

**ADDRESS TO THE 1966 ANNUAL CONVENTION OF THE
MINNESOTA ASSOCIATION FOR RETARDED CHILDREN, INC.
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"EUROPEAN FACILITIES FOR THE MENTALLY RETARDED—HOW DO WE COMPARE?"

The purpose of my trip, quoting from my application for the Rosemary Dybwad Award, was "to make a study in depth of voluntary organizations with and for the retarded in England, Ireland, Holland and Denmark". I proposed to learn how such organizations function in the areas of direct services, financing, parent and public education; also, to determine how they seek to influence legislation and how they relate to official and voluntary agencies. I later added Norway and Sweden to my schedule. In addition, I attended the 3rd International Congress of Societies for the Mentally Handicapped in Paris and the International Symposium on Mental Deficiency in Dublin.

The things I learned about Associations for the retarded were probably much less helpful, or enlightening, than what I learned about government services to the retarded.

Speaking about Associations for the retarded, Norway, for instance, with a population of about four million, has several organizations working for the retarded. However, the parents as such are not very involved. The work is more by groups and individuals seeking to establish facilities. Several of the Norwegian leaders have been so effective that they are practically one person organizations. The names of Heddy Astrup, Emma Hjorth, and Ragnhild Schibbye are spoken with reverence.

Sweden, on the other hand, with a population of seven and one-half million, has a highly organized National Association, which goes by the name F.U.B. The Swedish International League of Societies for the Mentally Handicapped was founded in 1952. It now has 22 county Associations with a total of 8,500 members; in addition, there are 80 local Associations. The Association is very effective with the government.

Denmark, population 4.8 million, the Association for the retarded was effective in passage of a national law governing services for the retarded. They do not have paid professional staff but I did meet with several Association leaders.

England has well organized Associations with professionals. The volunteer's role is different than we know it. In England, I was the guest of Lord and Lady Hutton, parent leaders, and was able to learn a great deal of the parents' point of view.

Most of my time was spent talking to experts in charge of services for the retarded and visiting both residential and community facilities for the retarded. These are the things I primarily want to talk about. The five points I want to cover are: 1) Philosophy and Attitudes; 2) Organization of Services; 3) Staff and Staff Training; 4) Cost of Services; 5) Facilities.

I. PHILOSOPHY

The philosophy I found can best be expressed by the words of Bengt Nirje, Secretary General of the Swedish National Association:

Walsh: Actually, the key then is trying to achieve the same good standard of life for those retarded children as you want for people who live in general society.

Nirje: Yah, our aim is to create such facilities, and we are far from it. Our aim is to make the conditions of life as similar or the same as for the rest of the population. You have to do it for human dignity and human decency.

These countries regard services for the retarded as a right, not charity. The retarded are treated as individuals. They are not grouped and herded.. In five weeks, I saw no bare-footed, naked, or bruised patients. The government has for many years recognized and carried out its responsibility.

I had a note from Martin Papish, of Pennsylvania, an early leader at our NARC, recently. He said, "Fifteen years ago at a conference at Southbury, Connecticut, I described our institutions as warehouses where the children are inventoried as merchandise—taken off the shelves occasionally—dusted, and returned to the bins." "Honestly", he continued, "with all the grants and all the studies and all the planning, when I visit institutions and observe the facilities for the profoundly retarded I can't see the kind of improvement that 15 years should have brought about. I am deeply discouraged by this."

Dr. N. Speijer, who is in charge of mental retardation services for The Hague district of Holland, has said, "mostly with the mentally handicapped we look at their negative points and consider these first. There exists a strong under-evaluation of the subnormal for the very reason that we look at this negative side and not at his potential." How many times have you heard adult retarded referred to as boys and girls ?

Our inadequate, broad classification of the retarded does not allow sufficiently for an individualized personal approach to the problems of the retarded.

Aren't the retarded, who are members of our society, entitled to their share of the benefits of an affluent society ? Must they be the last to receive consideration ? The handicapped of all kinds—the sick — the aged — should be the first cared for.

II. ORGANIZATION OF SERVICES

I was impressed by the degree to which each country was organized into districts to serve the retarded. Each district has a central institution and professional staff responsible for all services. In Denmark, where there are 11 districts, a team consisting of a doctor, psychologist, educator, and administrator, is in charge. There is also a board or commission to advise and work with the professional team. The districts are under the leadership of a National Director of Services for the Retarded.

In Sweden, I asked Bengt Nirje about enforcement of standards for services:

Walsh: You have high standards and expect good care for the mentally retarded. Who has the responsibility for inspecting these various facilities and does this person have the authority to do something about the facility if it doesn't meet standards?

Nirje: Yes, he sure has. The Swedish law on mental retardation gives the responsibility to create programs to each county..the county parliaments have central boards responsible for the planning and to provide the facilities. Then the King appoints a general inspector for the area and it is his job to inspect the facilities and see to it that they are up to standards. If they are not, which happens, then he can close down the place or he can give them an order that in a few months they have to provide extra personnel or send away some of the persons living there. As a matter of fact, today you visited a place where you saw some persons who came there because the inspector had closed down a very unsatisfactory small home for women and, also because he had inspected another home and found that there were too many persons there so he ordered it cut down 25%.

The problem of mental retardation is large enough to warrant concentration on it by people who are experts, and spend their full time learning and doing.

III. STAFF AND STAFF TRAINING

Certainly the people who work with the retarded in institutions and day activity centers are dedicated, hard-working, and willing. However, especially in our institutions, the people who have responsibility for the retarded person on a daily basis, are the least well trained. The present six-month training for Psychiatric Technicians is not adequate to prepare them for the task assigned to them. Again, Denmark is a good example. They have a special training center where students enroll for a three-year course of practical and theoretical training for work in day activity centers, institutions, or sheltered workshops. They attract young people to this field as a career. Since 1961, one thousand students have been graduated. St. Mary's Junior College in Minneapolis is to be commended for establishing a two-year curriculum to train people to work in the mental retardation field. An extension of this to all Junior Colleges could help solve our problem, but in addition the salaries for Psychiatric Technicians must be increased to attract more and better trained staff.

IV. COST OF SERVICES

Services in facilities in all the countries I visited are without cost to the participant. Just as in this country there is no charge for public school, or for state residential schools for the blind or deaf. Under our present law, the mentally retarded adult who may be working as many as 52 hours a week in the institution is liable for the full cost of care, if he has funds. This adult who works 52 hours per week, 208 hours per month, even at \$1.00 per hour, would be earning \$208 per month. This is a big price for board and room and yes, he may be paid 50¢ to \$1.00 each month for cigarettes, candy, etc. If an 8-year old child inherits \$5,000, he must pay \$1,800 per year to the State until only \$1,050 is left. \$750 for burial and \$300 for his store account is set aside. Now this 8-year old could be discharged back to the community ten years later, but would not have funds to supplement any earnings he might have.

There is also the situation when a retarded person is placed in the institution for the benefit of society. This person also is liable for the full per capita cost of care.

V. FACILITIES

I cannot talk about facilities without thinking not about the fine residential care centers I saw on my trip, but about the "warehouses, hen houses, herd-care facilities we have provided for many retarded in Minnesota.

Somehow we have been able to plan and construct institutions designed to cause severe and detrimental "institutionalization" of the mentally retarded.

Sweden again has, I know, the right approach. "We in the Swedish Parent Association want the institutions not to be institutions at all but the conditions there should be as homelike as possible. The conditions there should not be too different from the situation in the private home. In that way, you can have a continuum of existence in the family and in the care home and you wouldn't be alien in any place."

Minnesota's state institution services can be greatly improved through careful, thorough program planning and careful planning of additions and replacements of buildings.

Use of large dormitories, day rooms and dining rooms cause severe and detrimental "institutionalization" of the mentally retarded. Large buildings and grouping of large numbers of retarded can at least double the problems of the institution residents.

Proper planning can not only stabilize the number who need institutional care, but it can also create a wholesome, productive and pleasant living atmosphere for those who do need long-term care.

Our institutions can serve as short-term training centers for many retarded, but not as they are now constituted.

We need to eliminate the need for much sedation of patients (tranquilizers).

We need to provide dignity and comfort for many patients who are now living miserable and degrading lives.

What about the cost? It will be no more than it would be under our present system. We would be following the older countries and have the benefit of their experience.

It's truly amazing and almost unbelievable that a few thousand miles away, ten hours by air, the problems we are struggling with are being solved.

We need to move now while the climate is right and community support is at a peak.

There are sure to be some people who disagree with some things I have said. Certainly, some retarded benefit from our present facilities. With so many involved, some are bound to respond and fit in.

My recommendations are:

- 1) That all future buildings at state institutions be small, for 16-20 patients, with bedrooms for no more than three patients.
- 2) Each institution should have a work occupation center.
- 3) The state should support community supervised living units. These should be for 12 to 18 retarded each. Most of these retarded would work in the community and pay board and room. 60 to 80% of the operating costs could be covered by residents' payments.
- 4) State institutions should provide consultation for a region around the institution.
- 5) There should be a thorough study of charges for services both in institutions and community facilities. The present systems are haphazard and inadequately applied.
- 6) Centers for staff training should be established and salary levels of staff increased in order to attract and hold good people.
- 7) Strong centralized leadership through a Bureau or Division on Mental Retardation should be established in the Department of Public Welfare.
- 8) There should be a system of central registration to provide for adequate attention to the needs of each retarded person.
- 9) We must change our attitudes about the retarded. They do grow up. They do become adults. They can do more than we let them.

The time has come to stop changing terminology, to stop repainting and reorganizing old programs.

Our programs for the retarded are, I think, something like the boots and shoes referred to in the following quotation from George Elliot's story "The Sad Fortunes of Reverend Amos Barton": "Boots and shoes are the greatest trouble of my life. Everything else one can turn and turn about, and make old look like new; but there's no coaxing boots and shoes to look better than they are."