A community-based rehabilitation programme for persons with disabilities
Background and purpose

It is estimated that well over 8 per cent of the population in Sri Lanka are disabled, with over 90 per cent of these people unemployed and completely dependent on their families for support (United Nations Report, 2003). More often than not these families live in extreme poverty with no welfare system and have neither the skills nor resources to support a child with disability.

The disabled in Sri Lanka are often socially marginalised, have limited mobility and many do not even have basic nourishment, clean water and sanitation. The United Nations Commission for Rights of the Child expressed "serious concern" for Sri Lankan children with disabilities in their report dated June 2003.

Since 1987, Navajeevana has become the main service provider for the rehabilitation of people with disabilities in Southern Sri Lanka. This area is estimated to have the highest rate of disability in the country at around 20 per cent (including mental health). Around 80,000 people are suitable candidates for treatment, and we currently assist about 2,500 of them. Navajeevana is recognised as a leading practitioner in South Asia and beyond, as evidenced by the growing international support and sponsorship of our activities.

Navajeevana works in the remote inland and coastal areas of the Southern Province in Sri Lanka (specifically in 5 of the 11 Divisional Secretariat sub-districts of the Hambantota District: Katuwana; Angunukolapella; Beliatta; Tangalla; and Walasmulla, and, one division in the Matara District: Dickwella).

Our primary goals are to:

- integrate our clients into the world of education, work and community life;
- provide an inspiration and model for the rehabilitation of children and adults with disabilities across a wider geographic area; and
- care for physically or mentally disabled people alike.

We also help to resource, train and support similar programmes at both a local and national level, with a view to:

- changing attitudes towards disability;
- educating, informing and assisting the prevention of disability;
- promoting work and welfare for the disabled; and
- relieving the heavy burden of disability that falls upon the families, and communities of the disabled, especially wives, mothers and daughters.

Operations and performance

Navajeevana’s rehabilitation programme is delivered via five core operating units:

1. community-based rehabilitation;
2. therapy & communication;
3. prosthetics & orthotics;
4. community mental health development; and
5. education.
Community-based rehabilitation

Community-based rehabilitation (CBR) is at the heart of Navajeevana’s approach. Prior to being identified and aided by a rehabilitation service provider, many of the disabled are confined to their homes. This is often due to family members’ ignorance of the options available to them and/or because of physical and financial constraints. Mainstream hospitals and medical practitioners are insufficiently and inappropriately resourced to service this gap. In short CBR is about identifying those in need and facilitating and coordinating support from family caregivers, specialist service providers, volunteers and the community in general (in terms of awareness and acceptance).

The CBR unit operates as follows:

- clients are identified either by clients approaching Navajeevana, medical practitioner referrals or by volunteers searching in the field;
- field officers visit clients in their homes regularly to assess and service their basic rehabilitation and vocational & income generation training needs;
- out-reach clinics are run periodically in remote areas by specialist service providers from the other four operating units at Navajeevana; and
- clients are referred to the Navajeevana pre-school where appropriate and ultimately, transitioned into mainstream education and employment where possible.

The ‘can pay should pay’ policy adopted in 2003 was a success and was continued in 2004. Navajeevana is able to maximise the benefit to those most in need by charging those who can afford to pay for services.

In 2004 the CBR unit identified 960 new clients with disabilities, 476 of which were candidates for CBR. Rehabilitation commenced for 420 of these clients, and at the remaining 56 were placed on the waiting list, which had a total of 1004 clients at the end of 2004.
Therapy & communication

The therapy & communication unit consists of physiotherapy, speech therapy and audio services.

Physiotherapy

A large proportion of current clients (over 50 per cent) have a physical disability caused by a neurological disorder (including cerebral palsy), accident injury, stroke, pre- or postnatal neglect and/or birth trauma, congeries or other common causes.

In addition to manual techniques of physiotherapy, the unit applies electrotherapy and prescribes clients prosthetic & orthotic devices, wheelchairs, special seating, walking and other assistive devices where necessary.

The unit contracts out for the customised manufacture of all but the prosthetic and orthotic devices. While the manufacture of wheelchairs has been a challenge, two were delivered for clients’ use in 2004. Nine special chairs and one standing frame were also manufactured and delivered for clients’ use in 2004. Receiving donation of wheel chairs keep manufacture low.

Close links are maintained between staff from the unit and medical practitioners, the Ragama Rehabilitation Hospital, the Chitra Lane Childrens Resource Centre, Child Vision, Social Economical and Environmental Development (SEED) and Senehasa.

The demands on this unit are increasing and expected to surge over the next 12 months as victims of tsunami require physiotherapy.

Speech therapy & audio services

About 20 per cent of current clients have a hearing disorder and/or speech impediment. Hearing disorders are often caused by prenatal exposure to loud noises. Speech impediments are often symptoms of other disorders such as cerebral palsy, autism, Parkinson’s disease and multiple sclerosis (as opposed to cleft lip and palate conditions).

Awareness of audio services is relatively high in the Hambantota district largely because of Navajeewana’s work over the past two decades. Audio unit facilities and trained staff are used to diagnose the extent of clients’ hearing disorder and custom-made ear moulds to fit hearing aids properly.

Although the number of speech-impaired clients continues to grow steadily, awareness of speech therapy in the region (including among local medical practitioners) remains relatively low. The Faculty of Medicine at Ragama University continues to support Navajeewana in its efforts to raise awareness in the region. The aim is to raise the referral rate of speech-impaired clients from medical practitioners to Navajeewana, to bring it in line with the incidence of impairment in the region.
Prosthetics & orthotics

With the assistance of Motivation Sri Lanka and USAID, Navajeevana established a prosthetics & orthotics (P&O) unit in July 2004. The unit diagnoses, manufactures and fits prosthetics & orthotics for its clients. The unit employs four staff to operate a casting process. It has a machine room complete with kiln, grinding and shaping equipment; and a workshop for fashioning items.

In-house production of these items expands Navajeevana’s capacity to provide a holistic service to its clients by enabling a close collaboration between P&O unit and the other operating units.

The devastation of tsunami is expected to cause a surge in the demand for the unit’s services over the next 12 months.

Community mental health development

In partnership with Basic Needs Sri Lanka, Navajeevana services the mentally ill in the Angunakolaapelessa division and the Katuwana division (commencing in 2004). The unit’s activities include raising awareness about mental illness (including emotional disorders), recruiting and training volunteers, conducting field visits and organizing consultation workshops in the community to treat clients.

In 2004 Navajeevana conducted 6 village-based rehabilitation committee meetings purely to promote mental health and 6 medical clinics for persons with mental disorders.

Medical practitioners work with Navajeevana by prescribing medication and advising field officers on the dispensing of medication over time.

The tsunami has caused widespread emotional trauma in the region, which is likely to result in a significant increase in the demand for the unit’s services in 2005.

Education

This unit consists of pre-schools for children with disabilities awareness programme for families, volunteers, local community and partner organization and training of carers.

Pre-school

The pre-schools continue to grow and develop every year with the assistance of sponsors and an expanding community support network (volunteers and staff). The school continues to offer basic reading and writing classes for children at different levels (depending on their particular level of development) behaviour modification training, income generating activity training, library services, a playground, dance classes, and audio testing facilities. The school plans to add sign language to its suite of services in 2005.

The schools provide an essential foundation for learning for children who would otherwise not attend school at all. The lack of understanding about their special needs and capabilities results in severe communication constraints and consequent frustration for
both the child and family members, and the pre-school plays a key role in facilitating social interaction and communication for the children.

The pre-school is an essential part of developing children who have received CBR and services provided by the other four core operating units at Navajeevana. The relative poverty of these clients makes the pre-school one of very few opportunities to receive a basic education and, wherever possible, integration into mainstream education.

Integral to the success of the school has been the involvement of the mothers in the programme. Parents themselves learn how to best care for the special needs of their child and to support teachers’ efforts by continuing the education at home.

In 2004 exposure to the wider community included a Grandparents’ Day. The grandparents were invited to the pre-school and the children presented 6 items of songs and dance, and gifts. The grandparents and parents were also given the opportunity to ask questions, tell stories about their grandchildren, and discuss issues related to the children’s disabilities.

The school term concluded with the annual sports day that was filled with events and activities. The children practised with great enthusiasm weeks before the day under the watchful eyes of teachers and parents. Many discovered hidden talents giving them an elevated feeling and much joy and personal satisfaction. Friends and family attending the event were able to see for themselves the capabilities and development of the children. Such events serve to diminish negative perceptions and discrimination in relation to the disabled in the community.

These and other socializing events proved very successful as a means of building relationships between disabled children and their families, as well as the broader community. This approach has seen many special moments of estranged parents and extended family members touched, moved and inspired by the capabilities they never thought their children possessed.

After a relatively short time at the pre-school most children show marked improvements in their ability to express themselves and conduct basic personal, social and household functions. The similar schools in other regions have been based on this model and are achieving similarly successful results.

The challenge for Navajeevana and its CBR framework is to expand its resources and activities to be able to service the many disable children who are unable to attend the school because they are not yet identified and/or they face insurmountable physical and financial obstacles. Navajeevana’s project partners, such as Meta Australia and Liliane Fonds, Hope for Children are assisting by improving access for these children by subsidising transport and equipment costs.
Community education – awareness, prevention & training

In response to the lack of understanding and awareness of disability in the region, an increasing part of the education and units unit’s resources are devoted to community education awareness and volunteer training.

In 2004 Navajeevana conducted over 50 community awareness programmes reaching hundreds of people, on issues relating to disabilities and mental health. Other programmes included - parent awareness, clinics for the disabled, disability prevention, government health forums, schools awareness, family development and home management, all aimed at engendering a more knowledgeable, tolerant and supportive community attitude towards disability.

Navajeevana’s work would not be possible without our network of volunteers and there is an expanding programme of work in place to develop their skills and knowledge.
Tsunami disaster response

On 27 December Navajeevana redeployed its existing resources and amassed substantial additional support from international and local sources, in an effort to provide immediate relief to victims of tsunami in the Hambantota and Matara district. Navajeevana has since been entrusted to provide leadership and assistance, in partnership with Government, to the people of Kudawella as they commence the physical and emotional rehabilitation of their community.

The Grama Niladhari division of Kudawella consists of North, South, East, West and Central with a collective population of almost 6,000. Nearly half of these people were directly affected by the tsunami including 56 deceased and 5 missing persons. Almost 2,000 people in Kudawella were displaced including over 1,000 children and more than 600 elderly people. Over 330 homes were destroyed and 60 fishing vessels lost or damaged beyond repair. 83 persons with Disabilities have been affected, 380 enterprises lost. The fishing activities have come to a dead half.

In the wake of this disaster of epic proportions, Navajeevana now has the opportunity to resurrect and develop Kudawella in partnership with CBM, the Government and other NGOs and donors. Specifically, Navajeevana has responsibility for the reconstruction of damaged homes on existing plots of land and for the construction of new homes on new plots of land. Together with the people of Kudawella they will facilitate the transformation from chaos and devastation to functionality and dignity in the community of Kudawella.

In Navajeevana’s view an integral part of this development is empowering the people of Kudawella by enabling them to participate from the beginning of the project to ensure their collective traditions, values and dreams are realised, as far as possible, in the end result.

Navajeevana has a long-term vision for the community of Kudawella beyond the urgent task of reconstructing homes.

Alternative Employment opportunities for women and small scale business enterprises for men is seen urgent.

UNESCO CLUB and FRIENDS of Kettwig have generously contributed for the support of fishing boats.

The new village will be an "inclusive village" – the first of its kind with access for disable and their inclusion in every activity will be facilitated.
Management and staff

After almost two decades of operation as a registered charity, Navajeevana registered as a company limited by guarantee in 2004.

With over 70 full time staff, over 100 trained volunteers and a growing community support network, Navajeevana is in the process of reviewing its management structures, with a view to developing more efficient structures, procedures and specialist skills to support the growth of the organisation.

Particular points of note include:

- A directorate of 3 people, established in 2003, continues to be responsible for overseeing internal affairs with accent on management training.
- All management and staff underwent 5S training in 2004 that proved to be very effective.
- The process of external relations, fundraising and related reporting functions will be a particular focus of management in 2005.
- Additional resources will be employed where appropriate.

Looking forward – the year ahead

- Expedite the new building programme of the Navajeevana Rehabilitation and Social Inclusion Centre.
- Plan for required training of therapists and technicians to support future need.
- Support new INGO’s working in the South to develop similar CBR programmes in other areas, so that Navajeevana becomes the trainer and supplier of required services. Networking.
- Develop livelihood support, job placement vocational training and micro credit facilities to make persons with disabilities economically independent.
- Encourage and develop “inclusion” approach in all activities.
- Create awareness of inclusion in pre-school education and make it happen.
- Adapt total communication method following sign language training.
- Continue providing further support to Motivation and Basic Needs to develop the Mobility and Community Mental Health Programmes.
- Provide housing and livelihood support for Tsunami Affected disabled, volunteers, staff and community outside Kudawella as funds permit.
- Make 3 year strategic plan with CBM co-worker (Project Manager).
- Develop better management procedures, monitoring, evaluation of activities.
- Address needs of institutional strengthening and skills development.

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