

CEYLON ASSOCIATION FOR THE MENTALLY RETARDED

COUNTRY REPORT – SRI LANKA

By Mr.E.M.G.Tilleketrtna –President Ceylon Association For The Mentally Retarded

The island of Sri Lanka is a Socialist Democratic Republic situated in the southern tip of the Indian subcontinent and in close proximity to it. Previously known as Ceylon, was a British colony till it was granted independence in 1948. The country's basic exports are agricultural,. Namely, tea, rubber and coconut products. Gems and spices are also exported and in the last fifty years the industrial base of the country has been expanding,,mainly for export and these products and commodities are the mainstay of the foreign exchange earned by the country.

The land area is 65 610 sq. km and its climate varies from the costal area to the center and nevertheless is still very much tropical with rainfall out of two monsoons. For administrative

convenience the island was divided into nine provinces with 25 districts. As per Central Bank Annual Report – 2005, the mid year population was 19,668,000. Gender – wize the population in balanced are the population deusity is 314 persons per sq.km .The age-wise distribution of the population being

0 – 14 year	5,240,000
12 – 64 year	13,168,000
64 year & over	12,60,000

The statistics that the per – capita is US \$ 1300 and that the rate of employment is 92.3%of the labour force of 8.14 million persons – comprising of those over ten years of age and able and willing to work- may be compelling reasons for foreign donor agencies to phase out assistance to projects, for the reduction of poverty , in Sri Lanka.

How ever, the statistics that ; -

- 1) 6.6% of the population lives on less than US\$ one a day;
- 2) 45.4% of the population lives on less than US\$ two a day;
- 3) the rate of inflation as at January 2007 is 20.5%; and
- 4) the mythical figure of 92.3% as the rate of employment produced by the department of census and statistics by deeming a person as employed if he/ she had worked for paid, profit or family gain for one our or more during the week before the survey ,

should jolt donor agencies from their complacency or feel good factor – induced by the per capita income and the rate of employment – and rethink their policy decision to phase out financial assistance to low cost projects – such as the CAMR's training programme – which have a wider reach for the benefit of the target groups.

(1)

The mobilization of indigenous resources ; to carry on such projects is , at present, a difficult task due to socio – economic factors indicated above

The mentally retarded in Sri Lanka is a group that has been neglected up to the mid 1950s. Hitherto those were treated in a large number of cases as lunatics or idiots. With

the setting up of the Madiwela Home by a psychiatrist the neglect has gradually over the past 50 years transformed itself into a more humane approach in the upliftment of these disabled persons. In 1969 the Ceylon Association for the mentally Retarded was founded and incorporated by an Act of parliament in 1971 . The Association did much in stimulating in the treatment and care of the mentally retarded. In the 1990 's the State was influenced by these activities to recognize mental retardation as a disability that required a different approach to present and uplift mental retardation to a condition spelt out by the UN Declaration on the rights of the Mentally Retarded persons by resolution 2856 (xxiv)

. In 1995 the state introduced legislation for the protection of disabled persons. The Act, however, had not enough teeth to enforce the protection envisaged. It also did not realize that the mentally retarded with impaired mental faculties could not be equated to persons with other disabilities. The National Council for the Disabled was formed as a result of this Act but the beneficiaries were largely other disabled persons. The State then realized that an amendment of the Act was necessary and set up a committee to formulate a policy in the case of all disabilities which was accepted by the government . The problem rises out of the fact that the mentally retarded generally require completely different treatment. Reference has been made in this application elsewhere regarding the setting up of community based programmes, residential homes and day centers. An estimate of the numbers of mentally retarded as revealed in the census of 2002 does not exceed 75,000.

This figure has little bearing on the factual situation and the world wide averages of 2-3 % of the population which would raise the figure to almost 350.000.

The target group is, on the basis of the figures given above , beyond the reach of NGO's without State intervention. The educational system of inclusive integration and the setting up of special schools barely touches the periphery of the problem. The Association therefore accepted in principles that “half a loaf is better than no bread” The attitude of society is slowly but surely

changing on the basis that these persons are human beings whose rights are in no way inferior to that enjoyed by their more fortunate brethren.

LITERACY RATE AND EDUCATION SYSTEM

Due to the keenness displayed by Sri Lankan parents, of all classes , to educate their children to ensure for them opportunities for upward social mobility, essential to breakout of the poverty trap, and coupled with the policy of all governments ,since independence, to provide free education from the primary up to and including University Education (graduate and post graduate courses in various disciplines such as Medicine, Engineering physical and bio-sciences, commerce and human science etc)and compulsory free education to all children of school going age ,upto the age of 14 years, the literacy rate ,for males is 90.5% and for females is 82.4% (2)

The educational system as could be discerned from schedule B(Statistics speak louder than words) reveals the emphasis placed on general and university education overlooking the importance of technical and vocational training . This is partly responsible for the shortage of skilled man power and for the high unemployment among the educated youths. To rectify this anomaly educational reforms have been introduced since 1998, to improve the quality and focus of education at the primary, secondary and tertiary levels to minimize the mismatch between educational attainment and labour market requirements.

EMPLOYMENT RATE &INCIDENCE OF POVERTY

The quarterly labour force survey,conducted by the department of Census and Statistics, reveals that the rate of employment ; out of total work force of 6.7million,during the 3rd quarter of the year 2001 , was 92.2% However, as the labour force is defined as persons aged 10 years and above who are able and willing to work, in a given,reference period , and that a currently employed person being defined as one who would for pay, profit or Employment ,revealed by the survey , should not lead one to conclude that the level of poverty is minimal as of the 13,926,000 households, in the country, about 50%are surviving on an income of less than 2 U.S. dollars per day Hence, to uplift the living conditions of those households a poor relief scheme, at a total cost of 4.6% of the current government expenditure, is in force.

SITUATION OF THE PEOPLE WITH INTELLECTUAL DISABILITIES

Up to around the middle of the 20th century the awareness in Sri Lanka, about this category of disabled persons ; who are at the bottom of the heap of those who are differently abled , was minimal . In fact , they were deemed to be mentally ill or referred to as idiots and many of them were languishing in the country's mental asylums or confined to a room in the rear portion of the house and, very often, chained or the doors and windows kept locked as, on reaching the age of puberty, the males displayed a tendency to roam about the house or garden without clothes, even masturbating in the presence of their parents and siblings.

That this category of persons were not mentally ill and ,hence, should be segregated from those who are mentally ill and treated with loving care was recognized, in Sri Lanka (then Ceylon) , by Dr.L.A.Senanayake (psychiatrist) during his tenure of service as the superintendent of the mental hospital Angoda. After his retirement , from government service, along with daughter Connie Welikala formed the Ceylon Association for the Mentally Retarded , in 1969, which was subsequently incorporated by an Act of Parliament in 1970 (Act No.10 of 1970) Incidentally, on the 20th of December 1971, the United Nations General Assembly proclaimed the Declaration on the Rights of the Mentally Retarded persons by resolution 2856 (xxvi). The rights spelled out in the U.N. Declaration may have influenced the landmark judgment handed down by the U.S. Supreme Court, in 2002 , viz, that the execution of mentally retarded people was unconstitutional although, M.R. people, frequently ,know the difference between right

(3)

and wrong they were less able to learn from mistakes, engage in logical reasoning or control their impulses, Further, it added that mentally retarded defendants faced unusual

risks of being wrongfully executed because they might unwittingly confess to crimes they did not commit “ This judgement clearly indicates the scope of the intellectual incapacity of M.R.persons and ,hence , the responsibility of parents, guardians, carers, instructors and civil society to be he trustees of the rights of M.R.persons throughout their lives (from the cradle to the grave)

In response to international undertakings and relentless lobbying by organizations for and by the disabled and the CAMR representing M.R.persons ; A Disabled Persons Act was passed by Parliament in 1996.

In terms of this Act the following infrastructure was put in place sans an action oriented Strategy.

- (a) A National Council for persons with disabilities to promote and protect the rights of the disabled persons;
- (b) A National Data Bank and a Resource Centre;
- (c) An Act of Parliament to protect their rights;
- (d) The National Institute of Education to have special facilities for teacher training and curriculum development to provide education to children with disabilities;
- (e) To provide vocational training for the disabled in 26 trades;
- (f) A policy to allocate 3% of the public sector employment to people with disabilities;
- (g) To implement community based re-habilitation programmes, to identify each and every person with disability, in the country, and to provid rehabilitation services for those need.

However, due to the absence of an action oriented strategy,the budgetary constraints and apathy on the part of the bureaucrats and their lack of knoeledge about the nature of mental retardation, the limited facilities provided to other disabled persons were extended to MR persons too Some of these facilities were inadequate and inappropriate Viz...

- (a) Induction of MR children between the ages of 5- 14 years to normal schools which proved to be a failure as MR children , being very slow learners laking concentration, logical reasoning and less able to learn from past mistakes, were unable to cope with the curriculum for normal children and the inability of the teachers to devote more time to these children as the pupil / teachers ratio in government schools being 22:1
- (b) An attempt made for the first time , in June 2002 , since the establishment of the Department of Census Statistics in 1871,with the help of enumerators (whose knowledge about the Mentally Retardation was limited)to identify MR persons. The census revealed that there are approximately 275,000 Mrpersons out of a population of 16,864,544 which is 1.6%of the population surveyed.

(4)

- (c) Action taken by the Social Services Ministry, through the Social Services Department to set up special pre- schools for Mrpersons at least one in each town of a district

To progressive expand this scheme 107 per-school teachers have been trained since 1998, at the Pelawatte Training Center and ts also setting up another training center named “national institute of Education “ at Navinna.

d)A subsidy of Rs.400 per month per MR student ; from a low income family or an orphan who is resident of a special school of a special school (per – vocational) run by NGO’s and registered with the Social Services Department , is granted by the Social Services Department and the Samurdhi Authority.

Rs. 100 per month by the Social Servoces Department

Rs.300 per month by the Samurthi Authority

Presently the number of such centers registered registered with the Social Services Department is 47 ; 31 of which are affiliates of the CAMR . The student population in each centre ranges from 25 – 90.

(e)The Ministry of Sports have set up a special unit to conduct sports events for all categories of the disabled

In 2002 ,the Ministry of Social Welfare , on representations made by various organizations for the disabled , directed the National Council, set up under Act 28 of 1996, to formulate a National Policy to deal with all disabilities grom the cradle to the grave

The sub committee which was set up for this purpose; which included the president of the CAMR had, completed this task

This new policy , we are reliably informed, incorporates the following features for the care, education and future welfare of the MR persons;

- 1.Emphasis to be placed in providing occupational therapy in special day centers and residential homes to be set up by the government /private sector organizations;
- 2.The setting up of homes for destitute children and adults to be cared for in their twilight years;
3. The setting up of communes where people with varying disabilities can help one another;
- 4.Compulsory registration of units working for or caring for the mentally retarded for closer supervision;
- 5.To provide financial assistance for the retardee and his/her guardian in appropriate cases.

(5)

The formulation of the new policy is timely and a step in the right direction but, sans an action oriented strategy, may go the way of policies formulated hitherto into the dustbin of history due to lack of political will, bureaucratic apathy and corruption. Hence, the necessity to setup an Independent Social Welfare Regulatory Commission to monitor of unregistered Homes, for the mentally retarded, setup by unscrupulous social workers and droves of foreign of and local pedophiles who could levy unconscionable fees, convert these homes to body parts banks for transplants or exploit the propensity of MR boys for their uncontrollable sexual appetite to masturbate or engage in homo sexual activities.

ACTITIES OF NON- GOVERNMENTAL ORGANISATIONS FOR MENTALLY RETARDED PERSONS

The CAMR, which is an apex body in the field of MR in Sri Lanka, had from its inception carried out awareness programme, Island wide, by way of seminars, workshops, training programme for parents, of MR persons, teachers and carers attached to its 45 affiliates in various parts of the country. As the net working meetings, up to 2004, had been conducted in English, which is not the language of communication of 99% of the citizens of Sri – Lanka, these meeting have not had the desired response. To rectify this situation the CAMR held a convention, in October 2002, in Sinhala at the “Nisansala Centre” Ja- Ela, and thereafter have held several provincial training courses and workshop.

ACTIVITIES OF PARENTS ‘ ORGANISATIONS

As a consequence of the “ net working meetings” conducted by the CAMR, several parents’ organizations have been established in the major cities and towns of the country. These parents’ organizations are actively involved in pressurizing the government and NGO’s to set up special day care centre, vocational (day & residential) centers and residential centers for orphans and elderly MR persons. They have also set up counseling, centers for parents of MR children. They have been able to, a certain extent, breakdown the social barriers which, hitherto, stood in the way of MR persons interacting with society even marginally. As 78% of the population reside in rural areas; where the level of poverty is very high and where people are less aware of the nature of mental retardation and of their duties in protecting the human rights of MR persons, the CAMR and its affiliates in collaboration with the parents’ organizations, which are fully operational, are taking the initiative to set up parents’ organizations in those areas.

(6)

ACTIVITY OF SELF ADVOCATES ,FAMILY SUPPORT AND JOB AVAILABILITY

As Mrpersons are less able to learn from mistakes or engage in logical reasoning or control their impulses their ability to from associations to fight for their rights, as done by other disabled persons , is virtually nil . Also the prospects of their being employed or self employed are limited to those who are mildly retarded,,i.e..those whose I,Q's are between 50 –70 .But as the bulk of the Mrpersons fall into the moderate,severe and profound categories with I,Q's ranging below 50 the chances of their being employed or self employed are nil .However, the CAMR is of the view, with the experience it has gained by running a vocational training center for boys and girls over 14 years, for the past 20 years, and a residential home for boys over 14 years, for the past 2 years, that MR persons could; if their aptitudes for special skills are identified, be made to perform certain tasks either singly or in groups under constant supervision of trained instructors. The tasks that they could be made to perform are; agriculture, horticulture, packaging , music, dancing, drawing, painting, gardening, landscaping ,and sports activities.

With the extended family system which prevailed till about the seventies of the 20th century ; when grand parents, aunts &uncles, nephews &aces were available to provide necessary support to parents of MR persons , been replaced by the nuclear family system due to the rapid liberalization and the globalization of the economy and consequent expansion of urbanization, the family support which existed earlier is increasingly on the decline .Hence , the clamour for day care – centers and residential homes for the MR persons.As budgetary constraints prevent the government front meeting this demand the private sector, which is the engine of growth under the global market economy, is socially and morally obliged to meet this demand and, in a ridiementary manner, is presently engaged in this monumental task . The tax incentives for donations in cash ,to approved charities, also motivates persons to fulfill their social Obligations.

Presently no insurance company is willing is provide life, medical or annuity policies to MR persons as they are deemed to be incapable of entering into a legally binding contract. The CAMR will ,in the near future, through the National Council for the Disabled discuss with various insurance companies and workout the logistics where by, for a small premium or a reasonable lump sum payment , an insurance or annuity cover could be provided for MR oersons to enable parents, guardians or wardens of residential homes to meet the hospital bills or the cost of maintaining elderly MR persons.

(7)

The Social Security Board, an appendage of the Social Service Department, has introduced a pension scheme for the self employed and those employed in the informal sector & domestic services. Under this scheme those who are handicapped are entitled to receive a pension on reaching the age 40. But as the majority of the MR persons can never be employed or self employed but could be made to perform certain tasks, which are repetitive, under the guidance of the qualified instructors, only a very few MR persons will benefit from this scheme.

The CAMR and its affiliates have requested the National Council for the Disabled to establish.

- (a) A group pension Fund for MR persons between the ages of 18 to 40;
- (b) A foster parents' fund for MR orphans under 18 years of age.

Both funds to be administered by the Social Security Board.

COMMUNITY BASED PROGRAMMES FOR PERSONS WITH INTELLECTUAL DISABILITIES;

As the parents and guardians are anxious about the future welfare of their MR children, attention is presently being focused, by the National Council for the disabled and SHIA, to set up communes, where people of varying disabilities can be of help to one another. If these projects are implemented sans political interference, bureaucratic apathy & corruption and self-serving NGO's lacking transparency and accountability, the anxiety of the parents and guardians could be greatly reduced as such measures will enable MR persons to better their existence and interact with society, even marginally, should they survive their parents and siblings in the light of better health services provided by the government and the private sector.

ANY OTHER ACTIVITIES /PROGRAMMES TO EMPOWER PEOPLE WITH INTELLECTUAL DISABILITIES

The Special Units of the Ministry of Sports and Cultural Affairs have since 1996, organized various sports events –music, painting drawing and drama competitions for the Mentally Retarded persons. In fact exhibitions and sale of items produced by them have been held at least once a year by the CAMR and its affiliates and the sale proceeds distributed to the trainees. The catering, for the fellowship the 34th AGM of the CAMR, was done by the trainees of the Sumaga Training Centre run by the CAMR. The CAMR has decided to invite the oldest trainee of Sumaga as the chief guest for the New Year celebrations, to be held in April 2003, and as part of the process of empowering such persons to continue this practice in the future in keeping with their motto "Nothing for us Without Us". The CAMR is on the look out for a mildly retarded person to be inducted into the committee of management.

OTHERS

A problem causing concern to the parents, guardians, teachers and carers of MR persons is the uncontrollable impulsive urge of the MR persons, on reaching the age of puberty, to masturbate or indulge in homosexual activities. As this problem has been swept under the carpet and physical force used to prevent this type of deviant behavior, the time is ripe, for the activists in this field, to focus attention to this problem as the right to sex, even deviant, is a human right they are entitled to as other human beings. Hence, should not research be undertaken by psychologist & nutritionists to find ways and means to curb this tendency? by;

- (a) Medication (b) Nutrition (c) Neuro – surgery.

Regarding medication ; If Viagra could increase the potency surely a drug could be found by research to reduce one's potency.

Regarding Nutrition :As domesticated bull elephants when in must, are controlled by diet (large quantities of cucumber, curd and water) it may be possible by a suitable diet, to reduce the potency of the MR persons.

Regarding Neuro –Surgery ; As epileptics who could become mentally retarded are presently being cured by neuro – surgery by the removal of neurons from the brain ,could not a similar procedure be adopted to curb one's libido?

As it is this uncontrollable sexual impulse of MR persons, which inhibits parents,guardians,or siblings from caring for them in their homes; as stipulated in clause 4 of the resolution 2856 (xxvi)of 20th December 1971 proclaimed by the U.N. General Assembly on the rights of mentally retarded persons. The institutions set up (day care and residential homes) too, find it difficult to cope with this problem, as the majority of Teachers and carers are females in the age group pf 20 – 40 , hence, finding a solution to this problem should be on the top any agenda for the care and welfare of such persons.

SURGERY FOR FACIAL RECONSTRUCTION AND TONGUE REDUCTION

The CAMR has sought the assistance of the German Health Foundation ; an NGO which regularly gets down teams of plastic surgeons from Germany, U.K. Australia to perform plastic surgery on burns victims, from poorer families requiring such surgery. In response to this request. Dr. Charles Viva; the president of Interplant U.K. held a medical clinic at the Sumaga Training Centre, run by CAMR, and had identified 3 boys for facial surgery and tongue reduction free of charge at the National Hospital, when the team next visits Sri – Laanka. As the CAMR considers this to be an essential long term measure; to enable this target group to integrate, as far as possible, with society with confidence, it proposes to initiate action to request the Ministry of Health to set up a Child Development Unit at the National Hospital ; with facilities similar to that available at the Singapore General Hospital , to perform such surgery by our eminent plastic surgeons for the benefit of the poor section of society . However, due to financial constrains, foreign donor assistance will be necessary to get this project off the ground.

(9)