NEW CHALLENGES IN THE CARE OF THE MENTALLY RETARDED -- AN INTERNATIONAL PERSPECTIVE *

Gunnar Dybwad, Director, Mental Retardation Project -- International Union for Child Welfare, Geneva.

The rapid increase in knowledge about mental retardation and about new methods in the treatment and rehabilitation of the retarded which has characterized the past 15 years has pointed up the desirability of international exchange and communication among those working in the field. My wife and I have just come from a small international seminar on sheltered employment held in Frankfurt, and it was very impressive to us that a physician from New Zealand, who has worked in this field for the past ten years, travelled 11 000 km. just to attend this three-day conference where he could exchange ideas and experiences with experts from 15 other countries, and gain a better orientation to new trends and practices.

This symposium, by the way, made it quite clear that there is not any one country where one can find the latest techniques and approaches to sheltered employment – everyone found new knowledge to take home.

For the past several years my wife and I have travelled in more than 20 countries, and have been in correspondence with colleagues in many additional countries, on every one of the continents, and I am glad to follow Mr. Bank-Mikkelsen's invitation to discuss with you today, from an international point of view, "new challenges in the care of the mentally retarded".

Coming to this annual staff meeting of the Statens Andssvage-forsorg provides me with a new and interesting experience. I do not know any other country that brings together, in so large a number, a broad cross-section of its mental retardation staff for three days of intensive discussions, but this is quite in keeping with the outstanding development of staff training in your country.

Things are of course far more comfortable for a country with services of mediocre quality, because one can always keep up without trying very hard. But once a country is among the leaders, as Denmark is in mental retardation, then one has to be forever alert to learn, to improve, to keep up with new knowledge and new methods in care, treatment and rehabilitation and with new ways of training and utilizing personnel. We have a saying in the U.S.A. that a laurel wreath is not something to sit on and rest – it is a distinction that has to be earned every day anew. Obviously not everything that has proven successful in one country at a particular time is of necessity usable in that form in another country. The point of international exchange and international communication is not for one country to copy what another is doing but to study what has been successful (or unsuccessful!) somewhere else, and see what can be learned and adapted from it.

* Presented at the Annual Staff Development Conference of the Danish Mental Retardation Service, in Nyborg, February 15-17, 1966.

I shall speak to you mainly about the more severely retarded since that is the main topic of your meetings this year. My examples will be taken mainly from institutions because much off the day care ("externat") of the severely retarded is still patterned after institutional experience and is frequently staffed by persons with institutional background.

However, in discussing institutional problems, I shall ignore those that usually receive attention in public meetings, as for example, whether institutions should be large or small, whether they should be located in the open country or near cities, whether there should be different institutions for different types of mentally retarded persons or whether it is better to have all types and all grades in one institution together.

Instead, I want to discuss with you today some thoughts and observations on the details of the day-to-day routines which make up institutional living and which, according to the plan of the central administration, represent what is called care, or treatment, or education, or recreation, or rehabilitation.

Merely to enumerate in one sentence all these broad objectives indicates the complexity of the task that is faced by our "externats" and "internats", but these are only the objective goals. Subjectively, with regard to the individual persons under care, the further requirement is added that all these programs be carried out with full consideration of individual needs – but not only that -- because with regard to children and young people, yet a further requirement is made that whatever happens to them under care should resemble as much as possible what the normal child experiences in his own family.

Certainly this is a task which requires the utmost skill and knowledge and, may I add, personal devotion on the part of all the staff. Team-work, close cooperation between the various professional groups involved in these programs, is obviously a prime necessity.

Team-work is never easily accomplished when one deals with large organizations, but I want to call your attention to one particular problem involving this team-work which has impressed itself on my wife and me as we have travelled from country to country: in few fields of human welfare has there been such radical progress, such radical shift, not only in knowledge and skills, but also in attitude towards the problem of mental retardation, objectively, and towards the mentally retarded, subjectively.

This is of course what I tried to present to you last night in my presentation on the Dynamics of Mental Retardation. But such matters are far more easily presented in theory than they are realized in practice, and the problem I want to underline here is the following: an internat or externat for the mentally retarded is a complicated instrument that must be kept in balance. This means that when we have discovered new knowledge, new skills, new methods in medicine, in education, in social work, in rehabilitation, they cannot be applied effectively unless we carefully consider <u>what changes the new approach in one area of activity necessitates in all the other areas.</u>

I realize that presented in such general fashion this may sound rather theoretical. However if you stop to think of your own experience, I am sure you will remember occasions when you were informed of some procedure involving, for instance, the educational program, and you wondered how this could be worked into the already existing routines, time schedules and personnel requirements.

Therefore when I now proceed to talk with you about the impact of new challenges on old procedures, I want you to know that as people who have themselves worked for many years in institutions, my wife and I realize from own experience how difficult these problems are in day-to-day practice.

As one visits many institutions in Europe and North America, (and from plans I have seen, the same would be true in the developed countries elsewhere), one recognizes quickly which buildings are set aside for the severely retarded. They are usually in the rear of the institutions grounds, often hidden behind trees, farthest away from the building housing the directorate of the institution, farthest sway from the administration building and the gymnasium, the auditorium and the other buildings devoted to education and recreation. Not only are the severely retarded often housed in larger buildings, but their day rooms and dormitories (group bedrooms) are built to accomodate much larger groups than those for the less severely retarded. Frequently one finds less color on the walls and furnishings. Indeed, there is unusually little furniture, the absence of tables in the day rooms being a particularly puzzling characteristic of the buildings for the severely retarded in traditional institutions.

Two comments need to be made at this point. One is that we have seen some institutions, built within the last three years in modern architectural design, where nevertheless there were no tables in the dayrooms for the severely retarded. The other is that, as I hope to point out to you, the main problem on which I wish to focus is not the furnishings themselves, but the basic thinking behind institutional practices, thinking which is not necessarily changed merely by the purchase of additional furniture, or a change in architectural design. As I tried to point out yesterday evening, we are dealing with long established prejudices which mark the severely retarded as essentially unresponsive and incapable of intellectual and social progress. Demonstrations in Denmark as well as in other countries have now amply proven that the severely retarded are indeed able to respond. Moreover, careful psychological experiments have brought to us scientific knowledge about the factors which promote, and the factors which hinder, such growth and development.

One factor which has been clarified by such studies is that the more severely retarded have difficulties in learning to relate themselves to other persons, and in an institution, this applies particularly to the staff. Therefore what we have done in the past was in direct opposition to existing need. On the wards for the severely retarded we had large numbers of staff taking care of large numbers of individuals. Moreover, for administrative convenience, we usually divided the assignments of the personnel by function, that is to say, one or two would supervise all the bathing for the whole group, while others meanwhile supervised the day room, etc.,etc..

Controlled experiments have shown distinct improvement in the performance and progress of the severely retarded when such a ward was subdivided so that one staff member looked after all the needs of a small number of those in the ward, whether it was in the day-room at mealtime, during bathing or any other activity. Thus the individual retarded person was no longer confronted by a, to him bewilderingly, large succession of staff members , but could begin to form, in his very slow way, a personal relationship. This type of

organization may be bad for what is called "ward efficiency", but is important for the efficincy of the retarded individuals. There should be no question which efficiency is more important.

Similarly, psychological experiments have shown that we need to give more thought *to* the visual and auditory environment of *the* severely retarded. Where institutions have departed from the old gray institution wall color and have tried to provide more cheerful surroundings, they usually have decorated the walls with pretty pictures of the style of Hans Christian Andersen's fairy tales or, in the U.S.A., Mickey Mouse. Yet there are indications that the severely retarded, in his development from primitive to more refined sensory reactions, will respond to the simple basic colors in simple geometric designs. I have not yet seen studies as to the type of music or simple rhythm to which the severely retarded respond most favorably, but undoubtedly here, too, wo have much to learn.

Let me now turn to a quite different aspect of the routine on the wards. In most institutions great emphasis is put on cleanliness and orderliness. Much time, indeed all too often, too much time is spent on polishing the floors and windows and on shining the tile in the bathroom and toilets. But after all the polishing of the ward itself has been done, then all too frequently one can ohserve procedures more immediately affecting the severely retarded himself which are not suitable to help him develop his own sense of personal tidyness and appropriate social behaviour. Just one example may illustrate quickly to what I am referring:in the pressure of ward routine, it can frequently be observed how one child is being fed in bed or at table in a room where there are other beds, while right next to him another staff member changes the dirty diapers of another child. The staff members doing so would, in their own personal life, react with horror if they or their children were subjected to this kind of living. I don't think I need to go into further detail how our past beliefs about the insensitivity of the severely retarded have indeed made it very difficult for them to develop that kind of sensitivity which is essential to social acceptability.

It is on this same basis that there is increasing objection to the open toilets (i.e. a row of toilets without any partitions between them) so characteristic of institutions, and unfortunately, also of some of the day facilities for the retarded. Just because the training of severely retarded children is a long process due to their slow rate of learning, it is so very important that we train them in correct patterns of social behaviour, not in ways dictated by the convenience (or should I say again "efficiency"?) of the institution.

This last statement should of course apply very much to the question of daily scheduling of activities. We still encounter in our travels institutions where the rhythm of life, i.e. the sequence of the main daily activities, varies all too much from what would be an accepted way of life in that particular country or locality. This especially applies to the early hour when the severely retarded are put in bed. Even more questionable appears today what used to be the mark or the sign of a well run institution: a tight schedule of activities from the time of rising to the time of going to bed. To be sure, this was once an infinite improvement over the previous institutional lethargy or chaos. Today, however, it is recognized that even the severely retarded child or adult needs to learn to develop initiative in chosing some activities of his own. For this he will need space, time and guidance.

I am very much impressed by the way in which new patterns of institutional architecture, notably those developed in the Nordic countries, are providing this space. I am referring specifically to the small rooms for two, three or four children or adults which are no longer designed just as bed-rooms, but as a combination of living- and bed-room. We have seen quite a few of these new institutions, but, particularly as far as those for children were concerned, the tables and chairs seemed to be unused and everyone was gathered in the common day-rooms. I do not underestimate the difficulties of such a shift in institutional routine. The fact remains that the architects have designed buildings for us which we have not yet learned to utilize to their full potential.

One might well say that this task of developing initiative is a crucial issue in the new patterns of training of the severely retarded. Professor Jack Tizard of England, in his famous Brooklands film, has given very good examples of what happens when everything is done for the children, instead of demands being made on the children. The fact that this part of the film was taken at the Fountain Hospital, a very old and unattractive London institution (which has since been closed), may mislead some who see these pictures to think that this is a thing of the past. Unfortunately however, neither modern buildings nor modern and attractive furnishings provide of themselves a correction to the old practice. All too often old routines move into new buildings.

I would like to mention here a particular area of institutional living where this whole question puts us before some rather difficult decisions, and that is the management of mealtimes. On the one hand, the modern institution is emphasizing the importance of eating in "family style", with the food being served at a small table. On the other hand, a good number of progressive institutions haver found that mealtime is an excellent opportunity to stimulate self-help, particularly in children, by encouraging them to get their own food and bring it to the table, and to assume responsability for clearing their own dishes from the table. Here again institutional "efficiency" quickly points to broken dishes and food spilled on the floor. Yet it is a wonderful sight to see the proud smile of the severely spastic child who has finally succeeded in bringing his tray to the table without a major upset.

In the report on our visit to Denmark last October my wife and I commented most favorably on something we had seen in Karens Minde, but in no other institution in any other country: pictures of the children hanging on the wall of their own living room. We thought this was an excellent way of helping these severely retarded children to a feeling of their own identity.

Such photos can help the children both to pose the question and give the answer to "Who am I?". But we must be equally concerned with the development of another part of what psychologists call the "self-concept" (concept of self), namely, the answer to the questions "What am I worth?", "What can I do?".

Of course many institutions provide some opportunity for the children to "do something" in the kindergarten room, but unfortunately too many such activities tend to have a rather artificial value only. In the real life situations, or, as the new term goes, in the Activities of Daily Living (ADL), there remains too often the old institutional pattern which fosters overdependence.

The comments just made with regard to kindergartens should not be interpreted as a lack of appreciation of their role in the development and training of the severely retarded young child. Indeed, whether such children are in an institution or are living at home or with foster parents, a good kindergarten experience is absolutely essential, far more so than for the normal child. However, in order to be more effective, kindergartens will have to improve their programs, but particularly their selection of children. In many countries, and we must say Denmark among them, older children long past the normal school entrance age are assigned to kindergartens because of the unfortunate confusion regarding the concept of mental age to which I referred last night. Boys as old as 10 and 12 years of age can be seen sitting in kindergartens in many countries, cutting out paper dolls, making silver stars or playing sing-song games not at all appropriate for some one of their chronological age and physical development.

The time has come to acknowledge that the severely retarded school-age child should have a special school program, adapted to his social and developmental needs as much as to his physical and intellectual capacity. Such classes, serving children with I.Q.s between 30 and 55, formerly referred to as imbeciles and today as moderately and severely retarded, are in existence as part of the public school system in various countries, whereas in other countries they are operated under other public or private auspices. One hardly needs to emphasize that the existence of such programs enables many families to keep their retarded child at home.

From the point of view of the kindergartens, the removal of these older children naturally will make it possible to provide the younger ones with a more intensive program. Reduction of the size of kindergarten groups will very much aid in achieving better results, but so will attention to the physical surroundings. For the very young severely retarded child spatial concepts develop slowly. He gets bewildered not only when he is with too many children but also when the room of the kindergarten is too large, (several smaller rooms being preferable to one large one). Many kindergarten rooms we have seen are so full of equipment, knick-knacks, and large collections of the children's work that they must be bewildering (and this of course means frustrating) to the children.

The point just made that kindergarten rooms should not be too large must be balanced against the need for a program which does not limit the kindergarten experience for these children merely to sedentary occupation. Both indoor and outdoor play space is a great necessity because one of the important functions of the kindergarten is the teaching of free play.

There is growing recognition throughout the world of the fundamental importance of <u>early</u> training for the severely retarded. This represents a real change, indeed, a direct reverseal of previous thinking. Many countries had laws (and quite a few still have them) delaying the age of school admission for retarded children in general, and in particular for the severely retarded, where such services were available. These old laws and policies were based on the simple assumption that because retarded children are slow to develop, we should be slow to admit them to educational services.

Today's thinking goes in the opposite direction: because retarded children have difficulty in learning even the simple steps of human adaptation which the normal child usually absorbs just by imitation,

and because they need considerable guidance and exercise to develop the sensory and motor skills basic to all further learning and social experience, severely retarded,even more than other children, need kindergarten training. (Time does not permit me to broaden my discussion to include the whole subject of needed guidance to parents of these children, so that already in the pre-kindergarten years they can provide special stimulation and repeated learning experiences.)

In view of the importance which is given to the kindergarten training today, institutions in many countries are now adding well-trained kindergarten teachers to their staff. This is a most welcome move forward, but unfortunately there always seems to be the tendency to repeat the same mistakes with every innovation we introduce to institutional programs. What one often observes, for instance, is that the institutional kindergarten program is considered as somewhat of a reward for good behaviour: because available rooms for kindergarten training are inadequate, since the institutions did not originally plan for this, only selected children are given such training and the ones selected are children who appear alert and active and do not cause major problems. This reminds me of the old saying that "the rich get richer and the poor get poorer." It is of course especially the "poor"children, those who are unresponsive, or those who cause trouble on the wards, or those who show particular agressive behaviour who need the intensive guidance of the kindergarten teacher.

Also, one invariably finds the kindergarten groups overloaded. With the severely retarded very young child, a group of 5 or 6 is not only all the teacher can handle but also as large a group as the children themselves can profitably utilize. This necessary limitation on the number of children in the group can be balanced out by having shorter periods for each group, so that each morning and each afternoon several different groups of children can receive this training.

But even this still does not yet adequately meet the needs of the institutional situation. Reference was just made parenthetically to the help parents need in the care and guidance of their young severely retarded children. In similar fashion it now has been recognized in some progressive institutions that it is by no means enough for the kindergarten teacher to take certain children out of the ward for more intensive training elsewhere. What is needed is to have the kindergarten teacher participate on the ward to assist and guide the ward staff in giving all the children there more meaningful play and learning expe-riences.

Obviously one kindergarten teacher cannot do all this, and obviously not all institutions can immediately adopt such a program to the full extent. What can be done, for instance, is for the kindergarten teacher to have selected children for part of the morning only, and to spend the rest of the time in the dayroom of the ward (or outdoors) with the rest of the children. Another useful system is to, allow one of the ward personnel to work with the small kindergarten group while the kindergarten teacher works with the other staff member in the larger group.

All of this points up one essential change of orientation toward which more progressive institutions are moving: a much more effective coordination and eventual integration between the ward personnel and the educational staff. The goal of such institutions is to have the day-to-day routine on the children's wards, the Activities of Daily

Living, reflect increasingly sound child development principles.

With the removal of the older children from the kindergarten groups, various countries have developed new progrms for the severely retarded, under such names as junior training centre, life classes, beskaeftigelseskolen, Klassen fur Praktisch Bildungsfahige, instituts medico-pedagogiques. The problem all countries are struggling with in these classes is to develop a lesson plan , a curriculum, that has real meaning for these older severely retarded children. In that respect much has been learned from the sheltered workshops, because there severely retarded young adults have had a chance to demonstrate how well they are able, with proper guidance and training, not only to be engaged in useful work, but also to adjust to a working situation.

Psychologists and leaders in the field of special education are at present trying to translate this new knowledge about the work performance of the severely retarded into a sensible school curriculum.

I have perhaps dwelt too long today on the new tasks of those working with the young severely retarded child, but their work is so basic that from its success will depend the changes that can and must be made in the programs for the older children and for the adults.

Time does not permit me to talk on some other topics much under discussion in various countries. One of them pertains to urgently needed improvements in the physical education, in the outdoor activities of the severely retarded. But this is a subject on which you already heard last year from Dr. Annalise Dupont, and again yesterday from Mrs. Nadja Mac.

It relates quite closely to the task of improving the leisure time activities for this group so they can be more appropriate for the different needs of the older child, for the adolescent and for the adult.

Care of the multiply-handicapped, severely retarded with such severe physical deficiencies that his learning potential is extremely limited unless we first undertake extensive medical corrective steps, is another area where most remarkable progress is now being made in some countries, including of course your own. And it would have taken at least half an hour to give you an adequate account of the international seminar in Frankfurt last week which dealt specifically with sheltered employment for the severely retarded.

All of you here are engaged in a very exciting field of work, a field of work where rapid and indeed revolutionary progress has been made, requiring a constant effort to keep up with new knowledge and to learn how to apply it. But I also hope that you all feel it is a field of work which can provide us with much personal and professional satisfaction, a field where we can measure the results of our individual efforts not just by helping the helpless, but more and more by seeing how the helpless can be taught to help themselves.

It is a field of work which you share with colleagues from many other nations, as some of you may have been able to experience at the International Copenhagen Congress on the Scientific Study of Mental Retardation in 1964 (and *may* I say here that your foreign colleagues agreed that it was the finest, best organized and most hospitable congress they had ever attended). In our work for the mentally retarded

my wife and I, during the last 18 months, went from the Kingdom of Greece to the socialist republics of Yugoslavia, went from communist Poland to authoritarian Spain and from there on to the democratic Nordic countries. It was deeply interesting that, notwithstanding the strong differences in political philosophy and governmental organization, in cultural heritage and economic development, the basic day-to-day problem in the care of the mentally retarded presented the same challenges.

I have discussed with you today just a few of these challenges. It is my sincere hope (and may I add, a hope of the International League of Societies for the Mentally Handicapped), that ways will be found to organize international exchanges of staff, so that some of you may change places"with your counterparts in another country for a period of several months, and thus have an opportunity both to benefit yourselves from what can be learned in such other countries, and to let them have the benefit of knowledge and methods developed here, which have made Denmark an acknowledged leader in this field.