

Reviews

Mental retardation, poverty and community based Rehabilitation

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A person with moderate mental retardation would, in a western country, be "diagnosed" early on in life. Consequently, such a child is likely to be sent for special education. Given the high level of job requirements, such a person is unlikely to be employed in the open market later in life. Mental retardation is one of the most frequent disabilities; in most studies, mental retardation is found in about three percent of the population. Persons even with mild mental retardation have very large difficulties finding employment and are for this reason often deprived of opportunities for suitable and productive income generation; this is why most stay poor. But disability does not only cause poverty; poverty itself causes disability. This study follows an analysis, based on a review of the Swedish programme for mental retardation during the period 1930-2000.

It is concluded that in Sweden a very large proportion of mild and moderate mental retardation has been eliminated though the combination of poverty alleviation with a community-based rehabilitation programme. For these situations a pro-active programme analysing and meeting the needs of the target groups should be useful as a means to achieve poverty alleviation.

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Introduction

As the burden of health and costs related to mental retardation are very considerable for this life-long condition, it would be cost-effective to implement a similar strategy elsewhere. Disability is a global phenomenon of huge proportions. Before estimating its magnitude, an account will be given of the projected development of the world population (Table 1) (1).

The world population is growing rapidly: by about 40 percent from 2000 to 2035. The growth, however, is uneven. In the more developed regions, there will be no increase, whereas in the less developed regions it is forecast at about 50 percent. The increase is most pronounced in the older age groups (Table 2). As disability is more common among the elderly, this rapid increase of the population aged 65 and above will have clear implications for the future prevalence of disability.

Table 1. World population, as projected (medium-variant) by United Nations, 2000-2035

POPULATION IN MILLIONS			
Year	In more developed regions	In less developed regions	Total
2000	1,187	4,904	6,091
2205	1,197	5,293	6,491
2010	1,206	5,684	6,890
2015	1,214	6,072	7,286
2020	1,219	6,458	7,672
2025	1,221	6,819	8,039
2030	1,212	7,159	8,371
2035	1,201	7,468	8,669

Table 2. Population in less developed regions, projection by age groups

AGE GROUP	POPULATION IN MILLIONS		GROWTH
	2000	2035	
0 - 4	555	583	+ 5%
5 - 14	1,052	1,170	+ 11%
15 - 29	1,326	1,704	+ 29%
30 - 64	1,724	3,211	+ 86%
65+	247	800	+ 224%
TOTAL	4,904	7,468	+ 52%

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Several global estimates of the prevalence of disability have been made in the past. The most often cited is the one made by the author in 1974, which was published by WHO in 1976 (2).

A person with moderate mental retardation would, in a western country, be "diagnosed" early on in life. Consequently, such a child is likely to be sent for special education. Given the high level of job requirements, such a person is unlikely to be employed in the open market later in life. Instead, at the age of 18 (or so), he or she would be given a disability pension for life. A similarly afflicted person in a developing country might not stand out, as there are so many other children suffering delays in their developmental milestones. When this child attends school, his or her learning problems might not cause much concern; perhaps he or she will drop out of primary school just like so many others. Such a child might conceivably be working in agriculture or performing household duties later on (3).

Estimates of causes of disability

Three factors have led me to revise the calculations downward. The first one concerns malnutrition. The experts consulted in 1974/75 saw protein-caloric malnutrition as causing disability in about 100 million people, mostly children. Their views have changed, and this condition is now seen as a reversible impairment. It is not considered to cause chronic disability, except for some less frequent conditions such as xerophthalmia and cretinism, which affect some seven to ten million people. This change of view alone would have reduced the global prevalence rate calculated in 1974/75 from about 10 percent to about 7.5 percent.

The second factor is that, in 1974/75, the duration of life after the occurrence of a disability (for a person in a developing country) was overestimated, and this reduces the estimated prevalence further. The third factor is that in the 10 percent estimate were included a certain proportion of slightly disabled people. In view of the sometimes unclear borderline between ability/disability, and the fact that slight disabilities less often lead to needs for rehabilitation services, I am proposing that we confine ourselves to identifying those, who are moderately and severely disabled (4).

Current estimates based on causes of moderate and severe disability can be seen in Table 3. The table draws on a series of inquiries made in all relevant divisions and units of WHO. It is based on a large number of data and estimates from scientific

publications, professional observations and field studies (5, 6).

Table 3. Causes of disability and estimated prevalence of moderately and severely disabled people in the world, estimates for 1998

CAUSES OF DISABILITY	GLOBAL SUGGESTED RANGES OF ESTIMATES OF THE PREVALENCE OF MODERATELY & SEVERELY DISABLED (WORLD POPULATION 6,000 MILLION)
Congenital or perinatal disturbances	
Mental retardation	20 - 30
Somatic hereditary defects	10 - 25
Non-genetic disorders	15 - 20
Communicable diseases	
Poliomyelitis	5 - 10
Trachoma	8 - 10
Leprosy	3 - 4
Other communicable diseases	40 - 50
Non-communicable somatic disease	
Functional psychiatric disturbances	20 - 25
Alcoholism and drug abuse	30 - 35
Trauma/Injury	
Traffic accidents	20 - 25
Occupational accidents	10 - 12
Home accidents	15 - 20
Other	2 - 3
Malnutrition	7 - 10
Other	2 - 3
ESTIMATED TOTAL	300 - 350

Mental retardation is one of the most frequent disabilities; in most studies, mental retardation is found in about three percent of the population. Persons even with mild mental retardation have very large difficulties finding employment and are for this reason often deprived of opportunities for suitable and productive income generation; this is why most stay poor. But disability does not only cause poverty; poverty itself causes disability.

Below follows an analysis, based on a review of the Swedish programme for mental retardation during the period 1930-2000. It demonstrates that the incidence and prevalence of mental retardation can be reduced by over 90 percent through a poverty alleviation programme in combination with an adequate community-based rehabilitation programme. This preventive programme has in Sweden removed two percent of the population from the group of inactive and economically dependent people and added them to the group having full productivity.

1. Definition of mental retardation

According to Sheerenberger (7), the elements of the definition of mental retardation were well accepted in the United States by 1990. These included: onset in childhood, significant intellectual or cognitive limitations, and an inability to adapt to the demands of everyday life. An early classification scheme proposed by the American Association on Mental Deficiency (Retardation), in 1910 referred to individuals with mental retardation as feeble-minded, meaning that their development was halted at an early age or was in some way inadequate making it difficult to keep pace with peers and manage their daily lives independently (Committee on Classification, 1910).

Definitions of mental retardation characteristically include three criteria:

- (1) significantly subaverage intelligence, accompanied by
 - (2) significant limitations in adaptive skills, with
 - (3) an onset during the developmental period.(FN 3).
- The Social Security Administration in USA defines MR as "significantly subaverage general intellectual functioning, with deficits in adaptive behaviour, initially manifested during the developmental period (before age 22)" (FN 2)

2. Prevalence of mental retardation.

Some examples of the outcome of prevalence estimations are shown in table 4.

The numbers from the WHO Country reports, which are the lowest, suggest that the problems related to mental retardation are still unrecognised at the country levels. Those from WHO-HQ are based on consultations of experts and scientific data; those are close to the estimates of AAMR and ARC. The data from the North-Western University are indeed much higher and seem to reflect another reality in the developing countries, where samples of the general population score relatively much lower on Western performance tests. This has led to criticism of such tests as culturally inappropriate. Studies in the different States in USA confirm that the prevalence of mental retardation is higher, where there is a higher proportion of educationally and economically disadvantaged minority populations, and children of immigrants in Sweden also score lower than those of the "native" population.

Table 4. Prevalence of mental retardation, estimates by various organisations

Prevalence estimated sources	WHO, country reports (1996)	WHO , technical HQ Unit (1994) and ARC	Northwest ern University, Education	American Association on Mental Retardation
More developed countries	0.5 %	3 %	2-3 %	2-3 %
Less developed countries	0.6% - 0.7%	3 %	8-10 %	3%

3. Causes of mental retardation

I would now like to distinguish between "organic" and "functional" mental retardation. "Organic" MR, specially its severe forms, is caused by pathological processes in the central nervous system, such as brain damage, caused by, among others by:

1) Prenatal factors

--Genetic factors related to chromosomal abnormalities (for example, Down's syndrome, fragile X syndrome, chromosomal translocations, Klinefelter,s syndrome, Prader-Wlli syndrome, cri du chat syndrome).

--Other genetic causes, including metabolic disorders (phenylketonuria, galactosemia Tay-Sachs disease, Hunter's syndrome, Hurler's syndrome, Sanfilippo syndrome metachromatic leukodystrophy, adrenoleukodystrophy, Lesch-Nyhan's syndrome, Retts' disorder, tuberous sclerosis. autism).

--Abuse of alcohol or drugs (such as cocaine/crack and amphetamines) and most likely smoking by the mother during pregnancy.

--Other problems that the mother has during pregnancy and may affect the fetus: malnutrition, toxoplasmosis, cytomegalovirus, rubella, syphilis, HIV, listeriosis, severe anaemia, exposure to radiation:

2) Prenatal factors

--Premature and low weight birth,

--Damage at birth or soon afterwards (such as direct, mechanical trauma to the brain causing intracranial haemorrhage, hypoxia (often causing cerebral palsy)

3) Post natal factors

--head injuries,

--icterus and severe early malnutrition such as Kwashiorkor, marasmus)

--infectious disease, such as measles, whooping cough, encephalitis and meningitis after birth.

--metabolic: Reye's syndrome , hypernatremic dehydration , congenital hypothyroidism, hypoglycemia (poorly regulated diabetes mellitus).

Specific risks for “organic MR” as those above are only detected in about 25% of all. “Functional MR” is known to be associated with environmental factors. For instance, poverty and conditions generally seen among disadvantaged populations all over the world: malnutrition, lack of education of parents, low degree of social and cultural stimulation, lack of access to schooling and mainstream public services and lack of simple rehabilitation interventions that can be provided through a low-cost community based system (CBR). Adding to this are the negative attitudes and discriminatory behaviour that often lead the family to hide a MR Child and to forego using health and other services that are accessible and competent (8).

Functional physical disability can be reduced and even eliminated by CBR programmes that provide the child – mostly using family and other local resources - with training in daily abilities, such as self-care, communication, mobility and behaviour; such programmes should include the provision of aids and appliances that can help to overcome specific difficulties. The question for today is: does it help persons with MR is the same way?

4. Studies of mental retardation carried out in Sweden.

Long term studies about mental retardation are indeed rare, and in the following I will summarise the experience from Sweden, where the first scientific studies of mental retardation started about 1930 and have been followed up until now (9). Similar results have been published from other countries (10)

Sweden around the year 1930 was one of the poorest countries in Europe. It had an unemployment rate of over 20 percent of the active population, there was little industry, a total collapse of the entire economy, many beggars in the streets, a large rural population with poor education, insufficient health care, some malnutrition, highly visible alcohol abuse, a lot of communicable disease and frequent epidemics. Earlier about one quarter of the population had immigrated, mainly to United States, because of the widely spread poverty among the rural population. . In short, it had a situation that will remind the reader about the situation in a developing, middle income country today.

The economy started to take off after the Second World War (from which Sweden was spared) and has since then grown so that Sweden now counts among the most affluent ones in the world. What

happened to mental retardation as a result of this poverty alleviation? Table 5 shows the economic development in Sweden from 1930 to 2000.

Table 5. Economic development in Sweden

Year	Gross national product per capita, basis, SEK year 1900=100
1930	210
1935	230
1940	300
1945	375
1950	440
1955	600
1960	700
1965	820
1970	1000
1975	1200
1980	1300
1985	1400
1990	1600
1995	1570

Sweden is a country which has developed in a rapid and successful way since about 1870. During the 110 years, between 1870 and 1980, GDP/capita grew in real terms (after eliminating the effect of inflation) with approximately 2,5 % a year - an impressive rate internationally compared.

During the 1950's and the 1960's the Swedish economy expanded in a particularly rapid manner. During the 50's the industrial production grew totally 35 % and during the 60's it grew with outstanding 70 %. Between 1960 and 1965 GDP grew in average 5,3 % a year with the labour productivity climbing 5,6 % a year. In recessions during the 50's and 60's GDP grew 1-2 % a year, and in thrives the corresponding number was 5-6 %. The rate of inflation was about 4 %, unemployment 2 % and growth of investment averaged 4 % a year.

Before 1950 most persons with MR who had been “taken care of” by the Government programme were confined to closed residential institutions. Such institutions were seen as causing severe regression of the abilities of those confined. By that time the new approach of providing more home-like conditions started. Eventually, and that took some 35 years to achieve, almost all of them are now living either independently or semi-independently in normal homes, mixed into ordinary blocks of apartments or in small villa.

It shows the changes in living conditions for the MR children. Followed by a period of time when the MR pupils received their education in boarding schools, there came a period of much improved residential home, with more homelike conditions, and then by

supporting the families to keep them at home and attending mainstream schools or day-centres. Since about 15 years this is now fully implemented.

But the dismantling of the residential system was only a part of the new approach. Since 1960 Sweden has implemented large-scale specifically targeted services to train, assist, and support and integrate persons with MR, as well other those with other disabilities. Special legislation has been proposed by the Government and approved by the Parliament, most of it based on a very wide political consensus. The political process has been continuous over the last 40 years, based on the experience and success of the rehabilitation programmes. This process has been community-based; the involvement of the families and of the persons with MR themselves has had significant influence, and the local communities where they live have taken over the full responsibility for planning, implementation and financing of all interventions and support. To sum up:

Sweden started by about 1960 a large-scale programme to change the very poor conditions for persons with MR, a programme built on the principles of what later on became known as a Community-based Rehabilitation approach. Most of the changes were fully implemented by 1985. Community-based rehabilitation (CBR) to transfer skills in rehabilitation and knowledge of disability to family and community members; training carried out with the family fully involved in all aspects improved economic support

- Dismantling of the residential centres, and replacing it with independent or semi-independent living in homes, fully integrated in the mainstream community.
- inclusion and better access to mainstream public services in health, education, training, income generation, social life, housing, recreation etc.
- decentralisation of administrative responsibility to the local communities to facilitate the integration process, cut bureaucratic red tape, create better awareness, improved attitudes and eliminate discrimination and the “apartheid system”.
- better access to mainstream health care: including early detection of disability and early stimulation programmes
- setting up of adequate support programmes, such as day centres (or preschools), in which the disabled children can be trained, especially as regards daily life abilities (self-care, continence, mobility, communication, behaviour)
- inclusive education, followed by training of basic

occupational skills

- protection of abuse and exploitation of persons with disability, including those with MR
- economic assistance, such as adequate disability contributions or pensions to help families with disabled members and encourage them to keep them at home,
- assistance to persons with MR to set up non-governmental organisations by themselves and empowering them,
- Long-term planning of the mainstream participation by persons with mental retardation.

We may conclude that Sweden during the years 1930-2000, and especially 1960-1980 implemented a proactive Government-lead combination of poverty alleviation and a community-based rehabilitation programme, targeted to all persons with disabilities, including those with MR.

5. Effects on mental retardation prevalence and incidence

In 1930 the prevalence of mental retardation in Sweden was calculated at about 150,000 or some 2.5 percent of the population (6 million at that time). Persons with MR were then not officially registered, so only about 18,000 were known to the authorities and out of them 12,000 were receiving a care programme, mainly in special hospitals or closed institutions. In 1930 about 75 percent of all the persons with MR were estimated to have a mild retardation, 20 percent were seen as moderately and 5 percent as severely retarded. This corresponds to a prevalence of 1.88 percent of mild MR, 0.50 percent of moderate and 0.13 percent severe.

In 1930 the mortality rate of persons with MR was very excessive, mainly because of neglect and because of tuberculosis, which often was acquired while persons with MR were in special hospitals. In the 1950s, before the start of an enforced Government programme of rehabilitation for MR it was rare to see any severely MR persons, (such as those with Down’s syndrome) surviving the age of 20. See Table 6.

Table 6. Average life expectancy of persons with Down’s syndrome in Sweden

Period	Average life expectancy, years
1920-1930	2-3
1950-1960	15
1970-1980	35
1990-2000	57

Source G, Annerén, personal communication.

Table 6 shows that the average life expectancy of persons with Down's syndrome was during the 1920-30 2-3 years, by 1950-60 15 years, by 1970-80 35 years and by 1990- 2000 57 years. It is still increasing. This increase is also seen among persons with a non-Down's syndrome cause for MR . Thus the prevalence rate should under these conditions be expected to increase to a much higher level. To better reflect the incidence rate. The life expectancy is still about 20 years short of the average life one in Sweden. In connection with our consideration of incidence and prevalence it should be remarked that since the 1950s legal abortion is allowed of a foetus with Down's syndrome. In 1999, a year when 88512 children were born and the average age of mothers was 30.0 years) 124 children were had a Down's syndrome at birth; 75 were aborted.

As survival rates were going up, an increase of MR prevalence was widely expected. But it did not occur at all. By 1980, the prevalence rate of MR had gone down dramatically to a total of 0.42 percent, or by 83 percent compared to 1930. (see table 7).

The prevalence of persons with mild MR was by 1980 0, 13 percent, with moderate 0,18 percent and with severe 0.2 percent. Thus there was a major reduction (table 8) of those with mild and with moderate MR. The slight increase seen in the group with severe MR is not significant. These numbers no doubt imply that the incidence of mild and moderate MR has been significantly reduced. Table 8 shows the development of the prevalence of MR in Sweden. In 1930 the estimated number of persons with MR was 150,000 in a population of 6.1 million. The prevalence is falling during the period 1930-1980, since then no major change is seen. The most rapid economic effects of poverty reduction were seen during the period 1930-1960. During that period the prevalence was reduced from 2.5 percent to 1.4 percent, a reduction by 40 percent.

Table 7. Development of prevalence of mental retardation in Sweden 1930-2000

Year	Population, million	Total number of persons with mental retardation, thousands	Prevalence percent
1930	6.1	150	2.5
1935	6.3	148	2.3
1940	6.4	145	2.3
1945	6.7	140	2.1
1950	7.0	133	1.9
1955	7.3	122	1.7
1960	7.5	106	1.4
1965	7.7	70	0.9
1970	8.1	50	0.6

Year	Population, million	Total number of persons with mental retardation, thousands	Prevalence percent
1975	8.2	40	0.5
1980	8.3	37	0.4
1985	8.4	35	0.4
1990	8.6	36	0.4
1995	8.8	37	0.4
2000	9.0	40	0.4

Source: K. Grunewald, 2001

In 1930 there were practically no efforts for rehabilitation of persons with MR. A mere 6.7 percent of all such persons was included in the public service system, which at that time consisted mainly of residential institutions. By 1960 this proportion had increased to 19 percent, still the approach of residential institutions was dominating, and the care did not include almost any community- and family-based efforts at rehabilitation.

From 1960 to 1985 the service delivery coverage of the group of persons with MR went up from 19 percent to 100 percent and the content of these services totally changed. Persons with MR in Sweden have finally have reached a considerable level of quality of life.

After the time when this effective, and much more pro-active programme for community- and family based rehabilitation started, the fall of prevalence rate is very pronounced: from 1.4 percent prevalence to 0.4 percent. Consequently from 1960-1980 two thirds of the remaining prevalence "disappeared". After 1960 the economic development continued; the combination of poverty alleviation and the rehabilitation programme very clearly appear to be extremely effective in preventing disability related to MR. After 1985, when this programme was fully installed the prevalence rate has remained at the same level of 0.4 percent, it looks as if – for the time being - the maximal rate of reduction MR has been achieved.

Table 8 analysis the change in prevalence of MR by severity. The prevalence of mild MR has been reduced by 95 percent and that of moderate by 72 percent. There is a slight increase of severe MR but this change is not statistically significant.

Table 8. Change in prevalence of mental retardation, by severity. Sweden 1930 to 1980.

Severity of mental retardation	Prevalence 1930 Percent of population	Prevalence 1980 Percent of population	Change Percent
Mild	1.88	0.10	-95
Moderate	0.50	0.14	-72
Severe	0.13	0.17	(+28)
Total	2.5	0.42	-83

Source: K. Grunewald, 2001

Table 9 shows the relationships between prevalence and incidence rates at various levels of life expectancy; we will now apply it to the situation in Sweden for persons with MR. Let us assume that by 1930 the life expectancy of all persons with MR (and not just those with Down's syndrome) was 20 years. That year the prevalence in Sweden was 2.5 percent, and the incidence can be calculated at 125 per 10,000 populations. In 1990 the prevalence was

0.4 percent and the average life expectancy almost 60 years. Thus that year the incidence rate comes to 7 per 10,000. The reduction from 125 to 7 per 10,000 in incidence corresponds to 94 percent. However, the prevalence is the sum of accumulated incidence rates over the entire life time of the group of people studied, minus the accumulated mortality during the time period. The incidence accumulation for mental retardation is, however small as it starts and most is detected before age one. As incidence rates were higher in the past, we can conclude that the present non-accumulated incidence rate is lower than the 7 per 10,000, and thus the reduction should be somewhat higher than 94 percent (11).

It may be concluded, that taking into consideration the very large increase of life expectancy occurring at the same time as a fall in prevalence, the incidence of MR has been decreased by over 90 percent, mainly in the categories of persons with slight and moderate MR.

Table 9. Relationships between prevalence/ incidence, at various years of life expectancy

Prevalence Per 100	Annual incidence per 10,000 population							
	10 years	20 years	30 years	40 years	50 years	60 years	70 years	80 years
3.0	300	150	100	75	60	50	43	39
2.5	250	125	83	63	50	42	36	31
2.0	200	100	67	50	40	33	29	25
1.5	150	75	50	38	30	25	21	19
1.0	100	50	33	25	20	17	14	13
0.5	50	25	17	13	10	8	7	6
0.4	40	20	13	10	8	7	6	5

The reasons for the decrease in incidence are several: genetic counselling, improved maternal and child health care, early interventions and monitoring after the birth of a disabled child. Such interventions

have been undertaken not only in Sweden, but also elsewhere. Table 10 shows the result of a review of 40 years of such prevention in USA. FN 6).

Table 10. Effects of prevention of mental retardation during the last 30 years in USA

CAUSE	ESTIMATED NUMBER OF CASES PREVENTED ANNUALLY	APPROACH USED
Phenylketonuria	350	Newborn screening and dietary treatment
Congenital hypothyroidism	1,000	Newborn screening and thyroid hormone replacement
Rh incompatibility with severe jaundice	1,000	Use of anti-Rh immune globuline
Hib diseases	5,000	Anti-Hib vaccine
Measles encephalitis	4,000	Measles vaccine
Rubella	Not known	Rubella vaccine during pregnancy
Lead poisoning	Not known	Removing lead from the environment
Brain damage due to road traffic accidents	Not known	Helmets and special child seats
Improper diet with lack of folic acid	Not known	Folic acid during pregnancy
AIDS of the mother	Not known	AZT treatment of the mother
Genetic causes	Not known	Genetic counselling and abortions

Source: D. Alexander, 1998

The poverty alleviation programme, has contributed to reduce the incidence of “functional” MR, and help to lessen the burden for the family of persons with “organic” MR. The examples seen in table 10, how what can be achieved through an improved health care service to decrease the “organic” MR. A large part of the reduction of incidence and prevalence of MR is due to the implementation of an adequate community and family-based rehabilitation programme.

Conclusions

It is concluded that in Sweden a very large proportion of mild and moderate MR has been eliminated through the combination of poverty alleviation with a community-based rehabilitation programme. An analysis of the results makes it evident that there has also been a decrease of the incidence by some 90 percent; this is ascribed to the concurrent large scale improvements of the maternal and child health care system. The implementation of the programme has spanned some 30 years. Two percent of the population has been removed from a status of economic dependency and added to the

group having full productivity. The costs for such a programme have not been calculated, but it would be reasonable that to assume that it is cost-effective.

There are other implications of this study. Difficulties to adapt to the requirements of mainstream education and work – what we may call “productive ability restriction” - are common among recent immigrants to the industrialised countries and these persons may unfairly be seen as having a functional MR. Conversely, it is common that interested foreign investors considering economic development projects in a low-income country refrain as they face problem using labour who have such restrictions. For these situations a pro-active programme analysing and meeting the needs of the target groups should be useful as a means to achieve poverty alleviation.

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