

THE NEED FOR MEDICAL CARE AMONG MENTALLY RETARDED ADULTS. A 5-YEAR FOLLOW-UP & COMPARISON WITH A GENERAL POPULATION OF THE SAME AGE.

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INTRODUCTION

Mentally retarded persons are known to be vulnerable with regard to physical and mental health. The medical needs of mentally retarded children are mostly discovered and dealt with by their parents and by interested pediatricians and their trained staff. But, medical needs among mentally retarded adults may easily be neglected, since their parents if alive are old, and there are rather few specialists and medically trained staff ready to help them.

The current deinstitutionalization and normalization schemes may also contribute to undiscovered and unmet medical needs. Social needs are sometimes emphasized more than their medical needs. When mentally retarded people get sick, they are often requested to apply to the ordinary health care services, where staff is not used to dealing with mentally retarded patients.

The aim of this article is to report the findings as regards medical needs and utilization of health care services in a group of mentally retarded adults during a five-year-period, and to compare these findings with the corresponding results in a neighbouring health service district in the same county.

POPULATION AND METHODS

This study was carried out in a health service district in the county of Uppsala, Sweden, from the 1st of July, 1982, to the 30th of June, 1987. The district serves an area with a population of about 48,000 inhabitants. There is a general county hospital with 135 beds for acute medical and surgical care, local health centres with a total of 10 general practitioners, and out-patient clinics for dermatology, gynaecology, ophthalmology, and psychiatry. Certain medical specialities, like neurology and audiology are situated 45 kilometres away at the University Hospital of Uppsala.

During the study period one consulting physician, the author, was able to follow up forty-one mentally retarded persons, who lived in group homes assisted by staff, trained in social work. Single persons lived nearby with their parents or in their own apartments. Table 1 shows the distribution of individuals by age, sex, and type of residence. They were all between 20 and 62 years of age when the study started and five years older when the study was finished.

TABLE I
Distribution of individuals by age, sex and type of residence
at the beginning of the study

	Men (n = 27)	Women (n = 14)	Total (n = 41)
Age (years)			
20 – 44	18	10	28
45 – 64	9	4	13
Residence			
– group home	18	5	23
– sheltered apartment	7	4	11
– with parents	1	4	5
– own apartment	1	1	2

In the health service in question, there is a day-centre close to four group homes, each with rooms for six persons, and 11 sheltered apartments nearby. When the study started in 1982, 23 persons lived in the group homes, 11 persons in sheltered apartments, and 7 persons lived together with their parents or in their own apartments.

Table II gives diagnoses and also the level of mental retardation. One fourth of the individuals had Down's Syndrome, and the same proportion had mental retardation of unknown origin. None of them was profoundly mentally retarded, i.e. IQ below 20. Severe retardation was defined as an IQ between 20 and 35, moderate retardation between 35 and 50, and mild retardation between 50 and 70.

TABLE II
Distribution of residents by type of mental retardation and level of mental capacity

Type of mental retardation	Level of mental capacity			Total (n = 41)
	Mild (n = 16)	Moderate (n = 13)	Severe (n = 12)	
Down Syndrome	–	4	6	10
Microcephalos	–	1	1	2
Kernicterus	–	2	–	2
Hereditary oligophrenia	2	2	–	4
Post-encephalitis	2	–	3	5
Perinatal anoxia or trauma	3	3	1	7
Unknown	9	1	1	11

The Swedish Board for the Provision and Services for the Mentally Retarded has decided that mentally retarded adults in sheltered living quarters or working must have a physical check-up every other year. The consulting physician visited the day-centre once a week for two or three hours. She made the bi-annual check-ups

and helped the residents with acute disorders by physical examination, prescription of drugs, or referrals to other specialists. All these measures were documented.

The need for hospital care was also followed-up and recorded. At the end of the study the actual number of admissions to hospital was retrospectively revised from the hospital records. Out-patient visits to different specialists and to general practitioners were also checked at that time. The results have been compared with corresponding data from a population study in a neighbouring health service district.

The proportions of people aged 20 - 44 years and 45 - 64 years in the general population were 58 and 42 respectively.

When the study started in July, 1982, 33 of the 41 individuals (80 per cent) had one or several chronic diseases (Table III). Adipositas is defined as a combination of height below 165 cm and weight of over 100 kg. Psychosis means, that there was a need for constant or periodical treatment with neuroleptic or anti-depressive drugs. Sixteen persons had a combination of two or three chronic diseases. Four persons had severe impairments of vision, congenital amaurosis or cataracts, and three persons had severe impairments of hearing. Twenty-one persons were independent of another person in performing their personal activities of daily living, and 20 persons were dependent.

TABLE III
Distribution of individuals by type of chronic disease

Medical diagnosis	No. of individuals (n = 33)
Adipositas	3
Chronic bronchitis	2
Chronic obstipatio	4
Coronary disease	2
Diabetes	1
Epilepsy	9
Hemicrania	1
Hypertension	4
Neurofibromatosis	1
Nephrolithiasis	1
Cerebral palsy	3
Psoriasis	2
Psychosis	10
Scoliosis, contractures	3
Senile dementia	1
Stricture urethrae	2
Ulcus/dermatitis cruris	2
VOC cordis	1
Total	53

RESULTS

During the 5-year period 16 patients (39 per cent) were admitted to hospital 69 times altogether. One person was admitted 20 times, and his data are given separately in Table IV. He was admitted twice to the neurological department due

to seizures, twice to the psychiatric department due to deep depressions, and finally 16 times to the medical department due to myeloma with bone destructions, which required intermittently cytostatic drug treatment.

TABLE IV

Number of admissions and length of stay per type of hospital department. One person had very frequent hospital admissions and his data are given separately within parentheses.

Type of hospital department	No. of admissions		Length of hospital stay (in days)	
	(n = 15)	(n = 1)	(n = 15)	(n = 1)
Medicine	19	(16)	97	(116)
Surgery	14		165	
Ophthalmology	4		11	
Psychiatry	2	(2)	14	(50)
Neurology	1	(2)	5	(23)
Rehabilitation medicine	2		35	
Total	42	(20)	327	(189)

The department of rehabilitation medicine mentioned is a centre for research into hyperlipaemia and atherosclerosis and has special dietary programmes for people with adipositas. The reasons for being admitted to the medical department were circulatory diseases, infections or seizures. Admission to the surgical department was due to cholecystectomy, gastro-intestinal disorders (oesophagitis, hemorrhoids, severe obstipation), and nephrolithiasis. Table IV gives the number of admissions and length of stay by type of hospital department.

Thirty-nine of the 62 admissions can be regarded as acute admissions, and the other 23 admissions were due to planned surgery, cytostatic drug treatment, or to rehabilitation (here: for undergoing a course of slimming). The length of hospital stay was in total 516 days, which gave a mean value of about 8 days per hospital admission (range 1 – 53 days).

The number of hospital admissions per person and year in the group of mentally retarded persons (the MR-group) was compared with the data from the general Swedish population in a neighbouring health service district (the GP-group). Table V shows the results for the whole MR-group (n = 41) and also the results for the whole group minus the person who had an extreme number of admissions (n = 40). The figures for the GP-group are the mean number of admissions to the departments of medicine, surgery, psychiatry and gynaecology during four years (1982 - 1985) related to the number of individuals in the population who were of the same age as the mentally retarded persons.

As expected, persons aged 45 - 64 years had more admissions than younger persons both in the MR group and in the GP-group. Even when the mentally retarded person with a total of 20 admissions was excluded, the mean number of hospital admissions per individual and year was three times higher in the MR-group than in the general population.

TABLE V

Mean number of admissions to the hospital per individual and age in the group of mentally retarded persons (MR) and in the general population (GP)

Age (years)	MR - group (n = 41) (n = 40)		GP - group (N = 10.727)
	20 - 44	0.31	0.18
45 - 64	0.28	0.28	0.09
Total	0.30	0.21	0.07

The mean length of stay was in total somewhat higher in the MR-group, but when the mentally retarded person with the extreme number of admissions was excluded, the mean length of stay in the younger MR-group was somewhat lower than in the GP-group. (Table VI).

TABLE VI

Mean length of hospital stay per individual and age in the group of mentally retarded persons (MR) and in the general population (GP)

Age (years)	MR - group (n = 41) (n = 40)		GP - group (N = 10.727)
	20 - 44	2.72	1.42
45 - 64	2.08	2.08	1.11
Total	2.52	1.64	1.46

Table VII shows the mean number of visits to a doctor per individual and year in the MR-group and in the GP-group respectively, by the two age-groups. The MR-group visited a doctor twice as often as the GP-group. Even when the health check visits were excluded, the MR-group made more visits than the GP-group.

TABLE VII

Mean number of visits to a doctor per individual and age in the MR-group and in the GP-group, respectively, by age. (HC = health check visit)

Age (years)	MR - group (n = 41)		GP - group (N = 10.727)
	All visits	HC excluded	
20 - 44	3.9	3.4	1.9
45 - 64	4.7	4.2	2.4
Total	4.1	3.6	2.1

Table VIII gives the number of hospital admissions and number of visits to a doctor related to level of mental retardation. As far as the hospital admissions are concerned, the results are given for the whole MR-group ($n = 41$) and for the same group excluding the person with the extreme number of hospital admissions ($n=40$). The differences between the three levels of mental retardation were rather small. Persons with severe mental retardation had more hospital admissions than the other two groups, and persons with a mild mental retardation visited a doctor less often than the other two groups. But the sample is rather small, and the effect of one person's hospital admissions may seriously affect the result for the whole group and no conclusions can be drawn.

TABLE VIII
Mean number of hospital admissions and visits to a doctor
per individual and level of mental retardation

Level of mental retardation	No. of hospital admissions		No. of visits to a doctor ($n = 41$)
	($n = 40$)	($n = 41$)	
Mild	0.19	0.43	3.8
Moderate	0.17	0.17	4.5
Severe	0.25	0.25	4.2
Total	0.21	0.30	4.1

DISCUSSION

During recent decades, the average life expectancy for mentally retarded persons as well as others, has increased in Sweden. The possibility of surviving diseases has been improved, especially during childhood, and a medically orientated care system within the institutions has provided medical care for mentally retarded adults.

Today, about thirty per cent of the mentally retarded population in Sweden is 40 years of age or older. Many of them have been discharged from institutions and live in the community or intend to do so. Their social needs are important, and their medical needs must not prevent them from a normalized way of living.

Conroy (1985) found, that families of mentally retarded persons perceived far greater levels of medical needs than did staff in institutions and these were their major reasons for resisting deinstitutionalization of their relatives. Minihan (1986) also emphasized the importance of planning for physician services prior to deinstitutionalization, in order to avoid unmet needs and discontinuity.

Continuity is regarded as a prerequisite in primary care, and Breslau (1982) found, that the impact of continuity of physician care on parental satisfaction was greater when disabled children were patients than was the case among the general population of children.

In this study, mentally retarded persons could apply to the same physician during a five-year-period, but at the same time they could also apply to a general practitioner or to out-patient clinics in the same way as other people in the community can do. Though the sample is rather small it is felt that it is representative

of mild, moderate and severe mentally retarded adults who manage to live in group-homes, in sheltered apartments or with their parents.

A majority of them had one or several chronic diseases which required special health controls or pharmacological treatment. It has been supposed (Richards & Siddiqui, 1980) that age dependent diseases, e.g. arteriosclerosis with concomittant cardiovascular disorders, are less common among the mentally retarded than among others. In this sample 2 persons had coronary diseases, 4 persons had hypertension, and one had senile dementia. Probably, the prevalence of arteriosclerosis will increase with increasing age in this population.

The high number of hospital admissions was mostly due to acute disorders, which could not be dealt with in primary care. The differences in length of stay between the MR- and the GP-group were small, which shows that they received short-term medical, surgical, psychiatric, or gynaecological care and no long-term care.

Access to a consulting physician may have increased the number of visits to a doctor, but even when the health check-ups were included the results were only twice as many visits for the MR-group as for the GP-group. Schor et al (1981) for example, showed that previously institutionalized children paid three times as many visits to a doctor than the general population of the same age. With respect to the large number of chronic diseases, our results are rather modest. On the other hand, it is reasonable to suppose that access to a consulting physician increased the number of referrals to other specialists. Since mentally retarded adults run the risk of being neglected, as pointed out by Dybwad (1981) and other authors, an increased number of referrals to a specialist may be of benefit for the individual.

The high number of hospital admissions, most of them because of an acute illness, and the high frequency of visits to a doctor confirms the belief that this is a vulnerable group of individuals. The proportion of younger individuals was higher than in the general population, and with increasing age the need for medical care services can be expected to increase even more.

The high frequency of chronic diseases apart from mental retardation justifies the availability of a qualified consulting physician, who is familiar both with the mentally retarded persons, their families, and the local health and social care services in the community.

SUMMARY

Forty-one mentally retarded persons, 20 to 64 years of age and most of them living in group homes, were followed up over a period of 5 years as to their need for hospital admissions and visits to a doctor. Thirty-three persons had at least one chronic disease, and seven of them had signs of arteriosclerosis. Fifteen persons (36 per cent) were admitted to hospital 42 times altogether mostly due to an acute illness. Those of 45 years of age or older were admitted more often and made more visits to a doctor than did the younger ones. The results were compared with the general population of the same age in a neighbouring health service district. The proportion of younger individuals was higher among the mentally retarded, but they had three times as many hospital admissions and twice as many visits to a doctor as the general population during the same 5-year-period. The need for medical care among mentally retarded adults is considerable and may increase as they get older. This must not be neglected, especially when they are trying to live outside institutions.

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