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ABSTRACT

The past segregation approach to the care of the mentally handicapped in Denmark is reviewed; the present normalization-integration approach, resulting in part from parents' associations and recognizing the basic rights of the retarded, is explained. A survey is then given of the Danish system, including services, facilities, budget, and regional organization. (JD)

PROGRAMS FOR THE MENTALLY RETARDED OF DENMARK

by N. E. Bank-Mikkelsen

Cabana Motor Hotel
Atlanta, Georgia
October 7, 1969

Southern Regional Education Board
130 Sixth Street, NW
Atlanta, Georgia 30313

INTRODUCTION

The Mental Health Unit of the Southern Regional Education Board is pleased to present this speech by Mr. N. E. Bank-Mikkelsen, Director of the National Services for the Mentally Retarded in Denmark.

This speech presented on October 7, 1969, in Atlanta, was the keynote presentation of a meeting sponsored by the SREB, involving over 50 persons from 10 Southern states. The meeting was planned in conjunction with a visit to the United States by Mr. Bank-Mikkelsen and the Danish architect, Mr. J. Malling Pedersen. It provided an opportunity for southerners involved in mental retardation to hear, firsthand, of the Danish programs of staff development and training, overall programs for the retarded in Denmark, and a discussion of some of the more recent advances in the design of facilities.

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We are happy to be here in Atlanta. It is the first time Malling Pedersen and I have been this far South in the United States.

I had earlier become acquainted with the Southern Regional Education Board. In 1961, SREB sent a study group to Denmark, and I spent a week with the six participants, among which was Dr. McPheeters. It was during the early stages in the development of a new phase of our work with the retarded. Even so, we had something to show to the visitors. Some of our new facilities were coming into being at that time, and we had a very good discussion of philosophy and goals and so on. It was the first group from abroad which came to our country after we had new legislation concerning the mentally retarded in 1959. You know, the first guests you have in a new house you remember sometimes better than others. So I am happy to come here to the Southern states and discuss things with you.

In order to discuss our programs, I think it is necessary to tell just a little of the history of how our efforts in the area of mental retardation started. We started in Denmark in 1855. (As far as I know, you started in this country in 1847, by founding a school in Waverley, Massachusetts.) It was in this period that the pioneers of this field started to work, and they were very optimistic at that time. It was believed that mental retardation would be cured, and they were looking forward to that day when we could cure "idiotism." But of course, we never experienced any cure. In my country, after five or ten years, we dropped this optimistic goal and adopted the philosophy that we should just take care of the mentally retarded, and developed custodial care systems. We segregated the retarded from the rest of the population, and placed them in large institutions in remote places - often in very beautiful places - but out of sight, far away from the community, because we regarded them as a special group with special needs. We believed that these needs could be satisfied in such places. This development of custodial care continued up to the middle of this century. (You have many examples of this kind of care in this country.)

In the middle of the century something happened. I will not try to analyze it, because it is only in future years that we can analyze accurately what is now happening, or has recently happened. But one thing which has been very important all over the world is the creation of the parents' associations. Without the interest of this group in my country, we could not have done what we have done in the last 20 years. The parents' associations have represented a new point of view of the retarded - the old feelings of shame and guilt have not come to an end, but changes have occurred in the attitude of parents. Now they dare to admit they are parents of retarded children. We had a public discussion of what was needed for the retarded, and the parents claimed that their children should have the same rights as other children in society.

I think we cared pretty well for our retarded during the first part of this century, but we are doing things quite differently now. Our philosophy has changed; we are moving away from segregation and into integration theories and toward normalization principles. We discovered in the early fifties that we had to change this segregated, custodial way of caring for the retarded. We sat down in a governmental committee which prepared new legislation that came into force 10 years ago, the first of October, 1959. But early in the fifties we were already planning along these new lines. Especially we had started to think of building new physical facilities for the retarded. (Architect Malling Pedersen later on today or tomorrow will tell you about these developments, and I hope it will be possible to show some slides on what we are doing in this field.)

We changed the attitude of the past into what I call a normalization-integration approach. Normalization does not mean that we are trying to make the retarded into a so-called "normal" person. We don't know what normal is. We don't know what mental retardation is, either. Normalization means that we want to create as normal living conditions for the retarded as possible. What is normal life? That would be difficult to define, but normal life is something like the way all other people are living at the time.

I don't think that we could talk of normalizing without discriminating between children and adults, because the normal life of a child is very different from the normal life of an adult. In the past the mentally retarded were often looked upon as children throughout their entire lifetime, but of course children grow up and you cannot deal with retarded adults as if they were children. A normal life for a child is to be in the home, if possible. Yet we know that this is not possible for some of the mentally retarded; some are so badly damaged that their parents cannot have them at home at all. For these, we offer a "home" in one of our facilities.

A normal life means that you will have to consider the place you live, the place you work, and the place you spend your leisure time. These are three aspects of normal life. To live at home is normal for children. It is normal for children to go to school, to have leisure time, and for the retarded, to have a chance to learn to do what other children can do. If it is possible for retarded children to live at home they will need kindergarten or pre-school facilities, schools facilities and pre-vocational and vocational facilities later on in life. Our law of 1959 makes education mandatory from age seven to age twenty-one. This is one of the civic rights we now have given our retarded. If a child cannot stay at home, because of his condition or because of the home conditions, it is our duty to offer a place in a facility for that child.

It is our duty to give him a place where he can live, where he can go to school, where he can have leisure time. In these facilities we try to create as home-like a condition as possible. That means small institutions. What is small and what is large? In my opinion, an institution of 300-500 is of adequate size; more than 500, I would call a large institution. We will never in the future build institutions or facilities of more than 500, and we prefer to go down to between 200-300. And we prefer to divide them into facilities for children and facilities for adults. In these facilities, we have small living units; that is, houses with from 12-16 beds where it is possible to divide groups into subgroups of four or six. The smallest houses we have in our older and larger institutions contain five bedrooms. For children we have one, two, and four bedrooms, and we don't want to have more than four children in a bedroom. Let me admit that from the past we still have some dormitories of up to 32 or 36 beds, but this will be changed in a short while. We prefer to give them a small place to live with small rooms. In a facility of 200 or 300, we are aiming at creating a daily rhythm like they would have if they lived at home. They have living quarters and move from these living quarters to a kindergarten within the institution, or to a school. So they have the same rhythm of life as if they lived outside the institution.

For the adults things are a little different - it is not normal for an adult to stay at home. When one reaches the age of 18-21 years, it is normal to leave the parent's home. But all too often parents want to keep their retarded adult offspring at home, thus running the risk of over-protecting them. We want to break this attitude of parents and to offer these adults a chance to live outside their own homes. This is a hard job, but it will come in the future. Already now most of the retarded adults live outside large institutions, and many of them still live in their parent's houses. But the trend for living quarters for those who are mildly or moderately retarded and some who are severely retarded is toward the small group homes or hostels. This is a new development. Of course some of the retarded will have to stay in large facilities all their life because they are so severely damaged that they have to live in the same place all their life.

As I said before, we prefer to have one institution for children and in another place an institution for adults, because the children's milieu should be a little different from the adult milieu. Many retarded we have in large institutions will stay, but many can be moved out and live in the community in these small houses. We have more and more of these now with a maximum of 20-24 persons each, and preferably both sexes. Bringing sexes together provides real problems in my country, but we are progressing.

Retarded adults have a right to work, and they can and should have work in either sheltered workshops or in open industry. You can have sheltered workshops within the large institutions - you can also have sheltered workshops in towns and cities. We have quite a number of these now. Modern industry has been a good thing for the handicapped, because there is always something in modern industry that can be done by a handicapped person. It is much easier in some ways to be handicapped today than it was 25 or 50 years ago. At that time we placed them on farms to do the work there. They lived in loneliness on the farm and were dependent on the people of that farm. These were not good conditions for retarded people. Now we have them working in sheltered workshops where they do a very good job. At the same time we are using these sheltered workshops, we are creating living quarters for them. We now have about 20-30 hostels.

I will give you some exact figures in a few minutes. This is just to outline the normalization principles. I am talking about where to live, where to work, where to find recreation opportunities - the same needs that other citizens have in normal living. For instance, I can tell you it is now common for groups of our residential retarded to go abroad on holidays on charter flights, charter buses. They are going to Italy, Spain, Germany, and to the Scandinavian countries too. We have an exchange in the Scandinavian countries between institutions for the retarded so that they can visit each other during the summer holidays. Of course some of our personnel go with them. They are behaving very well. We used to say they are behaving much better than an ordinary Danish tourist will when he is abroad.

This is some of the philosophy behind the normalization principle. This came into being in the fifties. Those who want to study these principles should read the recently published book by the President's Committee on Mental Retardation entitled Changing Patterns in Residential Services for the Mentally Retarded*. It discusses normalization principles. I have written a little of it and two of my friends from Sweden have also contributed to it. Especially interesting is an article by Bengt Nirje, who is the so-called ombudsman for the parents' association in Sweden. He has elaborated very well on the theme of normalization in this book, and I highly recommend it to you.

I feel that the normalization principle will be a challenge to us in the future. It has been a challenge to us; we have had quite a fight of it in my country, because some of those who have been working in the field for many years did not believe in the human rights which are present in these normalization theories.

And behind our program is the attitude that we don't want any discrimination, negative or positive, for any group in our population. We want the retarded to have exactly the same rights as any other people have. As you may remember, there

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*President's Committee on Mental Retardation, Changing Patterns in Residential Services for the Mentally Retarded, ed. by Robert B. Kugel and Wolf Wolfensberger (U.S. Department of Health, Education, and Welfare, U.S. Government Printing Office, Washington, D.C., 1969.)

was the Jerusalem Conference in mental retardation last year, arranged by the International League of Societies for the Mentally Handicapped. The conference agreed on a declaration of general and special rights of the mentally retarded. It gave to the mentally retarded the same basic rights as any citizen; the right to proper medical care, physical restoration, education, training, rehabilitation and guidance, as would enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. The mentally retarded have a right to economic security; to a decent standard of living; the right to do productive work in a meaningful occupation; the right to live with his own family, or with foster parents; to participate in all aspects of community life; to be provided with appropriate leisure time activities; the right to a qualified guardian when this is required to protect his personal well-being and interests; a right to protection from exploitation, abuse and degrading treatment; a right to a fair trial. These are rights that we want to fight for. Also, the right to have a family, to have children, to have a sexual life. These latter rights are very controversial problems - more controversial in some countries than in others. It is our philosophy that the retarded have the same rights as other citizens and the same duties. If they earn money, they have a duty to pay taxes.

Let me tell you a little of our system, how we are working in the field of mental retardation. In Denmark we have a population of five million. The state is a small country 180 miles from west to east, maybe 200 miles from north to south. It is a small place which is rather densely populated. This gives us some advantages that other countries don't have. All our day facilities can be reached within one hour; all the children can reach our day schools within one hour.

The government is responsible for all kinds of services, ranging from hospital-like services to economic support to families that need economic support to have their children at home. We have registered about 22,000 mentally retarded in Denmark.

The prevelance figure for 22,000 mentally retarded persons is nearly five tenths percent. This includes all levels of the retarded, including the mildly and moderately retarded. We have compulsory education and we have adequate schools for all the mildly and moderately retarded, and all the retarded can and must go to school. We need a number of new schools - training schools - for the so-called trainable, and facilities for severely and profoundly retarded. These individuals also have a right to education. We are involved in public education for all levels of the mentally retarded.

During the first five or six years of a child's life we have only registered those who are severely or profoundly retarded. (A mildly retarded child can pretty well live his own life.) We have in our law a duty for all doctors, nurses, midwives, kindergarten teachers, kindergarten leaders, and so on, to refer to our system any retarded child with whom they come into contact. They are referred to our central office or to one of our regional centers. I think that we have registered nearly all those who are retarded and are in need of any kind of help. So I guess that the previously mentioned prevalence rate of five tenths percent would be correct. In some of the age groups we have more than a five tenths percent. The maximum will be in the age group of 16-20 years, where we have a prevelance rate of about .85 percent. But after they are through school, many are able to go out and support themselves and if they can support themselves, they should not be regarded as retarded, even if they have a lower than average IQ. So many of this age group will be dropped from our registrations and be able to care for themselves, maybe for the rest of their lives.

Of the 22,000 total, about 10,000 are in residential facilities. There are two beds per 1,000 inhabitants. You may ask is this enough bed places for the total number of retarded we serve. Of course, I cannot tell you exactly what will happen. I think more and more of our citizens will be badly damaged, because so many now will survive their births. Also, we will have more older people among the retarded, which will increase the overall number that we are responsible for. On the other side, maybe we can prevent some mental retardation, but it is too optimistic to believe that it will bring about a decrease in the number of retarded in our country.

I know that in most of your states you are planning a lower bed ratio of maybe one and a half per thousand. It depends a little on the definition of mentally retarded and what comprises the residential institutions. We must also consider the cost of residential institutions. A residential institution means a 24 hour service. I know that many of those 10,000 which in my country are now living in large institutions should not live there, but they came there at the time when we had only large institutions. If they have lived there 30 or 40 years, it's too late to move them. Sometimes you can do it, but it is very hard. They get accustomed to it after that period. But some of these can live in hostels. Many earlier were placed in what we called "family care," in a family where we put one or two together. However, we want to move away from families - move them away to live in hostels or group homes. We believe that it is much better for them, in general, to live in a group, where they have their own milieu. We have a number of 100-120-bed residential institutions. We are talking now about a total of 10,000 beds. The biggest institution now has 1,100 to 1,200 residents. It has come down from 1,600 to this, and it will come down further. The smallest facilities will be 10-12 bed, but many of them will be of different sizes.

The fastest development in the last 10 years has been the development of day facilities. Today we have about 150 day facilities, day institutions, and kindergartens, where we take in children ages three to seven. It is a kind of preschool. There are training programs in these kindergartens so that they are not simply babysitting operations. From the year seven, or maybe a little later, because they are not mature enough for public school, we have schools for the mildly and moderately retarded and we now have 10 or 12 training schools for the severely and profoundly retarded. But let me say here that in all of the larger facilities which we have inherited from the past, we now have kindergartens, schools, and sheltered workshops.

As I said previously, we want to have in these places the rhythm of lives; to live in one place, to go to work, to go to school, and so on. But the majority (12,000) of our mentally retarded population live outside residential institutions.

Many years ago we had about 30 or 40 facilities; we now have 120. This is remarkable, and we continue in this way, but not as fast as we had hoped, for we have economic problems. But we have been very lucky to have a good committee which is understanding of the needs in the field of mental retardation.

Let me tell of our budget. In 1959 our yearly operation cost was 52 million Danish kroner. Next year it will be about 600 million Danish kroner. We have some inflation, but take 20 or 25 percent from this, and it is still a real good development. It is not moving as fast as we had hoped for, but much faster than we believed in 1959. And we have in these days a very close cooperation with the parents' association. We also have parents who are criticizing very heartily: "Why are things not completely as they should be in this country?" This is very good.

Our operation cost will be about 85 million U. S. dollars per year. Besides that, we have construction costs of about 70 million Danish kroner which is about 10 million U. S. dollars per year. We feel that we need this amount for at least the next 15 years to erect houses, institutions, facilities, and to modernize some of the older ones.

Our system, in which the state is responsible, is the most simple system in the world. There is no question of federal money, no question of local money, and no question of private money - just a question of state taxpayers' money. It's easy. It's under the Ministry of Social Welfare. We have a directorate, a department, an agency; and I am responsible for this program in the Ministry of Social Welfare. We are administrating all the services from one central office. I am a lawyer, but I have been working in the Ministry of Social Affairs for some years and have been working with problems of the mentally retarded since 1946. I am chairman of this department and I am a civil servant. I have a board of eight people appointed by the Ministry of Social Affairs, including a representative from the Ministry of Education, one from the department of health, and one from the parents' association. I don't know if you have this system in any other countries. The parents' association is the center of the Executive State Board. There are also five politicians representing the parties in our Parliament. And we have a representative from the majority in Parliament, always. This has been good and has given us very little problem in our operation. These nine are the Executive Board, which is a multidisciplinary board. This is one of the key words in our organization.

This country of five million is divided into 11 regions. We'll soon have 12, with an average of about 400,000 to 500,000 in each region. Four hundred thousand is a typical region in a small area, because the country itself is small. In these regions by law, we shall have all kinds of facilities for citizens to fulfill the goal of work with the retarded - the goal of normalization and integration. In each region we have a central institution, not larger than 300 beds. We have a number of schools, kindergartens, sheltered workshops, hostels, and so on. We have about 270 facilities in all, about 25 institutions of different kinds in each region.

Our theory is to offer help where it is needed. Parents shouldn't have to send their children far away. They should be able to visit the child in the facility, and to have the child visit the home during weekends and holidays. The same is true for adults. In the central institution we have equipment for many kinds of treatment, but this is divided into a therapeutic area and living quarters in our new facilities. In some of the old institutions we don't have all the desired services. Although we have a system which is developing very quickly, it will take us time to have a complete change from the past. So we have still some places which we are not so proud of.

Each of the regions has a core administration consisting of four persons; a business manager, the chief physician, the director of education, and the director of social work. Again you see a multidisciplinary approach. We used to have a psychiatrist as a director for all the things going on within a district. Now we put four people around the table and ask them to work together in a team, and it has worked out pretty well. We had some problems in the beginning, but it is better than we hoped for. This is a new way to do social work, and I think in the future we will work this way, not only in the field of mental retardation, but in many other fields such as mental health, child welfare, and so on. We will have to put these professionals together and ask them to work together in a team with their different skills. I think we have done pioneer work in this process of working together in the field of mental retardation.

We are now planning new general legislation in the social area in Denmark. I think that some of the theories we have had in our programs will be transferred to other areas. I hope so, and believe earnestly that in the future we will have to help others plan.

We have a large staff, of course. We have administrators, doctors, psychiatrists, child psychiatrists, pediatricians, and other medical specialists, mostly as consultants. Our total staff in the medical field is 90 full-time physicians in the whole country. The total staff of teachers, including kindergarten teachers, is about 900 now. It was 125 ten years ago. But we have a vacuum in the number of social workers in my country - I would guess that we just have about 70 to 80 for all of our programs. Some other staff are working under the supervision of social workers as assistants. Then we have a staff, most of whom work inside residential institutions. We have special education and training for this staff. We call them care assistants, and they undergo a three-year training period.

Let me stress that the main principle is equality, equal rights, even for the profoundly retarded. In our interpretation of equal rights, we feel that we should endeavor to create normal living conditions. It means, too, that we should aim to integrate the retarded into communities.

I don't like to boast, but before ending my talk, I would like to relate a funny experience a few months ago in Germany. A group of teachers met in Berlin. They had been studying in the same year mental retardation and special education problems in Scandinavia and Denmark. They included a number of students from India. One of these teachers told me that they used to tell people when they were depressed that they should be either a cow in India or retarded in Denmark! I am telling you this because we have been so happy to have good conditions.

But as I told you before, we will have to keep up with much more development in the 70's. If not, we will have criticism both from the parents and from the population in general. Another important fact is that we have tried in the last 10 years to educate the people through public education, using modern communication means - radio, television, and the press; by inviting them to come and see how bad conditions were in some places and how good it could be and it is in other places; by pointing out that it is just a question of money. Staffing is not a problem; we have more applicatns to work in the profession and in our facilities and institutions than we have job openings.

This problem of educating the public to what is going on and what we can do is a major part of my job. It may be the most important part of all, because it is creating a good public understanding that the legislators must follow. We have in our country no complaints from taxpayers about money going to this field. There are many other problems that taxpayers are complaining about, but they are not complaining about paying money for the retarded. We want the future of the retarded to be brighter and brighter, and we want to do things better in the future.