

Differently abled Enabled



Differently



Disabled



1991 - 2016



Celebrating 25 Years of Journey with the People



Disabled, Differently-abled, Enabled

A report on the quarter century journey of PCTC 2016

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People's Craft Training Centre (PCTC)

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DISABLED AND 'DIFFERENTLY ABLED'

The terms handicapped and disabled are used to refer people with disability (PWD). In the 1980s 'Differently abled' was proposed as an alternative on the ground that this term conveyed a more positive message and so avoided discrimination towards people with disabilities. However, this term has been criticized as not corresponding to the issue and also sounds patronizing. As a result in general, 'disabled' is still dominantly used as an accepted term.

Disability is an impairment that may be physical, cognitive, intellectual, mental, sensory, developmental, or some combination of these that results in restrictions on an individual's ability to participate in what is considered "normal" in their everyday society. A disability may be present from birth or occur during a person's lifetime.

'Disabilities' is an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives.

- Disabilities, World Health Organization

From the Founder

DESERVE MY GRATITUDE

I believe in Life before Death. I also believe that in my lifespan, I need to giveback something that is due from me for all I had received from this world. I also feel that the purpose of my life is achieved, if my modest contribution would make this world, even in a small way, a better place to live for my fellow human beings.

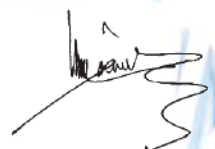
I had been working in the field of development since 1976 with various programs like non-formal education to the school drop outs, leprosy rehabilitation, and raising awareness of rural deprived people for a dignified life. People's Craft Training Center was a response to a felt need as expressed by the community to do something for the polio affected children in rural areas.

Later the organisation has taken a shape towards what it is today. Many people have travelled with me in this journey and also supported the journey. I need to mention a few in a special way...The Salesians of Don Bosco for the inspiration during my school and college days; Mr.Novemoney, who initiated me into this work after my graduation; and Sr.Theodore Issac who has been a real "Sister" to me all along.

Enfants du monde, France had faith in me and provided the initial support. Mrs. C.Bowman from UK, and Mrs. Marie Jose Wouters and family maintained their relationship with me and the organization all these years. Mrs & Mr. Cecile and Rudolf Meier and a group of friends from Switzerland had been a great support to sustain this organization without deviating from the core objective for the last twenty-five years.

All friends who supported this journey and all those from the community whom PCTC serve, deserve my sincere thanks for this opportunity they had given me!

My wife, my children and all my family members deserve my grateful appreciation. But for their support, I would not have made this as my way of life.



-Xavier Mariadoss,
Managing Trustee and Programme Director

PCTC - Celebrating 25 years of journey with the people



The Beginning - Responding to a request

“In June 1991, Mr. Antony from Maruthuvambadi village came to me with his son Sakaraiyas. At that time, PCTC was in the formation stage. Sakaraiyas was a polio affected boy. Antony came to me seeking some help for his son, unaware that PCTC neither work with disabled children nor its activities address disability issues. But this meeting became a game changer and paved the way for PCTC to work for disability and related development issues”.

When asked about the inspiration behind the formation of PCTC, this is the incident Mr. Xavier Mariadoss, the founder and Managing Trustee of PCTC recalled. This beginning is still fresh in his mind.

Sakaraiyas was a polio affected child requiring special care and support. Antony, earlier had taken him to several hospitals with a hope that the defect could be rectified, but only to realize later that he and his son had to live with it. While looking for some place for help, he reached Xavier as he was referred by someone to approach PCTC.

This journey, inspired by the condition of Sakaraiyas and his father's desperate need for help, has completed twenty-five years now supporting and sustaining thousands of disabled children, adults, and their families. In these years, though disability was the core programme, PCTC responded to other allied social issues that included women empowerment, children development, environmental awareness, and social movement building.

Every organisation emerges in a context; a context that includes people, their needs, values, and visions. This is more so in case of inspired persons and organisations with social objectives. In other words, such social organisations are missions instituted by inspired people to address certain issues, and serve communities in need. PCTC, as many other social organisations, had an

inspired pre-institutional phase that ignited the beginning and culminated into what it is today.

After his graduation in 1976, Mr. Xavier Mariadoss the person behind this initiative, started working with St. Thomas Hospital and Leprosy center, as Non-formal educator for school dropout children in 120 villages. Later he worked as a social activist in Thiruvannamalai and Vellore district areas associated with North Arcot Rural Development project. This programme was a social action movement formobilising youth to address social issues with a right-based approach. After five years, in 1991, Xavier left this work with an idea of starting an organisation to focus on life skill education for young girls from rural areas in Thiruvannamalai district.

But all this changed when Antony entered in the scene with his son Sakaraiyas. Sakariyas was an inspiration to young Xavier and an eye opener in his own words that “disability in rural areas is one of the uncared realities.” There was a high level of stigma attached to disability resulting in discrimination. Families who had such children had no clue on what to do with these children and how to cope with their problems alongside their struggle to subsist. In the case of poor families and women this is more intense. Xavier was convinced that this was an unattended area and decided to move forward to deal with this issue. Instantly disability became the core issue and PCTC decided to work for the affected children like Sakaraiyas to find a meaningful place for them in society. Thus children affected by polio became the focal community of PCTC.

Subsequently, PCTC was registered as a Trust on 13th August 1991 with a core objective of community based rehabilitation for children with special needs, especially who are affected by polio. The journey of PCTC started from here and reached twenty-five years with achievements, lessons, and challenges.

People's Craft Training Centre (PCTC)

Areas of Operation

PCTC was registered in 1991 as a Trust and currently works in Thuringapuram Block of Thiruvannamalai district with its administrative centre in Kondam, Kariyandal. The Block, with 47 Panchyaths and 273 Villages, has a population of 124,000. The area has four Primary Health Centres (PHC) and 106 Integrated Child Development Service (ICDS) centres. The population of people with disability in this Block is 2689.



Tamilnadu, literally the 'Land of Tamils or Tamil Country' is one of the 29 states of India. Tamilnadu lies in the southern most part of the Indian Peninsula. Tamilnadu is the eleventh-largest state in India by area and the sixth-most populous. The state was ranked sixth among states in India according to the Human Development Index in 2011, with the second-largest state economy. Tamil, which is one of the longest-surviving classical languages in the world, is the language of Tamilnadu. The State, with a population of 72,147,030 as per the census 2011 which is estimated in 2016 as 77.88 million, is divided into 32 districts.



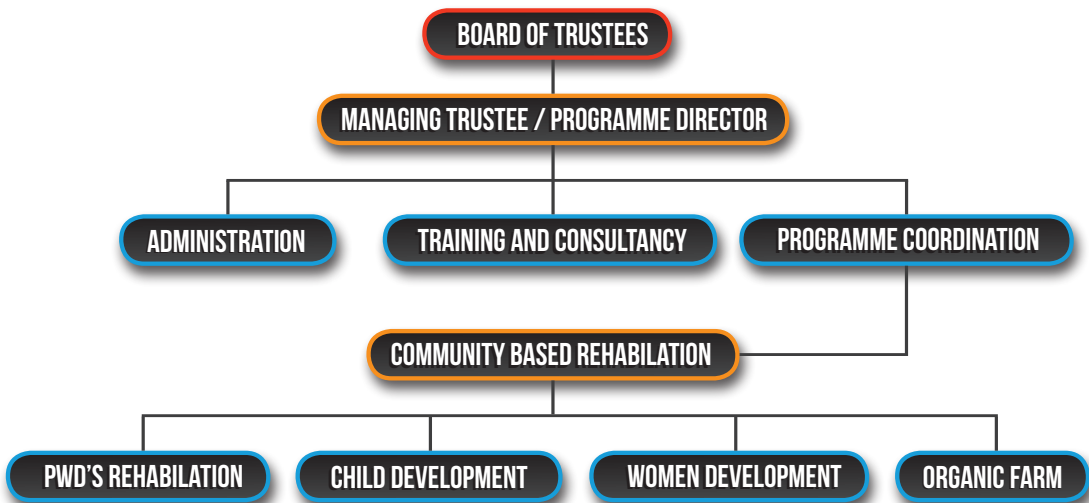
Tiruvannamalai District is one of the 32 districts in the state of Tamilnadu, in South India. It was bifurcated in 1989 from the former North Arcot District as Tiruvannamalai Sambuvarayar and Vellore Ambedkar districts. Tiruvannamalai District has an area of 6,191 sq.km divided into ten Taluks, 18 Blocks, and 860 Villages. Tiruvannamalai town is the district headquarters.

Projects and Activities - Expression of a social commitment

PCTC, initiated with a vision for “Collective self-reliance and total development through community participation”, works for people with disabilities, women, children, and other deprived sections of the society. The core programme is rehabilitation and empowerment of people with disabilities (PWDs) with supporting programmes such as women empowerment, community health, children development, and environmental awareness with organic farming.

The team functions under the leadership of Mr. Xavier Mariadoss, the Programme Director. The organisational structure is divided into Administration, Training and Consultancy, and Programme Coordination. The community based approach cuts across all programme interventions with an emphasis on community based rehabilitation.

PCTC works on PWDs Rehabilitation, women development, child development, and organic farming as the four major programme areas. The activities are implemented with four integrated organisational structures like Day care centers, Vocational training centers, Thulir centers, and Farm.



Day Care Centers

Two Day Care Centers function, one at Kariyandal attached to the PCTC campus and the other in Nookambadi village. Both the centers are in nice and quiet locations surrounded by trees and with adequate farm land around. Sufficient and separate facilities are available in the centers for different activities such as learning, playing, massaging, and working. Students get opportunities both for indoor and outdoor activities. A well developed programme that includes health care and education is followed in these two centers with trained teachers and other workers. The combined activities for the day includes prayer, breathing exercise, special education, physiotherapy, daily living skills training, group education such as songs, stories, plays, and dance.

Rehabilitation workshop

The rehabilitation workshop was one of its kind in a rural area when there was a big need for aids and appliances for the Polio affected person. Later as the need decreased, the workshop was modified to make seating devices, braces, splints and mobility devices for the people affected by Cerebral palsy and multiple disabilities. The workshop is able to upgrade its skills to support the emerging needs of the people with disability and especially for the children who are in the early intervention program. On an average every year the workshop is utilized by more than 150 disabled children and adults.

Vocational Training centers

PCTC conducts vocational training courses for the disabled students once they come out of schooling. Their talents are more often go unnoticed at home by their parents. This is mostly due to lack of awareness and knowledge to identify special skills the disabled children inherently have. PCTC, along with the ongoing training, identifies the special talents in each child, later to develop it through skill training programmes. This is done based on the assessment of each child and their level of physical and mental capacities. On an average, 25 children learn skills at a time that enable them to earn their livelihood.

Carrying the mission

T. Murugesan from Arapakkam village is a polio affected person who started associating with PCTC as a volunteer twenty years back. Though a volunteer, Murugesan almost spent full time in PCTC as a community based rehabilitation worker. He was also trained in community based rehabilitation and community health. He is an active member and leader in the self-help group in his village. Currently, he is the treasurer of the District Level Federation of the disabled people.

Murugesan is married and has two children. His son has completed engineering degree. Murugesan supports the members to avail government schemes and ensures that the benefits reach the right persons. He is a vibrant leader spending much of his time in federation activities and strengthening the disabled movement in the district.

Murugesan talks with confidence and as a leader moves around meeting people and visiting offices in his motorized three-wheeler. He is well aware of all government schemes, government orders related to disabled people, and the guidelines for accessing such benefits. His confidence and dynamism show that not only he has overcome his limitations, but also acquired leadership qualities and good communication skills.

Murugesan has a long list of actions he has undertaken to address various needs of federation members and also to strengthen the federation. PCTC deserves appreciation for being instrumental in developing such leaders from among the communities who own their development and commit themselves to carry the mission further.



Thulir Centers

Thulir centres are established in selected villages to support school going children of the village. PCTC runs six such centers in the Block. Children in rural areas have lesser opportunities compared to their peers in the urban segments. These centers provide learning opportunities such as supplementary coaching for regular studies, soft skill development, and prevention of school dropout, especially among girl children. Students are also exposed to health education and environmental awareness.

Farm

PCTC has a 16 acre of land developed into a model farm. This farm is being used by neighbouring farmers to learn sustainable cultivation practices and organic farming. The farm has fruit trees in six acres. The rest is used for cultivating paddy, vegetables, and rearing livestock. It is envisaged that, in addition to promoting organic farming, the farm will generate income for sustaining the organisation and its work among people with disability and other less privileged and marginalised sections.

Resources

Initially, during the time of formation, PCTC availed training support from organisations that had expertise in working with disabled people and later started mobilising funds for specific programmes in the form of time bound projects. All along, these funds were utilised for sustaining the impacts rather than direct standalone service delivery that causes dependency. Self-reliance cuts across all aspects of PCTC, both in programme implementation and also in organisational management. Currently, the funding is more or less for the organisation to cover its services in disability areas. The federation of women and the disabled people function independently.

The Journey - Treading quarter century

The journey of PCTC from 1991 to 2015 includes programmes and projects that attempted to address some of the emerging issues and fulfill certain community needs. Though some of these programmes were dependent on availability of funds and limited to time bound projects, PCTC to some level succeed by equipping the community to continue the initiatives even after the completion of the projects. The linkages established during the project period with government and other agencies also contributed to the continuation. In addition to disability issues which being the core area of response by PCTC, the other key programme areas included

community health, women empowerment, child development, and environment.



Disability, the core programme

Though the initial plan of PCTC was to organise life skill education for rural young girls, disability of children became the focus as this issue was brought to the fore based on interactions with people and facts from the villages. Once the key area of intervention was finalised, PCTC began identifying and equipping staff to work among disabled children. Handicap International, Pondicherry offered training for the initial team, including the Programme Director. This was followed by another team in 1992.

In 1992, a survey of disabled children was conducted by PCTC in Thurinchapuram Block of Thiruvannamalai District. This covered 11 Panchyats in this Block. After the survey, the earlier decision to cover only polio affected children was changed to cover all types of disabilities, both physical and mental. Yet, primarily the focus was still on children below 18 years of age who are affected by polio. The key issues identified were stigma and discrimination linked to disability, lack of knowledge and facilities to care the disabled, and poverty issues affecting the care givers. The complexity around disability also led to a realisation that disability cannot be addressed by providing specific services in an institutional setting; rather it requires integrated

and comprehensive measures to bring lasting changes. The decision was that PCTC should pursue a community-based approach where the affected will not be isolated from the family and community but, the families involve in the programme making it participative, holistic, and effective.

Once families affected by such children were identified through the survey, a parent meeting was organised in April 1992. Initially, parents needed continuous convincing even to participate in the meeting. Those who participated in the meeting also assumed and expected that PCTC will take care of their children totally and they can be free from giving care to these children.

“You take them and do something” was the attitude of the parents. PCTC clearly stated that caring the disabled children was the responsibility of the parents and community, while PCTC’s role will be to facilitate the process of rehabilitation and help them in all possible ways to improve the quality of life of the affected children and also work for their possible level of ‘independent living’.

By 1993, PCTC was well established as a centre with a core programme for rehabilitation of the polio affected children with a team of trained and competent staff. In 1995, PCTC became a full potential centre for the polio affected children, offering training on various areas and supportive equipments.

Efforts to prevent disability through awareness education and promoting healthy practices

Early detection

Sensitising parents and communities to accept disability and care the disabled

Appropriate rehabilitation measures

Providing special education

Skill training for self-employment and income generation

Support to avail social security measures through government schemes

The rehabilitation programme was consolidated by 1995 and the services were extended to all villages in Thurinchapuram Block. The community based approach in rehabilitation of the disabled children demanded a close association with their parents and the villages. This resulted in PCTC expanding its scope to cover children with other disabilities such as cerebral palsy and mental retardation.

With technical support from Rehabilitation of the Disabled in India (RDI), Pondicherry, a pilot programme was started in 1995 with seven children affected by cerebral palsy and mental retardation. Subsequently in 1996, this was expanded as a programme to cover the whole block with support from Child Relief and You

(CRY), Chennai. Around 25 children were helped in that year with formal training and treatment. In addition to that, 60 children were benefitted through home based care by CBR team. During this period, technical support was provided by Spastic Society of India, Chennai. A rehabilitation plan was in place for all the 1,841 persons with disabilities in the area of operation.

Rehabilitation of the disabled children being a comprehensive programme with a community based approach, PCTC at this time was drawn into issues related to the conditions of rural children and disabled adults. This was a logical response to the reality faced by the staff in the villages.



“Our thoughts will be with you. Wishing and praying for the success of PCTC. Built brick by brick with such a passion to help the community and make a difference to their lives. Like me there must be many others who are witness to this achievement.”

**Mr.K.Krishnaswamy, MBE
Asst.Regional representative
British council.**

“கடின உழைப்பு பணியில் புதுமை தெளிந்த சிந்தனை தொலைநோக்குப் பார்வை” வாழ்த்துக்கள்!



எம். ஏ. நவமணி
ருக்கோட். இந்தியா-
கன்னியாகுமரி

Women empowerment

As part of the emerging comprehensive and integrated development approach, in 1995, PCTC decided to address women issues. This was planned more as an empowering process to bring positive changes in their social, economic and health status. As part of this response, women self-help groups (SHG) were formed in 1995 – 96 with a community-managed savings and credit programme. By 1997, PCTC has already promoted 30 SHGs for women. Animators, who facilitated the formation of groups and supported members in group management, were paid through a service charges collected from members in each group.

In 1998-99, when the Women Development Programme was launched by the Government of Tamilnadu, PCTC encouraged the groups to get affiliated with the scheme that enabled access to a range of benefits for the members from government and banks. In 2000, this process was completed. By this time, 430 SHGs were already linked with banks for credit. These groups were federated at the Panchayath level, cluster level with a few Panchayaths together, and at the block level following the organisational system proposed by the women development scheme

of the government. In 2010-11, PCTC formally withdrew itself from the SHG promotion and federating process, leaving it to the community to continue. This withdrawal process, in addition to making communities take responsibilities, also motivated them towards self-governance. Though this resulted in some hardships and a few groups dissolved due to a variety of reasons, the move led to a high level of community ownership and sustainability.

During this transition process and after, PCTC extended all possible support whenever the groups or federation required help for promoting income generation activities or working on specific village development initiatives. This women movement has developed a set of women leaders from the villages, linked thousands of rural women to mainstream banks, and helped many women to start business for improving their livelihood. Moreover, many groups integrated people with disabilities as members, in some cases even on concessional terms, and supported them. This was a small step for integrating disabled people with community initiatives.

Women Federation: Vizhuthugal, the branch roots of banyan tree

As part of the women development programme, PCTC promoted women self-help groups (SHG) from 1997. These groups operated a savings and credit scheme by contributing a savings amount as fixed by each group. Members avail loans from this fund based on agreed guidelines. Group leaders and members are trained in maintaining accounts and managing self help groups. Specifically, this included accounts training, skill training, and value addition training for local agricultural products.



In 1998, PCTC was recognized as a facilitating agency by MagalirThittam, the women development programme of the Tamil Nadu Government. In 2000, the block level federation called Vizhuthugal was formed. In 2011, there were 791 groups. Following the model proposed by the government, PCTC enabled the self help groups to form a Panchayat level federation (PLF) and helped the groups to function on their own. Along with welfare programmes, insurance schemes were also introduced and managed by the federation as a social security measure. This was a great step towards self-governance and sustainability of the federation.

Currently, the PLF is independently functioning. Whenever PCTC initiates a program in the villages, it is implemented in collaboration with the federation. Specially, this was done in a few community based programmes such as anemia prevention program, Thulir program, early identification of disabled children, trainings, and family life education. Federation plays a major role in supporting the annual people's festival organised by PCTC.

Community health

PCTC, as an organisation working with PWDs is integrally linked with health issues. This scope was broadened over the years beyond the borders of disability related concerns to encompass community health issues. Community health interventions with an emphasis on prevention and traditional remedies were identified and promoted. Siddha system of medicine, the native system of Tamilnadu still popular in villages, was promoted wherever found effective. Dr. Micheal Jeyaraj, one of the trustees, was the guiding force.

Siddha system uses a set of oils and ointments for external applications for various ailments related to skin, bones, and muscles. This suited more for physiotherapy and massaging for the polio affected children to strengthen and improve their functioning. A Siddha clinic was also established with qualified doctors in 1999. Herbal medicines and home remedies were encouraged which was timely for people

living in remote villages where hospitals are not available in the vicinity.

Panchakarma, a treatment using Siddha system of medicine for muscles and joints, complements the developmental and sensory integration. This includes massage with herbal oil, herbal hot pack treatment, and abdomen stimulation by hot and cold water.

Regular village level camps were also organised to reach people. These camps, in addition to providing cure for primary ailments, also helped to create awareness on health issues from a prevention perspective which included preventive health care for children with disability.

As part of the community health programme, people were motivated and guided to develop community herbal gardens in their houses and in common places in villages. PCTC had a herbal

Disturbing but satisfying experience

Genova Micheal, fondly called by many as Jenó, worked in PCTC as parent trainer for 12 years. She belongs to Kariyandal village where one of the PCTC Day care centers functions.

Genova joined PCTC in 2001 as a Community-based Rehabilitation Worker in the National Program for the Rehabilitation of the Disabled. She underwent six months Care Givers Training organized by the Ministry of Social Justice, Government of India. Geno efficiently managed the Day Care Center, early Intervention Programme, and Parent training programmes. After 14 years with PCTC she moved to Chennai for family reasons, but still continues with PCTC as a volunteer. She is always available whenever her services are required. She started as a Community based Rehabilitation worker and when she left she was in charge of the Day care centre at Kariyandal.



"Back in 2000, I came here to PCTC looking for a job. Initially, as a Rehabilitation worker, when I was visiting villages to talk to parents with disabled children, I faced frustrating experiences. Many even yelled at me for suggesting them to send their children at an early age for improvement. A few times I even thought of leaving the job because I could not manage. But later, I visited the villages as a team for strength to face them and parents also started listening to us. It was a joyous occasion when parents decided to send such children to school and later, after seeing the improvement, start loving us and becoming very close to us. They share their difficulties and seek support to manage situations at home. It had been a disturbing and very difficult experience when parents share their agonies, but was also satisfying when parents return with some confidence after talking to us."

garden in its campus with a large number of medicinal plants. The promotion also included herbal exhibitions and CDs with more than 250 photographs of medicinal plants for people to identify.

A 'Student Doctors Program' (kutti Maruthuvar) among school going children complemented these efforts, where students were taught to identify herbs for common ailments. PCTC is a member of Tamilnadu Voluntary Health Association (TNVHA), a State level federation to promote preventive primary health.

Children development

PCTC initially started working for disability issues, particularly with children affected by polio. In the process of working on disability issues of children, other concerns associated with children in general also started surfacing. This resulted in a reflection process within PCTC on how to respond to the wider issues that rural children face. As a response, a child development programme emerged.

Children in rural areas have lesser opportunities compared to their peers in the urban segments. This caused greater influence on their career in future. Realising this, PCTC promoted activities for students in all villages linking with the disability programmes. This was based on the conviction that creating a young cadre among the students in the age group of 11-18 years would enhance their participation in the ongoing programmes and also would enable them to identify their potentials to build a prospective career in the future.

This programme was named as Thulir Thittam (Young Plan), to be organised around centres in villages where children can come and assemble for studies and other skill development activities. The venue for these centers was provided by the village. Initially, eight such centers were started and currently six function.

The key activities of Thulir are:

- ▶ Supplementary education
- ▶ Special summer camps for children
- ▶ Talent search competitions for school children
- ▶ Support to continue education for deserving students
- ▶ Prevention of drop-outs at secondary level of education, especially among girls
- ▶ Career guidance, supportive training, and secretarial assistance
- ▶ Opportunities for students to exhibit their social commitments
- ▶ Computer training
- ▶ Internet access
- ▶ Learning musical instruments
- ▶ Library

In each centre special classes are conducted, students are assisted to complete their home work, and participate in a reading session to improve reading skills. Special attention is given for 10th and 12th standard students, since they appear for government examinations.

Health education and use of simple herbs for common ailment is taught. A variety of competitions such as essay, poetry, drawing, skits, formation of pyramid are conducted to bring out the hidden talents among the students.



Environment and Climate Change

PCTC takes efforts to enlighten women and school going children on the importance of global warming and issues related to environmental sustainability. The inputs are on waste management, tree plantation, renewable energy, organic farming, rain water harvesting, bio gas, and construction of toilets. In Porkunam village, PCTC has installed a solar power system for the federation building. Wherever women groups ensure their participation, PCTC establishes model projects on renewable energy, bio gas, organic farming, and agro enterprises. More than 3000 saplings were distributed to the members of the self-help groups and Thulir children.

The green revolution in India, though brought self-sufficiency in food production, increased the use of fertilizers and pesticides causing great harm to land and environment. PCTC owns 16 acres of land as a model farm, where organic farming is being practiced and neighbouring farmers use as a learning centre for demonstrating innovative farming practices.

This farm is being utilised as a training place for adolescent people with disabilities to learn cultivation and raising livestock. It is envisaged that in the longer run, the farm should generate income to support the maintenance of the centre.

An invitation to collaborate

Mr. Vengatesan belongs to Thiruvannamalai. His association with PCTC started from 2010 when he came in contact with the organisation through the Leprosy Mission programme. Currently, he is the Secretary of the Thiruvannamalai District Federation of the 'Differently-abled' persons. He works as a consultant to the Leprosy Mission and a member of the district rehabilitation committee in which the district Collector (district administrative head) is the chairperson. Vengatesan, being the district secretary, is well aware of the prevailing issues around disability and disability rights.

"I would say assertively that there was a drastic change in the life of disabled persons in Thiruvannamalai district from the year 2011, when the federation was fully developed and self-reliant. All NGOs working in disability area in this district came together as a network which was a pioneer initiative by PCTC in this district; and perhaps in Tamilnadu State. We developed a data base that helped us to lobby with facts and figures. This also helped to initiate many measures to improve life and livelihood of disabled persons in the district. This model was taken up by the government to be implemented in other districts at that time, but slowly the interest faded away for unknown reasons" states Vengatesan.



Vengatesan feels that in recent years there is a tremendous impact created on the life of the disabled in Thiruvannamalai district. As part of the inclusive education, many children have joined the mainstream and completed school education and even many at college level. Now they are looking for jobs that suit their training and qualification. Vengatesan proposed: "It is time that we jointly initiate a coaching programme for the educated to apply for government jobs and participate in competitive examinations. We need to join hands to achieve this in the current year; if not, in the coming years. We should start working on it now which would enable many to find jobs."

My mother fails to answer my question



E. Renuga, 12 years, is from Seelapandal village. Her parents are farmers. Renuga has an elder brother and an elder sister both studying. Renuga studies 8th standard in a nearby government school. Since this school has only up to 8th standard,

next year when she completes 8th standard, she will be moved to another government school where her elder sister already studies.

Renuga, an active participant in Thulir Thittam, always lives with a question in her mind. Why when she and her sister are studying in government schools her brother is sent to a matriculation school paying fees? She has been asking this question to her mother many times and gets a reply, "You are a girl; you will not stay with us always and support us. So there is no meaning in spending for your education. Your brother, our son, will stay with us and support us and so we invest on his education". But Renuga could not understand this. She argues that she will also

support them after education. But her mother ignores her assurance. Renuga disturbed by this answer, asks her father. But her father always avoids directly answering such questions by sharing a joke or asking her to ignore what the mother said.

Renuga is preparing now to go to the government school next year. She is willing to go, but do not understand why she and her sister are treated differently from their brother? But she had made one decision; that she should study well and support her parents to prove that they are wrong. She feels discriminated for reasons she could not understand. "I told my mother that I will also feed you, but she smiles and moves along" says the perplexed Renuga.

Thulir Thittam gives some hope to such students to improve their studies and score better marks. Along with the studies, they also learn other skills to become more competent. Renuga is trained in street theater and she writes poems and essays. Perhaps one day, she might write a poem about her experience being a girl child or perform a street play displaying the differential treatment of a girl child.

"Twenty six years of association and ten years of participative collaboration with PCTC provided me with ever growing opportunities for learning from their vision driven strategies and impacts created in the community.

Focus on self-reliant sustainable resources, marginalised people specific approach, undiluted by attractive project offers that are alien to the cherished values of the organisation, introspection to be relevant to the emerging needs of the community and optimum transparent and participatory management are values to be assimilated from PCTC by any development organisation."

S. JOHNSON RAJ, Executive Director, Pro-Vision, Nagercoil.



PCTC, as I have seen, heard and experienced in the past 15 years, is a beacon to the marginalized, disadvantaged and the Differently-Abled persons in Tiruvannamalai district. It has not been a 'Preacher' but a 'Facilitator', not 'shown' the way but 'gone' the way and above all not established an Institution in isolation but built up Communities who are the pillars of that institution. The People and the Nature that PCTC has nurtured will invigorate the organisation towards its Golden Jubilee. I am privileged to have had the opportunity to learn from the Guru Mr. Xavier now and then"

Mr. M.L. Alphonseraj, Island Trust, Kothagiri

Milestones

PCTC has implemented specific time bound projects, when such interventions were required and resources available. Some of them are still ongoing and integrated with the disability programme. The table gives a gist of programmes with key objectives and outcome.

Rural children Development	<p>programme</p> <p>Supported by Enfants Du Monde, France</p> <ul style="list-style-type: none"> To educate rural children and children affected by polio on civic responsibilities 47 children clubs formed and around 1500 school children and children with disability reached <p>1992</p>	Community based rehabilitation	<p>program for children with disability</p> <p>Supported by Swiss Friends - Mr.Rudolf and Cecile Meier</p> <ul style="list-style-type: none"> CBR program for the rehabilitation of children with disability CBR programme for all children with disability in Thurinchapuram block with interventions <p>1992</p>	Scholarship assistance to	<p>deserving school children</p> <p>Supported by Friends from UK - Ms. Cathy Bowman</p> <ul style="list-style-type: none"> To provide educational assistance for deserving school going children More than 600 children supported with educational assistance <p>1992</p>
Rural development	<p>Supported by Marie Jose Wouters, Dutch Quakers</p> <ul style="list-style-type: none"> To sensitise people for their participation in rural development New initiatives for women, children, environment, social forestation, and livelihood support <p>1992</p>	Community Health Programme	<p>Supported by IGSSS - India</p> <ul style="list-style-type: none"> To educate rural families on primary health care and immunisation 30000 people were reached in 15 villages <p>1994</p>	Interface on Disability	<p>Supported by SPASTN & UNICEF</p> <ul style="list-style-type: none"> To train field workers of health and ICDS staff on early identification of children with disability 663 workers trained through a 15 day certificate programme <p>1997</p>
Integrated community based Rehabilitation	<p>program for Children with CP/MR</p> <p>Supported by CRY, Chennai</p> <ul style="list-style-type: none"> Initiating a pilot CBR program for the rehabilitation of CP/MR children by creating awareness among rural people that children affected by CP and MR can be rehabilitated towards self reliance <p>1997</p>	Organisation of Rural Women	<p>and PWDs</p> <p>Supported by Andheri Hilfe, Germany</p> <ul style="list-style-type: none"> To form self help groups in 15 villages 30 Self help groups formed and linked with banks. PWDs were integrated in these groups <p>1998</p>	Women Development	<p>Supported by Ministry of Social welfare, Government of Tamilnadu</p> <ul style="list-style-type: none"> To form self help groups and empower women 10,500 women in 791 groups. Rs. 80 million credit availed. 47 federations self-sustained <p>1998</p>

Our sincere appreciation for your constructive contribution and dedicated meaningful support services towards empowerment of vulnerable community and specially the challenged people. I as a person associated with PCTC & you in different occasions, I strongly register my impressions in this unique occasion that you have created sustainable development traces through your shared vision and dynamic leadership.

Dr.Saminathan, Poets - Gudiyatham, Vellore District.



Networking to promote community

based rehabilitation program

Supported by Caritas India/ CBR Forum, Bangalore

- To orient NGOs to get involved in CBR program for people with disability
- A network formed with 13 NGOs and a collective programme initiated at the District level

1999

Initiating girls with disability

into vocational training

Supported by SPASTN, Chennai

- To impart skill training for 12 girls with disability
- 11 girls trained and self employed

1999

Reproductive and child health

Supported by Ministry of Health, Government of India

- To educate adolescent girls in 10 villages on reproductive health
- 350 girls trained. A hand book published on adolescent health

1999

Aids and appliances for

children with disabilities

Supported by Castricum, The Netherlands

- To provide accessibility devices to children
- 211 children were given mobility devices, and some of them had surgical correction to use them

2000

National programme for the

Rehabilitation of the Disabled

Supported by Ministry of Social welfare, Government of India

- To identify needs of PWDs
- 2000 persons assessed for their needs and enabled to avail Government benefits

2002

National Trust

Supported by Ministry of Social Justice, Government of India

- To train care givers (6 months) for caring children affected by CP, MR, MD and Autism
- 30 care givers trained and utilised in different parts of the District

2002

Integrated education

for the CWDS

Supported by Sarva Siksha Abiyan

- To provide integrated education for children with disability in public schools
- 343 children with disability enrolled in schools, support services provided for retention

2004

Tsunami Rehabilitation work

in Tarangambadi

Supported by Demains, France

- To provide rehabilitation assistance to tsunami affected people in Tarangambadi area
- 50 families supported for house repair, skill training for 10 families, toilet construction in 30 houses and day care services for children with disability

2005

Vazhikattum Thittam

Supported by Ministry of Social welfare, Government of Tamilnadu

- To educate PWDs on their rights and government schemes
- 2050 PWDs reached in Thurinchipuram Block

2009

Rural Children development

program

Supported by 2 Bears, UK

- To form Thulir centers, and educate children on climate change, clean and green environment
- 13 Thulir centers formed, 300 solar lanterns distributed during electricity crisis and mobility devices given to 50 disabled children.

2010

Anemia Prevention program

among adolescent girls

Supported by Demains-France

- To sensitize adolescent girls on the prevention of Anemia
- 150 girls from 5 villages benefitted from this program

2015

PCTC is improving the lives of disabled children and motivating their parents since 25 years in Tiruvannamalai District with great success. PCTC is filling the gap where the government is not able to reach.



Mr. Rudolf Meier, Rovio, Switzerland

Reminiscence





Cherish my days

Elumalai, who belongs to Madavilagam, village joined PCTC in 1992 and worked for more than 15 years. Elumalai underwent 'Rehabilitation Training' at Handicap International, Pondicherry; Master Training for 'Interface on Disability', SPASTN, Chennai; and Adolescent Health Training in NIPCED (National Institute of Public Cooperation), New Delhi. He worked as the coordinator of Rehabilitation programme, coordinator of women development programme, and in promoting children's Clubs. Being a trained teacher, after working for more than 15 years in PCTC, he is now a science teacher in a Government High School. He continues to be a volunteer with PCTC.



He recalls his experience and memorable days in PCTC. This is evident in his statement, "Though often challenging, it was a purposeful period in my life. The lessons I learned during my time in PCTC often disturbs me in an insensitive context but at the same time it also helps me to be more committed to my job and help weaker students with special attention. In the school, since I am more patient than other teachers to support poor learners, everyone suggests such students to come to my class. I happily do it," says the teacher. He continued to say that PCTC has helped him to be sensitive to people with disability and to understand them better in society.

From a shy girl to a village leader



At the time when PCTC promoted self-help groups, E. Thamayanthi from Kothanthavadi village started associating with PCTC as an animator. Thamayanthi was an active animator with high level of involvement in all programmes related to women development and self help groups.

"I was very shy in the beginning. I lacked confidence even to move out of my home alone. I always needed someone to accompany me. Later, after my involvement in the SHG and federation, I started visiting government offices and banks as part of my role as a group leader. This brought in a lot of confidence in me. The shy person in me slowly started dissolving and even I started speaking in public meetings. With the support of many women and their families in the village, who witnessed my work through the SHG and federation, I contested in the Local Body Election and became the Panchayath President. Now my work is not limited to SHG or federation, I work for my village to make it the best and self-reliant village" Thamayanthi narrates her graduation from a shy village girl to the vibrant elected village leader now.

The leadership qualities she developed over the years, has led her to actively participate in all development activities of the block which elevated her to this position. "It is hard to bring the desired change in my village, but I will achieve it soon", said the confident Thamayanthi who is married and has a family with two children to take care.

"I first met Xavier in 1984. I realised that in those days he had a great concern for those in society who are disadvantaged. I could never have realised what that concern would grow into. He has influenced for the good so many lives, each to their own need."



Mrs. C. Bowman, UK

Good practices and Impact - Outcome of activities

PCTC, in the process of completing twenty-five years of service to people with disability, also responded to a few development issues. Though many factors such as vision, leadership, committed staff, community participation, and external linkages directly contributed to the impact, overall the outcome could be more attributed to the community-based approach PCTC opted for and the good practices followed. This is expressed by people with disability benefitted from PCTC, care givers, and current and former staff. They validated this through their testimonies and reflections. There are also tangible evidences as indicators for the changes that have happened in the life of many disabled people.

Good practices

Early detection and intervention: Early detection and intervention is one practice that makes a difference in the life of the disabled persons. In the initial years of PCTC, disabled persons aged above ten came forward for rehabilitation and treatment. Currently the average age is around five. The major benefit would be an improved quality of life compared to late response.

PCTC achieved this through constant field visits and meeting of parents. The signs of delayed development of children with perceived risk were registered and followed up to identify the children who require support. The necessary contacts in the villages were established through the various development programmes that enabled the process of identification.

PCTC believed and also experienced that the early detection of disability is the fundamental practice for early intervention, which is essential for rapid development. The therapeutic and educational roles get integrated to produce

best results and to offer all required services for such children. After a considerable period of intervention and rehabilitation activities, remarkable improvement is noticed in the conditions of the children who are referred early. Specifically, early identification and intervention reduce incidents of seizures, improvement in general health, and better cognitive development in children. This also brings a positive change in the attitude of parents towards their children, as they notice tangible and faster improvement. Moreover this early improvements strengthen the ability of the parents in dealing with their children.

Two early intervention centers function effectively with the support of parents. In both these centers, new equipments are added and the facilities changed to be more disable-friendly. Children were assessed for assistive devices and based on the assessment, developmental aids, positioning and mobility devices are provided.

Parent's education and community awareness: Though disabled children attend centers and receive supports related to mobility and education, it is important that this continues at home. As parents and in some cases grandparents, are the care givers at home, it is essential to orient them. Broadly, parent training aims at orienting and equipping parents the essentials of caring their disabled children.

The training and counseling process includes:

- Primarily owning responsibility for the care of their children while at home
- Supporting measures to change their behavior as taught to them at the center
- Helping the children in their effort to improve daily living skills
- Continuing easy to follow simple therapies taught to them
- Taking care of the child's general health

Since the training to parents are given based on the nature of each child and their needs, parents become aware of their children's condition and know how to respond to their specific needs. This approach also encourages the parents to proactively participate in the programme, because they are not studying

how to care a disabled child, but rather they learn how to care their own child. Being sensitive to disability issues, they also support the total disability programme. This parental involvement in the rehabilitation process and continued support at home improves integration in schools for inclusive education.

They give back love



Kanagavalli belongs to Mel Palandal village. She is married with three children. She joined PCTC in 2015. Earlier, she was an SHG animator and identified to work in PCTC as an assistant in the Day Care Centre. She proved to be a good motivator in the short span of time with PCTC.

Working with children with disability was a new experience for Kanagavalli and it was hard in the beginning. She said that, "many people ask me how I feel about this job. But to me, though initially I had some difficulties to understand the new situation, now I do not find it hard to care them or relate with them; rather I enjoy their spontaneous love and affection. Now I cannot even miss or absent one day. I take leave only if it is unavoidable. If I miss a day, next day they ask me why I did not come. They miss me and I also feel missing them if I could not attend them even a day."

Makkal Thiruvizha (People's Festival):

Makkal Thiruvizha is an annual event organised by PCTC, which is celebrated by the community. People associated with all PCTC programmes like self-help groups, children programme, and differently-abled persons and their parents participate in this event. This annual event, celebrated each year in different locations, includes competitions, sports and games, and cultural activities. On an average, around 3000 people participate in this event. More importantly, disabled children actively participate in all the competitions and cultural events.

A prominent person from the area where the event is organized will be invited to be the Chief Guest. Competitions like kolam (traditional drawing of symmetrical patterns) showcase the talents of women self-help group members. Children participate in traditional games like kabadi. Folk forms like karagattam are played.

The occasion is also an opportunity for the annual reunion of former staff who turn-up in large numbers and participate in the occasion. The Makkal Thiruvizha has become an opportunity to convey their continued relationship and express their solidarity with PCTC. Along with the festivities and reunion, an interaction with the community representatives is also held on issues affecting them. The session is also used to collect some feedback from the participants on their expected responses from PCTC to address those issues. This process of engaging the community provides insights to reflect the past activities and also plan for the future. As this serves as a live feedback session, many mid term corrections are also made based on these suggestions. The event, though outwardly looks like a platform for meeting and having fun, it promotes a bond and feeling of belongings among the participants. This also paves the way for improved participation of all stake holders in the programme activities.

Volunteers: In addition to the volunteers from the District, PCTC also receives a stream of volunteers from overseas. These volunteers who stay for a period of time help PCTC with their expertise and experience. These volunteers come with a range of specialisation in fields like tourism and social tourism, care givers, educators, fabricating designers, business consultants, and social scientists. They stay for a period of three months to one year. Some of them, who find the work interesting, make repeat visits when they get another opportunity to volunteer. The volunteers, in addition to contributing their skills, also bring a cross cultural learning to PCTC staff.

Inclusive education and Vocational training: PCTC organises vocational training programmes for enabling the disabled persons to be independent for their income. Economic independence is a major self-sustaining process that helps the affected people to regain their dignity as a person.

Along with vocational training, PCTC also promoted inclusive education where children could attend regular schools and study. A scholarship scheme is also available to support deserving students to continue education.

A range of suitable self employable and job oriented skill trainings are being organized. It includes a long list of craft oriented, agriculture related, and tradable skills. The skill training for vocations and integration in the mainstream schools not only support for income security but also contribute to the larger mainstreaming aspects of persons with disabilities.

Community organisation with a 'rights perspective': PCTC was instrumental in organising communities, both the disabled persons and women, into people's organisation with a right perspective. They are equipped, enabled, and linked with government to avail their entitlements. This is evident from

the statements of the federation leaders. Murugesan, the federation leader states confidently, "I know what scheme comes and who are all eligible to be the beneficiaries. But we should also respect the guidelines. When we go to work, we should do what is possible for us. We should not use our limitation as an excuse. It is our right to demand and find employment from government, but we should also respect our responsibility". This statement explains the 'rights approach' the federation is talking about. The women federation was also formed in the same way and currently linked with government agencies and banks for accessing resources for development.

Facilitative role of PCTC: PCTC from the beginning maintained its role as a facilitator. Even when PCTC was managing project implementation directly, community participation was encouraged and adequate space created for communities to engage in such activities.

This pattern changed when people were mobilized and equipped to function as community organisations. Even in the rehabilitation programmes of affected children, PCTC emphasised the role of parents and communities. This approach enabled to reduce dependency of the community, improve participation of the beneficiaries, and at some point to take up ownership. This clarity on its role as a facilitator contributed considerably in sustaining the impact, though dilution in some areas happened due to the transition of certain roles from PCTC to the community. Being an advocate of community-based approach for development, PCTC has done justice by developing self-governed people's organisations through a facilitation and capacity building process.

Enabling mainstream linkages: Another important practice is the linkages developed with the mainstream organisations and government. Members were encouraged and helped to access benefits and avail entitlements as persons with equal rights in society. This mainstream approach also helped to confirm the understanding that the state is ultimately responsible to its citizens and this is more so in the case of people with disabilities. This also defines the role of supportive organisations like PCTC that these organisations neither exist to solve social problems directly nor have the mandate and capacity to do so, rather facilitate people to solve their own problems through mainstream linkages. It is true that at times the quality of services is compromised in a mainstream system; but they are permanent, ongoing, and right of the people.

Networking: In 1997, PCTC initiated a network of NGOs implementing programmes for people with disabilities in Thiruvannamalai District. Thiruvannamalai District Forum for the Rehabilitation of Disabled (TDFRD) with 13 NGOs emerged as a result of this effort. Enumeration of PWDs in all the 860 panchayats

of the district was done with 200 volunteers in two-month time with the participation of the 13 NGO members. A software was developed to record and analyse the data. Government linkages, through the district Collector, were established with an attempt to use the software in all districts of Tamilnadu. A vision document for rehabilitation, implementation of the national rehabilitation programme for the disabled, and the participation in the Vazhikattum Thittam were the key achievements of the collective.

CSI Diocesan Ministry, Vellore Diocese, a member of this Collective, in its report on September 2000, states, "The CSI Diocesan Ministry of Vellore Diocese has proudly completed its first year service by August 2000 in 'Empowering the Differently-abled' in 9 blocks of Thiruvannamalai District through the strong network programme with like-minded NGOs. In a short period of one year, the programme gained more clarity in Disability Management and Community Based Rehabilitation (CBR)".

I am one of the firsts



Banumathi, a polio affected person from Kusalpettai village, has a different story. She joined PCTC in 1992 as a resident learner when she was six years. From 1994, she was in the transitional home till completing 8th standard in school. She could not walk when she arrived in the center. Later due to physiotherapy and training she started walking with calipers.

Banumathi recalls her days in PCTC. "It was my home" she says fondly recalling her early days. "There was a lot of stigma and due to this I developed self-pity. Being a girl child, everyone looked at me and my parents with pity and often with a spell of sarcasm. PCTC changed me. I started talking to others only after I came here. Mingling with other students, who also had some problems like me, helped me to face the odds and fight to overcome difficulties." says Banumathi.

"I am one of the first in PCTC" claims Banumathi. She declares, "PCTC is my home then and even now". She also says that she feels high whenever she visits PCTC. Banumathi is married and has two children; and she is a leader in the women wing of the federation. Banumathi, once a person withdrawn with self pity, now is a motivation for many young girls with disability.

Impact generated

From the beginning in 1991, PCTC believed in a community-based approach for the rehabilitation of the disabled persons. Institutional care was available, but with a significant role for the family. In 1997, there was a clear shift as a result of a new learning; a shift from the model of institutionalisation to adopt the practices of maintaining the person in the family and in the community as well.

The aim was to maintain children in their living context and to have a continuous support system in a family environment. This avoided isolating children from their homes and also prepared parents to realise that it is their responsibility to take care of the children rather than shifting the role to some other agency. Moreover, this approach enabled to transfer the necessary knowledge to the communities in order that people themselves can identify problems and try to find solutions using existing local resources. The long range plan was to transfer responsibilities to the respective communities with capacities and mainstream linkages, so that the role of PCTC is limited to facilitating such a process and outcome.

The striking factor in PCTC initiatives is a comprehensive approach of integrating development responses with the rehabilitation of disabled persons. This is obvious in various programme initiatives over the years that complemented the core programme of rehabilitation of persons with disabilities. Thematically PCTC programme included disability, health, livelihood, and environment with an emphasis on community-based approach which encompasses sensitisation process, preventive measures, community organisation, community participation, and mainstreaming for inclusive and sustainable development.

This comprehensive approach also brought in a right perspective that encourages the affected communities to avail benefits as their entitlements. In addition, the efforts to strengthen livelihood options - through skill development, access to credit, and supportive training, also formed part of the sustainability process.

Specifically the impact is indicated in the higher level of awareness among parents; improvement in availing government benefits; early arrival for training and treatment; promotion of inclusive education, and reduction in social stigma and discrimination. The major role played by PCTC is indicated in many documentary sources and people's experiences, and evident through tangible and direct effects of the interventions.

- Acceptance of the disabled persons and willingness to treat them improved in families and villages. This is indicated in the attitude change of family members and the difference in treating the affected persons compared to early years. As a result, many disabled children and adults earlier hidden away in houses or almost abandoned in streets, now experience a new life with others
- In the past years, only affected children above 10 years came to the centre, currently children as early as 3 to 6 years come for treatment
- The level of self-reliance for children and adults increased in many counts such as movement, work, and earning through vocational training, career counseling, and supportive training
- As many of the disabled persons who have undergone the services expressed, their self-pity is changed to self-respect, and despair turned into hope for living
- Families are now familiar with practices and equipments required for disabled persons and

widely use them. This is augmented by training and the easy availability of assistive devices due to localised fabrication of rehabilitation aids, calipers, crutches, and other adaptive devices.

- Skills transferred to care givers especially to parents and grandparents
- Improved level of school integration and inclusive education as a result of motivating the affected persons and sensitising parents and teachers
- Networking, collaborations, linkages, and mainstreaming efforts helped to strengthen service facilities and sustain the support base
- Access to credit for disabled persons improved with PWD self-help groups and their linkages with formal banks
- Disability Rights Group (DRG) played the role of advocating for the rights of PWDs and

policy changes at the government level. There is a clear shift in approach among disabled persons from a 'beneficiary of a service delivery' to a right approach in availing benefit as their entitlements rather than charity

- Institutional care is replaced by community-based care where the affected are encouraged to live in families and the families and communities participate in the rehabilitation process
- Access to scholarship and other schemes and availing government benefits improved, specifically integration of children in ICDS centers and schools benefitted many children
- Women from poor economic background have achieved in terms of savings and credit, revolving funds, credit from banks, and access to government schemes. The women SHG federation and its linkage with government and banks enabled improved awareness and economic strengthening.

Further to serve



Vijayaraj joined PCTC in 1994. He still continues as part of PCTC. Though he joined a few years after the formation of PCTC, he became an active player in the history of the organisation. Vijayaraj currently works as the CBR Programme Coordinator, around which all other initiatives are integrated.

"I was employed in Bombay at that time. It was a private sector job with good salary. But I was not happy to work in a distant place with a mechanical life. Moreover, I often became homesick. So, I was looking for an option to work near my home and also a job that gives me some freedom and satisfaction. At that time, I got to know about a job opportunity in PCTC through its Programme Director. I decided to leave Bombay and join here. As soon as I joined, I was sent for training. After the training, with some confidence I started working in PCTC." recalls Vijayaraj on how he left Bombay and became part of PCTC.

According to Vijayaraj, in the process of working for the development of people with disability, he also developed his skills to work better. He considers the possibility to involve in a variety of development programmes, to meet and associate with people with diverse backgrounds, and to participate in training programmes, as learning opportunities. Moreover, there is a sense of satisfaction in helping people with special needs which gives a meaning to the vocation.

He says, "I continue in this work with a positive mindset, willingness to work hard, and with a hope that this centre could be further developed to serve people with disability. I think I can find joy in my rehabilitation work, till my spirit sustains me to continue".

PCTC can claim to have impacted on three core areas of disability in their quarter century journey.

1. **Acceptance:** Increased awareness and decreased stigma and discrimination have helped better acceptance of the disabled persons. This is made possible through a well planned but long years of sensitization efforts. In a strongly stigmatised traditional context, such a change is striking as one of the core impact.

2. **Lifespan:** Secondly, the average life span of the disabled persons has increased. This is evident from records where in the early years people with disability die at an early age due to lack of mobility, food, shelter, health care, and acceptance. Currently the situation has changed. Many people live for longer period with better health condition.

3. **Quality of life:** Above all, along with the improved acceptance and longevity, the quality of life of people with disability has improved. The increased level of acceptance, nutritive

food, mobility, and income earning capacity are the key factors that brought change. Even the conditions of those who cannot move are better due to the linkages established with the ongoing government support.

Many external factors could have also played a role; but many people who have undergone the process and experienced the changes establish the inevitable role of PCTC in the form of testimonies.

These changes perhaps are not in par with the set goals or standards for the disabled persons for defining a quality life, but rather arrived by comparing their status now from what they were in the past years. There is still much to be done to achieve such standards.

To sum up, the impacts of PCTC involvement in the life of disabled people in Thurinchipuram Block of Thiruvannamalai district are the improved community acceptance, increased longevity of life, and enhanced quality of living.

In 2009 a visit was organised to the People's Craft and Training Centre (PCTC) to see at first hand the work done by humanitarian organisations in Southern India. We were so impressed with the dedication of the staff of PCTC, that we wanted to contribute further. The name of the charity stems from a handmade gift given to us by a member of Staff of PCTC; the gift became a symbol of the humane dedication of Xavier Mariadoss (Founder of people's Craft Training Centre) and his staff and it was appropriate that this became the name of our charity.

Gavin and Julia-Founders of 2Bears.uk



Since 1981 I have known Xavier Mariadoss. When he started the PCTC I followed this project. It is amazing what he and his staff achieved: disabled children are found in the villages. They have got education and that increased the chance of an income in grown-up life. Their parents learned to meet the special needs of the child. The garden, workrooms to make tools and so on are also kept by some handicapped people. It affords them an income. I am impressed by the night schools in the villages as well: here many children get extra support so they can do better in day school. I wish PCTC all the possible success!

Marie-José Wouters MD, Amsterdam

Grandfather as the care giver



Periyasamy from Anandal village is a retired teacher. Santhosh, his grandson is a disabled child requiring special training and education. The parents of Santhosh were shattered when they came to know that their child is different from other children. The growth was slow comparing to other children of his age. This caused inferiority complex in them. The stigma on disability in the village added to this. "It was difficult, but I first decided to accept what has happened to my grandson. I started caring him and learned that an unconditional love and extra care will improve the condition." said the grandfather.

Periyasamy decided to be the care giver of his grandson. His acceptance, patience, and efforts brought some improvement in the child. As a care giver, he was regular to all parents' training and meetings. More than care giving, he learned to be a community based rehabilitation worker. His efforts for more than five years resulted in some visible changes in the life of his grandson; and this became a witness to many other parents in the vicinity to believe that change is possible with special care and training.

Santhosh is now receiving a government grant which is exclusively spent on him. The balance amount is saved in his name as fixed deposit in banks. "Parents should not use this money for any other purpose at any pretext. This money belongs to the disabled children which should be spent only for their development." says the care giver.

Now Periyasamy is a well equipped person to understand and also respond to disability related issues. Moreover, he is a motivator of other parents.

Managing a Business

K. Murugan, a member in the Federation of the disabled persons, is 31 years, married, has two girl children, and has bought a piece of land to construct a house. The self-employed young person, is the proprietor of 'Friends Electronics', a service centre for television and home appliances at Mangalam in Thiruvannamalai. Mrurugan sits in his service centre and with a confident smile and receives his customers and friends. One notices him as a person with some disability, only when he stands up and takes his crutches kept near his table. He walks out with this support and rides in his motorized three-wheeler designed to drive using his hands. Murugan is polio affected, who has overcome his initial disabilities and now enabled to manage a business.

Murugan testifies that he owes all what he is now to PCTC and to his father who initially used to carry him on his shoulder for moving from one place to other. Murugan joined PCTC for day care in 1992. He had some knee and ankle contracture removed and provided mobility training and caliper. Initially it was difficult for the PCTC staff to convince his

father since he was not willing to send his son to a special school fearing some risk. By constant follow up he was convinced and Murugan had the opportunity to undergo training and slowly started walking with the help of crutches.



He has already trained around 10 young disabled adults in mobile and TV servicing and four of them have started their own shops in different places.

"I am what I am now, because of PCTC", states Murugan. Murugan, who has proved himself as a successful self-employed person, is confident, and demonstrates to other persons with disabilities, that it is possible to overcome and excel.

Lessons and challenges - Learning and changing

PCTC, committed to the mission of working for disability issues, continued to uphold this for 25 years as its core programme. The decision to work for disability issues though spontaneous was a hard choice. It becomes more complex in a rural setting, where disability is combined with other poverty issues. The inherent stigma attached to disability, the scattered rural villages that lack basic amenities and transport facilities, and the overwhelming poverty conditions that could hamper any attempt for community self-reliance are some of the inbuilt impediments in the journey of PCTC.

It is universally accepted that “There is a global correlation between disability and poverty, produced by a variety of factors. Disability and poverty may form a vicious circle, in which physical barriers make it more difficult to get income, which in turn diminishes access to health care and other necessities for a healthy life. The World report on disability indicates that half of all disabled people cannot afford health care, compared to a third of non-disabled people. In countries without public services for adults with disabilities, their families may be impoverished.”

Perhaps this is the lesson and also a major challenge for any organisation that commits to work with disability in a low income context or country. This impediment appears to have existed all along the journey of PCTC as a major challenge.

Learning and changing: A few shifts in PCTC approaches and practices over the years, based on emerging trends and development thrusts, show it as a ‘learning and changing organisation’. The journey started with a specific focus on polio affected children which later got expanded to other areas such as cerebral palsy and mental retardation of

children; subsequently to cover disabled adults also.

At the next stage, the programme moved to other developmental areas associated to children, and women. Thematically, this added livelihood, health, and environment along with disability, in an attempt to redefine the organisational objective in line with the changes in the sector. The struggle to work on new development areas of empowerment while keeping the rehabilitation of the disabled as the core programme in it was a challenge. Further, internalising these changes and integrating them into the organisation was a struggle that was managed by PCTC through a process of training and participation of all stakeholders. There are also clear shifts happened over the years from an institutional care to community based care; special education to integrated inclusive education; building self-governing community organisations by promoting federations of women and disabled persons; and networking of organisations in the District for collaborative efforts.

Stigma and self-pity: In general, stigma and related discriminatory practices are common in rural areas. This is a challenge staff face when they approach parents with disabled children. Many staff often report indifference and even abusive situations they faced. Initially they handled this difficulty by visiting parents as a team. As Genova, a former staff expressed, “when we go as a team it provides some mutual support to withstand such reactions from parents. Eventually we learned that this is not their mistake but the desperate conditions they face make them react like this. When they realise that they have to live with this lifelong, it disturbs them. Once we understand this we become more responsible and matured enough to handle such situations.”

The dominant superstitions and the notion that disability is a punishment for past sin are factors that hound affected families. This becomes intense in a poverty context. There is also a dominant perception that these children are not productive and so there is no purpose in investing time and money on them. It is a real challenge for the staff to break this mindset and prepare the parents. In many cases even the disabled children themselves require support who experience discrimination and suffer from despair and self-pity.

Staff training and retaining: PCTC faced another major difficulty in the form of staff availability and retaining of trained staff. Working on disability issues is a difficult job which requires compatible aptitude with special training. When a trained staff leaves, it becomes difficult to continue the programme till a new staff is identified and trained. The problem of 'trained staff leaving the organisation' started from the first year of formation of PCTC and it continued. Though many staff attribute values and find some meaning in working with these children, other reasons make them leave. In the case of women, this happens very often due to marriage and other family reasons. Initially, it takes time for a new staff to settle down. In many cases, the satisfaction of supporting people in need and the love and affection given in return by the disabled children encouraged staff to stay. But in general, the work demands patience, a will to help, and energy to stand the difficult situations.

PCTC, the facilitator: Another major

challenge was in defining and maintaining the promotional and supportive role of PCTC and the self-governance and independence of the community and federations. Establishing linkages with the government and mainstreaming for sustainability proved to be the key learning in the later years. But translating this learning into practice was a difficult task. Moreover, this also brought in the challenge of ensuring the quality of services. When government system took over, there was an assurance for sustained support. But the quality of service to some level declined as it is common when a large system, especially the government systems, functions. In addition, the government schemes and policies always had inherent conflicts in matching with the needs of the people, problems of identifying the right beneficiaries, and the difficulty to change even when an element is found irrelevant.



PCTC also faced conflicting situations while deciding the roles of federations and the relationship between PCTC and the federation. The major issues are self-governance, independence, PCTC role as facilitator, and mutual support and collaborations for common programme. Though defined and practiced as independent entities, the struggle still prolongs with a need to redefine the roles and relationships.

PCTC, more than 25 years of efforts and commitment to bring people with disability into main stream. Not an easy challenge in a context where many priorities are emerging. However stubbornness and patience have demonstrated that change can happen and organisation like PCTC are essential at local level to help identify these situations, alert decision makers and push for change encouraging the most deprived to defend their rights and find their space in a society that often forgets them. Congratulations for those who devote a lifetime to fight this causes with little leans but with a big heart, thank you PCTC.

Marc Bonnet-UN anti-mining Program-Columbia



Federation for People with Disabilities

In order to make the disability program more community oriented the mobilization process of the disabled adult persons started around the year 1997. In 2009, when Vazhikattam Thittam of Government of Tami Nadu was initiated, one of the objectives was to educate disabled persons on their rights and make them aware of government schemes. By chance, the Leprosy Mission partnered in this programme. Village level groups were formed and later these groups federated at the Block level and affiliated with the District level federation. Such groups were promoted in all 47 panchayats in the Thurinjapuram Block. Majority of the district level office bearers are from Thurinchapuram block.

The federations functions as a collaborator of PCTC in the field. New programmes for people with disabilities are currently channeled through these existing federations. The self-help groups of the disabled persons and the federation serve as a link between the community and PCTC and various government departments. The village level groups help members to join the NREGS (National Rural Employment Guarantee Scheme) of the government for employment. Further, they enable members to avail government schemes and ensure that the benefits reach the right people. The federation also works to ensure the three percent reservation for PWDs in various government schemes.



The federation participates in all programmes for the disabled such as: programme for children with disability; day care centers; early identification for early intervention; parent sensitization and training; vocational training for adults with disability; livelihood support; skill training for self-employment; formation of village groups for their basic rights; skill training in cutting and dress making for young girls; organizing family life education and pre-marital education; career guidance; credit assistance for economic activities; insurance program; and evening classes with the support of the women in the villages.

Currently the federation, having more than 5000 members at the District level and 900 at the block level, works with a right based approach that attempts to sensitize on disability and availing entitlements.

"I first met Xavier Mariadoss in August 1991 in Pondicherry, through Handicap International and the Cluny religious community. He was just starting PCTC, with great leadership. Twenty-five years later, my involvement in supporting PCTC's activities remains rooted in PCTC's objectives - which have stayed the same throughout the years: providing physical care whilst raising awareness on the need for everyone to try and improve their living conditions, hand in hand with others."



Ms. Marie - Thé RIVIERE, France

Way forward - From here to where

PCTC has been providing preventive, curative, educational, and rehabilitative services for people with disabilities to improve their quality of life. PCTC believes and works for the collective self-reliance of people with disabilities with a community-based approach. This journey that began with a focus on 'disability' has been enriched by a range of development measures in the form of time bound projects, community organisations, organisational development, networks, collaborations, and community participation. It seems that some of the activities are timely responses found appropriate at a particular period of time. But the thread that united all these activities was the issues around disability and children. The journey had many milestones as achievements along with challenges, lessons, and resulting changes. A few shifts are also eminent in the journey, an outcome of a 'learning and changing' process adopted by the organisation. These shifts show that PCTC has been a 'learning and changing' organisation to retain its relevance in the context of emerging problems and evolving responses.

In this background, an attempt to understand PCTC as an organisation reveals that PCTC is an organisation with a focus on 'disable people' with an integrated development approach that encompasses the socio-economic context and poverty issues. PCTC has learned over the years, that poverty and the 'resource poor' conditions are major factors that affect the life of rural communities and especially the life of disabled persons.

Over the years, the unified PCTC and its programmes have become a three layered functional structure. One is PCTC, the organisation and its core disability programme. Secondly there are time bound projects with

external support for specific outcome and defined target communities. Thirdly, there are community federations that function independently but with undefined links with the other structures and mutual support.

The development projects stop once the project period comes to an end. The sustaining process of the impact generated through these projects, falls on either PCTC or the community federations. A better clarity and formal arrangement is required to define roles of each player in such situations. There seems to be some expectations that do not match well with the perceived roles of each player. This exists both at the perception and practice levels. For example, the independence of women federation and its direct linkage with government is seen as a sustainability measure by PCTC. Though this is accepted by the federation leaders, they also express that their relationship with PCTC seems like very informal, often making them feel as "left out". Besides, there are expectations preferring the earlier formal association and support. This understanding comes to the fore when the village level groups face a conflict that could not be resolved internally. In some cases, such conflicts without any external moderation results in dissolution of the group. This necessitates a need and structure to sustain the impact generated over the years. This is also apparent at a different degree in the federation for the persons with disability.

Secondly, even after twenty-five years, PCTC does not seem to be caught in a cross road looking for direction. The overall organisational direction is clear and well defined, and continues to be relevant: "working for the collective self-reliance of people with disability with a community-based approach". But what PCTC looks forward at this stage is a recalling,

reviewing, and reflecting process for learning and changing towards effective functioning and to further sustain the impact within the framework of its mandate.

The major overlapping area or uncertainty for improvement, which challenges the sustainability of generated impact, seems to be in the independence and interdependence among PCTC, projects, and the community organisations. A self governing system ensuring independence of each functional system is already in place, but there is an eagerness expressed in forums to redefine this with more clarity for better ownership, coordination, and cooperation.

As federations are involved directly with people, there are suggestions and proposals to start new services that are required to address the emerging needs of the community. For example, the federation of the disabled wanted to start a coaching programme for educated members to avail government jobs. The federation is looking forward to the support of PCTC and other stake holders to initiate such a programme. Rather than reviewing case by case, a formal arrangement between these functional structures could definitely bring clarity and synergy.

A well defined coordination mechanism, as a joint initiative, integrating specific projects, women federation, federation of the disabled persons, and PCTC, would perhaps address both these concerns: sustaining the impact, and supporting new initiatives. This arrangement in the form of a forum or coordination committee would ensure the independence of each entity and at the same time to support each other as collaborators using their specific skills and capacities. In addition to sustaining the impact generated, and supporting new initiatives, this will also address the feeling of 'left alone' at the community federation level.

Thirdly, though PCTC started its work in one block, the experiences were disseminated to the whole district through a process of networking and collective functioning. Earlier, PCTC has taken the lead role in the formation of this network and implementation of joint project. In the coming years, PCTC could plan to formally share its community based experiences and its success in 'sustaining through mainstreaming' to other NGOs that will bring changes to thousands of people with disability and to address disability issues in this region.

This could be done, if resource could be mobilized, through a regional or state level collective of interested organisations for learning together and equipping their staff to replicate such experiences.

To sum up, the twenty five years of PCTC as an organisation could be understood broadly in two phases. One is the promotional and strengthening phase where the programme activities were implemented, community capacities built, self-help groups promoted, federations formed, and linkages established.

The second phase is more a consolidation process for self-reliance, where the community federations were made independent with self-governance and direct linkages. In this current phase, there are no formal organisational linkages, though all come together for specific initiatives decided case by case. This seems to be an association based on the relationship in the past, rather than a structure and role oriented.

Looking into the future, the third phase that PCTC enters, could be a phase of coordination and programme integration. This process of coordination and integration definitely necessitates ownership, independence, and self-governance of each entity or functional structure, but at the same time collaborates.

Concluding reflections

During the process of documenting this journey, I thought I should share my experiences and reflections as an epilogue. This process is an effort to comprehend PCTC and its work over a quarter century. It was a difficult task to capture the journey of an organisation of over twenty-five years with a combination of organisations, people's movements, and project activities and their inherent complexities.

I know Xavier for many years through our professional associations. I have met him during many occasions, since we work in the development sector. I also knew PCTC as an organisation, from what Xavier shares with us and through documents he sends to us.

This time, through this documentation process, I had an opportunity to experience PCTC. I studied many documents and reports related to PCTC; I was there in Thiruvannamalai with PCTC team for four days; I listened to the current and former staff; I talked to many persons with disabilities benefited by PCTC; I visited the Day Care Centers, met parents and care givers, and interacted with disabled children, adults and community leaders. This exposure made a difference on what I knew earlier and what I experienced after the interactions. This was an opportunity not only to know PCTC, but also to comprehend some important issues around disability. Now I feel that I know PCTC and disability issues better than earlier.

Twenty-five years is a significant period in the life of an individual and also an organisation. Sustaining a social organisation in a rural context for such a long period itself is a challenge and an achievement. The twenty-five year journey of PCTC also seems to be a combination of achievements and challenges;

but, PCTC has been instrumental in changing the lives of thousands of persons with disability and their families.

During the interactions, what touched me instantly is the spontaneity with which the staff responded. The striking points are the closeness they have developed with the parents and children in the villages and the meaning they find in this job. The initial association with the client families has developed into a bond between the benefited families and PCTC through the staff. I visited a few homes and met the children and parents. I was moved. While the role of staff and PCTC and their relationship with the family touched me, the velocity of the issue that I witnessed disturbed me.

The disability issue raises a lot of questions in the minds of the parents: Why this? Why this to me? What I will do? Who is there to understand me and support me? How I will manage this? What will happen after me? Perhaps these questions appear in the minds of all. Such instances even challenge the meaning of life and the responsibility of society to these lives. Along with these unanswered questions, instead of staying with the questions, there are people and organisations like PCTC, who respond in their limited ways to support the affected and also redress the intensity of the issue. PCTC has a long list of such committed supporters too.

This certainly comes from a social commitment and an organisational conviction that there is a way forward.

I wish PCTC to find its way forward from here, to achieve their aspiration of being more effective in future to reach more people and touch many families.

**Our sincere thanks to our supporters in our journey towards
collective self reliance**

			
<p align="center">Marie Jose Wouters & family</p>  <p align="center">Quaker Hulpfonds Nederland</p>	<p align="center">Swiss Friends Through Mrs.& Mr.Meier Rovio</p>	<p align="center">Mrs.C.Bowman & Mrs.P.Chatterjee and Friends from UK</p>	<p align="center">All the Volunteers And Mr.Krishnaswamy &</p> 
			
 <p align="center">Dist. Adiminstration, Tiruvannamalai</p>			
<p align="center">Dr.Hugo Grote And friends from Germany</p>			<p align="center">Members of TDFRD Net Work Tiruvannamalai</p>

Community Health Federation

Disabled Day Care Centres

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Adaptive Devices Rural

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People's Craft Training Centre

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