

GOING DEEPER 2 | DISABILITIES

Accepting children with disabilities into Thai society

by Wasan Saenwian

CHRISTIAN CARE FOUNDATION FOR CHILDREN WITH DISABILITIES (CCD), THAILAND

Introduction

I am the Executive Director of CCD, the Christian Care Foundation for Children with Disabilities, based in Pakkred, Nonthaburi Province, just outside Bangkok.

Our Mission Statement is: to demonstrate Jesus' love through helping develop disabled children to their highest potential through holistic approach and to have equal rights, opportunities, good quality of life and full integration into mainstream society.

I will now show a DVD which presents a summary about CCD and its work.

3-MINUTE DVD

CCD was formed, and continues to develop, as a Christian response, with these objectives:-

- to create a Thai NGO that would seek to improve the conditions for children living in the Government-run Homes for abandoned and orphaned disabled children
- to de-institutionalise children
- to provide educational opportunities suited to the capability of the child and the opportunity for integration into mainstream schooling, where appropriate
- to teach social skills and enable whole or partial integration into mainstream society
- to provide physiotherapy
- to provide support, training, advocacy and equipment to families with disabled children living in the community by going to them, not bringing them to us
- to change the perceptions of the Thai people in relation to disabled people
- to give love and care to the children by way of a holistic approach
- to demonstrate and share God's love in and through our daily work

As the video has shown, it was clear that the most urgent needs were as follows:-

- Basic care for physical needs
- A structured environment
- Physiotherapy for the physically disabled.
- Education – both academic and basic social skills
- Love

The Homes were basically “warehouses” for the storage of disabled people, where they could be shut away - they are the “forgotten” children, brushed aside by and invisible to Society. The culture and religious beliefs of the Thai people as a whole are such that many do not wish to associate or be involved personally with disabled people (even though they may assist at “arm’s length” by donations to the Home) and they do not believe them capable of learning. Families in the community likewise would be shunned and struggle to cope with day-to-day living, officialdom, poverty and ignorance and are often incapable of understanding and using

the “system” to gain any official help. We could not bear to see the suffering of these children and determined to do what we could to alleviate and improve their condition –to be the key to unlock their prison and to demonstrate God’s love in a practical way. The project was not based on any research but only an instinctive desire to show God’s love to these abandoned souls.

No research was undertaken before the formation of CCD, its daycare centres, Rainbow House –each was simply a Christian reaction to the situation that my wife, my staff and I could see every day around us:-

- children confined to a ward or home, when they were capable, with assistance and training of getting out and/or independent movement
- children who were capable of learning, either academically, vocationally or socially
- children who would be more physically able with therapy, training, operations and/or equipment
- children and families who needed Christian love

In order to meet the objectives it was necessary to provide the facilities to deliver the services required.

1. Daycare Centres-initially, in the case of the Government Homes, this was by:-

- opening day-care centres with trained staff, including teachers and physiotherapists,
- assessment by the staff of children and young people
- selection by reason of their ability to improve when in receipt of education, training and, where appropriate, physiotherapy,
- delivery of those services

However, the Daycare Centres are only single rooms with very limited facilities and this limits the services delivered. It is not possible to have specialised equipment nor sufficient physiotherapists or other specialised teachers in each centre, partly through lack of room and partly lack of funding and resources.

2. Residential Home: initially this was in a number of ordinary houses in the community, but there were many problems – often neighbours complained and were difficult and there had to be a number of moves.

CCD was not fully able to fulfil its vision by delivering services in the way it wished, so decided to raise funds to build and open a dedicated facility:-

- To provide a permanent home for children capable of independent movement and the ability to benefit from academic education, with the intention of integrating them into mainstream schooling.
- To provide the staff and facilities to support all its projects
- To provide a training centre

The establishment of Rainbow House has met all these criteria. At CCD we felt that the only answer was to build our own Home, purpose-designed for the children and all our needs. This was a response based on our observations and experiences, not dedicated research. Thus in 2000 was born the project to build one of the first rehabilitation centres in Thailand and, indeed, South-East Asia. Rainbow House is a purpose-built, dedicated facility which provides a home for about 40 children, with designated areas for teaching, vocational skills, therapy and leisure. We have also recently opened a Sharing Shop, which has a number of purposes, to raise funds, to raise awareness and show people that the children do have abilities and potential and to train some of the older children in retailing skills.

The older residential children have now all been accepted into and attend mainstream schools, whereas at one time this would not have been permitted. Some will go on to vocational training and some will attend university. The younger children receive schooling at Rainbow House daycare centre, together with a number of the more able younger children from the Government home and also the local community.

The children at the daycare centres all have IEPs (Individual Education Plans) and receive schooling and/or activities according to their capabilities, with the intention of helping them to be as self-sufficient as possible and to learn social skills. It is anticipated that at least some will be able to live normal lives in the community.

Some 60 children are served by the Rainbow House daycare centre. All these children are all living in and going out in local society, showing that in many ways they are no different to other children. Thai people are learning to accept the children and this changes their perception of disabled generally.

The other prong of CCD's work is the community-based rehabilitation project. We could see that there was still a vast unmet need in the community, where parents had not abandoned their children, but were struggling to cope with caring for a disabled child (and sometimes more than one) and also care for the rest of the family and earn a living. These children and their families are just as invisible to Society as those in the Government Home. Often the strain is too great and parents separate, leaving (usually) the mother to cope by herself.

Here the need is for:-

- Support for the family members, which usually includes extended family
- Training in how to care for children
- Networking
- Equipment

In 1999 we decide to start a community-based rehabilitation project. Before we started we carried out preliminary research:-

- To ascertain where we should open our first project, through 3 organisations that already operated such projects.
- To observe these organisations to see how they ran their projects and what we could learn from them.
- To ascertain how many organisations were already in the areas we were considering, how many Government service providers and what type
- To ascertain the beliefs of the local people and gather information as to whether the parents would co-operate with if we started a centre in their area, by means of a questionnaire sent to local families, details of whom we obtained through the local Health Station.

Following the results of these enquiries we decided to open our first office in a town in Nakhornpathom Province, where there were many disabled children but very little Government input. The intention was to:-

- Deliver services to the child, its family, the local community and the local Health Workers.
- Provide a centre where parents could bring their children, meet other families with similar problems and share experiences
- Co-ordinate local professionals and service providers
- Act as advocates for those unable to cope with bureaucracy (in local government, schools and the health service)
- Provide training to all concerned in the basic care of the children, such as basic physio, feeding, lifting and education.

We took a number of steps before we started the project:-

- We went door-to-door visiting the families, making friends with them and building up their trust in us, so that they believed in us. In the provinces people only go to the hospital if actually sick and often miss appointments, as they are made for the convenience of the hospital staff, not the patient. Also past experience showed them that many organisations came with good ideas but acted the same as the hospitals or lost interest, so initially they were suspicious of us
- We then held a seminar/workshop for the parents at which we asked the parents themselves to set the goals of the centre, eg they name the centres themselves. This was so that the parents had ownership and thus the project became sustainable

- We obtained information about the families and a history of the children

However, after an initial period, the families made it clear that they were not receiving the services in the ways most suited to their needs and this was also apparent from the observation of the staff. Many could not come regularly, because they had no transport, it was too expensive or too far or they had to work. After some discussion with the local families it was decided by all concerned, both CCD and the parents, that the answer was to open a local centre in one of the villages, supported by the CCD office but run by the parents. A Health Station agreed to provide a room but later that became unavailable. So one set of the parents offered to base the centre in their own home, as they had spare room. Families living nearby could access the centre and the staff were able to have more regular contact with the children and their parents. Then more and more families further away heard of the centre and its success and also wanted the same benefits. As a result, 4 local “satellite” centres have now been opened in sub-districts around the central office, “owned” and run by the families themselves, with support from CCD. All planning is done between CCD and the parents jointly and regular meetings are held. As far as I am aware this format is unique in Thailand. As a result:-

- More families can now receive services (currently over 400)
- Families tell other families in their villages and the number of centres have increased as a direct result of families requesting a centre local to them
- The numbers at each centre grow by word of mouth- CCD does not need to go out and seek families
- Families are trained in the care of their children and pass on their knowledge to others
- Villages are appointing carers of disabled children as local “Health Volunteers” because of their knowledge, where one the family would have been sidelined
- Disabled children are attending regular mainstream schools and receiving education appropriate to their abilities, where previously they were not permitted to attend school
- CCD advocacy services and transport enable families to attend hospital and other official appointments and understand what has occurred

As in our day care centres each child is diagnosed individually and an IEP prepared for him or her. Parents are given general trainings but also specific trainings tailored to their child’s needs, taking into account the disabilities and age of the child. For instance, we are giving a set of seminars on the teenaged disabled child. One parent told us later how, after she had attended a seminar, she went home and later noticed her son behaving inappropriately. Before the seminar, she said, she would have smacked him and told him off. Now she knows how to deal with the situation so as to help her son and she has passed on this information to other parents in the same situation.

Our staff act as advocates and facilitators. They take people to their appointments (at hospitals, schools and government departments), go in with them and then explain what has been happening or decided. They also provide transport where required. They liaise with schools - for example, a girl with Downs Syndrome was unable to attend a special school because of its distance. After initial teaching by CCD a local mainstream school agreed to a trial period, which has now become permanent. This girl is one of their keenest pupils and has paved the way for acceptance of others by the school.

Project development is moved forward by the parents themselves, with support from CCD staff, such as assistance in writing proposals to obtain funding from the Government or local charitable organisations. Parents are also learning about the different disabilities. They can identify the disabilities of the children in their community and encourage those families to attend the centres. There is no need to seek people out, as the people come continuously. And the local communities are also gaining, as parents become more knowledgeable and can pass this knowledge on. Parents who would have been avoided or shunned are now being asked by others in the village to act as their official Health Volunteers. A new project has been opened this year in Nonthaburi Province, which we expect to expand in the same way.

CCD is also innovative in running the camps and mini-retreats as shown in the video.

It has been necessary to teach by example. When official service providers, such as the Government Homes, teachers, health officials, have seen how the children respond to our care and understand their capabilities, they have, over time, altered their response and procedures, for instance:-

- Substantial works of building, renovation and improvement of the environment are being carried out at the Government Homes
- More and better staff are being employed at the Homes
- Children are now permitted to attend mainstream schools
- Specific special-needs classes are being set up
- Government policies in respect of the disabled have been radically revised

Much of this will have a “knock-on” effect on people in Thai society generally, as they come into contact with more disabled people, are influenced by the change in Government approach and see the disabled as individuals not a category

But it is not only at local levels where we see changes being made.

- Some years ago I was asked to advise the Government when they were formulating new policy for dealing with disabled children.
- This year we had our third one-week conference followed by a 5week training course. This has grown from a small low-key Conference held at Rainbow House and attended by some Government staff to a major one-week Conference at the Prince Palace Hotel in Bangkok, supported and totally funded by the Department of Social Development and Welfare and opened by the Minister himself.
- CCD has received a number of awards, including one presented in September this year by a member of the Royal Family on behalf of ????
- VIVA?

It is very encouraging for CCD to have such recognition and reflects the important change in attitude of the Thai people and the Thai Government towards disabled people that has occurred over the past few years.

So we might ask how we know we are succeeding. There are many indicators, may be not all quantifiable, but nonetheless obvious, which can be seen by the changes that have taken place over the last 21 years as a result of the work initiated by CORD and continued by CCD:-

- Children have access to mainstream schools, which previously was not permitted. This gives them the opportunity to go on to appropriate further education, whether university or vocational training
- Teachers are learning that disabled children do have ability to learn and they are adapting their teaching practices accordingly
- Children who would have spent their whole lives unable to communicate, both in the Homes and in the community, are being empowered and recognised as people in their own right. Many will learn to talk, where previously this would not have happened
- Parents are taking charge of their own lives and are learning how to cope with their children and make life better for the whole family
- Parents are learning about the various types of disability and are able to pass that knowledge on. As a result their local community is benefiting
- Children are receiving operations and therapies that enable more physical flexibility and freedom. Many become capable of independent movement
- Families receive equipment that helps the child to be more self-sufficient and self-reliant, thus benefiting the whole family
- The Government is becoming more openly involved. The Homes are receiving new buildings, renovations and new staff. New policies are being formulated, recognising the rights of the disabled

person to a life of dignity. Government funding is available to NGOs such as CCD to assist in many projects.

No specific steps have been taken to gauge the effectiveness of the project. Its growth is self-explanatory.

It is, of course, necessary to keep all projects under constant review, to ensure that the goals are being met. Each Project prepares quarterly reports, giving goals, accomplishments, problems and proposed solutions, together with details of activities undertaken and trainings in the period. Staff meet together regularly, both at CCD and with parents, to discuss and plan. There is a quarterly meeting attended by all staff and volunteers where the quarterly report is shared and experiences and advice can also be shared.

CONCLUSIONS

Disabled children in Thai Society are invisible because:-

- The response to their needs has generally been based on what is convenient for the service provider
- Thai people do not wish to associate with the children and their families through ignorance and lack of understanding

It is clear from the above that an organisation must be prepared to be flexible and “think outside the box”. CCD found that the normal accepted methods were not necessarily the most effective-

- The provision of daycare centres and working in the Government Homes is insufficient to provide the services and facilities at a level and of the quality required to meet the needs of the disabled child
- Expecting families in the community to come to the service provider at the convenience of the service provider is ineffective. It is necessary to meet the families where they are, ask them what they want, provide centres local to the communities served and services tailored to the actual needs, not the ones “perceived” by the service provider.

CCD’s responses, which are innovative and not, as far as CCD is aware, part of any widespread or customary practice in South-East Asia, have been:-

- The foundation of Rainbow House as a dedicated facility
- The establishment of localised CBR centres run by the families
- Explaining to, teaching and training service providers (eg schools, health workers), resulting in the empowerment of the child, who is then treated as an individual with an ability to learn (previously not accepted). This results in an improvement in his situation and a consequential benefit accruing to other children and their families outside the CCD “umbrella”
- Most importantly, by showing God’s love every day in our dealings with all people, CCD is causing changes in the perception of disabled people at local and Government levels.

We at CCD have found it inspiring and uplifting to see how God has been at work amongst a Buddhist people and we have much to thank the Lord for. CCD has gained recognition, respect and a small but growing amount of influence. And as a result children who have long been invisible are now beginning to be treated as human beings with a right to respect and equal treatment. We still have a long way to go but every journey starts with the first step. We thank God for His mercy and His grace.