindergarten, camps for older children including a summer camp (2015), sports days, etc. In addition, children join activities organized by/for parents, one of which was observed as a happy occasion, with the children spontaneously communicating and actively participating.
   - Maternal and Child Health networks do health checks for each CP child, 4 times per year, and maintain records.

Issues to consider

- DPF Rehabilitation Centre only has one therapist (formerly employed, now acting as volunteer when needed) and one retired teacher; this is due to lack of formal positions. It is difficult to maintain professional staff which effects service standards and continuity.
- Children are referred to higher levels for intensive training and surgery, but there are no written records of referral goals, nor discharge plans and recommendations from the higher centre, which means that no specific follow-up occurs and some training effects may be lost or not achieve their full potential.
- The rehabilitation therapy plans and goals for each child are mainly focused on physical aspects of the child's development and not explicitly related to daily activities of the child.
- Children who are regularly attending school, may not need the twice/ monthly sessions at the DPF Rehabilitation Centre, and it may even have detrimental effect on their education. The child and parents may follow a self-monitoring and reporting mechanism, to decrease dependence on the Rehabilitation Centre, and cultivate self-management and coping skills of the young person.
- There are several older children with severe disabilities, who cannot go to school but receive DPF services. It is timely to explore future plans for these children and future adolescents.

1.2. Family Members

- Parents in Pujiang believe that their children are improving in function and social skills after attending the rehabilitation training; some parents insist on their children continuing at the rehab centre for many years.
- With support from Pujiang DPF, a parent's mutual support association has been established with a parent taking up the role of president, and ensuring they have regularly meetings and activities. On the day of the evaluation, the social activity observed included more than ten mothers and grandmothers playing simple games, joking with each other and enjoying themselves. The children present are also happy to watch.
- Parents reported that they highly appreciated the many activities, and felt that they could communicate openly, unburden themselves, and relax together. Although more difficult for parents living far away, increasing transport options (such as electric cycles), things are easier.

Issues to consider

- Some parents hold high expectations for the physical improvement of their child and do not put much emphasis on developing the child's abilities in daily skills including play.
- It is noted that mainly women participated in the social activity, among whom were many grandmothers, (although it was said that fathers and grandfathers would take part on weekends). Most grandmothers did not consider any future plans for the child other than the child stays with the grandmother rather than the mother for various reasons.
- Many families looking after children with severe disabilities feel great stress.
- Through the short observation, the mutual support association seems to be mainly for social activities; there is no systematic planning to give full play to the role of parents associations and how to make good use of their experience and power as a group.

1.3. Service Providers

- The rehabilitation staff team at the DPF Rehab Centre is not complete, with difficulty to employ and keep experienced staff. To solve this problem the County DPF is considering inviting rehab services from Chengdu (contract basis), but the exact scope of service and objectives are not yet determined.
- County DPF has established good partnerships with other government departments including: the Maternal & Child Health network, for regular health check-ups for all children with disabilities; the Education Department for home schooling, admitting children in regular school, balanced with rehabilitation provisions and holding joint activities with regular kindergartens; and with County Financial Department for supporting families and children in poverty and difficult circumstances.
- County DPF has mobilized many different community resources (enterprises, organizations and volunteer teams), particulalry for social integration activities, both enriching the lives of the CP children and increasing public awarenss. The summer camp held in both 2015 and 2016 was an excellent activity with benefits not only for the children but also for the rehab therapists and student volunteers ('we didn't think about all the daily routine before'), the officials and the parents ('the first time my child has managed alone').
- There has been good co-ordination of resources from different departments to ensure holistic and integrative activities for the children with cereral palsy
- Prior to 2015, Chengdu Education & Rehabilitation Centre, acting as resource centre, sent their own experts twice per year to assess the children and train the staff, and this was very much appreciated by the therapy staff. Since then, the resource centre co-ordinates expert visits from Chengdu, but these are not so systematic nor targeted at local needs.
- Pujiang DPF directly links with the provincial level Ba Yi Rehab Centre to assessment or to arrange for parents to take their children for intensive training. The records do not reflect clearly the specific objectives nor the follow-up action plans, and the resource centre role in this activity is not clear.

Issues to consider

- Pujiang County DPF needs to urgently decide how to manage the unstable staff team issue
- The parents mutual-support association has achieved the first step of coming together and holding social activities; the next step may include systematic planning to fully use resources.
- County DPF is currently considering the introduction of medical rehabilitation services through a contract with an expert centre: while this may be very beneficial, there is a risk of excessive emphasis on medical rehabilitation and loss of the holistic approach. Parents are easily persuaded to focus on medical therapies to the detriment of education and social rehabilitation.

2. Outcome 2: Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching

2.1. According to the Pujiang DPF Report, there are 40 children with Cerebral Palsy (aged 0-18 years) while there are 51 persons receiving services (11 persons are older than 18 years); and 45 children are receiving some kind of educaition, about 88.2%.

Receiving education	School	Preschool	Home School	Completed primary schl	Severe/multiple impairments
Yes	22	8	13	2 (university)	
Not at present					6

2.2. Integration into schools:

- 2014-16, Pujiang County Special Education Regulations supported the CP children to gain admission to regular schools (there is no special school in Pujiang). All schools now have resource teachers who have received some training in inclusive education.
- In one school (Da Tang), there are 11 children with disabilities; the children attend regular class in the morning and the resource teacher takes them in the afternoon for daily living skills and social adaptation training; since in the afternoon, the regular students have elective classes; and it is also approved if the child with disability wants to attend an elective class.
- Resource teachers are concerned about the psychological issues; and one resource teacher at Da Tang has a psychological speciality.
- Teachers make arrangements for other children to assist the disabled children.

2.3. Home Schooling

- A teacher with special education background does initial assessment and education plan in the child's home; then a volunteer teacher follows-up (10/semester; each session is 2 hours); the children must have basic cognitive abilities to be accepted for this programme.
- The special education teacher also goes twice/week to the DPF Rehabilitation Centre to teach the children in attendance (small group teaching).
- DPF and Education Department are planning a review of the home schooling, with external expert(s) invited.

2.4. Role of County DPF

- DPF has strongly promoted the regulations, co-operating with Education Department, schools, especially to help the teachers in how to guide the child's rehabilitation training, assistive devices and environmental adaptations.
- DPF invites all children attending school as well as those receiving home schooling to participate in social integration activities twice per month, when they can also receive more rehab therapy guidance.
- Currently, they are discussing with Education how to combine home schooling with home rehabilitation training.

Issues to consider

- The Education Department makes the detailed home schooling plan, but there are no clear indicators for monitoring, nor recorded progression of educational goals to guide the child towards attending regular school.
- There are varied approaches to ensure that all children can have an education opportunity, making good use of government regulations. There is at yet no overall review of the results, challenges and the different requirements of different children.
- DPF frequent requests children to attend rehabilitation and social activities, which may pull children unnecessarily out of their school schedules. In other counties, teachers have noted this

issue, but not in Pujiang; however the rationale for attracting children away from school may need to be considered.

- The schools organize special support for the children with disabilities (eg. Other classmates to care and help them, setting up special afternoon classes, etc), but it is also important to consider the 'labeling' effect and if there are other, more inclusive solutions.

3. **Outcome 3: The experiences of the project are summarized and published in a proposal to relevant government departments for promotion**
   3.1. Pujiang County DPF is twinned with Da Yi County and Qiong Lai County to share ideas and experiences.
   3.2. On several occasions County DPF has reported and shared their experiences during provincial meetings, particularly on working with other government sectors, and mobilizing community resources for children with disabilities in education, health and social integration activities.
   3.3. One teacher at Da Tang School, who has a speciality in psychology, is writing papers on this aspect of inclusive education.

Pujiang County: Summary and Recommendations

Characteristics

Pujiang has established family mutual support platform, holds regular activities for the social development and integration of children, offers a variety of educational opportunities and has good partnerships with other government departments (health and education), as well as community organizations, enterprises and volunteer groups. There is a small centre, providing some expertise and support focusing on daily functioning and education more than physical impairments. In order to ensure rehabilitation therapy for children, the county invites professionals to provide assessment and advice, and helps families to apply for places at the provincial rehabilitation centres.

The lack of a stable therapist team is the major challenge for Pujiang. To solve this issue, they are presently discussing with Ba Yi Rehabilitation Centre (provincial level in Chengdu) using a "service – purchase agreement" approach to provide regular rehabilitation therapy in Pujiang. However, to date no agreement has been reached.

Challenges

1. The evaluators feel that there is a big risk of the medical therapies overpowering the excellent holistic model established. Some medical professionals may not understand the need for consistent and common goals setting required by a holistic approach, and they may unconsciously encourage parents to neglect education and social integration activities in favour of intensive medical rehabilitation.
2. There are more than ten young adults as well as some teenagers using the services of DPF Rehabilitation Centre or receiving home visits. However, parents are anxious about the future: who

will take care of their children? There is an urgent need to consider the needs of adolescents and transition to adult roles, including independent living services and training in livelihood skills.

3. The parents mutual support association is well-established. However it lacks professional counseling and support, which is necessary to proceed from purely social activities and informal peer support.
4. The education sector has invested considerable resources to ensure that children with disabilities can attend school; however to attain the goal of full participation of the children, there is still work to do regarding individual education planning, use of assistive technology to access the curriculum and longer term planning for each child to support increased participation and achieve transitions to higher levels of education or livelihoods trainings.

Recommendations

1. County DPF should be clear about criteria and expectations when contracting medical rehabilitation services, and the role of medical rehabilitation in a holistic approach to enabling a child to attain an education and participate in family and society.
2. County DPF may consider to make use of government resources and programme, in order to provide more stable career opportunities to rehabilitation professional staff based in Pujiang.
3. Similarly, DPF may explore government and community resources to extend their services to adolescents and young adults needing livelihoods counseling and training.
4. The introduction of professional social work resources can provide strong support to the parents association to help them strengthen their structure, overall direction of development and specific objectives and plans in addition to social activities. Other activities may include: child-care for other families' children when needed (for respite care, or when family emergencies arise), organizing activities to train up children's independence; training some parents to take up roles in the rehabilitation centre, advocating and/or conducting activities in life skills and livelihoods, etc.
5. County DPF may assess children's need for educational assistive technology and support the school to introduce these to increase each child's participatory level (eg. reading or writing on a tablet or computer will allow the child to complete assignments and stay up with the class discussion); where DPF does not have this expertise, they should invite experts (e.g. Occupational Therapists) from Chengdu.
6. County DPF may teach school-age children to monitor their own physical and functional problems and to learn how to cope, including doing their own exercises to prevent physical decline, and to ask for help when they have concerns. The child and family can make a regular reports to DPF Rehabilitation Centre, to maintain records, and DPF should intervene only if there are major concerns.

Conclusion

Pujiang County has developed a wide and strong platform to provide services for children with Cerebral Palsy and other disabilities, making full use of a very wide network of partners, including government and non-government, schools, companies and volunteer groups, who support their long list of activities. It is a viable and sustainable approach if some professional physio, occupational and speech therapy is added. While developing more professional services, the community rehabilitation service network must not be neglected; it needs continuous support to maintain and develop, including the integration of parents' resources.

Xinjin County, Chengdu City, Sichuan 四川省新津县

Xinjin County has a population of over 300,000 (2010) and is under the administration of Chengdu City, to which it is linked by train (30 minutes), bus and highway (40-60 minutes). Xinjin County has completed all project expectations and is moving forwards with confidence, especially with their family mutual support, social development (of children) and integrative activities, educational opportunities and work with other government departments (health and education). With strong government commitment they are able to integrate and use all the various resources.

Findings

1 Outcome 1: Children with CP in project counties can access to professional rehabilitation services in local DPF rehabilitation centers

1.1 Children

- Xinjin County has a total of 312 children with different disabilities (0-18 years) of whom 42 have cerebral palsy (2016). All children with cerebral palsy have files including a personalized rehabilitation training plan. Services are provided through various channels.
  - Each child is assessed twice per year by experts (Chengdu resource centre invites experts from the provincial level).
  - County DPF staff visit each child twice per year in their home to assess and monitor the rehabilitation plan.
  - For children with mild disability, the therapist will go to the school and work with the resource centre teacher to ensure the rehabilitation training is continued.
  - For children with moderate disabilities, they attend school (or kindergarten) for half-day and training at the rehabilitation centre for half-day; of which one hour is exercise and one hour is education (cognitive class). The latter is conducted by a teacher with special education or Occupational Therapy background.
  - For children with severe disabilities, the therapist and special education resource teacher visit child in their home.
  - Infants and very young children go to Chengdu centres for early intervention.
- All infants will have regular checks by the maternal and child health network and those with suspected delayed development or disabilites are referred to the DPF (quarterly reports).
- Social integration activities: in addition to festival activities (Childrens Day, Moon Festival, etc), a monthly activity helps children to integrate training, social and community skills and abilities.
- Training in the rehabilitation centre includes daily living skills, self-care skills, and age appropriate housework to increase independence (the twin boys are learning to cook).

Issues to consider

- Although children are referred to Chengdu experts and institutions for intensive rehabilitation or surgeries, there are no clear records of objectives and follow-up recommendations and plans (according to interviews and documentation checks).
- When infants and young children are identified as having potential disability, they are referred to Chengdu institutions (this assumes parents have both funds and time) for early intervention, but again there is no record of follow-up and what happens in the longer term.

- Parents of older children reported that the child is practising self care and daily living skills at home, but they also hope they can learn to be independent in future; although they have no future life plans as yet.
- One young man has graduated from university in the law field, but he now works in a shop: developing systematic supportive employment services may improve job matching (e.g. clerical practice or similar work in a law office initially).
- There are many areas of 'labeling'of children going to school as needing special care, which could be diminished. For example, a child is given special exercises during physical education classes, where a more inclusive approach is to ask all children to do the same beneficial exercises; then support (enable) the child with special needs to participate in the main class activity. It is not easy to come up with good solutions, and probably it is initially necessary to invite an inclusive education consultant and/or Occupational Therapist.

1.2 Family

- Parents trust the Xinjin DPF Rehabilitation & Education Centre's training and staff members, and report that the staff team works seriously. This centre expects parents to participate and complete home assignments. Parents appear to be more deeply involved in the child's programme than observed at other DPF centres.
- There is a parents 'wechat' group to facilitate communication and support.
- County DPF rehabilitation staff together with township/community staff often organize social actvities including aims to provide psychological support and share ways to help the child within the parents groups.
- Parents accept the significance of education and are willing to let their child attend school, which is a change occurring in recent years. However, one parent said that an integrated class in teh rehabilitation centre is better suited to his child's activity level and the child prefers the rehabilitation centre activities.

Issues to consider

- How to manage the balance between parent involvement with their child's rehabilitation activities, the child's need to learn some independence (whether psychological, social or physical) and the parents life pressures? One of the skills every child must learn is how to cope and problem-solve (self-manage), while parents must learn how to stand back and hand over responsiblility to the child as appropriate. This is an important learning outcome of rehabilitation training.
- As the children in this project are growing up, new issues arise, particularly how to develop their independence in adolescence stage, prepare for transitioning to adulthood, switching the focus from rehab training to daily life activities, personality development and social skill, as well as pre-vocational training.

1.3 Service Providers

- Xinjin DPF Rehabilitation and Education Centre has three positions for rehabilitation staff, which were recently confirmed as government-supported contracts, thus stabilizing the professional team and also indicating the government support for DPF rehabilitation work. The three staff have good professional background and have absorbed the holistic concepts of this project.

Through observing them, we see the morning exercise class is age appropriate and well-conducted. For the younger children in the cognitive and fine motor function class, the teaching technique is good, stimulating participation and active learning.

- The children's files clearly record the assessment and training plan, but there is little mention of daily activity goals. We did not see any records from referral centres.
- County DPF has good co-operation with Health and Education sectors, as evidenced by early screening of all children for potential developmental delay or disabilities, follow-up home training, and provision of educational opportunities. DPF role is to provide technical expertise to the other sectors as required
- County DPF plays a leading role in mobilizing community and government resources. There are active volunteer teams from government departments, businesses, colleges and volunteer associations leading and supporting social integration activities with parents and children.
- Rehabilitation therapists and resource teachers have good communication; the schools appreciate the suggestions and support from the therapists.
- DPF rehabilitation staff and Education resource teachers report that they are both involved in home visits, but this was not clearly reviewed by the evaluators.
- Chengdu Education and Rehabilitation Centre (resource centre) invited health experts and other professionals from Chengdu (Ba Yi Rehab Centre, Hua Xi 2nd Hospital) to conduct assessments and suggestions for the children twice per year, and these are highly appreciated by Xinjin DPF staff.

Issues to consider

- The innovative model of half-day school and half-day rehabilitation training is beneficial for children, especially because it encourages more children with disabilities to attend school. However, if the aim is equal access to education, we must set up strategies for children to graduate from half-days to full-day school attendance. Use of appropriate educational assistive devices may be crucial to achieving this goal for most children, in addition to the child acquiring coping and self-management skills.
- Some of the children attending training are already adolescents, and their rehab plans need to include planning for their transition to adulthood, including the way we communicate and work with them, the responsible attitudes we expect of them, as well as planning for job-specific skills (soft and hard skills), according to their individual abilities and interests.
- DPF staff show interest in learning more about use of mobility and postural equipment as well as assistive devices to improve hand skills, etc. The move to get children into regular or special schools, requires an in-depth knowledge of assistive technology and environmental adaptation, to support the child's efforts to keep up with the class.

2 Outcome 2: Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching

2.1 In 2016, there are 42 children with cerebral palsy, of whom 22 are attending regular schools and the rest are visited at home for rehabilitation training and schooling (of these, 10 children also attend the rehabilitation centre for training and classes). All children have access to education.

Receiving education	School	Preschool	Home School	Completed primary schl	Severe/multiple impairments
Yes	22		20		
Not at present					(6)

2.2 Xinjin has no special school. The County Education Department has a special education resource centre, which supports 7 special resource teachers. Each kindergarten and primary school in Xinjin has a resource room and resource teacher, and the special education centre co-ordinates the education for all children with special needs including those at home. This is an interesting and effective approach for other counties to consider.

2.3 Thus Xinjin has achieved integration in kindergartens, primary school, DPF Rehabilitation Centre, vocational training school. Government provides the resources to ensure stablility.

2.4 DPF Rehabilitation Centre staff go to the schools twice per year, to advise the resource teacher on exercise training; for children with severe disabilties, the rehab staff and teacher do a joint assessment and rehab plan and may do the home visits together also.

2.5 To establish the integrated education classes, DPF encourage some children to try half-day at school and half day at the Rehab Centre; thus ensuring that children with more severe disabilities can also get education in a regular school environment.

2.6 The local government provides policy and financial support including for staff, ensuring the stability and sustainability of this approach.

2.7 Each of the two schools visited, have a resource room and part-time resource teacher. In one school, the room is spacious and used for training, and with special furnishings for children. In the other school, the room is smaller, has a library, reading teables, and all children with special needs (including counseling or tutoring) can use the room.

Issues to Consider

- Home schooling for children with severe disabilities should be reviewed, to ensure that the teaching plan is relevant and practical according to the developmental prognosis of each child, and parents expectations. This may vary from educational (cognitive) learning to daily living and community skills.
- To review the advantages and disadvantages of sending teacher and rehab staff together to a child's home. While it will solve some issues such as common goal setting, consistent approach and regular progression, it means that there is only one visit instead of two, decreasing the frequency of support.
- The evaluators noted that the children attending school receive a lot of assistance and special treatment, perhaps constraining development of their full potential, whether mobility or learning. For example, the child can walk alone but other students demonstrate how they help him to do exercise in the physical education class. This overprotection or constant labeling as 'needing' the help of others may affect the child's psychological state. One key to enhancing quality of integrated education is to problem solve how to increase a child's full participation in school activities, by improving or changing the environment, using appropriate assistive devices and improving child's self-confidence. The resource room in each school is an important area for integration, not only for special services. The resource room can be the safe place for each child,

whether with disasbility or not, with a welcoming and non-judgemental (or non-labeling) atmosphere.

3 Outcome 3: The experiences of the project are summarized and published in a proposal to relevant government departments for promotion

3.1 Xinjin DPF project is deeply understood by the County governor, and has the policy and financial support, including facilitating inter-sectoral collaboration .

3.2 Xinjin Education Department has piloted inclusive education for children with special needs, which has had major input to policy change in Chengdu City.

3.3 County Education Department and DPF have shared their experience many times, provincially and nationally.

3.4 The Education Department with the Special Education Centre is presently exploring the experiences and lessons learned from the home schooling, in order to disseminate widely.

Xinjin County: Summary and Recommendations

Charateristics

Xinjin County has a comprehensive programme for children with cerebral palsy, with a range of integrated rehabiltiation and educational possibilities for the children, as well as family and social activities. The rate of children receiving education is high. The most recent project years have developed this balance of educational and rehabilitation training opportunities to ensure preparation of the children for school and parent acceptance of education, as well as maintain children's physical and social training. There is also good co-operation with health, to ensure screening of infants and young children for potential develomental delay and disabilities are referred to DPF. The county DPF has strong support from the county government as indicated by the active contributions of the vice-governor during the evaluation visits, and significantly, by the provision of contract positions for three rehabilitation therapy staff.

Challenges

1. Educational strategies for integrating children with CP are established and working well. The next step facing the DPF and schools is how to ensure full participation and inclusive environment while accepting the differences of each child. This requires a continous review of quality of participation and problem solving.
2. Both the rehabilitation training and the experts consultants (sourced by the resource centre) tend to focus more on changing and preparing the child without considering how to change the environment, which latter is a fundamental (although difficult) principle of inclusive education. DPF rehabilitation staff and resource teachers have received little training in assistive technology (from basic to more sophisticated) to improve a child's participation in an educational environment.
3. The school readiness assessment is not systematically recorded. The evalutators did not find evidence of consistent planning, for preparing a child to move from primary to middle school or other agreed destinations.

4. For children who cannot continue in school, planning and training for daily living and community skills and vocational training, and this needs to be addressed by DPF Rehabilitation Centre and parents.
5. The referral mechanism to higher level experts is not clearly documented, with expected outcomes of the referrals and follow up summary and practical action plan on return from specialist referral.

Recommendations

1. Capacity build in the areas of assistive technology and Occupational Therapy approaches especially for improving children's independence in daily activities and participation in education and social activities; including mobility, dressing, eating and all kinds of communication devices (from hand writing to computer use), and environmental adaptations including a child's desk and chair etc.

- Provide training for DPF Rehab Centre staff in school readiness checklist (assessment) and training; establish school admission guidelines which includes the child's need for assistive devices of all kinds, their selection, adaptation of the devices (tailor made for the child) and the required training to use them.
- Follow up children facing challenges in school (or home school), to problem solve, and plan for their future destination, whether studies, university, livelihoods training, or a meaningful life at home and community; to support children's smooth transition and adaptation.
- Develop programmes for adolescents including vocational training; discuss with young people and their families the long term planning for adolescents and young adulthood.
- Clarify the referral mechanism with higher level rehabilitation institutions to develop a mutually agreed guidelines for assessment, interventions, documentation and follow-up (discharge plan) that is relevant to each child's personal goals, environment and potential.
- In Xinjin County, the evaluators had no opportunity to observe parents mutual support activities. Staff reported that parents are active and initiating a number of activities, and do not always require subsidies from DPF. It is recommended that the County DPF check and analyze the parent activities to consider how to make full use of this resource to support DPF plans; and also to follow-up, if some particular parents or families are commonly left out or not actively participating for various reasons (including distance, financial means, working location, personalities, age).

Conclusion

Xinjin County has a well-established approach for children with disabilities. This project has consolidated the collaboration of rehabilitation therapies and education using a flexible, broad perspective so that several different pathways are available for children with different needs at different ages. It is timely to review the successes, to identify any gaps or children who fall through the network and what is the next phase to improve the quality of education and transitions to adolescence and adulthood.

Resource Centre for Pixian, Pujiang and Xinjin Counties

Chengdu Education and Rehabilitation Centre, Chengdu Disabled Persons Federation

Summary Statement

Rehabilitation services for children, under the Chengdu Disabled Persons Federation (DPF) has had a significant reorganization over the project duration, which has focused on restructuring and decentralizing rehabilitation services to district/county and community levels, instead of investing major resources at city level. The previous city level rehabilitation centre for children with cerebral palsy has been transformed into a resource centre with the role of capacity building through organizing training, inviting experts as required, supporting development and access to community services near the child's home, and helping local service organizations to fully utilize policies, project funding and support. Since the Chengdu Education & Rehabilitation Centre (Chengdu Centre) no longer provides front-line services, they have time to organize quality improvement activities and strategies. This approach should be evaluated and lessons learned disseminated.

The Chengdu Centre continues to support and monitor all three counties, discussing their annual plans and budgets, and taking up the role of a resource centre by liaising with expertise and analyzing and sharing experiences. Some examples include: child rehabilitation and education assessments, ensuring children with disabilities get health checks, disseminating new materials (books, etc.), supporting organization of new activities such as the summer camp in Pujiang; and in order to disseminate the experiences of the project counties: inviting project counties to report to the 21 district/counties of Chengdu, while specifically organizing peer visits and matching of counties.

Findings

The key roles of the Chengdu Centre for this project are:

1. Project management (including annual planning, budget control, and ongoing advice)
2. Linking with expertise (referrals, assessment)
3. Capacity building activities for all counties as well as district and community level services
4. Giving guidance for new (innovative) activities and strategies, and use of new policies and government funding opportunities
5. Dissemination of successful experiences to all districts & counties in Chengdu, a city of 14.5 million persons (2014) including semi-urban and rural counties under it's administration.

Outcome 1: Children with CP in project counties can access to professional rehabilitation services in local DPF rehabilitation centers

This objective is a major focus of the Chengdu Centre's work in the project, and they haves organized many activities to support the three counties.

1. Organizing child assessment by experts for the 3 counties: although the actual number of children assessed is one way to report the output, it is noted that expert visits also are a «hand by hand» teaching opportunity for local staff and through demonstration it also changes the way that families, front-line staff, officials and the community understand rehabilitation and the breadth of activities that enable a child's growth and development to her/his full potential.

1) Trainings, which are also open to new community rehabilitation services in Chengdu districts and non-project counties. This is excellent way to create mutual support networks between front-line workers as well as managers and officials; and to discuss and share successful (and less successful) approaches to non-project sites.

Although it requires much effort and co-ordination to invite the experts from provincial level hospital (such as Hua Xi Second Hospital) and the Education Bureau, these experts have in fact, become strong advocates for holistic rehabilitation, developing links with community and family services and supporting community programmes. Assessment and teaching visits to project counties stimulated an education expert to write a book on psychological perspectives and has resulted in invitations to County DPF staff to participate in seminars in Chengdu. One expert speech therapist after visiting the project sites, acknowledges how it has changed her understanding of the needs of children and their families: 'in my opinion, helping children with Cerebral Palsy is not only about training, but should be the establishment of an all-round development (including education) intervention plan.'

Issues to consider

- The Chengdu Centre is a very stable and workable model of a resource centre. However, it is noted that the county rehab staff prefer the previous working method (pre 2015), with frequent visits from Chengdu Centre's professional team, since they understood the holistic approach and also perhaps, found it easier to discuss challenges. It is also noted that the experts visiting in recent years tend to focus on the physical issues of the child (body/structure).
- The counties are contacting Ba Yi Rehab Centre and other centres of expertise sometimes through the Chengdu Centre and other times directly. There needs to be a rational, co-ordinated use of expert resources.
- The referral system with the experts does not demonstrate clear and useful communication of the expectations (functional goals) for each child referred, nor the follow up interventions, on returning home. There is an urgent need to improve the quality of communication (discharge planning), with both sides needing to be more explicit. This is to ensure effective, consistent and efficient use of expensive resources and the child and families' efforts and time.
- The Chengdu Centre has strong links with some excellent district and community rehab centres in Chengdu; some of which have excellent experience working with families. It would be useful to invite staff from these centres to participate in county visits, enriching the expert resources.

Outcome 2: Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching

- The first project phase started to explore education for children with cerebral palsy, and Chengdu City Government then set up a new special education plan (2006-2010) explicitly requiring DPF to ensure that children with disabilities get preschool education, particularly using approach of rehabilitation and preschool centre for children 0-7 years. The project played an important role in the establishment of this policy
- The counties all use Conductive Education classes for the children, giving the children an opportunity to function in a class (group) situation; and have introduced regular kindergarten and home schooling

also. The counties all co-operate closely with the Education Department, both contributing to policy formation and taking advantage of current policies. Chengdu City's '2011-2016 Special Education Plan' strengthens the requirements for inclusive education. The ratio of children with cerebral plasy receiving education of some kind, in each of the three counties is quite high , although actually attending normal school is less than 50% (Pi Xian: 25/84; Pujiang: 22/40， Xinjin: 22/45), but this is nevertheless, greatly improved from the first phase of the project and significantly better than other counties in Sichuan and China.

- The three counties have already arranged education for CP children with milder disability; most children with moderate to severe disability receive education through the rehabilitation centre and home schooling
- Each county's rehabilitation centre provides training for the children to prepare to attend school, including writing, communication with classmates, and other abilities.
- For children in school, Xinjin DPF rehabiltiation staff will visit the school resource centre and discuss with the teacher how to continue the rehabilitation training; DPF centres will communicate with the schools and do simple environmental adaptations. Although the counties have some differences, they are using the resource teacher and classroom model, to provide individual training and counseling to the children.

Issues to consider

- To explore increasimg the number of seriously disabled children in regular schools by transitioning them from home schooling to a classroom environment; this will require use of assistive technnology for mobility, seating, communication, and learning. There is little expertise in this area, but there is much experience overseas to learn from.
- Resource teachers are very supportive of the children, and there are a variety of approaches including half-days, special classes, reduction of expectations, etc.However, support should always be enabling so that children can reach progressively higher goals and not be labelled as 'needing help' unnecessarily. In today's world, assistive technology may provide the help they need to achieve their learning goals and perform activities.
- Home schooling (sending education to the home) is relatively high in all three counties, but there needs to be a review of child assessment, interventions (assistive devices and environment as well as training), learning goals and overall goal of home schooling. The goal for each child may be to transition them to regular school, teach them to contribute to their family, or live safely in their own community and home.
- The project has followed some children over eight years, thus raising clearly the issues facing adolescents with cerebral palsy, many of whom have obtained an education and thus have higher expectations of their future lives. The planning and support for each child transition's from primary to middle school and to further education or vocational training is not clear

Outcome 3 The experiences of the project are summarized and published in a proposal to relevant government departments for promotion

Chengdu DPF consider sharing and promoting of project experiences and results is very important, as demonstrated by:

- Project outcomes are reported to the disability, health and education sectors to promote policy formation, including two reports focused on special education and special assistance required by children with disabilities.
- Through the program of twinning of county DPF, each of the project sites has shared its experiences with 2-3 other counties or districts; this is innovative and practical.
- These counties have also been invited to present their experiences at government work meetings

Issues to consider

- The counties rehabilitation and education integrative models have unique, relevant and practical characteristics; and their approaches should be studied and written up for dissemination and discussion.

Challenges

- Within this project the Chengdu Education and Rehabilitation Centre role is to organize, co-ordinate and guide the development of services and ensure quality service provision. The Centre has gone through a major change in the current project period from being a front line rehabilitation centre for children with cerebral palsy to serving as this resource platform. This means that the daily training and education services for children throughout Chengdu (including the counties) are now closer to the homes of children at community and district level, as they should be. They only require expert services for assessment and special procedures. The Centre has maintained its holistic approach throughout the mentoring also. However, we note there are challenges with the referral system, where the communication with higher level expertise may be difficult for counties, and there are no strong mechanisms for ensuring sharing of documentation, setting up common goals and strategies.

- Since the professional rehabilitation staff team at county-level is not yet stable, the counties still require some front-line services through the referral system; and they need support to attract stable staff, who can provide consistent fundamental services expected of a community-based rehabilitation centre, as mentored by the Chengdu Centre.

- The county-level Rehabilitation and Education Centres were set up as preschool centres (0-7 years) but now the children are growing up and the service coverage has increased to cover all children in the county. The issues facing adolescents are becoming obvious, including smooth transitions in school, preparation for adulthood including living and livelihoods issues, and also new requirements for fitness to cope with a normal day (job), and for assistive technology. This requires consideration of from a policy perspective as well as attention and capacity building of staff.

- At both the rehabilitation centre and school, the children with cerebral palsy need more assistive devices to increase their abilities and participation in daily activities. However, the rehabilitation staff have very little knowledge and access to up-to-date approaches to prescribing, training and adapting assistive technology to enable CP children a level of independence. Perhaps there is also an implication of “we failed to train the child enough so we have to give him a tablet computer to

complete his assignment". This is a false statement and the reason for not using assistive devices needs to be explored and solutions found.

Recommendations

1. The evaluation found that the urban districts and counties have good basic structure and services for holistic rehabilitation. The imperative now for Chengdu DPF is to focus on quality service standards and capacity building.

2. We suggest introducing professional Occupational Therapy (OT) services; establishment of a unified checklist or assessment for school readiness; design guidelines for preparing child, family and the schools for school admission; how to assess and increase the level of the child's participation in the school life; and guidelines for planning for transitions whether within a school, between schools and leaving school (for whatever reasons).

3. Introduction of assistive technology related to daily life and school; this may require an assistive technology professional (with educational expertise; in other countries this is often an OT) at the resource centre level initially.

4. Establish a stable team of resource experts, all of whom have a consistent holistic perspective to rehabilitation, so that assessment and training recommendations are also consistent, practical and relevant for the child and the county centre; with the goal to improve access to education, develop methods for independence in living skills and also successful transition to adolescence and adulthood.

5. Organize a review of the inclusive education practice, particularly the integration of education and rehabilitation training, to analyze the results, lessons learned and provide insight for the future.

6. Compile the experiences of the education of children with disabilities, their families and teachers, and use it as advocacay and promotion materials for other counties and districts.

Wei County (Wei Xian), Hebei Province

Wei Xian is a typical large, rural county, with a population of 1,060,000 (2016), under the administration of Handan City in southern Hebei Province. Wei Xian, over the recent ten years, has worked to set-up community based rehabilitation (CBR): establishing a three-level network with a county level rehabilitation centre to support and monitor the townships (rehabilitation officer and committee) and the many villages (community rehabilitation worker who is usually a village doctor, and community rehabilitation co-ordinator) and families. This network aims to provide basic rehabilitation therapy, and facilitation of education, social integration and family activities, etc. However, the county faces continuous difficulties to hire professional rehabilitation therapy staff to work at the county rehabilitation centre, who should be the key professional support team for the communities.

1. **Outcome 1: Children with CP in project counties can access to professional rehabilitation services in local DPF rehabilitation centers**

   1.1 Children

   - There are 206 children with cerebral palsy (age 0-14 years) identified in this populous county; of which 115 children have received project services, most of them living in communities closer to the county centre.
   - Wei Xian rehabilitation services are divided into 2 parts: institutional based (hospitals) rehabilitation training and community (family) services.
   - Institutional rehabilitation: Wei Xian DPF could not find therapy staff, so in 2015, DPF signed a contract with two county hospitals to provide the rehabilitation training for cerebral palsy children. There are currently 26 children (7 months-4 years of age) receiving services at the Maternal and Child Hospital. The County Traditional Chinese Medicine Hospital is responsible for older children's rehabilitation training (not visited). During the visit to the Maternal & Child Hospital, 2 staff (non-professional) background but trained and closely supervised by the Handan rehabilitation expert) were observed with 10 children, providing individual training, guiding the parents, and conducting a group activity. Training fees are reimbursed by health insurance and the rest supplemented by DPF project funding. Family members need to pay about RMB 700-800 (USD 100-110)/month.
   - The director of the Maternal & Child Hospital is enthusiastic to develop rehabilitation and has sent 3 doctors for external study, with the intention of expanding rehabilitation services.
   - Community (family) rehabilitation: DPF staff organize regular social activities for some of the children and their parents, using events such as the national day for people with disabilities, children's day, kindergarten activities and parent education trainings.
   - DPF invites provincial (or Beijing) experts twice per year to assess the children and counsel the families, although the experts' time is always limited and the visits maybe delayed. During a one day visit, the expert may assess up to 20 children; thus the expert mainly focuses on physical issues and giving brief advice to the parents. The case records record the physical and mobility problems, with no functional goal setting and no notes on relevant progress.
   - According to the recommendations of the experts, DPF will provide assistive devices for the children, including for walking, standing, sitting and wheelchairs. Recently, the provincial expert has recommended purchase of regular tricycles (used by many community residents) as a good

solution for two children to go to school independently. Another child's seating and standing devices are also appropriate. The parents need more guidance on the use of this equipment.

- When children require orthoses (braces), they are screened, assessed and fitted by a Handan orthoses company. There is no record in the child's file of the assessment or rationale, only a selection from the "product list", and no follow-up records were found.
- Poor families of children with disabilities can apply for the "poverty allowance" with help from DPF, and the DPF regularly provides other financial subsidies and support.
- For children living in remote areas, a local community rehabilitation coordinator may provide some services, but this evaluation did not check any information systems or statistics.
- DPF's partnership with the Maternal and Child Hospital has established a system of infant and child screening with early referral for those suspected of disability or developmental delay. The Hospital reports every 6 months to the DPF. This has proven successful, with more than 20 newly identified children registered and provided with early intervention in 2016.
- Among the 4 children visited in their homes, one has severe disability requiring professional rehabilitation and tailor-made assistive devices, and two children have complex disability issues that require provincial level (at least) interventions. It is noted that all these children receive continuing support from the County DPF, in spite of the difficulties presenting.

Issues to consider

- Early detection and referral mechanism is relatively complete, but early rehabilitation services may be improved. The Maternal and Child Hospital has few staff with only basic competencies in early stimulation and rehabilitation. Capacity building for the staff team and service expansion is required. The Hospital has already sent doctors for further study and they should also consider to send therapists for a consistent approach in the professional team.
- The two county hospitals are providing rehabilitation, including some cognitive and activities training for the children with cerebral palsy, but since the services are taking place in the hospital environment, and reimbursed by health insurance, the focus is still on the medical ("fix it") approach. It is necessary to ensure a holistic rehabilitation approach, which must include early childhood education to prepare for kindergarten, preschool and primary school. For the children attending hospital-based therapy, there must be a complementary and systematic plan for early education, at appropriate levels.
- The community (family) rehabilitation training seems to be dependent on expert guidance from Handan. But time is valuable and it is necessary to optimize the use of existing resources. The DPF centre may consider to train county staff to monitor the children's progress; then request experts for specific advice for those more complex children. Experts (with community experience) are best utilized to train and empower local staff.
- County DPF are increasingly working with experts from Handan City. It remains important that experts focus on what is feasible and relevant to children and families in their communities, coming to agreement of specific and achievable functional goals to improve the daily lives of the children.
- Case records are unable to give a clear profile of the child: there is little consistency between experts' assessment, prescribed assistive devices and orthotics. The records are not clear about the rationale, and there is no comprehensive planning to reach common medium or long-term goals. It is advised to review how records are kept and work towards a more unified and

integrated record. This may be helped if DPF staff write a regular progress report on each visit, which has a clear link to the previous visit report (progress or change since last visit, new problems, solutions or advice discussed with parents, specific plans to work on before next visit and hoped for functional goal)

- County DPF is aware that children with disability in remote areas are not receiving rehabilitation assessment or services and a strategy is required to gradually extend the existing networks to cover the whole county.
- It is observed that the children, especially as they grow older, do require timely referrals for specialized medical and rehabilitation assessment and treatment (eg. hip surveillance & interventions, spasticity management, sleeping or pain issues, etc). These referrals may be delayed or never made due to insufficient funding (no national funds for older children) and lack of expert resources within the province. These issues require mobilizing of funds from various sources, and policy support, and needs discussion at provincial and national levels.

1.2 Family

- Activity records and reports from DPF shows that social integration activities with parents and children are conducted regularly and parents are willing to participate.
- Parents are happy with services provided by Disabled Persons' Federation: DPF contacts the school, helps to apply for subsidies and assistive devices, etc. These are of great help to parents.
- Parents support the rehabilitation of children, and are willing to spend time and effort on their child with disability, including taking the child to school and hospital. Families are willing to make life adjustments and arrangements. For example, one mother reported that they have rented accommodation in the county-city and the father is looking for a job, in order that their child can attend rehabilitation.

Issues to consider

- Parents are concerned about the child's medical rehabilitation issues and physical therapy management and are investing time and energy to make their child “better”. It is crucial that parents understand their child’s future and are involved in longer term, comprehensive planning.
- Parents groups are focusing on psycho-social support activities but these groups could be used to develop peer counseling and help with long-term planning for children

1.3 Service providers

- County Disabled Persons Federation and the Rehabilitation Centre
  - In 2014, DPF decided to co-operate with the two hospitals for rehabilitation therapy services; however the DPF Rehabilitation Centre maintains eight staff positions, as well as rooms with simple equipment. In addition to other activities, the staff are responsible for organizing social integration activities for the children and parents, registration, information gathering and dissemination, co-ordination of expert assessments and follow-up, provision of assistive devices (application and process), etc.
  - In the early stage of this project, the centre staff had received professional training from various projects, but due to ongoing personnel changes, few staff have rehabilitation expertise, that allows them to monitor the quality and process of rehabilitation and

community rehabilitation. At present there are many children in more remote areas of the county, who are not receiving professional services.
  - There is good co-operation between the DPF Rehabilitation Centre and the Maternal and Child Hospital, to ensure early detection of children with disabilities, with early interventions

- Rehabilitation Services: Maternal & Child Hospital and Traditional Chinese Medicine Hospital
  - These two county-level hospitals in cooperation with Handan City Orthopedic Hospital, provide the rehabilitation services for children with cerebral palsy, under the technical guidance of the head of rehabilitation of Handan City Orthopedic Hospital (Dr Wang).
  - Dr. Wang has participated in many of the project's training activities, and he reports enthusiastically that he has greatly benefitted, including what he has learned from the project courses on Conductive Education and Occupational Therapy.
  - County DPF pays the fees for the hospital-based rehabilitation but the agreement appears very general with no clear records of expectations of the training or service outcomes.
  - The Maternal and Child Hospital will expand services for children with disabilities, which has the potential for promoting the overall development of rehabilitation in Wei Xian.
- Resource Centre
  - Provincial DPF Rehabilitation Centre has become increasingly active in providing expert services for this project; staff have a strong holistic approach to rehabilitation services. However, they have limited manpower and have restrictions in providing frequent support to Wei Xian and have thus connected the County with the rehabilitation expert at the Handan City Orthopedic Hospital
  - The Handan City expert has also benefited strongly from the project training, and consistently promotes and models a holistic approach. He has constructed the partnerships with the local county hospitals, and also provides training for some Wei Xian children in the Handan hospital.
  - It is not clear how much Handan City DPF are involved in mentoring the CBR work of Wei Xian.

Issues to consider

- Wei Xian DPF has a team of staff at their rehabilitation centre: in order to ensure their effectiveness, it is import to continuously capacity build and develop staff roles. DPF staff may then ensure participation of children in preschool, school, and that they have support to transition to middle school and adulthood. Some of these staff may specialize in specific areas such as assistive technology or education or adolescent groups, etc, in order to reduce the reliance on external expertise when possible. Some of these staff may be used to support community services in remote areas of the county.
- The provincial level DPF Rehabilitation Centre, although acting as resource centre for this project phase, cannot support all the needs. The current situation, where Handan Orthopedic Hospital's rehabilitation department acts as the direct support, (in partnership with the local County hospitals) is a good temporary solution. However, it's not sustainable to depend on one person and it is necessary to consider a broader support base, and continued capacity-building in Handan.
- Due to manpower and geographical issues, there are children living in remote areas of Wei Xian who are not getting services. The existing CBR network needs increase monitoring and support to ensure that no child is left without basic services, which includes educational opportunities.

- Potential expansion of rehabilitation services at the Maternal & Child Hospital will mean increased capacity for children with cerebral palsy; however there is the danger of overemphasizing medical interventions, rather than holistic rehabilitation services.
- Hospital services do not replace an early education and rehabilitation centre for children with disability and this fact needs to be discussed, with County DPF protecting the rights of children to attend kindergarten or preschool (or similar activity-based learning classes) and ensure that each child has the opportunity to an education, at the appropriate ages.

2. Outcome 2: Children with CP can access to basic education, including regular kindergartens and school, special education schools, rehabilitation schools and home teaching

2.1. Wei Xian records 115 children with Cerebral Palsy receiving services of which 24 are attending school and 16 receiving home schooling.

	School	Preschool	Home School	Completed primary schl	Severe/multiple impairments
Receiving education	21	3	16		
Without education					75

2.2. In 2014, Wei Xian County released: "Wei Xian Integrated Education Development Action Plan", piloting integrated education in 3 middle schools, of which two are private schools. The evaluators visited one school, teachers of two others filled out the questionnaire, and one participated in the report session and interview.

- From the questionnaires and interview, it is seen that the children attending school have moderate movement and walking disabilities, but with better cognitive functioning.
- Teachers and fellow students give support to children, helping to decrease physical barriers (waiting for parents to send their children to the door, accompany to toilet, etc), and providing learning support (extension of time for assignments and exams).
- The teachers participated in 1 day training on integrated education held by DPF; and are willing to support the children's schooling, but the teachers hope the children could have more rehabilitation training to improve their physical functioning and overcome movement barriers.

2.3. Special education school in Wei Xian does not have special resource classroom; but the school has provided training to all county teachers about children with special needs; the special school is also responsible for those 16 children receiving home schooling and this number is planned to increase. The regular schools also have no resource classroom, but in the pilot schools for integrated education, there is one teacher responsible for support, co-ordination and reporting.

2.4. During home visits by the evaluators, two of the children are each using a tricycle (new) to solve the problem of transportation to school. It is reported that they participate in all classes except physical education. The teachers report (questionnaires) that the children slow writing ability is a problem. They also note that attendance at middle school will be a problem due to the distance to the school, unless they can live independently in the middle school dormitory

2.5. County DPF organizes for the children to get an expert assessment and guidance once to twice per year, including the children going to school; and DPF assists with co-ordination with schools and encourages parents to contact schools directly also.

Issues to consider

- The number of pilot schools is relatively small and the selection of two private schools may be due to smaller classes and higher degree of co-operation and willingness to trial new ideas. The challenge facing Wei Xian is how to promote the lessons learned from the pilots to other schools and increase the number of children in school.
- There must be continued advocacy and education about the rights of all children to obtain an education.
- There appears to be little practical support for the teachers in the pilot schools to understand how to help the children with disabilities improve their participation in classes. DPF may consider how to consult on the need for assistive technology, or other educational technical support for including children with special needs; relevant experts in this area may conduct special assessments and provide coaching.
- Home schooling is launched: the challenge for DPF is how to strengthen co-operation with Special Education teachers to support and improve the home schooling; and work towards common goals for each child, some of whom may be able to attend school in future.

3. Outcome 3: The experiences of the project is summarized and published in a proposal to relevant government departments for promotion

Wei Xian DPF has been invited by Handan City DPF to share their experiences in CBR, integrated education and working with children with cerebral palsy with other counties; and also has presented at Hebei Provincial DPF meetings including the following areas:

- Service purchase agreements to provide services, management and service quality standards.
- Co-operation with Health Department to ensure early screening of infants for developmental delay and disabilities, reporting and provision of early stimulation and rehabilitation.
- Pilot project on integrated education experience and lessons learned.

Challenges

- Wei Xian DPF lacks sufficient staff specialized in children's rehabilitation services: the existing staff do not have strong enough experience to monitor and improve quality of services, nor to extend the service coverage to the vast population. This is typical for rural counties. Even with the establishment of a 3 level service provision system (county-town-village), the system cannot function without some professional expertise in rehabilitation and education of children with cerebral palsy at county level. The support of Handan City expertise is good and consistent; but it is not going to solve the problem of helping each and every child.
- County DPF has moved forward to solve this problem by contracting rehabilitation services to the hospital system. However, it is only a partial solution since holistic rehabilitation requires a continuum of services; hospital therapists' interventions must be complemented by activities to prepare children for preschool and kindergarten, both individual preparation and learning how to play, and behave in group and classroom environments.

- Parents may consider that medical rehabilitation is the best solution and without continuous promotion of education, children will miss out on play, kindergarten and school; it is the responsibility of DPF to ensure the quality of services they are purchasing are both adequate and adding to the child's functional abilities.
- Children going to school cannot be neglected: they will have many challenges, some of which can certainly be solved by expertise in technical aids (assistive devices) and rehabilitation therapy skills; in addition all children's plans should consider coming adolescence period and preparation for life skills.
- Children require medical assessment, and potentially new surgical intervention, new assistive devices and support during adolescence. These often require high level expertise (referrals) and major funding.

Recommendations

1. Extend basic services to all children with Cerebral Palsy (and other disabilities) in Wei Xian, using the CBR strategy which is already established in the county.
2. Strengthen the CBR network to ensure it is effective, through capacity building.
    - County DPF is recommended to invest in their own rehabilitation centre staff to increase their capacity as advisors, supporters and monitors of the community rehabilitation co-ordinators and township DPF representative. All county staff must be excellent advocates of holistic rehabilitation. But each staff may specialize in a specific area according to their own interest and competencies: e.g. Communication and psychological skills; group skills (social work skills); education and schooling; preschool & play groups; assistive technology (including IT) for school and adolescence, marketing and promotion, etc. CBR workers, parent groups, township teachers. The use of social media (we chat/qq) means that regular contact with remote community workers is relatively easy.
    - Community rehabilitation co-ordinators and rehab workers should be supported to work towards goals related to daily activities of the child, as well as exercise; community rehab staff need incremental training approach, with frequent support and encouragement, perhaps making use of social media as well as visits.
    - It is important to continuously check and improve records kept by CBR staff and county DPF Rehabilitation Centre staff; to ensure they are focusing on functional (daily living skills) goals and that these are achieved and progressed.
3. In the area of education: continue to increase number of children in schools; and set up close communication between the Education Department, special school (principals and teachers) and the rehabilitation centre staff.
4. Review the level of participation of the 24 children attending school and discuss with teachers, rehab staff, city and provincial experts potential solutions for improving the quality of their education experience, including setting mid to long-term goals for each year, transitioning to middle school or an alternative.
5. For home schooling, the children presently receiving home schooling should be reviewed, particularly the specific rehabilitation therapy goals and education goals. Is there potential for the child to attend school in the future? If this is not currently realistic, are the goals going to help the child and/or family have a better quality of life. It is probably best to do this analysis of home

schooling before extending the service to other children so that future children and teachers can learn from the experiences.

6. Consider the needs for medical referral for severe physical disabilities of children with Cerebral Palsy; and report these issues to provincial levels, as many cannot yet be managed at county or even city level.

Conclusion

Wei Xian has faced the issues of manpower shortages through developing partnerships with local hospitals, while also improving the collaboration with community health networks and the Education Department to achieve all the goals and ensure sustainable services for children with Cerebral Palsy. They now face the major challenge of extending these holistic services to the more remote areas of the county, although with a stronger county rehabilitation team and the support and supervision of Handan City and the Provincial DPF this should be possible.

Resource Centre for Wei County (Wei Xian), Hebei Province

Hebei Disabled Persons Rehabilitation Centre, Hebei Disabled Persons Federation

Summary Statement

During the project's first phase, Beijing (China Rehabilitation Research Centre) acted as the resource centre for Wei Xian, to provide training, expert visits, and help to overcome challenges. However, in 2015, the provincial rehabilitation centre in Shijiazhuang City (provincial capital) was invited to take up the resource centre role, to ensure more frequent support. The centre has developed limited, but holistic services for children with different disabilities and thus can both accept trainees and visitors as well as provide expert advice and support and enthusiasm. The professional communication and referral system is clearly established and actively utilized.

Findings

1. This provincial rehabilitation centre has programmes for children with hearing impairment, autism, intellectual disabilities and cerebral palsy. The cerebral palsy unit is quite small, with 15 children attending daily and six staff members (doctors, teachers and therapist). They use individual training approach and Conductive Education (group classes focusing on integrating physical functioning, daily living skills and communication).

2. The director of the cerebral palsy unit reported that it took him five years to digest, practice and develop this integrated, holistic model, and to get his colleagues trained up and supportive. This project has been influential in his change of approach (from traditional medical model). The Centre approach has the following features:
   - Emphasizes a kindergarten environment, with the goal of training children to manage their self-care and prepare for education. In all aspects, (decoration, posters/photographs, classroom layout and equipment), the goal to promote comprehensive development, working towards education.
   - Training focuses on activities of daily living, embedded training goals in meaningful activities, The Conductive Education class observed used a supermarket shopping model to train sitting, hand function, walking, use of money, developing cognition and communication, etc.; and impressively, it was conducted by a Chinese Traditional doctor who had attended the project course in Conductive Education.
   - Parents are strongly encouraged to facilitate children's functional independence, rather than relying on the parent or grandparent to do everything for them.

3. From 2015, the centre was invited to provide expert assessment and rehabilitation services and guidance for Wei Xian DPF. The advice offered to Wei Xian parents is very practical (suggesting tricycles for children to get to school and strongly advising parents to send their children to school). To better support the needs of Wei Xian, the provincial centre connected them to the rehabilitation unit of the Handan City Orthopedic Hospital; which has now resulted in further co-operation with the county level hospitals. This demonstrates an important function of a provincial resource centre; to link up and mobilize resources and support networks.

4. As the provincial rehabilitation centre immediately under Hebei DPF, the centre is responsible for capacity building for counties and cities throughout the province, whether as teaching courses, providing expert teachers, or accepting staff for practice placements. The cerebral palsy rehabilitation service presently focuses on young children and is not able to expand to adolescents or adults, livelihoods, assistive technology and orthotics, etc. There is currently discussion about how to utilize the provincial centre more effectively to support counties such as Wei Xian to help maintain their community rehabilitation work.

Recommendations

1. Continue to strengthen the provincial centre, and in particular develop expertise in assistive technology (including mobility and orthotics devices, daily living devices, communication and educational devices).
2. Through visits, studies and practice, develop expertise in advising teachers in enabling children with cerebral palsy in the regular classroom.
3. Build up a multi-disciplinary 'assessment' team and the accompanying assessment records, planning and follow-up guides, with particularly emphasis on school readiness.
4. Focus training and support for Handan City (and other cities) to ensure they promote holistic approach in their trainings and their policies.
5. Require that all training includes practice in making functional (and feasible) goals for children.
6. Review the situation of adolescents and report the specific needs of a growing child with cerebral palsy, which includes both medical assessment and interventions (of physical structure and function, such as dislocated hips) and long-term planning for livelihoods and transition to adulthood.
7. Develop an active CBR Resource Centre to help counties with established CBR networks, maintain them over the years; if there is no interest from supervising units, these CBR referral and service provision systems in rural areas are likely to fall into disuse.
8. To improve the quality of CBR services, it is necessary to revise the existing system of recording information and service provision, for all persons with disabilities (including adults and children). Good records are the foundation of a quality system that both responds to and supports national policies.
9. Consider to add an Occupational Therapist and Social Worker positions to the Provincial Rehabilitation Centre. To bridge the gap (until these positions can be obtained), invite the local Rehabilitation Therapy and Social Work College students and faculty to provide (develop) expertise in supporting children in school or in home schooling.

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Overall Project Management

1. Social Service Guidance Centre of China Disabled Persons Federation (CDPF)

The Social Service Guidance Centre (SSGC) is the central project partner for both Phase I and II, with responsibilities for (1) implementation, monitoring and guidance, (2) organizing capacity building activities to bring the counties together for training and mutual sharing and learning and (3) annual planning and budget control. SSGC has good communication with Norwegian Missionary Alliance (Kunming). They have mutual understanding of the challenges and have achieved a good balance and strong partnership with common aims and agreement on processes.

The project leadership changed at SSGC due to personnel retirement, so that the second phase was assigned to an experienced staff, who had assisted in the first phase, and was familiar with the project and the counties, the challenges and the newly established aims for 2014-16. She reports to the directors of SSGC and is supported by CRRC's administrative department.

Monitoring was performed about twice per year to each county, sometimes coinciding with trainings and often NMA project staff would accompany SSGC. Many problems were solved and new ideas discussed on these visits.

The SSGC courses were designed specifically to address the issues raised in the evaluation of Phase I. All counties and resource centres were invited to attend, and different sites hosted each of the courses. Trainees were very appreciative of the content, including both concepts and skills, which were reported as particularly relevant to their situation. The courses covered: child and parents' psychological issues and communication skills, Occupational Therapy for children with cerebral palsy (including assistive devices for hand function, mobility, seating, etc.), inclusive education, working with families, etc. The framework for all the teaching was the holistic rehabilitation concept and this continuity throughout each training is also a very important factor to stimulate incremental change in knowledge and attitudes but also behaviour or practice.

The training courses also provided opportunities for the project site staff to visit their sister counties, compare and discuss their challenges and get new ideas from their peers as well as SSGC and NMA. These opportunities to meet are important for encouragement and inspiration.

This project is considered significant and successful by SSGC for the following three reasons:

- There is a clear trend of decentralizing the planning process.
  Initially, SSGC did the annual planning and led the counties to complete the required activities, so that the counties all followed a similar approach. In the second phase, the responsibility for annual planning and preparing the activity budget was given to each of the 5 counties. This meant that they could adjust the activities, timing and methodology to their own situation, local conditions (eg. manpower, resources and parents beliefs) and local government policies. The respective resource centre and SSGC reviewed and made suggestions before finalizing each counties annual plan with NMA.

  At first, counties' plans tended to focus on purchase of rehab equipment or training, but gradually over the project period, they became more precise and specific for supporting family mutual support

activities, social integration and educational activities. For example, Wei Xian purchased two regular tricycles (as commonly seen used by rural residents) that allow two young people to go to school independently, like their peers.

Each county thus developed its own characteristics and strengths, as noted in the county findings above, and thus they have greater potential for maintaining new activities and growing them at their own rate in accordance with local conditions.

- New and important achievements of this phase have inspired the SSGC management.
  Particularly noted are: (1) family activities and mutual support groups which have strengthened the voice of families as well as their acceptance of their children, while also stimulating staff to listen and increase communication with families; (2) developing educational opportunities for children with a wide spectrum of approaches from home schooling, special classes in regular schools, resource teachers & classrooms which are mentored by special education school teachers; (3) improving use of basic assistive and mobility devices and environmental adaptations by county rehab staff which facilitate a child's participation in home and school; (4) strengthening working relationships with other sectors (health and education especially) which are moving towards "mainstreaming" and a clearer understanding of responsibilities and the concept of "inclusion"; (5) promoting volunteerism through working with youth and women's organizations and local enterprises; (6) improved management functions; (7) deeper understanding of holistic rehabilitation and the need for lifelong planning, among all concerned staff and officials; (8) acceptance of innovation at county level such as the summer camp for CP children without their parents, the introduction of OT approaches, and the local problem solving and development approaches to manage the ongoing lack of specialized therapists; (9) the training for community health care workers in early identification and referral to DPF; and (10) use of their own city/provincial specialists as referred by the respective resource centre.

- Partnership with resource centres has strengthened and is critical for county support.
  SSGC has worked hard to develop the resource centre roles to provide not only professional expertise, but also mentorship, encouragement, and continual promotion of the holistic approach, especially with staff and leadership change-over. In addition, SSGC has helped the resource centres in capacity building, through skills training, (e.g. training in Dongguan on Conductive Education), concept and model building, (e.g. the Conductive Education programme in Yunnan is almost a kindergarten model, planning of parent school/centre, etc.) and in management knowledge.

2. Norwegian Missionary Alliance (NMA)

The NMA project team has facilitated the changes needed to achieve Phase II outcomes with great skill, through maintaining a collaborative approach to the partnership, coming to consensus on goals, strategies, activities and budget, while continuing with gentle pressure to move forward and overcome the challenges at each site.

NMA was key, not only in management but in sourcing the right balance of overseas expertise (eg. OT training and the first summer camp in Pujiang County). It is also worth noting here, that the inclusion of

a family member from Norway, in the evaluation of the first phase, was certainly an important stimulus for the increased attention to families in the second phase.

The decision and efforts of NMA to refine the project goals according to the Phase I evaluation, apply for further funding and continue to support the five most engaged counties are admirable and also validated by the successful achievement of outcomes. Time and readiness are important factors in growing a sustainable project that is supported by local regulations and policies.

Finally, NMA staff strong relationships not only with SSGC, but also the resource centres and county sites are clearly observable. It goes further than this. NMA project staff know the children, their parents, carers and front-line staff, and are deeply interested in their progress and passionate about improving their quality of life, and their work satisfaction.

3. Financial Management

The evaluators discussed the financial management issues twice with NMA and SSGC staff and also at each of the county meetings, where the financial staff responsible also attended with the financial records. We found only appropriate use of funds and strict review of budgeting and control by SSGC. We appreciate several issues:

- NMA encourages review of budget and activities part-way into the budget year, allowing for some flexibility and adaptation;
- The funds allocated to the different counties, did depend on the need, so that Eshan County in Yunnan required more support;
- The actual project funds were quite small and were seen as seed funds, which opened the door for the county DPF to leverage more funds from their own governments and from other local sources. This is especially so in the three Sichuan counties;
- All counties more than matched the project funds.

Concerns raised include:

- Eshan County may not be able to continue some activities without outside funding due to poverty issues, but the community rehab team is stable and will be sustainable.
- This project provided funds for adolescents with cerebral palsy, but their needs are not covered yet by national funding projects. In the future, funding for some more complex assistive devices (to support middle school and higher education) and complex surgeries will be a challenge that has to be solved.
- Funds were sometimes delayed, due to slow transfers between each level (this is very common in these type of projects).
- Future project budgets may consider to include central administrative support, since if projects require close monitoring and mentoring, which introduction of new concepts and methodologies do, a new staff (project basis) may be required or experts hired to do this on an occasional basis. Mentorship is crucial to achieve expected project results, especially in early lifeline of a project. However, as this was a second phase, it was NOT an issue, but should be noted for new proposals.

Discussion

I Project Effectiveness on Children and Families

Planning of Phase II had obviously taken seriously the results of the evaluation done in 2013 and has adjusted and refocused the project at each of the five sites according to the local needs, circumstances and actual professional resources. All project goals are met or surpassed, although the strategies used and emphasis is different in each county. Each county has plans to maintain and improve the reach and quality of services, according to their own situation. The respective resource centres and networks also recognize that they have also deeply benefitted from taking up the resource centre role, and they also have quality improvement plans.

1. Access to Professional Rehabilitation Therapy Services:

1.1. Problem-solving the lack of rehabilitation therapy professionals at county level

Pi Xian, Pujiang and Xinjin counties in Sichuan and Wei Xian (county) in Hebei are all solving this common issue through service purchase agreements of different sorts: inviting professionals from the nearby city (consultants); awarding a contract to a qualified rehabilitation organization, to set up rehabilitation therapy services in the county; or referring children to nearby rehabilitation medical centres, supported by national CP project funding. Positively, the government of Xinjin County, has stabilized the situation by providing three full-time positions for employing rehab therapists. It is expected that with the rapid expansion of the rehabilitation therapy profession which is now occurring, all these counties will be able to employ staff in coming five years, particularly in Sichuan.

Eshan County in Yunnan, is poor, rural and mountainous. It continues to use a traditional CBR approach, but without a local centre of expertise (city level). There is currently no funding to consider service purchase agreements, nor a nearby source of appropriate expertise for children's rehabilitation, as Wei County has been able to find. However, they have a stable community workers team, who have absorbed the holistic rehabilitation concept and are able to provide fundamental services and problem solving for children with disabilities. During the project, the provincial resource centre has supported them, and Eshan will continue to have the option to send children and staff for training, but the regular visits may not happen, except in special cases.

It is not realistic to depend on voluntary expertise in this situation, due to inconsistent visit schedules, inconsistent advice from different professionals, poor or no follow-up to monitor outcomes of advice, and so forth.

All five counties provide training to community health care workers (doctors, health centres, maternal and child hospital networks, etc), to ensure early identification and referral of disabilities, and follow-up; and indeed, all counties make good use of their community rehabilitation cadre (co-ordinator and/or commissioner).

1.2. Working with children with multiple or complex disabilities

In all counties, the DPF programmes are including children with severe disabilities and their families in the various activities to the extent that they are able, and this is a clear improvement over the first phase. The DPF staff and community workers are doing their best for them in terms of adapting the

environment, providing a special chair or mobility device, and also in visiting them at home and developing supportive relationships with the parents. In the past, mainly children with mild disabilities getting an education, but in these counties, some children with moderate physical impairments were attending school or receiving home schooling.

It is clear there is much more that can be done for these children, but even the resource centres consider that their management of children with severe disabilities is inadequate.

In this situation the project has included the children and the families successfully to the extent that they are able to do so, currently.

2. Access to Education

2.1. Counties have prioritized educational opportunities for children with cerebral palsy

Many more children are attending school and actively participating in classes, or receiving home schooling in all 5 counties.

2.2. Focus on Families

Counties have emphasized supporting families, through education and sharing sessions and particularly setting up mutual support groups; this is probably a crucial step to help change parents' attitudes on education, so that they realize it is a basic need and right, even for children who have physical and/or intellectual disabilities.

2.3. Rehabilitation is linking with Education

Local DPF staff have re-prioritized their rehabilitation services to link therapy goals with the fundamental abilities which CP children need to get into school, combining this with provision of mobility devices and environmental adaptations at home and school. Counties have strengthened partnerships with the Education Department and thus have both influenced and made full use of the local educational policies, with a variety of strategies to get children into school. This is particularly clear in the three Sichuan counties, where resource classrooms and resource teachers are supported by experts from special schools (Pi Xian and Pujiang) or Chengdu (Xinjin). Both Eshan and Wei Xian are progressing according to their contexts.

2.4. Home schooling ("sending the education to the home" policy)

This policy is now a regulation of Education Bureaus throughout China. It is appreciated by all stakeholders working with children with severe disabilities and those living in remote areas. However, there is also recognition in Sichuan that this approach now requires a professional review. In all counties the links between rehabilitation and home schooling could be strengthened, and home schooling may be considered as preparation for regular schooling for some children.

II Project Impact

Children and Families: the positive impact of this project on children and their families is very clear, as children come out of their homes, participate in social activities, go to school, use mobile phones to converse with their peers, or receive home schooling. Parents have also developed their social networks and although life remains challenging, there is also evidence of open and strong and mutually respectful relationships with DPF staff and other parents or grandparents. The project has brought a change in

attitudes and behaviour among families, as well as concrete benefits of educational access, social support, information and help to get financial subsidies.

Service Providers: equally significant is the change in understanding and thus change in behaviour of the local staff and the teachers and principals. There is a strong acceptance of children with cerebral palsy as having abilities, personalities and right to access mainstream services, and staff at all levels from community up, have increased their capacity to help the children achieve their potential. This is demonstrated in their everyday work and the manner of communication with children and parents, as well as the satisfaction, pride and enthusiasm in the activities observed and reported. The staff want to learn more and there is managerial planning for the project end, to ensure that most activities will not just continue but will be improved. The Summer Camp in Pujiang was an eye-opener for all staff from all counties, as well as the student volunteers (rehab therapist and social work students).

Unexpectedly to the counties perhaps, their challenges and successes have impacted the referral level: the resource centres, and even the hospital-based colleagues, who visited the county level for teaching and consulting, all remark how much they have learned by being involved in the project. Trainings organized by SSGC also influenced resource centre staff and the many small organizations beginning to offer rehabilitation and education services for children in the major cities. This is very important to ensure some consistency in the conceptual framework (holistic rehabilitation) so that parents are not getting mixed messages from different city/provincial level, service providers.

Policies: has the project driven policy makers or have policies supported the project implementation? While it is not possible to separate the directional influences in such a short evaluation, there is certainly reciprocal effect, as policy makers see change and newly visible needs (eg. now the children are not hidden at home and the education needs are visible) and the community service providers have used the new policies to improve accessibility and get their children into school.

Community: no assessment of impact on the community was made during this evaluation. However, observations of successful school integration, utilization of community health care workers and other community cadres (Eshan and Wei Xian), and enthusiastic involvement of parents in visible social activities indicates that the community is more aware, more accepting and more supportive of children with disabilities. All counties had records of volunteers. The Sichuan counties also mobilized many organizations and local enterprises to contribute and participate in a variety of activities with the children and parents, as well as in research and new initiatives.

III Project Efficiency

In these three years, there is a trend to integrate the project activities with ongoing services and programmes, particularly in Pi Xian, Pujiang and Xinjin, and to some extent in Wei Xian and Eshan. Partnerships with the Education and Health Bureaus meant that some activities were mainstreamed and did not require funds from the project. In addition, the funding from all levels of government support, mobilized at county level (eg. enterprises), more than matched the NMA project funds.

An annual amount for each project site has opened the door to benefit not only the children supported by this project, but also many children in the future. This project was timely and efficient.

IV Sustainability

There is no doubt that the current and future children with cerebral palsy, as well as children with other disabilities, will continue to receive rehabilitation and educational opportunities, and we are confident that the quality and extent of the opportunities will improve.

Pi Xian, Pujiang and Xinjin Counties in Sichuan are clearly moving rapidly forward, due in some part to their geographical locations close to the provincial capital of Chengdu with all the expertise available there, the strong government policies of Chengdu City supporting education, rehabilitation and required medical procedures, as well as providing a framework of service quality standards.

Both Wei Xian and Eshan face the issue of maintaining quality services. Wei Xian has developed a close referral link with Handan City; but it is a big county with a mobile population, so maintaining their community rehabilitation network will be crucial to extending services to all children with cerebral palsy. However, Eshan County's resource centre for children with cerebral palsy is further away, both geographically and administratively, being at provincial level. It will be necessary to strengthen the holistic rehabilitation approach at Yuxi City, which is the direct administrator of Eshan.

This project is very relevant to today's situation in China. Ms Zhang Haidi, President of China Disabled Persons Federation, has ensured that the new 13th Five Year Plan stresses the importance of rehabilitation and education for all children with disability. In her new position (from October 2016) as the new president of Rehabilitation International, it is understood she will promote CBR in less-resourced regions and countries. Thus, provincial and city-level organizations will get support to develop innovative and balanced (holistic) approaches to helping children with disabilities.

CBR services require ongoing and frequent support from higher levels for monitoring, problem-solving, and capacity building, and this requires input of financial resources and time for CBR supervisory and professional staff (who have a consistent holistic approach) from city or provincial resource centres.

General Recommendations for all Stakeholders

Recommendations for Access to Professional Rehabilitation Services

(1) In contracting specialized rehabilitation medical services from nearby city hospitals to set up a rehabilitation medicine facility in the county, there is a major risk of the medical model overturning the holistic approach. Parents certainly want a medical consultation and are often willing to try all means to "make" their child "better". DPF from national to county level, with support of parent associations, must consider the demands of normal child development and ensure that a child with disabilities has balanced opportunities across the psycho-social, mobility, daily living tasks, play and communication, educational and emotional developmental fields.

(2) It is clear from the feedback that Occupational Therapy (including provision & training with the correct assistive, communication & mobility devices,) and provision of psychological support including improved communication skills are important areas for the county level and community rehabilitation staff; yet these are under-developed in all rehabilitation centres, and there are few teachers at present. It is recommended that Occupational Therapists at least, are always included in visiting specialist teams, and that the position of Social Worker should also be created.

(3) Many specialist consultations are focused on physical impairments alone, and often take place in the DPF office, hotel room or local health centre. Specialist visits should be considered as a precious capacity building opportunity for both local staff and the specialist. The aim is to come to mutual agreement on functional goals for the child in the coming 3-6 months, and how the local staff, family and child can reach these goals (planning the intervention). Thus, the visit is best, where possible, to take place in the home or school, and only when necessary for physical examinations, in the health centre. The responsible local staff including the child's teacher if relevant, should always be present to discuss and give input to the recommendation, If possible, a team of specialists should be invited (e.g. Doctor and Occupational Therapist) need to brief the specialist about the child's environment (both physical, family, school, economic, etc.) so that goals and advice are tailor-made and realistic for each child's situation.

(4) Documentation currently is focused on the physical impairments of a child, and may not even refer back to previously noted problems and changes that have occurred since the previous assessment. Documentation should include the agreed 1-3 goals for coming months. It is important to keep documentation simple but really useful to the local staff, using a holistic approach. It should include places to record the child's: body structure (physical issues) and also daily activity abilities and challenges; level of social (play) participation; environment factors that inhibit or facilitate, including assistive devices, mobility devices, family support; and finally on personal factors such as emotional control and personality development). For adolescents it should include educational goals, potential vocational interests and capacity and what the plans are for the transition to mid-adolescent and young adult. It is strongly recommended to review the documentation template used and to request invited experts and referral centres to use the template.

(5) All counties should continue to capacity build for their community rehabilitation workers. Wei Xian and Eshan particularly need to pay attention to those workers in remote areas so that children are not neglected, nor miss out on early stimulation and appropriate rehabilitation advice.

(6) What is the function and role of a city-level rehabilitation resource centre? In comparing the five counties, it seems most convenient and realistic to use the city level DPF centre as the referral and resource centre for counties. For those more isolated counties, using a typical CBR service delivery system, resources must be invested in developing city level staff: holistic concepts and skills and the ability to teach and mentor.

(7) With the excellent government support for rehabilitation of children with cerebral palsy, parents request their children to attend higher level rehabilitation centres; however there is little practical communication between the county rehabilitation and the higher level except through the parents. It is more precise and professional and probably more effective to improve the referral system. The county should be more explicit about the functional goals and life skills the child will require in coming 6-12 months. For example, this child will enter primary school in September and needs to be able to do the following items. The specialist centre should send detailed documentation to the receiving county DPF when the child returns, about what the child can accomplish of the agreed goals and what are possible solutions for goals not accomplished. This is an accountability issue and standard professional practice. The documentation template for referrals may require renewal to facilitate this.

(8) All these counties need support and encouragement to continue to develop and grow. The three counties in Sichuan get this from Chengdu Education and Rehabilitation Centre and the current policies to support children with disabilities in the therapy and educational areas. For Eshan and Wei Xian, and other similar rural counties struggling to maintain elements of CBR, the city and provincial DPF may consider to develop a standard of supervision and support for community networks to help improve services, according to the local context and resources. This would normally be the responsibility of the City DPF.

2. Recommendations on Education for Children with Cerebral Palsy

(1) It is essential to continue to prioritize education. For children with severe disabilities, the CBR approach with community workers, local community teachers (or retired teachers) and use of the families' mutual support group and play groups are all options to support children's learning (whether basic living skills, social skills and/ or more formal education). An annual review of those children <u>not</u> attending school is highly recommended, and a report made to DPF to facilitate problem solving.

(2) DPF staff and therapists whether in hospital-based or community-based centres need to link each child's therapy goals with preparing for preschool and primary school. Issues arising will include mobility around school, correct seating in the classroom, toileting, upper extremity and hand skills for writing, how to participate appropriately in physical education, etc. In addition, DPF staff need to liaise with parents, community and school regarding transportation, adaptation of the environment, special support needs and how to gradual decrease the support if possible.

(3) There is almost no use of assistive devices and technology (IT) and yet, in many cases, these will ensure that a child can complete tasks and assignments in a reasonable time and keep up with his or her peers. There is a clear need to train Occupational Therapists to take up the role of assessment and prescription of Assistive Technology for children and adolescents to increase their classroom participation. There is no reason that a child of 5-6 years of age cannot use a tablet computer or similar to learn from.

(4) Children should not just receive an education but participate as actively as possible in each class as their peers, and have a plan for transitioning to high school and/or livelihoods training. It is recommended that an annual review of children with disabilities attending school could look at level of participation in classes and how to increase their access to all aspects of the curriculum. Parents should be involved with the child in making six month to one year goals to increase the child's self-management and coping skills, as well as preparation needed for promotion to the next school grade.

(5) There remains a tendency among us to over-emphasize the "disabled child's" special needs and identify the child as the recipient of our concern and love. This constant labelling may bring psychological issues and loss of self-esteem to the child in the long-term. In the Sichuan counties, the teachers are beginning to gather information and experience about the children with disabilities and it is worthwhile to compile for dissemination and debate.

(6) Wei Xian and Eshan both need to pay particular attention to ensure that all children receive an education and also what happens to the children after completing their education, so that they do not become home bound again, and lose the benefit of their school years.

(7) Family mutual support groups are at various levels of development in different counties, but in general, they are seen to provide psychosocial support through social activities. Some of these groups may consider to take up other roles, including for example, peer counselling, play groups, adolescent's pre-vocational groups, raising funds for summer camps, and working with DPF for other events, etc. Some parents may become an excellent resource for DPF.

(8) Adolescents with cerebral palsy: with the success of inclusive education, come the new concerns of how to meet the needs of adolescents. This includes physical (surgical/medical needs due to growth), requirements for new mobility devices and other assistive technology, sexual education, planning for transition to adulthood etc. This area needs investigation, pilot projects and compilation of good practice to disseminate. The project's summer camps are the first step to both family, child and therapist understanding of these developmental tasks.

Many of the above recommendations will require policy support, and for some pilot projects (assistive technology), needs surveys (common problems of adolescents), review of system processes (referrals for intensive rehabilitation), evaluation and research (role and scope of CBR resource centres at provincial and city levels with main objective to maintain community rehabilitation networks and support the non-professional staff at county levels. These may be done by national level in several

regions (with different economic and provincial resources development), and by external input of ideas (eg. assistive technology is highly developed as a way to increase independence and participation for children with all types of cerebral palsy in countries such as Norway).

Conclusion

This evaluation covers the second phase (2014-16) of a two phase project, for a total of eight project years. It is clear that the past three years have seen a consolidation, expansion and deepening of the activities, as well as development of new activities. Phase I focused on identifying children with Cerebral Palsy in each county, and trying to improve their physical functioning. Phase II has strongly promoted the right to educational opportunities for these children, focusing more on daily life skills, changing the environment, and developing social integration activities. There has been a strong emphasis on family support and activation, which has resulted in their looking at their children with new eyes and hope. In addition, children with severe and complex disabilities have been included to the extent that is possible, and there is clear change in the understanding that all children are valuable and have abilities.

The phase II project goals were achieved or surpassed in all counties. There has been a remarkable co-operation between the disability sectors (County Disabled Persons Federations) and the health and education services, demonstrating combining of resources and mainstreaming of services according to local conditions and resources. There are both project experiences which have promoted policy development, and use of local and national policies to support project activities.

It is noted that both phases were necessary, and time is a factor in allowing incremental development, which ensures effectiveness sustainability. The input of external financial and manpower resources was relatively small in Phase II in comparison to the local input of resources of all kinds. Sustainability is also ensured because of the inclusive development approach; that is the inter-sectoral collaboration and mainstreaming of services.

While the counties are facing many challenges they are all optimistic about future development and quality improvement of services. The family members and children are fundamentally satisfied, but they are not content: since they can see the improvement in their lives, they are anxious for more and will no doubt advocate for further service development in areas of assistive technology, livelihoods training and support. This ongoing cycle of development is established, promoting many new opportunities for exploration, pilot projects and research.

This is a very successful project bringing opportunities to many children with cerebral palsy and their families; capacity building for all stakeholders, & development of good practice for dissemination, policy development and future research.