

Miss Annaluxmi Sinnathamby Memorial Lecture delivered at "Vaazhvahan", Sabapathy Road, Maruthanarmadam, Uduvil on September 11, 2012

DISABILITY and its CHALLENGES

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Mr A Raveendran, Chairperson, Chief Guest and other guests

It is a great pleasure for me today to deliver this 6th memorial Lecture in memory of Late Mother Annaluxmi Sinnathamby founder of Vaazhvakam. I have had the privilege of associating with her for almost four decades. She was a dedicated teacher totally dedicated to the welfare of disabled children

When the education department introduced the system of "integrated education" of the disabled in 1972, she opted for training at Maharagama Teachers training school. She returned to Jaffna after the training and dedicated herself entirely to monitoring all children in the district following the system of integrated education. She was later involved in "Inclusive education" of physically challenged children, in Jaffna

In 1988 she collected 13 blind children and commenced "Vaazhvakam" at Tellippalai, as a home for the visually challenged. Today there are 37 children at Vaazhvakam she established 22 years ago

During the bombing and shelling I have seen her taking these blind children from place to place looking for a safe location to protect these children. I greatly appreciate her dedication to the visually handicapped

One of the greatest achievements of a great person is to find a successor to carry out the good work that a person starts.

Late Mother Annaluxmi Sinnathamby has found that person in Mr A Raveendran, the present President of Vaazhvakam as her successor. I would reckon this as her greatest achievement.

My lecture today deals with the challenges faced by the Disabled – especially in Jaffna.

Introduction

The issue of disability exists in every society. Persons with disability are marginalized from Society, and are crippled mentally, socially as well as economically. In Sri Lanka the civil war which went on for over three decades has left an adverse impact on the disabled and added more people to the group of disabled, making it an important factor in Reconstruction and Rehabilitation of the country

According to the World Report on Disability published by the WHO in 2011, about 15% of the world's population lives with some form of disability. Of these disabled 2-4% experience significant difficulties in functioning. The global disability prevalence is higher than previous WHO estimates, published in 1970s which was estimated to be around 10%.

This global estimate for disability is on the rise due to population ageing and the rapid spread of chronic diseases, accidents and wars, as well as improvements in the methodologies used in measuring disability

Persons with Disabilities are diverse and heterogeneous.

Stereo typed views of disability emphasize on the wheelchair users, and a few classic groups like the blind and deaf.

However disability encompasses a child born with a congenital defect to a person who has lost a limb in a landmine or a woman who is unable walk due to severe arthritis or a mentally ill person

The word disability is misleading. While disability correlates with disadvantage, all disabled are not equally disadvantaged. Wealth and status help overcome activity limitations and participation restrictions.

All persons including disabled have some ability. There is also a tendency to call the disabled as "Differently able" in order to emphasize the inherent capacity they possess. In rehabilitation activities the words such as "Differently able" "Physically challenged" are mostly used.

The United Nations convention on the Rights of persons with Disabilities, which came into force in May 2008 and the International treaty which followed, reinforced our understanding of disability as a human rights and development priority.

Globally, people with disabilities have a poorer health status, lower education levels, less income with higher rates of poverty than people without disabilities. This is mainly because of the barriers faced by the disabled in accessing education, health services,

employment and transport. For several decades we, including parents of the disabled have taken for granted that disabled have to be deprived of access to all these.

Persons with disability become marginalized from society and are crippled physically, mentally, socially and economically.

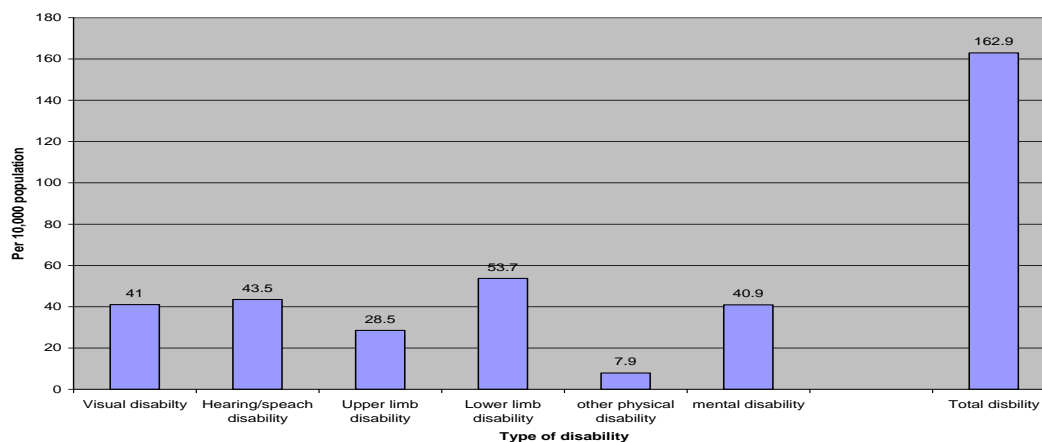
Prevalence of Disability in Sri Lanka

The data on disability in Sri Lanka is scarce. The Census of population and Housing 2001 has some data on disability. This data is also incomplete as this census was carried out only in 18 districts. The Northern district was excluded from the Census although the prevalence of disability is high in the Northern districts, which was affected by the three decades of civil war.

According to the 2001 census Sri Lanka had a population of 18,797,257. Out of this 274,711 (1.5 %) were disabled.

The Northern Province was the most affected Province during the 30 years old war. The war added a large number of disabled into the disabled community. But this number has not been included in the count. We hope that this data will be included in the publication of the 2011 census

Fig 1: Disabled persons by Type of disability



The prevalence of the different types of disability (according to the 2001 census in Sri Lanka) is given in Fig 1

According to this, 162.9 persons per 10,000 population are disabled. 41 per 10,000 were visually handicapped, 43.5 per 10,000 had hearing and speech defects, 28.5 per 10,000 had disability of their hands, 53.7 per 10,000 had disability of lower limbs, 7.9 per 10,000 had other physical disabilities. 40.9 per 10,000 were supposed to be with mental

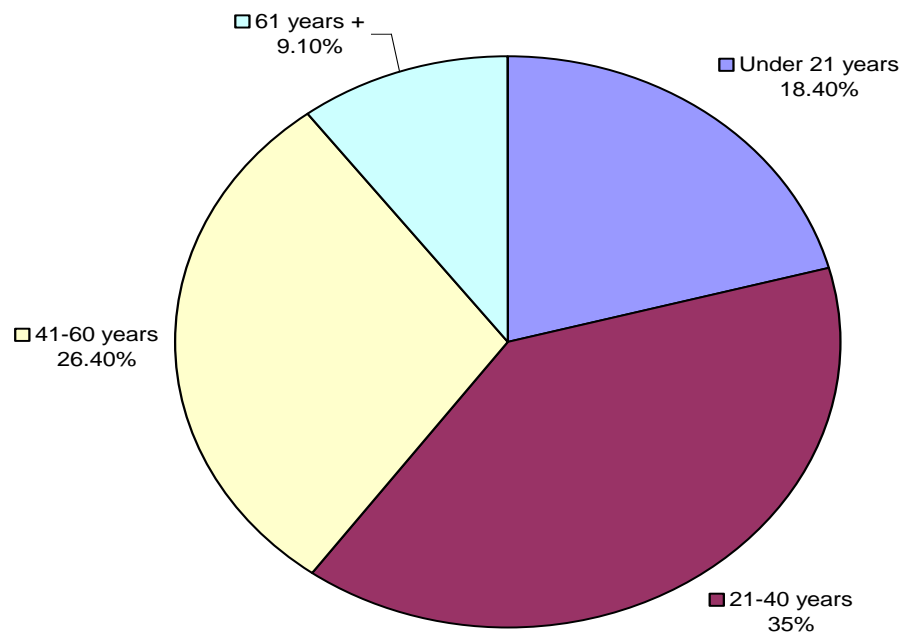
disability. All these probably come within the 2-4% of severely disabled persons mentioned by the WHO study.

In our society there will be more than 3-4 times the numbers mentioned in the Census figures.

As the 1981 census did not cover the North of Sri Lanka the data on disabled in the Jaffna district are in bits and pieces. Several organizations have data confined to specific areas where they work in. Composite data is lacking.

The Jaffna Jaipur Centre for Disability Rehabilitation (JJCDR) established in 1987 (initially named Jaipur Foot Program) has on record 5327 persons fitted with artificial limbs during the period, July 1987 to December 2011. 77.9% of those fitted with artificial limbs were males. 95.5% of those who had amputations had their lower limbs affected. Among those who were fitted with artificial limbs, a large proportion (35%) was 21-40 years old. The details are given in the figure 2.

Fig. 2: Limbs fitted by age Groups - July 1987-December 2011 in Jaffna district



Over half (53.4%) of those fitted with limbs at Jaipur Centre for Disability rehabilitation are under 41 years of age.

The association for Rehabilitation of the Disabled (AROD) based in Jaffna since 1990, has been collecting data of the physically disabled in the Jaffna District. The data is not complete; but there are approximately 4889 physically disabled registered as at April 2011. 58% of them are males. These are mostly disabled who contact AROD for services. There is likely to be a large number who do not attempt to access the services available

The distribution of the disabled by age groups is given in Table 1

A third of the disabled (32.6%) are under 30 years of age. Although only 4.3 % are under 10 years old, there are a large number of disabled children who remain unidentified. Most of them will be having mild to moderate disability, especially visual or hearing defects and delayed milestones.

No	Age Group	Percent
1	Under 10 years	4.3
2	10 – 19 years	10.9
3	20 - 29 years	17.4
4	30 -39 years	17.8
5	40-49 years	14.7
6	50 – 59 years	13.8
7	60 years and above	21.0
	Total	99.9

Source: Association for Rehabilitation of the Disabled (AROD), Jaffna

However, we have to accept that the number and category of disabled recorded in Sri Lanka – especially in the war affected areas is very poor. During the 30 years of civil war several children and adults were disabled and there is no proper count

Children are very much affected due to disability and services available and accessible to them is poor. In Sri Lankan law the able child comes under the Department of Probation and child care and the disabled child comes under the Department of social services.

The Sri Lankan Government has signed and enshrined into its constitution the Universal Rights of the child. These rights are for able and disabled children.

The social services department has guidelines for disabled children as well as the services the social services should provide

The social services guidelines include

- Early identification of the disabled child and his or her rehabilitation
- To protect the disabled child and provide him or her with all the rights
- The disabled child should be integrated into his or her family
- Every disabled child should attend school wherever possible
- Disabled child once an adult must have an independent life
- A disabled child or adult must have social skills training
- The disabled child should have an income

Services provided by the social services department includes

- Mobility aids
- Vocational training
- Finding jobs
- Income generation / self help / self-employment
- Development of preschools for hearing impaired children
- Help with housing for accessibility
- Establishment of Rehabilitation Centers
- Supply of hearing aids
- Supply of spectacles

All the above is mostly on paper. There is little evidence that these are implemented fully and the disabled families are aware of these facilities.

An able student in a residential institution gets a small allowance. A disabled child gets much less. Even among the physically disabled children, a mentally disadvantaged child is more discriminated

Discrimination of the disabled child starts from within the family. The parents refuse to admit the existence of disability from the start. This is related to the belief that the disabled child was born to them because of their bad “Karma”. Hence the parents through shame keep these children hidden away in their homes to prevent others seeing them. This prevents early detection and taking of rehabilitative measures

Some parents keep their disabled children concealed as this will affect the prospects of their other children – especially in relation to marriage. The other “out of sight is out of mind” technique used by Sri Lankans as well as other countries is to place the children in large residential institutions.

When a mother gives birth to a disabled child, she is subjected to emotional shock and strain. She is also subjected to embarrassment, shame and guilt and results in a burden on the family and the child. These have to be attended to by proper psychological counseling. The Public Health Midwives and Social Service Officers have to take a keen interest

Disability and Human rights

Disability is a human Rights issue because people with disabilities experience inequality when they are denied equal access to health care, education, employment, or political participation because of their disability. They are also subjected to violation of dignity when they are subjected to violence, ridicule, abuse, prejudice and disrespect because

of their disability. Some disabled are denied autonomy when they are subjected to forced sterilization, or confined to institutions against their wishes and regarded legally incompetent because of their disability

There are several International documents adopted by several countries which highlight the human rights of the disabled. Some of them are

- World Programme of action concerning Disabled people (1982)
- The convention on the Rights of the child (1989)
- Standard rules on the equalization of opportunities for people with disabilities (1993)
- United Nations *Convention on the Rights of persons with Disabilities* (CRPD). This is the most recent and which gives extensive recognition of the human rights of persons with disabilities. Its purpose is to “promote, protect, and ensure the full and equal enjoyment of human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity”.

Every body (including School children University undergraduates) must be educated on the rights of the disabled

What are the barriers?

There are several barriers to the improvement of the condition of the disabled

1. Inadequate policies and standards and non- enforcement of even the established standards
 - a. Lack of clear policy on inclusive education
 - b. Lack of access to facilities in public places and even in their homes
 - c. Low priority to Rehabilitation
2. Negative attitudes such as
 - a. Beliefs and prejudices
 - b. Parents and Teachers do not see the value of learning for disabled
 - c. Employers discriminate in selection of disabled
 - d. Parents have low expectations of the ability
3. Lack or inadequacy of Services for health care, rehabilitation , support & assistance
4. Inadequate funding
5. Lack or inadequacy of accessibility especially to public places in order to access services. Transport system, and information are also inadequate
6. Lack of consultation with disabled for decision making in matters directly affecting their lives.

How do these barriers affect their lives?

- They have poor health outcomes
- They have lower educational achievements Very few have had tertiary education, even though their intellectual capacity is good
- They are less economically active
- Experience higher rates of poverty
- Cannot live independently or participate fully in community activities

All the above are interconnected. They are linked to poor education, lack of access to employment opportunities and other related factors. They are also caused by barriers to education, employment and mobility

What can be done?

Disability is part of human beings. Almost everyone will be temporarily or permanently disabled at sometime in our life. Those who survive to old age will experience increasing difficulty in functioning.

Every effort must be made to

1. Enable access to all mainstream policies systems & services
2. Invest in specific programs & services for people with disabilities
3. Adopt a National disability strategy and plan of action
4. Involve people with disabilities in formulating, implementing policies laws and services. They should be consulted and actively involved
5. Improve Human resource capacity
6. Provide adequate funding and improve affordability
7. Increase public awareness and understanding of disability
8. Improve disability data collection
9. Strengthen and support research on disability

How can we translate recommendations into action?

The responsibility to put into effect all that has been said lies with all sectors of the society

1. The *Government* should
 - a. revise existing legislation and policies and make them consistent with the recommendations of the Convention on the Rights of Persons with

Disability and ensure that there is compliance and enforcement legislation

- b. Improve national and regional Disability statistics. In this, functional disability rather than that of impairment statistics should be collected
 - c. Develop a National disability policy
 - d. Allocate sufficient resources for disability rehabilitation
 - e. Government should ensure that their staff working with disabled (PHIs, PHM, PHNs of the Health Ministry and Social Service officers in the Department of Social services and Department of Probation and child care provide services and referral to appropriate institutions
2. *United Nations Agencies and Development agencies* should
 - a. Include disability in their programs
 - b. Provide technical assistance to Governments regards disability
 3. *Disabled persons Organizations* should
 - a. Create awareness among the disabled about their rights, services available
 - b. Support disabled children's education
 - c. Contribute to monitoring & evaluation of services
 - d. Conduct audits of environment to identify the physical and information barriers which exclude persons with disabilities from accessing the services
 4. *Service providers* should
 - a. Carry out frequent audits to identify the barriers to the disabled in their institutions and take corrective measures
 - b. Where necessary carry out individual service plans in consultation with the disabled and disabled organizations
 - c. Ensure that people with disability are informed of their rights and the mechanism of complaints
 5. *Academic Institutions* should
 - a. Include education on Rights of the disabled and UNCCRPD
 - b. Remove barriers to the recruitment and participation of students and staff with disabilities
 - c. Ensure professional training courses have adequate information on disability
 - d. Conduct research on lives of persons with disabilities, o disabling barriers in consultation with disabled persons organization
 6. *The private sector* should
 - a. Facilitate employment of persons with disability for appropriate jobs.
 7. *Communities* should
 - a. Challenge and improve their own beliefs and attitudes towards the disabled
 - b. Protect rights of persona with disabilities
 - c. Promote inclusion and participation of disabled in community and social events

- d. Challenge violence against and bullying of disabled
- 8. People with disabilities and their families should
 - a. Support other people with disabilities through peer support, information sharing and advice
 - b. Promote rights of the disabled within the community
 - c. Become involved in awareness and social marketing programs
 - d. Participate in forums to determine priorities

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