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FROM DISABLED TO DIFFERENTLY ABLED

Vidyajyothi Professor Lalitha Mendis

You would have realised from what Professor Gita Fernando and I said that the SLMA as the umbrella body of specialists and doctors in this country has a wide range of activities, an important one among them being advocacy and promotion and taking up position on national health related issues. In keeping with this, I have selected disability in Sri Lanka "FROM THE DISABLED TO THE DIFFERENTLY ABLED "as the subject of this address because I sincerely felt it needed serious attention and focus.

In the 30-40 minutes available to me I can only present a snap shot account of its many facets in Sri Lanka and hope that the windows I open may capture the essence of the present situation. Before I proceed, I will break with tradition and make my acknowledgements now rather than at the end of my address.

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Diversity is a fact of human society. The human species is comprised of a wide spectrum of persons hugely varying in appearance, intelligence, physical and mental ability?

The late prime minister of Sweden Olof Palme ,speaking at the Stanford University Law School in the 1970s summed up the divergence between the US and Swedish attitudes to persons with disabilities. He said, "Americans regard the able bodied and disabled as effectively, actively or not, consciously or subconsciously, two separate species, whereas – Swedes regard them as humans in different life stages: all babies are helpless, cared for by their parents; sick people are cared for by those who are well; elderly people are cared for by those younger and healthier, etc. Able bodied people are able to help those who need it without pity, because they know their turn at being not able bodied will come. An important, enlightened and liberal perception – We all pass through various phases, swinging between different shades and grades of disability.

The American concept in the 1970s a different species – disabled humans.

The Swedish concept - members of a huge spectrum of the same species of differently abled persons. In short ladies and gentleman THEY ARE US, WE ARE THEM.

What is the Sri Lankan concept? I invite you make that judgement at the end of this address.

DEFINITION

The 1980 WHO definition of disability in the context of health experience states –"It is a restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for human beings. "This may be considered as the medical model.

By contrast, the social model of disability focuses on human rights, and the functioning of the disabled within the environment, highlighting the role of society in labelling, and maintaining disability in the society through attitudes and physical barriers erected by society.

Both models agree that opportunities should be provided to the disabled to adapt to the environment through the dismantling of barriers and this is referred to as "fostering accessibility".

LAWS ON THE DISABLED.

Sri Lanka signed this convention on the 30th March 2007 but regrettably, so far, the government of Sri Lanka has not ratified it.
Constitution of the Republic of Sri Lanka Has a clause for special provision being made by law, for the advancement of women, children or disabled persons.

The protection of the Rights of persons with Disabilities Act No. 28 was passed in Sri Lanka in 1996.

Through this act a National Council for persons with Disabilities was established.

The Act provides for the protection of disabled persons against discrimination.

If they are subject to such discrimination, an affected person my apply to the Provincial High Court of Sri Lanka and the High Court is given the discretion to grant such relief or make directions . However, non – compliance with the provisions contained in the Act does not give rise to specific penalties and/or criminal or civil liability of any kind.

The Disabled persons accessibility regulations were gazetted in October 2006. gives detailed regulations with diagrams on how public buildings, public places and places where common services are available should be made accessible within 3 years..

However there is nothing to say in the Act that regulations which flow from the Act are given the same status in law as the provisions of the Act. It is usual for an Act to specify that the regulations enacted under its provisions have the force of law and are enforceable in a court of law – but not in this case.

So, there are gaps in the existing regulatory framework

The public Administration Circular No 27/88 of august 1988 Instructs all ministries departments and corporations to allocate 3% of the job opportunities in the public sector to persons with disabilities.- 20 years on, How many institutions have implemented this circular?

Sri Lanka has several more legal enactments pertaining to the disabled, a statement of national policy and more legal enactments are in the pipeline.

L & G, Passing more and more legislation, does not equate to doing more and more for the disabled?

What is important is:-

- To amend current legislation to address existing gaps
- To implemented them for the benefit of the disabled and
- To create wide awareness among the disabled, their care givers and well wishers of what redress is available to them through the law.

What is the size of the disability problem in Sri Lanka

There is a dearth of reliable data of how many disabled persons there are in Sri Lanka. Various estimates including a flawed census have yielded figures ranging from 3% to13%

Study	Estimate
Census of Population and Housing (2001)	1.6%
The CBR network for South Asia (2002)	3%
The Directorate for CBR programme	8%
Micro studies by AAKASA in the Central Province (1999)	6.5-8%
Navajeevana project in Galle, - 2004 including mentally ill	13%
UNICEF/Sri Lanka of all children	4%
Global statistics (Wikipedia)	10%

Global statistics show that of a world population of 6.6 Billion, 600,000 million i.e. 10% are disabled. So by global estimates, it may be predicted that any one time, Sri Lanka has about 2 million disabled persons.

SOME COMMON CAUSES OF DISABILITY

Malnutrition and poverty
According to a UNICEF/Sri Lanka Government report 4% of all children have disabilities related to low income, poor housing and sanitation, iodine deficiency, Vitamin A deficiency and maternal under nutrition.

Road Traffic Accidents
DR Shirani Hapuarachchi estimated in 2005 that there were annually about 2000 deaths and about 6000 sustained short term or long term morbidity and disability.

The 20 year civil war

Besides those who were killed in action, About 2200 officers and 39,800 other categories in the armed forces have been disabled. The number of soldiers who suffer from psychological disabilities is much more.

The number of civilians affected in both conflict zones and non conflict areas is unknown. Many survivors are left with physical disabilities, visual impairment, hearing impairment and psychological trauma.

To these causes of disability we have to add:-
- Disabilities in sight
- Disabilities in hearing
- Developmental disabilities
- Disability following Stroke neurological disorders and spinal injuries
- Disability due to multiple sclerosis
- Disability from old age.

I will touch on a few. – But first …….

How do the disabled perceive their problem? What do they want?

In a publication by Leonard Cheshire International there is a report on focussed group discussions carried out with 222 disabled people from 12 countries, all aged from 17 to 26.

These young disabled persons agreed on five issues that most affect disabled persons.

1. Access to education
2. Lack of employment
3. Discrimination
4. Lack of awareness and negative attitude by non disabled people
5. Poor compliance with existing legislation
6. Lack of access to health provision.

I have spoken of legislation in Sri Lanka, let's look at Education

THE EDUCATION OF CHILDREN WHO ARE DISABLED.

From the early 20th Century, missionaries and charitable groups took the initiative to address the problems of the disabled in Sri Lanka, for e.g. by setting up of the special school for the blind and the deaf in 1912.

It was only in 1964 that the first government school was opened for the physically and mentally handicapped.

Thereafter the practice moved slowly towards Inclusive Education whereby disabled students are admitted and catered to in normal schools. This concept of Inclusive education was adopted by the Ministry of Education in 1968

Special Schools

As at 2006 there were 25 assisted special schools in Sri Lanka that are governed by boards of management. The Education Department grants aid to fund teacher salaries, school text books , uniforms and special teaching aids. There are other special schools run by NGOs..

The schools for the blind and hearing disability at Ratmalana established as far back as 1912 provide models of special education institutions that enable children with sight and hearing disability to ultimately integrate with the society, to hold their own and enjoy accessibility.

The school for the blind has a capacity for 250 all together. The Principal has state of the art training at centres of excellence in India. With funding from sources mainly in Canada, the school is equipped with voice synthesised computers, Large screen TVs, 2 Braille printers which automatically translate text books into Braille and a well equipped music room. Students study here up to O-levels and those who are fit for A-levels are admitted to mainstream schools

Other children are given 2 years of vocational training in 12 fields e.g. weaving, rattan work, music, training in telephone operation etc.

The school encourages various forms of sport. They even play cricket using cricket balls with rattles.

This school serves as a resource centre for foreign countries such as Vietnam and Malaysia but surprisingly not for other schools for the blind in Sri Lanka.

The Ratmalana school has the capacity to supply all schools for the blind with text books in Braille which are in short supply but other schools and the Education Department has not taken up this offer.

The school for children with hearing defects can cater to about 250 children. Those who can are encouraged to sit for O-levels. As in the school for the blind, vocational training is given high priority. Students are given training in woodwork, cement work, masonry, lace making tailoring , patchwork etc.

Let us look at the successes of these two schools.

Of the students who recently passed through the blind school, 80 are employed. A totally blind student sent to St Thomas became the champion rover in the school, a student sent to Bandaragama central became the best student in the class,

Blind children became the champions in the 2002 and 2004 all island Interschool Western Music and Dance competition.

Over 85% of students from the school for those with hearing defects have obtained employment or are gainfully self employed. Some run their own tailoring establishments.-85% An impressive statistic and better than the statistics of arts graduate employment.

I have explained at length about these two schools with a purpose. Their relative success illustrates the importance of:_

Good and expert leadership by the Principal and teachers.
Boards of Management which not only attracts foreign funding but use funding effectively.
Above all they illustrate the importance of vocational training.

Unfortunately, vocational training is not seen as a priority in the training of students in other special schools assisted by the Education department. In all such schools including the two schools at Ratmalana, the Education department pays salaries only of teachers of routine subjects , not of those who provide vocational training.
The two Ratmalana schools raise funds for vocational training from well wishers.

Clearly, the all important goal and basic road way towards integrating these children into society through vocational training has not been understood acknowledged or acted upon.

Inclusive Education
From 1969 students with disabilities have been integrated into regular schools through special classes and more recently through enrolment in regular classes.

As at 2005 there were 877 such schools catering to just over 25,000 students in all provinces. About 1383 Special Education Teachers trained at the Mahargama teacher training institute are employed in these schools.

SPECIAL EDUCATION, IN SRILANKA IN 2005 .

PROVINCE	NUMBER OF SCHOOLS WITH SPECIAL EDUCATION UNIT	TOTAL NUMBER OF STUDENTS	AVERAGE NUMBER PER SCHOOL
WESTERN	115	4043	35
SOUTHERSN	78	1583	20
SABARAGAMUWA	87	1904	21
CENTRAL	235	5866	24
N.WESTERN	225	2916	13
UVA	46	4645	100
N.CENTRAL	79	1491	18
NORTH-EAST	12	3303	225
TOTAL	877	25751	

SOURCE – Ministry of Education

For a programme that began in 1969, almost 40 years back and considering that these 25000 or so children represent children with several types of disabilities, physical, sight, hearing and intellectual, this enrolment is low.

We do not know how well these special education teachers are trained what skills they have and whether they can handle children with developmental disabilities?

It appears that ,the concept of Inclusive Education has been borrowed from the West and transplanted to Sri Lanka without re-modelling it to the local context.

It would be advisable to have a model Inclusive Education school in each province. Foreign funding can be harnessed for the purpose.

ENROLMENT IN UNIVERSITIES IS ALSO LOW.

The UGC treats disabled students as a special category. The current practice is that the Universities informs the UGC of how many they can accommodate and this number is sent to them. In the last five years an average of 48 disabled students have been enrolled university courses. This is a very low enrolment. In some years, no students have been received by some universities.

I remember this being discussed by the University of Colombo Council. It is not enough for the Ministry of Higher Education and the UGC to request Universities to enrol disabled students, funds have to be provided to create a suitable learning and living environment. There are other problems. E.g. one university decided to install a lift to enable disabled students to attend lectures in lecture halls at the upper levels of the building. Other students protested that this expenditure could not be justified as it served only a few students and that the money could be better spent.

I refer you back to what the 4th point that the disabled identified. Lack of awareness and negative attitude by non disabled people.

1) Access to education
2) Lack of employment
3) Discrimination
4) Lack of awareness and negative attitude by non disabled people
5) Poor compliance with existing legislation
6) Lack of access to health provision.

Such problems may be avoided if the UGC provides a special vote for the disabled and there was advocacy on their behalf in the universities

Higher education university admissions – physically and visually disabled

Acad. year	University										Total
	Colombo	Peradeniya	Kelaniya	Ruhuna	SJP	Jaffna	Sabaragamuwa	Rajarata	South eastern	Eastern	
2002/03	3	4	7	2	13	6	2	1	3	3	44
2003/04	5	3	6	4	11	7	-	-	2	3	41
2004/05	7	3	3	2	10	7	-	-	3	3	38
2005/06	28	-	12	-	6	11	-	-	5	7	69
2006/07	17	4	-	5	11	7	-	-	3	4	51

Many Faculties of medicine are currently conducting courses for paramedical staff. The Faculty of Medicine University of Kelaniya is the only one with a Disabilites Studies Unit.

The disabilities studies unit (DSU)- Kelaniya

It began as a training unit for Speech and Language therapy , and 60 speech therapists have been trained so far. 30 of whom have been employed by the Ministry of health and 30 by NGOs.
The DSU conducts many short courses and is soon to begin a Diploma in Disability studies.
Clearly a very important training resource for the country which should be used to its full potential.

THE MINISTRY OF SOCIAL WELFARE
The needs of persons with disabilities are one of the many responsibilities of the Ministry of Social Welfare. And the Department of Social Services is a separate entity within it.
.
The Ministry set up the National Secretariat for persons with disabilities and a National Council. It commenced a Community Based Rehabilitation Programme (CBR) in 1992 .

Let us examine the purpose or objective of a CBR programme.

A CBR programme is required to support each and every child who has a disability related to the rights of the child recognised in the UN Convention on the rights of the child. It should ALSO provide support to parents and other family members to enable them to fulfil their responsibilities.

According to a 2006 report on Social care by the Ministry of Social Services and Social Welfare Rs 12 M had been allocated for the CBR programme.

22 Districts came under this programme

106900 disabled persons had been identified.
750 disabled persons and 400 government buildings had been provided with access facilities .

8162 volunteers had participated in the programme.

Although the CBR programme of this Ministry was begun with enthusiasm and many were trained, NGOs and persons working in the field do not see evidence of the CBR programme as a successful programme. It is mostly confined to providing assistance devices.

Giving a white cane to a blind person or a wheel chair to a person with physical disability is not rehabilitation. Rehabilitation is a process whereby the disabled person is gradually helped to function side by side with other members of the community and in this not only he or she the parents and family too need support.. In a report entitled HOME TRUTHS, by the Save the Children in Sri Lanka which was published in 2005, they said this having described what was expected of the CBR programme - “This study found no evidence of this being implemented in practice. “

In contrast let us consider elements of an NGOs conducting a CBR programmes e.g. the Sarvodaya Suwasetha Community Based Rehabilitation programme which is conducted in 14 Divisional Secretary divisions in the Kalutara district and 10 in the Galle district.

As of September 2007, 571 persons had been enrolled on the programme .

The types of services offered include:-

- Mobility training
- Training in daily activities
- Developmental stimulation
- Communication training
- Providing rehabilitation equipment
- Referral for Education
- Home based education
- Behaviour training
- Vocational training
- Income generation activity

The local branch of the Leonard Cheshire International are planning to set up CBR programmes in the Katana area.

An early detection system to recognize these children is important because there is evidence to show that if these developmental defects are detected very early, and special therapeutic interventions provided, 47% will be able to enter the normal educational system.

So it is the right of children with learning defecte and developmental defects to be detected early and provided with special education.

There are only two special schools for autistic children in Sri Lanka. One set up by the Ceylinco group, and another by the government at Maharagama ,but even here it is not certain if the education system they provide is tailor made for these children.

How may we detect these conditions early ?
One tool that is used to detect developmental disorders is the Denver Developmental Screening Test (DDST), commonly known as the Denver Scale. The scale reflects what percentage of a certain age group is able to perform a certain task. E.g. does the child smile spontaneously – something that 90% of 3month old babies do. Can he speak three words other than Amma and Thatha by the age of 21 months. And so on. Simple observational tests. There are 125 of them.

Health Care workers in Sri Lanka are taught this simple Denver scale about 45 items of the Denver Scale are on the present Child health Developmental record . Currently they are supposed to be assessed by the Public Health Midwife. by questioning the mother and through observation of the child, but in practice this happens erratically .

Currently, No records (weekly/monthly returns) are kept of developmental defects detected by the PHMs or of the referral of such children.

The Family Health Bureau is doing some work on this and they propose to include a more comprehensive screening programme from next year. The Denver score has been standardised for Sri Lanka, and it has been decided to include 122 of the 125 items in the new CHDR. The children are to be assessed by the MOH during their visits for vaccination. The plan is that all children will be developmentally assessed by a medical officer.

At a provincial level, Provincial Ministries and Departments of Social Services are responsible for providing various services which include:-

- Identification of persons with disability,
- directing such children to special schools,
- establishing and maintenance of pre schools for children with early childhood disorders, rehabilitation,
- vocational training,
- provision of self employment grants, and
- the organising of twining programmes with NGOs.

This is very impressive on paper and bears out that at least in theory the state does recognise the special needs of persons with disabilities.

However, what is known among persons working in the area is that:

1. There is an unfortunate lack of coordination of services
2. Financial constraints are a barrier to expediting effective programmes and prompt action
3. Parents with disabled children are often unaware of where they can access help
4. The situation is worst in the rural and estate areas.

Developmental disorders.
Learning disabilities are disorders that affect the ability to understand or use spoken or written language, do mathematical calculations, coordinate movements, or direct attention. Although learning disabilities occur in very young children, the disorders are usually not recognized until the child reaches school age.
In years gone by many of these children were said to be mentally retarded. However diagnosis is now more specific e.g.

The most common learning disability is dyslexia , a deficit in reading, others include dysgraphia - Impaired written language ability, or dysphasia a speech and language disorder. Some children have overlapping learning disabilites. Some of these learning disabilities can be lifelong conditions. Others may have learning disorders that are correctable.

Autism
Autism is a a part of a spectrum of disorders referred to as Autism Spectrum Disorders – ASD. Asperger's syndrome (AS) is related disorder.. It is a brain developmental disorder which is distinguished by characteristics such as impairments in social interaction, impairments in communication, restricted interests and repetitive behavior. Autistic savants are people with severe developmental or mental handicap with extraordinary abilities in a narrow field – abilities not found in most people. It is estimated that about 1 in 166 all children have Autism spectrum disorders.

Autism was recognized only around 1940 from the work of Hans Asperger and Leo Kanner. Michael Fitzgerald, child psychiatrist, Trinity College Dublin has speculated about historical figures who had autistic traints in several publications and books. Here are some historical figures on his speculative list.

Among artists – Vincent Van Gogh and Michael Angelo
Among scientists – Albert Einstein and Sir Isaac Newton
Among dictators – Adolf Hitler.

At present when such disorders are detected these children are referred to a Paediatrician for assessment. The paediatrician is probably running a busy clinic and the child may not get the deserved attention. Where the child should best be referred to is a community Paediatrician , also called developmental paediatricians who works in the field. We do not have such a category of specialist at present.

A surveillance system seems very necessary. For instance, we have a rough idea of the proportion of children who will have developmental defects in any birth cohort.1 in 150. It should therefore be possible for us to predict how many should be detected per MOH area or Division or District in a specificed time period.. If regular feed back forms are introduced and show that such detections have not been made, it would highlights the fact that particular MOH area or Division or District requires scrutiny. It is a surveillance system similar to the one used to estimate pregnant mothers which the Maternal and Child health system is doing very well and effectively at present and similar also to the AFP surveillance system in the Polio control programme which is also being done very efficiently. So, this kind of surveillance is not new to us.

The other point at which such children can be identified are in the pre-schools but pre-school teachers need to be trained. E.g.Sarvodaya has a network of field workers and about 4000 pre-schools island wide. This is a very important resource if these teachers and field workers can be trained. Teachers in normal schools too need training and awareness programmes so that they can catch children with developmental disorders who have been missed along the way.

Once detected and confirmed what can be done about these children?

They require a disease or disability specific special education by a multidisciplinary team ideally comprised of :-

- A Developmental or community Paediatrician
- Psychologist or psychiatrist and
- Speech therapist.
- Occupational therapist
- a sociologist
- Educational psychologists who play a key role in the assessment of the educational needs of children What is the current situation?
- The Ministry of health has recently appointed one Community Paediatrician which is grossly insufficient.
- There is a gross inadequacy in the number available speech therapists. Only the DSU Kelaniya trains speech therapists.
- Educational psychologists are a non existent category in Sri Lanka.
- There is only one centre to assess and deal with children with developmental defects and that is at the LRH.

So, it is apparent that the subject of developmental disorders is one of the most neglected areas of disability in the country.

- There is no structured detection system - The government maternal and child health programme has yet to get its act together with regard to detection of developmental defects through the Denver Scale.
- There are no personnel to deal with them at a district or provincial level.
- There is no firm link on this matter between the Ministries of Education and health.
- There is no awareness or sensitivity to the necessity for providing respite care so that at least for a few hours the care giver usually the mother is relieved of the burden or strain of caring for a child with a difficult developmental disorder..
- There is no programme to train pre-school teachers and teachers towards early detection.

It cannot be overemphasised that early detection and early intervention effective and ensures a better quality of life for the child. The financial cost of not doing so will run into millions for the child, family and society.

In the case of developmental defects, we see a dilemma worsened by modern technology. Premature babies survive. due to advanced medical technology and the period for viability has now been reduced to about 24 weeks. Many sustain developmental defects. While the developed countries have adopted mechanisms to buffer such problems, we in developing countries do not even realise the size of the problem. As far as I know, there is no follow study on premature children which has set out to assess the proportion that show developmental defects.

STROKE, SPINAL INJURIES AND HEAD INJURIES.

Every year many patients are admitted to our hospitals with stroke, spinal injuries and head injuries. Patients have hemiplegia, paraplegia or tetraplegia. The function of the bowel and bladder may be affected. We give these patients good institutional care at great cost and then they are returned many of them still disabled or handicapped to their homes or to local hospitals without adequate rehabilitation. When patients are returned to their homes, family members are not educated on how to cope with paralysed patients. Lives are saved at great cost, but what of the quality of the rest of their lives?

The National Stroke association of Sri Lanka has made a start by organizing special training programmes for care givers of disabled stroke patients at the Stroke Unit of Ward 16, of the National Hospital in Colombo.

NIPS – the National Institute for the care of paraplegics Sri Lanka is attempting to address the problems of patients with spinal injuries.

The Spinal injuries Association (SIA) is an organisation of paraplegics whose objective is to look after the interests of paraplegics.

A study of 64 spinal injury patients by Dr Raja Thalgahagoda who were admitted to the Digana rehabilitation hospital provides a profile of patients with spinal injuries.

62% were aged 20-50, 83% were males – younger than stroke patients and most of them the bread winners of the family.

On discharge from hospital only 22% had mild disability for which no appliance was needed.

58% had an income less than Rs 3000/- per month, so loss of income and poverty was an added burden, and very often the wife was forced to go to work leaving no one to care for the patient.

50% lived in homes with poor road access, making it difficult for wheel chair users to settle into their own homes.

86% had toilets with squatting plates which cannot be used by patients with severe and moderate disability.

What are the problems faced by this group of patients?

Rescue at the site of accident – There is a properly organised ambulance service with trained para medical staff only in Colombo . Very often patients are not handled in the proper manner at the site of an accident.. E.g.

A patient who fell from a tree in the Kandy District said that when people lifted him up, all four limbs went numb – he ended up as a tetraplegic. Was he handled properly soon after the fall?

In contrast :-

About 16 years ago a 16 year old schoolboy while playing for a rugby match, was injured when the scrum 'collapsed.. He said "I cant feel" as he fell down.. He was lucky as a doctor was on duty who realised that he had probably had a severe neck injury as all 4 limbs were weak, and so applied a cervical collar and transported him on a stretcher to the TH Kandy . A tracheostomy was performed and the patient ventilated. The Orthopaedic surgeon and the Neuro surgeon reduced and fixed the spine as he had a fracture dislocation at C4/C5 level. He first began to move a big toe in about 8 weeks time. He gradually improved and had intensive physiotherapy and occupational and was able to walk on a walker with much spastic weakness. The school and his friends collected adequate funds to send him for further rehabilitation to the Stoke Mandevile Spinal Centre in UK. He returned in 5 months time walking with a stick with some degree of spasticity. His bladder and bowel functions had returned to normal and he was weaned off the catheter.

He went back to school did O-levels and A-levels, followed an IT course, got a job in the private sector, married a girl who accepted his abilities rather than his disabilities and now drives an automatic car with a special licence.

The contrast in these two stories. One person ends up a tetraplegic, the pother is driving a car. The contrast highlights the difference it makes to the quality of life when immediate and correct attention is available at the site of the accident, and soon after and of the importance of specialised professional care and rehabilitation thereafter.

Assitance devices and disposables -This group of patients need assistance devices such as wheel chairs, toilet chairs, water mattresses, and disposables such as catheters, and urine bags. Volunteer organisations donate these in some cases but this does not happen in an organised fashion. E.g. a register could be maintained of disabled persons discharged from hospitals perhaps at the Divisional secretariat so that their follow up care can be coordinated between the Medical Officer of Health, NGOs and Social service officers or by

a properly functioning community based rehabilitation service.

As the Kandy study showed, at times their houses are inaccessible and conditions inside the house unsuitable with toilets with squatting plates, and unavailability of water on tap. Especially in such patients it seems essential to rehabilitate them in specialised Rehabilitation hospitals.

Rehabilitation in special centres:- There are only three rehabilitation hospitals in Sri Lanka.
The Ragama Rehabilitation Hospital,Ranavirusevana for the Forces and
The Digana Rehabilitation Hospital.

Sri Lanka does not have a single Spinal Injuries unit.
The Sri Lanka Association of Rheummatology and Rehabilitation has recommended to the Ministry of Health that Rehabilitation Hospitals be set up in every province with consultant rheumatologists and adequate numbers of trained staff.

Health Care personnel
Besides Rheumatologists these patients need the care of :-
Physiotherapists
Speech therapists and
Occupational therapists

As seen in the slide, the present numbers and available cadres in these categories are grossly insufficient. Thereare 1.48 physiotherapists per 100,000 population, 0.3 Occupational therapists per 100,000 population and 0.1 speech therapists per 100,000 population considering both line ministry hospitals and those run by provincial health ministries. The number in training too is also very low – 150 physiotherapists and 50 occupational therapists. Ministry of Health has no training programme for speech therapists. Speech therapists are trained only at the DSU Kelaniya.
The Ministry of Health has one Director for Youth, Elderly and the Disabled.
The extent and range of problems to be handles by this one person is far too wide.
There are no coordinating officers at the periphery dedicated for disability for this Director to establish a coordinated programme with e.g. this coordination may be achieved with one community health nurse per specified population number.

NGOs, INGOs AND ASSOCIATIONS
There are many NGOs and Associations dedicated to work with the disabled. There are pockets of good practice and caring individuals and organisations that have made a difference to a few of the disabled. What is now required is a well coordinated network and a sustainable system.

TWO STORIES

Story one.
A mongol child was born to a upper middle class woman. Her mother-in-law insisted that the child should be confined to the room when anyone visited the home.
Story two
A mother took her autistic child to the Majestic City play area. After sometime another mother objected and said “your child is not normal” . The child’s mother said “she has every right to play here, just as much as your child” and explained why to the objecting mother who finally understood and was in tears at the end of the episode.

STIGMA
PREJUDICE
ATTITUDES
There is much to be done to erase stigma and prejudice against the disabled in our country. Here the media and producers of teledramas and films can play a enormous role. I have yet to see a Sinhala teledrams or film that portrayed how a disabled person overcame disability and that despite disability one can be successful and well integrated into society.

There is much to be done to change attitudes. A Rights based approach should be nurtured rather than an attitude of charity towards the disabled.

Summary and Recommendations

The provision of adequate services and facilities to integrate the disabled as functional members of the society is complex. From what I have said so far you would have realized that :-

As much as the disabled, the problem lies with the system

I will not presume to give a grand solution but to make a few broad recommendations for consideration from which can flow more detailed action plans.

1. First, there should be a Rights based approach and attitude to disability
2 Coordination , periodic review and due process

It is quite apparent that there is at present poor coordination between the Government Departments involved such as the Ministries of Health, Education, Higher Education, Social Services and other stake holders who are contributing significantly such as NGOs, INGOs, the WHO and UNICEF. So a well coordinated system is needed.

There also does not appear to be periodic critical review of measures that have been implemented. External reviews have been done by organizations such as UNICEF and Save the Children of Sri Lanka, but there is doubt that due consideration has been given to the data collected by them and to their recommendations. Due process is lacking and is recommended :-

- Drawing up of Objectives and Expected outcomes of the programme
- Time based , Target oriented Action plan drafted in the form of factors requiring
- These to include Plans for immediate action, medium term action and long term action.
- Implementation of plan
- Constant review of implementation – preferable external review.
- Detailed reports of review
- Plan for remedial measures to address deficient areas detected
- Implementation of remedial measures
- Frequent cycles of review and remedial action
- Clear documentation
- Establishment of a Data bases.

Numerous projects in Sri Lanka fail because they are managed badly and this due process is detection system for developmental disorders.

We have traversed difficult terrain and passed many milestones.

Considering their general neglect, the and low priority they receive in the fields of education and health, and the stigma and prejudices they suffer, I am sure that many of you will agree that what ever lip service we pay to this term differently abeled, they are a Olof Palm perceived the Americans in 1870, “The disabled of Sri Lanka”.
What should our goal be? To address the issues raised by those young disabled and to work towards their full integration into Sri Lankan society

To get to this goal, there are many immediate, short term, mid term and long term measures to take, - many mile stones to pass.

And IF we do this, THEN, we can truly say that we have transformed, metamorphosed, the disabled to the differently abled.