

Gunnar Dybwad  
**The Mentally Handicapped Child Under Five**



## PREAMBLE

"One of the factors which interferes with clear thinking on the part of society's professional representatives in the area of retardation is misguided sympathy with the misfortune of the parents of retarded children, which feeds into circular mismanagement of the total problem through "weaseling" methods of coming to grips with its interpretation and with action.

Granted that to have a mentally retarded child is an unfortunate event, it is not the only unfortunate event that can and does happen to people, and action stemming from sympathy *only* is likely to be limited in value and not necessarily wise in judgment.

I submit that parents need, first of all, information. They need this to be presented sympathetically but factually and honestly. They need it to be personalized for their own child and their own situation, but in the framework of broad professional knowledge and experience with the total problem of retardation.

They need practical kinds of help with behavior management, understanding, acceptance, fostering growth in independence and self-sufficiency, avoidance of secondary emotion and dependency problems of the retarded child, avoidance of intra-family problems related to unequal distribution of parental attention and reward.

They need informational steering toward sources of help—not only counseling and supportive kinds of help, but planning help, knowledge of resources, and help in selecting those resources appropriate to their needs and situation.

I submit that we have often short-changed parents through trying to counsel them in accordance with what we think they want to hear, rather than what we know to be true. We have been fearful of putting our professional knowledge to the test of individual application."

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## The Mentally Handicapped Child Under Five

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Tonight I would like to talk about a group of mentally handicapped to which very little consideration has been given. We have made great strides in providing for the older children, for the young people, and increasingly also for the other retarded, but throughout the world the group which has been most definitely neglected are the youngest children, not just the pre-school children in the general sense of the word, i.e. those of nursery school age, but right down to infancy. Therefore we shall discuss here the needs of these children and how to meet them.

### **CASE FINDING**

One of the reasons why these services have not been provided rests with the problem of finding those who need them. The reason we are beginning, in most countries, to provide large scale programmes at school age is simply related to the fact that at school age, in all civilised countries, we come, for the first time, face to face with the total child population. In the younger age groups we may have some voluntary services of nursery school and day care centers, but the farther down we go the less efficient mechanisms we have for really dealing with these age groups in large

numbers. Thus our first problem is case finding. How do we get to know the families with very young retarded children? One of the fictions you can read in many of our professional books and articles is that we can only find, as very young children, the most severely retarded, while it is said of the group generally called mildly retarded (you refer to them as E.S.N.), that we are not able to locate them until they come into school or have been in school for a year or two, then fail, and then we pick them up.

This may superficially appear to be a correct observation of how things are, but a quite incorrect and actually quite unwarranted statement as to how things could be. The more we provide the right kind of nursery school services and the more we provide, at an earlier age, services to young mothers and their infants, the earlier we will be able to identify these children—thanks to our increasing knowledge about human behaviour and its deviations, and especially about the reactions of infants in their bodily development as much as in their emotional, social and intellectual responses. I am not going to elaborate on this; I merely want to point out to you that in this area of case finding we already have many problems that need to be solved and to which we must direct the attention of our research workers. We definitely should be able to discover children who need our attention before we let them linger in an educational system in classes which are not prepared to serve them, resulting in a great deal of frustration for the child and as much for the family and the teacher.

Now, of course, in the case of the severely retarded child, the initial case finding is easier. The question is what happens after the case is found, and here, unfortunately, we have a problem of communication. How do we communicate what is happening nowadays to professional people who have long left the University or other places where they were trained? Because many of the people who see the young parent who has a severely retarded child—the obstetrician, the paediatrician, the nursing personnel, the almoner or social worker and so on—unfortunately, are usually most inadequately informed of what can be done today for these children, their initial reaction to the parent is to say nothing. That is number one, a negative case finding—a case has been found but nothing has been said or done about it. Or we have another type of case finding. Here a case is found but the parent is told "just wait, this thing may grow itself out."

In the third and very frequent type of case, the parents are

met with a great deal of sympathy and offered every possible consolation and moral encouragement, but nothing is conveyed to them as to what can be *done* for the child, and so, although the case is found, nothing really happens because nothing really has been set in motion. This case finding continues to be a serious problem, not only with the mildly retarded where we have not yet developed the proper mechanisms to identify them, but also with the more severely retarded where there is identification but nothing sufficiently useful is taking place.

After case finding comes diagnosis which cannot possibly be discussed here in detail; it would carry us into theoretical considerations that would not be of great interest to you. Let me emphasise one point—it is not at all always necessary to provide the parent with a detailed diagnostic statement. Indeed with our present state of knowledge very often even the best of clinics cannot give one. What needs to be given to the parent is some practical information such as "here is a child with special needs and you can do thus and so about these needs." This is far more important for the parent to know than just the fact that the child is bestowed with a condition that has a strange sounding Latin or Greek name.

### **SERVICES**

Now what kind of services should be provided for the under fives, through proper communication with the various professions dealing with this problem of early identification and diagnosis? First of all parents need to know something about the problem they are facing. A lot has been talked and written about the emotional disturbances one finds in parents of mentally handicapped children. This is often the kind of emotional disturbance that would hit anybody, because it is an emotional disturbance as a result of uncertainty. If any one of us here in this room has to meet any kind of life situation with a sufficient degree of uncertainty we become uneasy, and if this uncertainty lasts long enough we become increasingly uneasy, until our own breaking point is reached. *I want to underline that the greatest source of emotional disturbance of parents is this uncertainty—just not knowing what has happened—just not knowing what can be done.*

### **PARENT EDUCATION**

Therefore, I am putting at the very beginning of my list of needed

services parent education, not parent counselling and certainly not therapy. First comes parent education, because parents have got to know: what is mental handicap and what is mental retardation, what is the difference? Why do we say one day mental subnormality and another day mental deficiency? What does it mean to my child? Is this curable, incurable? What can these children learn? What do experts from the various professions know today that would entitle them to make predictions for me? What are some of the needs of these children, and above all, in what ways are they like other children (rather than unlike other children)? Thus parent education is the first step—straight-forward, good sound education on the new principles we have developed about learning, exactly the kind of methods which we are using now in business and the professions to convey new information to people. This can be provided quite easily, and it should be one of the main responsibilities of the public departments working in this area.

### COUNSELLING

Of course, parents face problems of management, and those will differ very distinctly from family to family. It makes a lot of difference whether you live in a city or in a village; whether you have many other children or whether this is an only child; whether you are an older couple having had a lot of experience in raising children but not knowing what to do with this one, or whether this is a first child. There are many problems—it may be a situation of resentment by the brothers and sisters or interference from other relatives or neighbours and so on. These kinds of questions still do not call for therapy, they are in the area of counselling, either individually or through group counselling, where parents can get together and discuss with skilled persons some of these problems which are general enough to be discussed in a group and yet specific enough to provide needed assistance to the parent.

### PSYCHOTHERAPY

Naturally parents of mentally handicapped children are as much subject to emotional stress and strain as any other group, and so among them too there are those who indeed need psycho-therapy, possibly because long-standing friction between husband and wife comes to a head under the impact of the birth of a retarded child. In this type of case, of course, we may need to call on psychiatric assistance.

The important point I am making, is that these are three completely separate processes: parent education, in which we provide information; parent counselling, in which we deal with some generalised problems, and finally psycho-therapy when psychiatric intervention is needed.

### **PRACTICAL HELP**

Particularly for the young parent of the severely and profoundly handicapped child information and counselling is not enough — what is needed is also practical help with specific problems of management. This is, of course, especially the case with children who have a combination of physical and intellectual handicaps and with whom it is often not easy to determine how serious the intellectual disability is until the physical infirmities have been dealt with. This home management help can be offered in many forms of service, by many types of personnel and under the auspices of different agencies, depending on the local situation, but this is undoubtedly a primary field for the profession you call Health Visitors (in other countries called Public Health Nurses) who can concern themselves with aiding the mother with such important tasks as feeding the child, managing sleep problems, the handling of the child who is spastic or has other physical disabilities. The Health Visitor does function with a certain degree of independence in her day-to-day work, but never without the direction of a physician, and in this type of case, competent paediatric consultation is especially needed.

The Health Visitor will also need to consult a Nutritionist, not merely for choice of diet but also for help with other feeding problems: children who do not swallow, or children who have tremendous difficulty in moving on from a liquid to a semi-solid and finally to a solid diet. This is a problem of such magnitude in families that it is really unbelievable that the health professions have, for such a long time, all but ignored it. In my travels I have encountered case history after case history where mothers have spent as much as five full hours a day trying to feed a severely handicapped child simply because nobody told them the "tricks of the trade." And if a mother who has other children spends five hours a day on feeding her severely retarded child, it is merely a matter of time before this family explodes. Unfortunately, our health visitors as yet have not been trained sufficiently in this area, but the knowledge is there to be taught. Books and slides are available with illustrations

on procedures they could learn in five easy lessons, but because they have not yet been taught this, they are not helping the parents in this area.

### **FAMILY HELP**

This is as good a place as any to mention something else and that is the strange notion, which even very intelligent people constantly reiterate, that we really cannot afford to do so much for retarded children because we have to worry first about normal children. Well, I do indeed worry about the normal children in a family where the mother spends five hours a day feeding the severely retarded child. In other words, retarded children do not live in isolation somewhere—they live in families, and to the extent that the parents have to spend an undue amount of time and money on the retarded child, the family unit gets interrupted and disrupted. In such situations it is obvious that the so-called normal children are damaged far more severely than the profoundly retarded child whose sensitivity, unfortunately, is so encumbered that he is not so aware of what is happening.

So please challenge anybody who puts forth the idea that we cannot afford to help families with severely handicapped children because we first have to help the normal children; it is on account of the normal children in the family born or as yet unborn that we must be particularly worried about such things as feeding problems. By the way, a very excellent report was recently published in London on what happens to families with severely retarded children. It is entitled "Mental Subnormality in London—A Survey of Community Care," and I strongly recommend it to you because it gives very excellent examples of the difficulties faced by such families.\*

Thus nutritionists are very important, and so are home economists, to give these parents some management help—how to organise a household with a severely handicapped child, how to work out schedules, where to purchase special clothing, and so on. Obviously we need the health visitor and a physiotherapist should also be on the team at least for consultation. All this should proceed under the advice and guidance of the physician, but we cannot possibly expect busy physicians to concern themselves with these problems other than to give direction.

\*It can be ordered for 7s. 6d. from the National Association for Mental Health, 39 Queen Anne Street, London, W.1.



## **GUIDANCE IN CHILD DEVELOPMENT**

As essential as these professional workers who can aid with the child's physical problems are, we need still another type of person. Retarded children have a different and very often irregular pattern of growing up, so that the guidance they need from parents has to be of a special nature—a more intensive guidance, a more definite helping along. Most people in this room know how hard it is to guide children in general—they sort of run away from you, they walk before you have time to tell them how they ought to be doing it, and they are off on their first motor-bike ride before you ever have a chance to warn them why not to do that.

Children grow so much by themselves that when faced with a severely retarded child parents do need the help and the consultation and the comfort of talking with somebody who knows something about learning and growing and who can reassure them, but also very definitely keep them from pushing too fast or still more likely, not pushing enough. Thus we do need guidance in the home for the parents with a very young retarded child—also in terms of his development in acquiring the skills, abilities and aptitudes which young infants develop through their stages of growth. You will recognise that this type of professional worker really hardly exists—what is needed here is a child development worker, a specialist in infancy and early childhood education—using the term education in its broadest sense, beginning with the earliest stimulation of cognitive responses of the child.

## **HOME HELP**

There is something else parents need: You cannot expect a mother with a severely retarded child (and even a mildly retarded child if there are other children in the family) to be on deck all the while. Your country has pioneered for many decades the Home Help service, women who can come into the home to take over the household duties, be it once a week so that mother can at least go shopping in peace and quiet, or more frequently if there is a really severe problem. The home help or homemaker service assists the family in managing this problem of having a severely retarded child by giving the mother just enough relief to enable her to carry her heavy burden, and to keep the child in the home and in the family unit, at least during his early childhood. Obviously both the form and substance of the service will differ substantially depending on whether we deal with a specific

management problem or whether we are dealing with general deprivation in the social economic problem area.

### **SHORT TERM CARE**

Let me go on to another type of relief for the families with under-fives. Some of these services are already established and are projected to be increased in your community, but I want to spell them out for those in the audience who may not so much use them as help pay for them. We must provide relief to mothers by day care services whether for a few hours or all day. In other cases night care may be needed such as where a mother is able, willing and eager to have the child during the day with her, but, particularly with an overactive child with sleep problems, at night there is just too much disruption in the family. Weekend and vacation care is needed at certain occasions or just plain emergency care because the mother is sick. *By offering these services we will very often avoid the necessity for the vastly more expensive continuous care in an institution.*

### **PRACTICAL ECONOMICS**

Now I realise that there are some people who always carry on some strange arithmetic with regard to their pants pockets. If the money comes out of one pants pocket they think it is much less than if it comes out of the other pants pocket; but ultimately you all are the tax payers, regardless whether a service is under one jurisdiction or another. If you can avoid full twenty-four hour care over long periods at state expense and instead have a partial service on a local basis at a much lower cost, you all have gained very substantially. Therefore, you have to look at the total cost of this problem at a long range, and consider that these new programmes of day care, night care, week-end care, emergency care can make the difference whether a family can themselves shoulder the responsibility or whether they are forced to ask the public to take over the care of the child. This is a very important point, a lesson in practical economics.

### **BABY SITTING**

Another service which many people do not take seriously enough as yet, but which is developing into a real community service, is baby sitting. There are now communities which have trained baby sitters—young girls and older women—for handicapped

children. They have taken a course and have been given instruction as to what they may encounter with a severely handicapped child. They know how to deal with a spastic child or one with seizures, they have learned when one has to call a physician and so on. Availability of this service is so necessary in this day and age of migration when we no longer have Grandma and Aunt Emily in the same town. Increasingly industrial firms shift their workers around on the map and more and more we find young families all alone in a community without the traditional family resources on which to call for aid in "minding a child." That is why the community must step in and provide this service.

### **PAEDIATRIC CARE**

Now I come to a more difficult problem, and that is the general unavailability of adequate paediatric care to parents of severely mentally handicapped children. This is an international problem. Somehow still today the majority of paediatricians and family physicians are not interested in taking care of these children on a day to day basis—though they may be interested on a theoretical basis, in reading articles and following research reports. But they do not seem to relate this to the actual health needs of these children.

Part of this puzzling state of affairs is explained by a long-standing medical superstition that mental retardation is primarily a psychiatric problem and therefore not the business of the paediatrician or family physician. I have just come from a consultation visit in a country where this is well exemplified. When a mother comes there to the Mother and Child Health Centre with an infant afflicted with Down's Syndrome (Mongolism) she is automatically told that she must seek help from the Mental Health Service of the State. But when she goes there, she finds no help because her child does not need a psychiatrist but good child health care, and specific guidance from the paediatrician or general practitioner. We encountered exactly the same situation in another country. If you wonder to what extent this is a problem in England just take a look in what neglected health condition children of five, six, seven and eight years are admitted to services offered by the local health authority or the regional hospital board.

What we need for the very young severely retarded child is good health supervision, more intensive supervision naturally

than for the child without such problems, but health supervision that is very much along the procedures of ordinary maternal and child health centres. We are dealing with feeding difficulties and other problems of the child's growth and development which should be the daily bread and butter activity of the physicians there. Many of these children have disorders in their sensory apparatus with vision, hearing and so on which should be attended to already in infancy. There may be a problem of cardiac involvement, a disturbance in the digestive system, spasticity, and any number of infirmities which could be remedied or ameliorated but all too often are not being attended, and as a result children frequently are quite unnecessarily further handicapped beyond the unfortunate disability with which they were born. I know this is not a medical audience, but here is a problem which concerns all of us. How you can press for its solution is something you have to consider from your knowledge of your own community and of your own country, but action is needed.

### **DOWN'S SYNDROME**

Let me come back as an example to the child with Down's Syndrome. It is most distressing to see how many of them are inadequately nourished by being kept on a soft (baby food) diet, and therefore are not exercising their jaw and mouth muscles which are crucial to the development of language. Thus the basic language deficiency which all these children show is further complicated by this faulty dietary management, simply because the mother does not have the benefit of continual adequate health supervision for the child. A similar problem for children with Down's Syndrome is the need for weight control, a typical child health supervision procedure. Why should we allow these children to develop an obesity which particularly in later life will prove to be a major obstacle to their social adjustment, but which already during early childhood unnecessarily interferes with active play and that means, needed social contact with other children?

Children with Down's Syndrome have serious dental problems (again aggravated by inadequate diet), yet they typically receive less dental supervision and care than normal children. Poor motor co-ordination, poor muscle tone, deficiencies of vision and hearing, and of the upper respiratory tract are other typical health problems of the child with Down's Syndrome. All

have long been proven to be open at least to substantial amelioration if proper medical attention is provided, resulting in a considerable improvement in the child's response to education and rehabilitation.

### **SPEECH PROBLEMS**

Speech problems are, of course, not just typical of the child with Down's Syndrome—they constitute perhaps the outstanding deficiency common to most retarded children. Unfortunately parents all too often neglect to encourage speech development, and with more severely retarded children they become so discouraged with the child's lack of response that they assume he will never learn to speak and as a result they talk less and less with him. They need therefore the guidance and encouragement of someone who knows about speech development and can demonstrate to them appropriate ways to speech stimulation, seeing to it that the child hears a lot of speech, that speech is directed at him. At a later stage an expert may decide that there is also need for specific speech therapy, but that is another matter. Certainly in the area of speech development we face a tremendous challenge with the mentally retarded under-fives.

### **LESSENING DEPENDENCE**

All the supporting services I have discussed, beginning with parent education, will bring to parents assistance in the management of the mentally handicapped child such as in toilet training, sleep habits, eating habits, choice of food, adequate physical exercise involving both small and large muscles, appropriate play activities, toys and speech development. Very important also is training towards lessened dependence—in particular accustoming the child to be away from home. It is amazing how many retarded children have never slept away from home, and how many have never been away from mother for more than five minutes.

Therefore, I do want to emphasise that with retarded children who are slow to progress and to get used to new situations, it is particularly important that parents are guided in preparing the child to be away from mother—to be away from home. Of course, this needs to be done slowly so that they can get accustomed to this in small doses. Unless we enable the child to be prepared in this way for a separation we quite unnecessarily provoke a crisis

for him, which in turn provokes a crisis for the mother, when at a given age he has to be away from home and is not at all ready for this. So here is another very important consideration for the under-fives. One mechanism for doing so, which does not cost the ratepayers any appreciable money at all, and does not have to wait on the construction of buildings and hiring of staff, is guidance to parents of retarded children in organizing small informal play groups for three or four other children, which can meet in the families' homes or in some other suitable location.

In the beginning they might meet only once or twice a week and for only short periods, but this will cut through the social isolation of these children which constitutes for so many of them an additional handicap. As the play group progresses, one or two mothers can take over, so that the other mothers can go shopping or have a peaceful cup of coffee while the children thus get used—in an environment to which they are getting accustomed—to have mother go away for an hour or two. At first the children may do no more than play by themselves, with the other children present in the same room, but slowly some limited group play and group interaction may evolve, resulting in a readiness for entrance into nursery school or kindergarten.

### **NURSERY SCHOOLS**

I do hope that in this city which has taken the leadership in developing nursery school services for the normal child, you will consider to what extent you can accept some handicapped children in these nurseries. This has been done very successfully and if it were not so late I could read to you some very interesting accounts from South Australia where on a Statewide basis all nursery schools and kindergartens are co-operating in accepting handicapped children, so none has to accept more than it can easily absorb. Obviously it has only good effect if a few handicapped children, prepared for this experience, can be integrated in a normal nursery school or kindergarten.

### **WHO AM I? THE SELF-CONCEPT**

I would now like to refer briefly to another need of the under-fives. This is the development of a self-concept and a self-image. Normal children easily progress through a series of natural growth experiences which builds up in them a sense of self. Retarded children not only are slower to perceive, learn, but their cycle of experi-

ences is more limited. They need more learning opportunities and instead usually get less. Too often there is failure on the part of adults to accent the individuality of these children. The questions "Who am I?" and later "What can I do?" give a clue as to what we need to build up in them. Obviously a degree of realization of one's being handicapped will be crucial for the self-image of the older child and adolescent, but with the under-five retarded the accent must be more on "what can I do?" I have also been interested in seeing how some progressive mental retardation institutions have used individual and group photographs and slides to develop in the children a body image, which, of course, is an indispensable part of one's self concept as a person.

### **PHYSICAL FITNESS**

As a final point I would like to underline the need to be more concerned with fitness of all retarded children. Here again the physicians should take the leadership and convey to parents the great importance of this. Of course, we have had traditionally some very destructive attitudes. What did we used to do with T.B. people? We put them in a sanatorium and made them neurotic. What do we do with T.B. people today? We put them to work and keep them active. When a young child had a serious operation or illness he used to be excused from physical exercise and gym, when just the opposite was needed. It is just the same with the retarded children—they need more rather than less physical exercise than the normal child. Now it is of course difficult to guide them in this, but this why parents need professional assistance to know how much they can ask of their child.

This emphasis on physical fitness is not just for the purpose of improving the health, stimulating the appetite and so on, but there is a very important other factor in this. So far nobody has given us the slightest hope that we can improve the brain substance once it is impaired. We only can give these children a greater capacity of using what brain substance they have. However, we can definitely help them to overcome their other physical disabilities in many ways through appropriate medical steps as well as through training. We can give them the best possible skill in throwing a ball, and what will happen when they know how to do this?—they will be more acceptable to other children, and when they are more acceptable to other children they will be in

more social contact, and when they are in more social contact, they will in turn be stimulated socially by these other children to the extent that they are capable of absorbing more. So, therefore, physical exercise is not just a health measure as far as these children are concerned, but very specifically a step toward social acceptability.

### **LABEL THE SERVICES! NOT THE CHILD**

I would now like to make one further comment because when I read the Annual Report of your Society I was made aware that you have become involved with the present controversy as to who should administer and supervise educational services for the severely retarded. I agree with your implied position—I think it was more than implied—that eventually we must come to the point where medical services are administered by competent medical authorities and educational services are administered by education authorities.

However, there is one sentence in your Report to which I want to take strong exception because it reflects the kind of thinking which has created a lot of confusion from the Ministry up and down. This is the sentence *"Your Committee have, of course, pondered long and earnestly the question of who should care for the severely mentally handicapped child. Here again it is not a matter of sharp division but your Committee are confident that it will be possible to distinguish between those children who can profit from education and those who are in constant need of nursing care. That the severely handicapped children must remain the responsibility of the Ministry of Health has never been disputed."*

This is what I want to dispute. What is wrong here is the thought that the Ministry is responsible for any child. No Ministry should be responsible for children—families are responsible for children, and when no family is available somebody else—a person—but for heavens sake not some anonymous office in some Ministry. This is a totally wrong concept. Ministries are responsible for services, and as soon as you recognise this your whole problem is solved, because to the extent that a child needs health services, the Ministry of Health and the local Health Authorities will provide it; to the extent that a child needs education services, then proper education authorities will provide it, and to the extent that the child needs both, then both will have to be involved.

This is the crux of the whole problem with which you have been



struggling so long in your country. Similarly do not talk about ESN children, do not talk about SSN children—talk about children who need ESN services or SSN services. Children may need one type of service now and yet after we have given them this service for some time they may be able to profit from a higher level of service. *Label the services and not the child* and your problem will solve itself to the extent that it will enable you to make the proper administrative determination.

## **Discussion**

### **NURSERY SCHOOLS**

*Question:* You talk about integrating a certain number of children in ordinary nursery schools. Given the situation where perhaps it is possible to send a child to an Infants Department in a Training Centre or the alternative of giving it one of say two or three places in a nursery school, and assuming the child is of reasonable social adaptation, which is better for the child?

*Answer:* In general we have found that the younger the handicapped child is the easier he can mix with other non-handicapped children because at that stage their needs are less differentiated. But in the formal school programme as he moves up in the years the retarded child very obviously needs some specialised services which are quite different from the services given to the child without intellectual handicap. Therefore, I would say that other things being equal, I would certainly avail myself of an opportunity of having the child in normal nursery school, particularly if this can be done by subjecting the child to less travelling—if the nursery school is closer to home than the training center. This is not a new and brainy idea; it has been done for a long time now and we can feel quite comfortable about it. There is no need to be afraid that the handicapped child will suffer indignities at the hands of the other children—to the contrary we invariably make the experience that as long as we can control apprehensions of the adults the children get along just fine. It takes years and years to instil prejudice in children; they have to listen to the conversation of their parents, their teachers and other elders for a long time before they show prejudice. Children are capable of accepting differences. Let us here not be confused by the teasing of children. They tease each other, and teasing can be unpleasant, but

we have enough experience now to know we can safely put a handicapped child in a nursery school. If I may go one step further, we hope, of course, that eventually no school facilities for the mentally handicapped will be so isolated that there is no contact with other children.

There are some people who desire to isolate retarded children against all dangers of living—one can do so, one can keep them out of harms' way, one can tell the other children never to criticise a child because he is a poor retarded child, one can give them free run in the family home and one can later on place them in some private institution or some other place where they do not meet the world as such. But if you want the child to be integrated later on into the community, then it is ridiculous first to isolate him and then suddenly face him with the problem of social adjustment. To the contrary he will just have to learn slowly and to the extent that he can absorb, how to get on with others, and that can be best started at nursery school age and kindergarten age where we can have a full integration as long as there is a proper proportion of these children.

## **BOOKS**

*Question:* This is as much a plea as a question. You spoke about educating parents. I am an ordinary parent of a handicapped child. A fortnight ago I went into Blackwells looking for a book. There is plenty of Gesell, plenty of Piaget, plenty of Spock, but there is no Spock for parents of handicapped children. Could you please tell us if there is one or if not could you please write one.

*Answer:* I do not have to. Your country has made the greatest contribution to literature on mental retardation on a very high professional level. Clarke and Clarke, Gunzburg, Tizard, O'Connor and several others have produced in this country the world's most significant mental retardation literature on a professional basis. But the kind of literature you refer to in your question is the speciality of the United States, where our Government has published some very good brochures written by competent people about the domestic "how-to-do," in mental retardation. Furthermore, you will find in the United States not just these very useful booklets for parents of retarded children (and there is a Spock for parents of handicapped children), but also helpful guides for public health

nurses (health visitors) who invariably will have retarded children in their load. Similar guides exist for social workers, nutritionists and recreation workers. Some of them have been translated into other languages, but even though it is but six hours by air between London and New York, I have found that these materials are practically unknown in your country. I shall be happy to make some of these pamphlets available to the Oxford and District Society for Mentally Handicapped Children.

### **KEEPING CONTACT WITH THE CHILD IN AN INSTITUTION**

*Question:* I am concerned with mentally handicapped children in institutions, as a Hospital Board Member, and I feel that this question of over-protection may apply even more in a hospital than in the home. However, what concerns me most is that in the last hospital I visited I asked how many of the children were visited by their parents, and was told only twenty percent, and that the majority had in fact been abandoned. Now one cannot judge or condemn or criticise other people in difficulties which one has never had to face, but what I asked at the time was what can we do, what could we have done to help parents over the hump so that they would have maintained contact with the child. Any child brought up in an institution, however good, is handicapped and this is the kind of handicap I would like to remove if possible.

*Answer:* I saw an institution in England a few days ago and there the picture was quite different. This was an institution which invites parents to come, which lets parents of young children visit any time, any day, anywhere in the institution. They are welcome any place. In the past, the authorities in many countries have taken every conceivable step to separate the parent from the retarded child in the institution. They have made everything difficult from unreasonably limited visiting hours, requiring permission to see one's own child, censoring correspondence, to controlling packages, in short, living up to the old poor house policies of Elizabethan days. But today there are a few institutions who realise that the parent is the key person and that he can no longer be considered an enemy as some old institutions have done (I have worked many years in institutions and I can speak from long experience).

There are great differences in England as to how visiting by parents is being facilitated. For instance some local health departments will provide funds for parents who have financial difficulties to visit the children. These departments correctly think it good business, as the aim should wherever possible, eventually be to return the child to the parents' home and not keep him a life-time in an institution at public expense. Let me say, in all fairness, that the same problem exists in many general community hospitals, and there now rages a great controversy throughout many countries about unrestricted visiting on children's wards. This is a problem which we need to tackle and I am glad you raised this point. Only a few months ago I suggested at a Conference in Ireland, that a parent should take legal action to force an institution to let him see the child regardless of visiting hours and to let him see the room where the child sleeps. It is certainly grotesque to deny a parent access to the rooms where his child lives, his child who has not committed any crime and is not in jail. Yet this is, in many countries, still the case. We cannot stress enough the importance of keeping up at all times the parental contact, even when, as I think will continue to happen, the child has to be away from home for longer periods for training, education, medical treatment and so on.

### **FOOD AND SPEECH**

*Question:* What did the speaker mean by referring to food as a means of helping speech?

*Answer:* What I mentioned was expressed in a negative way. If a child, instead of eating semi-solids and later on solid foods, is kept on a liquid diet and does not chew, the muscles of the mouth do not develop adequately, and these muscles are needed for speech development. Now I do not mean that somebody who has for medical reasons to be kept on a liquid diet would never learn to speak. The point I am making is that it complicates language development and since children afflicted with Down's Syndrome already have speech difficulties you just add to this difficulty if they are not on a proper diet. Since so many of them have difficulty in developing proper eating habits, this is why we need the health visitor, supported by the nutritionist, in helping parents to cope with this problem. There is a distinct connection between adequate food intake, mastication and language development.

## GENERAL HOSPITAL CARE

*Question:* Should general community hospitals be expected to accept retarded children as patients?

*Answer:* There exists an excellent English report written about 1962 by a committee of the Paediatric Society of the South East Metropolitan Region in London, entitled "The Needs of Mentally Handicapped Children," and available from the National Society for Mentally Handicapped Children—it is on their reading list. This particular group which consisted of public health physicians, paediatricians, psychiatrists and social scientists criticised the refusal of hospitals to accept a retarded child for medical treatment. They did not expect a general hospital or children's hospital to accept a retarded child for prolonged residential treatment for his mental retardation, but they said that when there are medical conditions requiring it, then, of course, a child should be accepted. This means that nurses ought to be prepared for this, and surely training of nurses is needed not just for the mentally handicapped child but for all children with handicaps. Again, let us not talk about children but about services because if somebody asks why should a children's hospital accept a mentally handicapped child you say, because the services available in the children's hospital are the ones that that particular child needs at this time. You are perfectly correct to bring out this point and some of you might want to write to the National Society for Mentally Handicapped Children and look at this pamphlet and then look at your own community and see what happens there.