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ABSTRACT

The information packet contains six abridged readings on the education of parents of retarded or disadvantaged children. Specific teaching techniques such as recognizing individual performance levels are offered to maximize retarded children's learning. A handbook on parent councils discusses parent involvement in school programs for disadvantaged children and suggests ways of implementing a program or undertaking activities. The goal of a research center is described to be an increase in the educability of young children from low income homes through parent involvement, class based programs, and parent training in a home based program. Teachers are provided with guidelines for responding to parental concerns such as inability of the maturing child to understand and connect the sex act with pregnancy and its social consequences. A program is described in which a home teacher helps parents to establish individual goals for the family and the handicapped child and to eliminate the child's inappropriate behaviors by applying principles of reinforcement and shaping. Discussed are techniques that teachers and social workers can use to help parents recognize and cope with problems presented by a retarded child. (MC)

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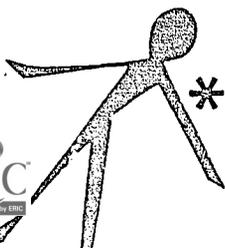
# INFO - PAK 1

## SELECTED READINGS

THE EDUCATION OF PARENTS OF  
HANDICAPPED CHILDREN

A GROUP OF ABRIDGED READING SELECTIONS  
FROM A SELECTED TOPIC AREA

USOE/MSU  
REGIONAL  
INSTRUCTIONAL  
MATERIALS  
CENTER FOR  
HANDICAPPED  
CHILDREN  
AND YOUTH



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SELECTED READINGS

THE EDUCATION OF PARENTS  
OF HANDICAPPED CHILDREN

CONTENTS

- 1** Chaney, Clara M. "Tips From a Parent and Teacher!" Indianapolis, Indiana: Communication-Dissemination Center, pp. 7-12.  
This material offers some specific teaching technique ideas for parents and teachers of Mentally Retarded Children. Suggestions include ways of setting the stage properly in order to let these children learn and recognizing individual performance levels. This material has been incorporated into the book, Motoric Aids to Perceptual Training by Clara Chaney, and Newell Kephart, published by Merrill Publishing Co. of Columbus, Ohio.
- 2** Title I, E.S.E.A. Handbook On Parent Councils. Columbus, Ohio: Ohio Department of Education, pp. 7-10.  
Parental involvement in school programs for disadvantaged children is discussed in this handbook. Specific ideas for implementing a program along with various activities for parent councils are given.
- 3** Brown, Carolyn Sauders. Components of Parent Training. Nashville, Tennessee: Demonstration and Research Center for Early Education, George Peabody College, pp. 12-14.  
The goal of this research center is to increase the educability of young children from low income homes. This article discusses a program to involve parents in the implementation of the basic goal. It gives suggestions for a classroom based program coordinated by the teacher and gives teachers suggestions that have been used for setting up the program. The article also describes the training of parents in a home based program.
- 4** Clark, Mary. "Parent Problems--Guidelines for Counseling." Lansing, Michigan: Department of Special Education, pp. 1-2.  
This article presents guidelines for teachers working with parents of retarded children. In addition to the guidelines it gives the teachers some insight into the concerns and problems of adolescent retarded children.
- 5** Terdal, Leif; Buell, Joan. "Parent Education in Managing Retarded Children With Behavior Deficits and Inappropriate Behaviors," reprinted from Mental Retardation, Vol. 7, No. 3, June, 1969.  
This article describes a behavioral program in which parents are taught to provide a special environment for their handicapped children. In each case goals are individualized to fit the problems and needs of the child and family. The parent is first encouraged to identify goals. These may include eliminating inappropriate behaviors and/or developing skills in their child. Through demonstrations by the Home Teacher and work with their own child, parents observe and practice principles of reinforcement and shaping.
- 6** Schild, Sylvia. "Counseling With Parents of Retarded Children Living at Home," from Social Work, January, 1964, pp.86-91.  
This article discusses techniques teachers and social workers can use for helping parents recognize and cope with problems presented by a retarded child. The emphasis is placed on dealing with the parents and their attitudes about the child.

## TEACHING TECHNIQUES

Parents and teachers must learn to structure for their children until they can structure for themselves. They must create controls until the child can control himself. Each of these children can achieve and succeed if we are but wise enough to set the stage properly. If you want the child to learn to identify forms by placing them in a formboard, and the task is very difficult for him, you don't dump out the whole set of forms and expect him to replace them. You remove one and have him replace it. Remove one at a time until he is comfortable in the task, then begin removing two, three, and so on.

It is possible to structure and control almost any task. One of our favorites is a pegboard. It gives us a media in which we can control the child and the task, and convince the child that he can perform. First we must elicit performance. The child must perform, for without performance there is nothing to structure or control. The second step is performance upon command. The instructor says to the child, "Take this peg and put it here." We have encountered some terrific resistance and some real patterns of rigidity in this one simple task, but the pegboard puts the instructor in control. If the child doesn't follow your instructions, it is easy to grasp his hand, force him to take the peg, and put it in the proper place. After you have forced the action several times, the child realizes that he can do it alone. From this point, you can go to putting the pegs in a line across the board. You can go on to making forms on the board, structuring each problem so that the child can perform.

There was a recent study done in the East on what makes a retarded child perform best from the standpoint of successes and failures. The results showed that a retarded child will perform best if he succeeds about 75% of the time, and my first thought was, is this so unusual? Don't all of us like to succeed about 75% of the time? If the task is so difficult that we are failing at least half of the time, we will soon lose interest in it. If it is so easy that we succeed all of the time, we will also lose interest. But just make it tantalizing enough by 25% failures, and we will keep trying until we get the task done. These children are very normal in this respect. As you are setting up tasks for these children, keep this in mind.

## THE TOLERANCE LEVEL

There are three levels of endeavor involved in working with these children. The first is the tolerance level. At this level, the child performs very easily. As soon as the child reaches this level in any task, you stop using it as a learning activity and transfer it to his playtime activity. Often mothers say that when they work with their children, it's hard to transfer learning activities into play time. Remember to transfer the task before the child becomes really bored with what he is doing. As soon as he can perform a task reasonably well, let him use it for playtime experimentation.

## THE CHALLENGING LEVEL

The second level is the level at which the child is encouraged to give it another try, and we call this the challenging level. It is at this level that you set the stage from day to day for those tasks that you will push. Here you will insist that the children perform, because these are tasks which they can perform with a little effort.

## THE FRUSTRATION LEVEL

The third level, called the frustration level, is the level at which the child cannot perform because he is not now equipped to do so. These are the tasks you must recognize and avoid. If you find yourself presenting tasks at this level and realize the child cannot perform, that he is becoming frustrated and so are you, don't set the task aside suddenly; simplify it. Break it down to the point where he just adds the last stages of the task and at least he will have had some measure of success.

These retarded youngsters are wise little people. If they find that you will set a task aside when they say, "I can't," or "This is too much for me," they are going to start using this excuse on more and more tasks in which they probably could perform.

If they can get out of performing they will do so, because performance is difficult for them. You will have to be ever watchful for their escape mechanisms. Often you must ignore them, for they will develop imaginary aches and pains. I remember one little fellow whose arm hurt very badly. We said, "Yes, we understand. Often we have aches and pains, but we still have to work." Thus we worked through the aching arm all day. When he came in the next day it was his leg. He complained that it hurt him also. Finally he got the idea that regardless of whether he hurt or not he was still going to have to perform, and he did.

## THE MATTER OF OBJECTIVITY

This brings us to another point. Never say, "Do it for Mommy," "Do it for Daddy," or "Do it for teacher." We don't want the children to perform to please us; we want them to perform because this is life. There are demands that society will make of them. If they learn to perform to please you, they can turn off the performance when they are unhappy with you. It gives them another means of resistance. Remember to maintain an objective attitude when working with these children. Study your child before you begin any special tasks with him. Begin to think of him as a child instead of "my little darling." Try to look at your child as a clinician would; then it will be much easier to make demands of him, because you'll know that you are doing it for his future happiness. You must convince yourself that your child can perform, and that he will be much happier once he does. All of us enjoy success, and these children are no different in this respect.

When you start working with the child do not say, "please," or "Would you like to do it?" When you give him a choice he has the right to say no, and you should abide by it. In the beginning simply say, "Do it. Here and now." That is all that is necessary, although you may say "Thank you" afterward.

When you are working with your child, demand that he work. Command him to perform, and try to keep as many of your commands as possible related to the task itself and not to the child. Don't constantly call him by name. Don't say, "Come on now, John, John do this, John do that." The child might feel that you're heckling him. On the other hand if you simply say, "Put the peg in the board," or "Draw the circle on the chalkboard," you are directing the command to the task that the child is performing, and you will get much better and much quicker performance.

### KEEPING IT SIMPLE

Keep your commands short, simple, and to the point. Don't talk too much. I know that the experts say our children learn from our talking to them, but I feel that we often say too much at the wrong level. Anticipate the child's need at a particular moment and answer only that need. One parent at the Center mentioned that his son asks questions about everything he sees and they answer very simply, but the next day he may ask the same question. As an example, he said, "Down the street there is one of those little mechanical horses that children ride. Each time we walk by Mike says, 'The horse?', and each time I answer yes, it is a horse. What else can I say?" I commented that maybe the boy really wanted to make conversation about the horse, but he didn't know quite how to go about it. I suggested that the next time the father might say, "Yes, that's a horse. What do you do with it?" They came back at noon all excited, saying it worked. Father said, "We asked him the question and he told us, 'You ride it.'" This was the first time the child had ever added the second bit of conversation. Always before when he asked a question they had just answered it, so there was nothing more for him to say.

If your child is in the habit of throwing questions at you, toss one back to him. If he says, "What are you doing?", say, "What am I doing?" He too might be trying to make conversation and not know how to do it.

Communication is dual. If these children are having difficulty speaking, they are probably having difficulty receiving. Too often a command is followed by superfluous words such as: "Come on. Why don't you do it? Look, it's not so difficult, just put it in here." By the time the child gets through to the last word you've spoken, he has completely forgotten the original instruction, so performance is impossible.

### BE POSITIVE

Give a simple command and wait. If the child doesn't perform, give it again. If he still does not perform, repeat it the third time, as you move him into the task. This is one of the reasons for starting with motor tasks. Almost any time a child refuses to do a motor task, you can move him into the task physically. If you have a child doing Angels-in-the-Snow (a task in which the child lies on the floor and moves an arm and a leg on command), and you instruct him to move his leg, but he refuses to move it, you can easily grasp his leg and move it. I have found this quite effective with older children, especially boys, to say, "You move it or I'll move it for you." They don't want me manhandling them, so to avoid it they will at least try to perform the task.

Let your voice carry confidence and expectancy when you are working with your child. Mothers often have difficulty here, because they have seen their children fail so often. When a mother says, "Johnny, do it," she says it with a hopeful tone in her voice, and her lack of expectancy is evident. If father says, "Marion, don't go through that door," while he walks toward Marion as fast as he can, Marion knows that he is coming, and he knows by the tone of his father's voice that he did not expect him to stop. If you need to work on this type of problem, when you say, "Don't go through that door," be sure that you're close enough to the door that you can prevent the child's exit. After two or three similar successes, you begin to gain confidence, and the child understands that you are serious. Then you can from a further distance say, "Don't go through that door," until finally you can say it from across the room and experience immediate obedience. You have to train yourself to speak in an authoritative voice.

### IN CONTROL AT ALL TIMES

When you are working with your child, your voice should be quiet and authoritative. The more you raise your voice, the more excited the child will become. I recently observed a teacher who spoke to her children in a very low, soft voice. The children had to listen to hear her. She gave a command softly and then waited. If necessary, she gave it quietly again and waited. If there was still no performance, she forced obedience. The children soon learned to listen to her, because they knew she would not raise her voice or give added clues once instructions had been given.

Initial work with your child should involve only short time periods. Adhere to a schedule, so that your child will become accustomed to performing at the same time each day. As you advance to the point where you can work with confidence and the child realizes that he can perform, lengthen the work periods and apply the above techniques to the activities of daily living.

During the initial work periods, be vigilant to prevent the child from gaining control of the situation. Remember that you are to structure the task for him, give the commands, and demand performance. You will find that the child will use many methods to avoid the task; however, you must recognize his methods and overcome them.

### GROUP ACTIVITIES

The teacher working with a group of children can use circle games, obstacle courses, or even a game of follow the leader across the mats using different ways. There are fifty or sixty ways to cross a mat, and what is easy for one child may be a learning experience for another. If you find it hard to believe, get a group of adults together and see how many different ways they can find to cross a mat. By using the problems that you use working with the children, you might introduce a new type of party game. See how many variations the adults can come up with, and then help the children learn what they have discovered.

You don't want to teach the children to do a specific task in a specific way, so instead help them learn to do each activity in many ways, so that if they are called upon to perform a learned task in a slightly different manner, they can adjust and perform. Try to work out as many variations as possible when working with a child, but don't let him change the task unless it is a "follow the leader" type situation and each child is to take his turn.

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## ADDITIONAL POINTERS

If a child is almost ready to perform and there's something holding him back, a quick "now," or even a quick swat will sometimes solve the problem. Only a quick swat can carry the element of surprise needed to get the results that you want. Don't spank and don't use this technique too often, because once it loses its startle effect, it becomes useless.

Do not give the child a choice at any time unless you intend to abide by it. Choices are not a good idea with these children, because a choice usually involves the time element. If you say, "If you do this, Johnny, we'll show it to Daddy tonight," or "We'll go get an ice cream cone," Johnny will probably want the ice cream now, or he will want to show Daddy now. These children have difficulty recognizing time variables; to them there is only now and the distant forever, no in between. A threat to spank is also ineffective; how threatening can the future be when there is no future?

## KEEPING ONE STEP AHEAD OF THE GAME

When you tangle with the problems of hyperactivity and distractibility, you're going to have to think faster than the child thinks. You will have to anticipate the child's move before he makes it. If your child is one who slides out of his seat or makes a dart in the opposite direction, watch carefully to see when the child begins to make the move. Move in and stop him before he is out of his seat. Once he is out and gone, even if you bring him back, he has won the battle.

One little girl was unable to resist feathers on hats during a time when most women wore feathers in their hats. The child would sit in church and grab hats before anyone could stop her. The mother began sitting next to her daughter where she could feel her arm as it started to move. She would then thrust her hand out in front of the child's arm, thereby preventing her from stealing the feathers. The child's habit was soon broken, because her mother had wisely discouraged its practice from the beginning.

## RELAXED ATMOSPHERE

Teach your child to relax, and help him learn to laugh at himself. Let him know that you don't mind if he makes a mistake, but encourage him to try again. Do not drill while you're working with your child; don't make him do the same thing over and over again. The first and second time that a child performs a task is the real learning activity.

## LEARN TO RELAX

Mothers and fathers must also learn to relax. This is probably the biggest order of all, but there is no group of children in the world who react to our emotions and our tensions as these children do. Occasionally a mother will complain that her child is in a bad mood, and later admit that she was upset in the morning, but she settled down after her morning coffee. However, it wasn't so easy for her child to settle down; he kept building tension all day.

Try to keep the home situation relaxed. I think one of the most difficult times in the home is when everybody comes home from school and work in the evening, for at that time, the excitement and tension in the home reaches its peak. If possible, the child should be taken for a walk to get him away from all the confusion, and to give the other members of the family time to settle the atmosphere. This would enable the entire family to spend a more pleasant evening at home.

#### SUMMARY

Children with learning deficits can learn more adequately than they are now learning. Each of them can experience learning now and for many years to come. Our problem is not teaching them, for I don't believe anyone ever really teaches children anything. Our basic concern is in setting the stage properly in order to let them learn. This is what we must do for retarded children; we must learn to think and feel as children. We must try to understand the problems which they encounter. If you keep these suggestions in mind, I think you will find that you can help these children learn to adapt and become useful members of our society.

### Organization

As soon as the council is established, some type of organization needs to be adopted. The members themselves should decide the kind and number of officers and committees they need. Until a definite organization has been established, the group may select a temporary chairman to see them through the initial steps of organization. Roberts Rules of Order can serve as a useful resource document in establishing the rules and procedures of the group.

Among the first considerations of the group would be the following: selection of a chairman, tenure of members, replacement of members, attendance requirements of active members, and an organization structure for the group. While many models of this last item exist, the group may wish to consider the following as an initial structure:

1. A chairman
2. Assistant or co-chairman
3. Recording secretary
4. Committee chairmen in such areas as:
  - a. Training
  - b. Parental involvement activities
  - c. Data collection
  - d. Evaluation

### Activities

The activities of a council are very closely related to the responsibilities which were discussed in an earlier part of this handbook. For Title I purposes, certain activities are spelled out in the regulations for the parent councils. They include:

1. Involvement in all stages of planning and development.
2. Involvement in operation of programs.
3. Involvement in the evaluation of programs.
4. After consideration of data, the making of recommendations concerning needs of children and programs available to meet these needs.

5. Reviewing evaluation data.
6. Commenting on applications when submitted.

Besides these specified activities, a parent council would also be expected to:

1. Participate in the direction and coordination of all parental involvement activities.
2. Participate in the planning of any training programs for parents.
3. Advise on dissemination activities, especially when directed towards parents.
4. Participate in the gathering of data on children to be served.

#### Support Needs

To fulfill its responsibilities and to perform its functions, the parent council has definite support needs.

The first of these needs is information. The local educational agency is responsible for initiating, conducting, and promoting an affirmative information program for the members of the group. The information required would include:

1. Data on the local educational agency as a system:
  - a. Structure and organization of the school system
  - b. Selection and recruitment standards for school personnel
  - c. School budget
2. Citizen involvement in other programs such as Model Cities, Head Start, etc.
3. The decision-making process in the school system.
4. The local community as viewed socially and economically.
5. The purpose and history of the program in question.
6. The law and regulations (federal, state, and local) which affect the program.
7. Past project applications and their evaluations.
8. Current project applications.
9. Future plans for the program.

10. Description of the planning process, together with stages and time schedule of the process.
11. Data concerning needs of the children.

More specifically, the parent council should know:

1. How Title I children and schools are identified.
2. The numbers of Title I children and schools and their needs.
3. The priority listing of needs.
4. The alternate approaches to meeting those needs.
5. Other programs (federal, state, local) which can be used to help Title I children.
6. Type and number of personnel needed.
7. Facilities, supplies, and material available and needed.
8. Budget requirements for program.

As well as information, these activities require the presence of certain skills such as:

1. Ability to participate in the group process.
2. Ability to perform problem-solving and decision-making activities.
3. Leadership skills.

The presence of information and skill needs such as these immediately raises the importance of a training program for the parent council. Ideally, the training program would consist of an initial orientation session backed by intensive follow-up sessions held in situations removed from interruptions. During these sessions, the members should gain a general understanding of the project and take part in a workshop on decision-making.

Because parental involvement in education involves a close working relationship, some areas of training should provide for joint participation of council members and school personnel.

School staff members should take advantage of the opportunity to relate more directly with parents by serving as discussion leaders for some of the training sessions devoted to subject areas in which they possess special knowledge. School board members could also participate in this way.

The joint training sessions might require outside consultant support, but should also tap the knowledge and experience of parents, other lay citizens, and the school staff.

Some of the techniques for group training might include condensed readings, case studies, role playing, small discussion groups, audio-visual techniques, special exercises, speakers, student ideas, frequent visits to classrooms, and panel discussions.

Training should be a long-term, on-going process. School districts will differ in the degree and kind of involvement that has been achieved. Therefore, some school districts will have to start at the beginning; others will need to broaden their concept of what is involved. Additional training needs will suggest themselves as the program progresses.

Training sessions must be scheduled with the availability of the participants in mind. All the sessions need not be conducted in the schools. Frequently, a location in the community -- some place which represents neutral territory -- is a better setting. Such choices will help to reinforce the partnership idea and make easier the redefinition of roles.

Apart from information, skills, and training, the parent council will also have support needs in several other areas. It may be necessary to have some secretarial assistance, a meeting place, translators for non-English speaking parents, suggestions for speakers and consultants, etc. The local educational agency must be prepared to provide this kind of staff support to the council.

In some instances, the support need will take the form of a financial expenditure. Examples of items which could be justified from Title I funds are: tuition and registration fees for workshops and conferences, the cost of providing meeting facilities, equipment, and supplies, and expenses incurred by the local educational agency in connection with visits by parents to Title I schools. Title I funds may also be used in the form of direct payment to members of parent councils for expenses incurred for transportation to and from meetings, babysitting fees, and direct expenses incurred while visiting Title I programs.

Reimbursement for loss of work to attend meetings is not an allowable expenditure from Title I funds. Membership on a parent council should not be equated with, or allowed to become, a substitute for regular employment.

In justifying the expenditure of Title I money for parent councils, the basic consideration should be the facilitation of proper functioning of the committee and the avoidance of hardships that would otherwise be imposed on members of the council if the proposed expenditures were not authorized.

It should be noted that any expenditure of Title I funds must be included in an approved budget. Proper documentation must be made to justify each expenditure.

## COMPONENTS OF PARENT TRAINING

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DARCEE, the Demonstration and Research Center for Early Education is a unit of the John F. Kennedy Center for Research in Education and Human Development, located at George Peabody College in Nashville, Tennessee.

The children we have worked with, both in the home and in the classrooms are biologically intact. They have no gross organic malfunctions. The only "exceptionality" which can be cited is the fact that they were, and are now, all from low income homes.

It seems obvious, but it is still important to state, that poor people lack many of the resources which are present in and available to middle and upper income groups. The lack of sufficient resources can have drastic effects on low income families. Several studies have validated the disproportionate percentage of these children who exhibit communication problems. Communication skill development has been a major focus of our curriculum. Our program, however, has been much more inclusive. Our central mission at DARCEE has been and remains to be, to improve the educability of young children from low income homes. Our overall objective, for the child has been "socialization for competence"—the development of cognitive, affective, and social skills. This work has naturally included involvement in the homes. We believe if any substantial, sustaining, difference is to be made, then it is through this transactional approach.

This approach is built upon the model in which the idea is to train the parents to provide experiences for children which will promote their growth and development. Living in poverty generally means that most of one's limited economic and intellectual resources and most of one's energy is directed towards keeping body and soul together. The remarkable thing is the amazing strength that so many people living in poverty manage to possess in such extremely limited life conditions. We try to build upon this strength and help parents take advantage of some options from which they see themselves as being cut off.

It is from this key notion of maximizing the options open to parents that our work has emphasized two important roles for parents: 1) as teachers of their children and 2) as the behavioral change agents for their families in general.

I would like to now describe three of the programs conducted by DARCEE which deal with parent training. First, we will explore a method in which parents were worked into a classroom based program for preschool age children. Then we will consider a program for preschool age children and their younger siblings conducted solely in a home setting. Third, we will review a home based program involving mothers and their infants, (aged eight to eighteen months)

### A Classroom Based Program

Our programs have been organized so that parents can start with things that they can do. They then proceed to work on more difficult skills depending on the reachable goals which have been set for them. In other words, the program is carefully sequenced. The experiences which are provided for the parents are arranged in an order that moves from easy to difficult skills. A sequence might look something like this: 1) observing, 2) limited teaching responsibility, 3) increased teaching responsibility, 4) complete teaching responsibility.

The starting point of one study was the darkened observation booth at our Early Training Center with its one-way vision screen. Under the direction of Mrs. Della Horton, the parent worker, the 20 mothers started coming to the center one morning a week just after school opened. The mothers came in groups of four. Their first job was learning how to observe, for a first, each mother had eyes only for her own child. They were apprehensive or even embarrassed when they saw a daughter afraid, or a son refusing to participate in classroom social situations, such as snack time. They hoped that the child would know what to do. Mrs. Horton had to teach them to see the classroom as a whole and to see how teachers could modify the behavior of their children and create a climate in which learning could and does take place.

The mothers came to understand the purposes and goals of large group activities, many were astonished to see children change before their eyes into attentive and interested pupils. They came to understand the reason behind the grouping at the small tables, where activities are planned for individual needs. They had small-group activities of their own in the conference room of the training center where they were taught how to use such elementary materials as puzzles and pegboards. They learned to role play assuming in turn the part of children or teachers in the classroom. They learned to ask appropriate questions and where to find the answers in books or experience. During all of these activities, their involvement was encouraged by Mrs. Horton, who devised various ways of rewarding them for good performance. One example of a "motivator", as Mrs. Horton liked to call it, was an outline of the human body. Designed for achievement motivation, the chart was blocked in part by part—head, leg, ar, etc. for each mother, as she successfully completed part of her work. As the

children in the classroom broadened their knowledge of the environment, so did the mothers. For example, when the children studied a map of the city, so did the mothers. They went on field trips either as a group or with the children. They went to museums, to parks, and other community facilities many of them had never used before. Like the children, they learned how to use the public libraries of the city. Both Mrs. Horton and the teachers encouraged interaction with the center by inviting mothers to special occasions, such as a Halloween party.

Mothers were given assignments to do with their children in their homes. The presence of the younger sibling was always encouraged. The influence of the mother's training on the younger siblings has been one of DARCEE's major concerns. We have called this "vertical diffusion" a label we have used for the effects of learning that may spread within the family.

After several months of these diverse activities the mothers were introduced to the classroom as participants, at first, during snack time and later in large group or selected activities time. At first, they assisted the teachers, then they gradually accepted increasing roles of responsibility. Sometimes, the mothers shared responsibility in pairs. In selected activity time, often the mothers read books to the children. The children could choose which book they wanted to hear. Knowing how to read a book to a child is an important skill, and not so easy as it might seem. At the outset, many had never read to their children, and were, moreover, shy and ineffective when doing so. We found reading to be one of the most valuable and inexpensive learning activities that could be carried on in the home. It is good training in verbalization and encourages interaction between mother and child.

Through this program, the mothers learned to observe, diagnose learning needs, and facilitate skill development in young children. Simultaneously, there was a good deal of cognitive and affective growth for the mothers themselves.

### In Home Program with Preschool

The same principles of sequence and gradualness discussed in classroom programs apply in home visiting programs. The sequence might be as follows: (1) Mother is very dependent on home visitor. A strong one-to-one relationship exists. (2) Mother is slightly less dependent on the home visitor. (3) Mother is more independent. (4) Mother is independent.

Building a strong relationship between the mother and the home visitor is vital. This means that the home visitor is a friend who listens and understands but, at the same time, does not pity or coddle the mother. She will not do things *for* the mother. Through their friendship, the home visitor helps the mother learn to do things for herself. She continues her support of what the mother is doing, but she does not take over what the mother is doing. We believe this type of relationship is extremely important in helping the mother develop a "can do" attitude. The mother gains more confidence in what she can do as the home visitor allows her more and more opportunities to do what she can do by herself. The home visitor has to be a sensitive person who keeps her eyes and ears constantly open to learn more about the mother and how she is progressing.

We have met with our mothers one hour a week in their own homes. At the beginning of the hour's lesson, the mother and the child perform a task that has been reviewed during the week. The home visitor conducts the lesson, which usually includes an action singing game. It is not uncommon for other children - either members of the family or neighbors - to sit in and enjoy the fun. Such participation sometimes effects children outside the family, and, in such a case, we have an example of "horizontal" diffusion, the effects of intervention being spread within the immediate community.

Reading a story is often a part of the hour. The home visitor in this manner serves as a model for the mother, who will be assigned book reading during the week. After the book has been read, a relevant activity may follow. No opportunity is lost to review the numbers and kinds of characters, the sequence of events in the story, and the colors and shapes that were used. The home visitor makes a special effort to integrate her intervention strategies into the already established home situation - both spatially and temporally. The teaching materials used are often common household items. Her visits take place at a time when it is convenient for the mother. Every effort is aimed at making the mother's involvement with our program a help, not a hindrance.

Occasionally, a mother must work during the scheduled time. If the father is home he is a welcomed substitute. If the activity is above the level of younger members of the family the home visitor furnishes them with suitable materials - such as plastic blocks that can be threaded on a string. In her home classroom, the home visitor provides for maximum learning by the parent and target child without excluding other members of the family.

Subsequent lessons in the home enable the home visitor to deal with the mother's individual problems - one may need further instruction on how to motivate her children; another may need extra practice in reading books or working with numbers.

The goals for the mothers in the home are identical to those for the classroom mothers. In both instances, our effort is to increase competence and confidence.

## **In Home Program with Mothers and Infants**

We have recently finished extending downward our home visitor program with preschoolers to work with mothers and their infants aged 8 months to 18 months. Beginning this early represents a truly preventative approach to working with children who may later develop educational difficulties. Within the next several months we shall begin a program working with toddlers in multiple child families as an extension of this work.

In the infant study, motor development and other aspects of physical growth such as crawling, walking, teething, growing of hair, etc. were observed, and, where possible, facilitated. Commercially available toys were carefully selected so they could provide the most appropriate stimulation. One example was the Busy Box. A wide variety of fine motor skills were needed for this very popular toy. While the children explored, the mothers were encouraged to say action words (push, pull, turn, spin, slide, pull open, dial) as well as to state the names of the objects. At the same time, emphasis was placed on home made materials and retrieval items that could foster development. Different sights and sounds could come from a juice can covered with contact paper, and filled with paper clips. The infant shook the can to see if it contained some interesting sound, or to see if it was empty.

A great deal of eye-hand coordination is required on the part of the infant to use the wooden peg bench, and the infant is able to hear the pounding sound of the knock on wood. The mothers became more physically involved as they became more secure. In training each mother, the home visitor systematically elicited increasing involvement of the mother in the conduct of activities until the mother became independent of the home visitor in serving as an educational change agent for her infant. The home visitor suggested activities that were feasible in the context of the household routine and the life style of the family. Activities were planned which were compatible with the amount of time and money that were available and activities that could involve several members of the family. Outdoor activities were designed to permit the infant to explore in his yard and gather leaves, sticks, rocks, grass, dirt, and flowers, in order to examine things from the outdoor environment. Each infant had a picture card file of objects cut from magazines and put on 5 x 8 index cards by his mother.

Mothers were trained in reading a book to a child, and in pointing out the pictures to the infant. Conversing with the infant was continuously emphasized. The mothers found that there are innumerable ways of soliciting and reinforcing infants' verbalizations that foster language development.

The focus of this particular program was on infant growth and development in terms of gross-motor development, fine-motor development, cognitive growth, language development, and personal-social competence.

In conclusion, I would like to comment, briefly, on the role of the parent trainer. As you have seen, our parent trainers have in most instances worked inside of the home. We have referred to them more often as home visitors rather than parent trainers. The parent trainers are bachelor degree level people whom we regard as professionals. We have also used paraprofessionals in other studies. The paraprofessionals have been parents from the original study who demonstrated both the desire and the competence to move into this role. Whether professional or paraprofessional, the role of the home visitor requires a unique combination of characteristics and competencies. The parent trainer is a resource teacher, a model, a reinforcer, an organizer, a friend, and a confidante. Mrs. Hardge, one of the original parent workers, often refers to the very thin line one treads upon when venturing into the territory of the home. Often the parent trainer must make decisions on the spot which have far reaching repercussions. These are the considerations one must make when selecting staff for this very important position.

I have described an approach for working with parents which we are quite excited about. The following DARCEE publications are available upon request. From these materials, one can gain a more thorough explication of our approach.

DEPARTMENT OF EDUCATION  
Lansing, Michigan

DIVISION OF SPECIAL EDUCATION

PARENT PROBLEMS -- GUIDELINES FOR COUNSELING

BY

MARY CLARK - BELLEVUE SCHOOL

Detroit, Michigan

I have had many conversations with parents who expressed deep and anguished concern over the problems they were facing with their maturing, retarded child and were desperate for guidance and information. The sudden realization that the child was reaching maturity with little or no understanding of the physiological changes taking place and no notion of how to appropriately control the sex drive, posed a real dilemma for the entire family, and often resulted in serious school problems, with the fear that they would spill over into the community. I would like to share with you some of their concerns and guidelines that I have found useful in counseling with them.

PARENT CONCERNS

1. How to impart information that will help them to handle aggressive sexual behavior that may have grave consequences.
2. Lack of sophistication and vulnerability in heterosexual situations.
3. Influence of dating siblings.
4. Inability to understand and connect the sex act with pregnancy and its social consequences.
5. Frequency and intensity of masturbation.

Parents of children who were retarded with no physical stigmata and who were functioning at the upper limits of their classification had further concerns:

6. Lack of choice in dating partners.
7. Marriageability of child.
8. Opportunity for the expression of sexuality either in or outside of marriage.
9. Lack of birth control information and how to use it.

GUIDELINES

If a good relationship has been established between the child, his parent, and the teacher, the teacher will be the one most often approached for guidance, since she is the one who will have the most continuing contact with the child beside the parents. However, it is important to remember that you cannot "give answers" but, you can help a parent to "think through" a problem. You cannot know the intimate family relationships and what influence they might have on a given behavior problem.

1. Be empathetic. Realize that parents of "normal" children also have their share of problems concerning sexual ethics but that retardation is an extra burden for the parent.
2. Recognize the fact that the parent is going to be involved with his child from his own point of view and from within the family's own belief structure.
3. However, emphasize the fact that if the child is expected to become a part of society, on any level, his acceptance by others will depend almost exclusively on social behavior that does not deviate from the social norms.
4. Help the parent to realize that acceptable behavior cannot be acquired in isolation. The child must become a fully participating member in the family constellation, on his level of competence, before certain codes of conduct can become important to him.
5. Be familiar with materials that can help the parent understand phases of development so that he is better equipped to impart information to his child.
6. Be familiar with agencies to which you can refer a parent who needs help with a problem that falls outside of your area of competence.
7. Parent meetings are an excellent vehicle for sharing information and many times can help to give direction to a parent who is experiencing a similar problem. However, some parental problems are of such a personal nature that the parent may not want to share his problem. It is extremely important to be sensitive to such a situation and to plan time for an individual conference.

## ***Parent education in managing retarded children with behavior deficits and inappropriate behaviors***

***Leif Terdal  
Joan Buell***

**I**n January 1967 a behavioral program was initiated at the Crippled Children's Division of the University of Oregon Medical School as part of a medical-behavioral-educational pilot project in mental retardation. The behavioral aspect of the program is designed to train parents of retarded children in methods of:

1. accurately observing their child's behavior and their own behavior;
2. eliminating problem behaviors at home;
3. building up in their child appropriate behaviors in areas such as self-help, verbal communication, social interaction and emotional reactions to stress situations.

Additional aims are:

1. to determine whether any generalities can be valid as to types of problems and extent of deficiencies relative to parent repertoires in handling retarded children;
2. to train personnel of various disciplines in observational techniques and behavior therapy.

The present paper describes a program in which trainees were involved in all phases of operation, data analysis, and treatment planning and implementation.

### ***Staff and Facility***

At present the staff consists of psychologist, speech pathologist, social worker, public health nurse, occupational therapist, physical therapist, research assistant, and special achievement teacher—all either trained or receiving training in the use of operant techniques.

The facility includes an observation room, a playroom with a one-way window, two office rooms for interviewing parents, a physical therapy room, and an occupational therapy room. Observation is also done in the child's home.

### ***Conceptual Framework***

The child, to be accepted in this behavioral-educational phase of the program, must have first undergone an intensive multiple-disciplinary diagnostic program. Children previously diagnosed as retarded attend the medical diagnostic program in groups of ten for two hours each day for four weeks. During the four weeks, they are observed by a pediatric nurse and other staff as they engage in group activities structured by a special achievement teacher. They are taken from the observation room to undergo neurological, pediatric, orthopedic and dental diagnoses and treatment for any physical problems such as seizures, dental problems, nutritional problems, and

visual and hearing problems. They are also evaluated by standard psychological, speech, occupational therapy and physical therapy evaluation procedures. At the end of this period the staff confers with parents to inform them of the findings and to make recommendations for the child's schooling and continuing medical and dental care. The goal is to assure that each child is functioning in an optimal health state. Selected children with the most severe behavioral deficits or the most markedly disruptive behaviors are seen in the behavioral phase of the program.

### ***Types of Behavior Treated***

Behaviors explored in the clinic include deficiencies in self-help skills such as dressing, grooming, feeding, toilet care, and deficiencies in speech and language such as vocalizing in jargon rather than in already acquired speech, echolalia, and low rate of speech. Inappropriate behaviors are varied but have included tantruming, hitting children, and even such extremes as putting eye glasses in garbage disposal units, smearing food on walls, etc.

In each case the therapists observe the child closely, pinpointing exact behaviors, the context in which they occur, the current social consequences, and the possible competing responses. Potency and variety of

available reinforcers are assessed independently. The procedure is based on operant principles: Skinner (1938), Bijou and Baer (1961), Holland and Skinner (1961).

### **Enlisting Parents as Cooperative, Effective Therapists**

The parents have come in with a plea for help. They find that they cannot handle their child in certain situations. Discipline may be a problem. Specifically, when they see that their child is lacking in many areas of performance, they become worried and seek help. Their child's behavioral problem and/or deficiencies may have either excluded the child from school programs or seriously interfered with the child's progress in school. For some families a major portion of activity and time is spent in attempts to cope with their child's behavior. They may even have curtailed normal social activities because of embarrassment over their child's behavior and their inability to cope with it.

The clinic requires parental participation since changes in the child's behavior are directly related to changes in parental management of the child. Improvement in the child's behavior will in turn reinforce the parents' attempt to try new approaches and responses to their child.

### **Interview and Observation**

Parental participation in the program begins with the initial interview. They are encouraged to report to the staff their concern about their child and they are asked to report situations in which problem behaviors occur and to describe how they handle them. The first interview also provides an opportunity to explain to the parents the need for clinic and home observation of the child's behavior.

The parents' report of their child's behavior serves as one basis for the development of the parents' own observational skills; i.e., staff observation and their own observations later in the program can be compared with their initial report. Their verbal report does not serve as a basis for giving guidance on child care and management.

More specifically, when first seeking help, parents may be able to see quite clearly what their children are doing part of the time, but they do not have a clear over-all picture. They are generally so concerned about specific nuisance behaviors that they frequently fail to recognize significant gains in adaptive skills that are possible for their child. For instance, a child who at the age of four continues to be spoon-fed by his mother, may occasionally put some food in his mouth. The parent, never having broken down the process of learning to eat into small steps, does not see this as an approximation but only as a messy habit of an uncooperative child. Also, few parents recognize a relationship between the child's behavior and their response to it.

### **Clinic Observations**

The setting event or context in which behavior problems occur can be replicated in a lab session, so that the child's behaviors can be observed as well as the parent's responses to the child. For example, a child may scream or cry when his mother gives him a command or fall on the floor

and bang his head when asked a question; he may hit the parent, or knock over furniture as the parent reads alone, but not while the child plays with her. Or, he may poke another child who is receiving parental attention. These behaviors can be replicated by instructing the parent to give a command, ask a question, read to the child, play with the child, or read alone and not respond to the child, etc. In this way, observations can be made as to the specific context in which certain behaviors occur, as well as to the reinforcers that maintain those behaviors.

A lab session also provides an opportunity to evaluate the potency of parental attention as a reinforcer for the child. This is accomplished by observing the play behavior of a child and mother and recording data regarding frequency and/or duration of a particular response class. It could be time spent playing with a particular toy, time spent in one section of the room as opposed to another, etc. The mother is then instructed to respond to the child whenever a specified behavior occurs and to withhold responding when any other behavior occurs. The parent is also told that when she does respond she should try to encourage the child by joining him in his activity, commenting on what he is doing, and avoiding criticizing the child or giving him verbal directions. After about five minutes a reversal technique is employed in which the originally reinforced behavior is put on extinction (the mother is instructed not to respond to the child when the behavior appears), and a different play behavior receives attention from the mother.

In this way it becomes clear whether the parent's attention is reinforcing to a child; i.e., whether, when the parent attended verbally or by smile or touch to one behavior, this behavior continued or increased in frequency. In most cases a mother's talking to a child while he is doing a puzzle, for instance, is enough to insure that he will stay with the puzzle. If he shifts and she does not, he will, if her attention is reinforcing, return to the puzzle. In some cases this is not true. A child's responses may be reinforced by termination of the mother's attention. In one case when the mother

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followed instructions and expressed interest to the child, her child hit her, used abusive language, and at other times simply left what he was doing and went to something else. This information was put together with: (a) the fact that in group activities when a teacher had said, "My, you're doing a good job," the same child hit her and went into a tantrum, and (b) the fact that during home observations both the father and mother, while the child was slumped over, tears on his face, refusing to eat, used such sarcasm as, "Well, look at that handsome boy we've got. Isn't he fine, mother?" The conclusion was that verbalization from adults, which to most children would be reinforcing, was to this child aversive.

In another case, the mother and father stated that their child knew how to walk for three months before he would walk in their presence. (Friends and relatives informed them that the child walked but would stop whenever his parents entered). They also indicated that if their child vocalized something which sounded like a word, he would not repeat it if either parent expressed an interest. In a separate lab session both parents were instructed (individually) to join their child while he was engaged in an ongoing activity (playing with a toy telephone) and to show interest and respond to him. The child's response in each case was to stop playing, suck his thumb and stare into space. In these cases giving the parents advice, without taking into account that their parental attention was aversive to the child, would have been expected to worsen the situation.

In the majority of cases, parental attention is a strong reinforcer, and the lab session serves to demonstrate to the parents the effects of positive reinforcement for a desired behavior and withholding positive reinforcement for an undesired behavior.

### **Home Observations**

Although time consuming, home observations provide an invaluable source of information about environmental factors that relate to a child and his behavioral problems. Home observations are based on interview information about what situations

seem to be most troublesome for the family in dealing with the problem child. The time before, during, and after dinner frequently is relevant for a wide range of behavioral problems.

To prepare for home observations, parents are told that the staff wants to observe their child in situations which are as natural as possible, with all members of the family behaving toward the child as they normally do.

During a home observation, the observer takes either a running record of exact verbalizations and actions or, in a later visit, a count of certain behaviors. In each case he is recording not impressions and vague descriptions but actual occurrences: verbalizations, movements from room to room, screams, hits, laughs, hugs, directions, requests, statements, etc. and in exact temporal sequence. During the time that he is recording, he in no way interacts with the parents or the child, nor does he conduct any interview during the home observation.

The observer has asked to be completely ignored. If, at first, the child approaches him he may say, "I'm working now," and from then on he makes no response whatever. After a few minutes the child ignores him also. The parents frequently report that "this is just about the way it always is." Two or three different observers return with very similar data from separate visits.

### **Evaluation of Data, Treatment Plan**

The observations provide highly specific information which gives a context in which to view the child's problem. For example, one child who reportedly never did as he was told was observed to have received 35 commands during a 20-minute play session. When the child ignored commands and went on playing, the mother dropped her request and continued playing with him. When the child began following through on a command, the mother turned away from the child. In this way she was actually putting "following commands" on extinction. Another child who yelled frequently was found to be ignored when he spoke in a normal voice and responded to when he

yelled. A third child, whose mother complained, "He will not sit still when I read to him," was observed as his mother "read" to him. The mother gave her child a series of questions about words that were too difficult for him and then severely criticized him for his incorrect answers. When his squirms escalated to jumping in the air and shrieking, he was told, "O.K. I won't read to you anymore." Apparently "reading" had become highly aversive to him and he had learned ways to terminate it.

Children with serious delays with self-help skills were typically confronted with situations in which parents criticized the child as he was attempting to dress or feed himself, and, when the child gave up, the parents dressed or fed the child. One nine-year-old mildly retarded child was spoon-fed by his mother; a four-year-old was not allowed to touch food even at meal time and thus never went through the finger-feeding and spoon-feeding stages.

Speech and language difficulties were similarly analyzed. A child who seldom initiated speech but who echoed was observed at three home sessions. Over half of his utterances were echoed back to him; e.g., when he said, "I want a truck," rather than bringing him a toy, his mother replied, "You want a truck." A four-year-old girl, who in speech evaluations showed no recognizable speech, and who had a pattern of bizarre hand movements, was observed in her home. She was an only child. She had no toys. Both mother and father mimicked her hand movements and smiled when she imitated. In three one-to-two-hour sessions, not one utterance made by either parent to the child was recognizable as a word by either of two observers. Without a series of home observations, the therapists would not have known how strongly the child's environment supported the behavior deficits.

By the time three to four clinic and home observations have been completed, the parents have observed the effect of their attention on the behavior of their child, and have discussed these observations with therapists. It is at this stage, as all the small parts are put together into a whole, that the parents can help

choose what problem they want to work on first, to what extent they want to include siblings in the treatment plan, and whether they want to start with clinic sessions or whether they want to start at home.

When the parent decides to work on a certain problem behavior or to try to build in a needed behavior, the first question to be answered must be "What behavior on the part of the parent will we help him change in order to alter a behavior in the child?" Whether or not the parents will withhold attention, contingent on a problem behavior, and give it only contingent on behaviors that are incompatible with the problem behavior, depends on whether we have found the parents' attention to be a reinforcer for this child.

In cases where parental attention is a strong reinforcer, teaching the parent to withhold attention contingent on a problem behavior is only part of the solution. In some cases the mother has found it difficult to give warm loving attention when the child is doing well. The patterns of response which involve "leaving him alone when he's not getting into trouble," are so strong that it has taken several sessions to teach the mother to respond to the child as he is behaving appropriately. Occasionally a therapist has taken the child into the playroom and worked on shaping a small behavior using social reinforcers, while the mother and another therapist watch and discuss what is going on. As the mother sees the therapist at work, she is encouraged to try different ways of motivating her child. It is as she uses these patterns and as they begin to show results, and only then, that she begins to find the child himself more reinforcing to her, and begins to find more confidence in working on problems and building in new behaviors. It is at this point that the parent can usually begin to see small approximations toward other useful, desirable behaviors to which she could respond in her child.

The situation is more difficult in cases where parental attention is not a reinforcer. For one thing, when parental attention is not reinforcing to a child, the pattern of parent-child interaction will be unusual because many behaviors of the parent will have been extinguished by a lack of

response on the part of the child. Play between parent and child will be absent, and the parents will generally interact by punishing a child and attempting to suppress an ongoing behavior. When the child is not actively causing a disturbance, the parents will not intervene. In these cases the parents must first be taught to use potent extrinsic reinforcers and to pair them with a class of verbal and gestural responses on their part that can eventually be used as reinforcers. They must also be taught when to reinforce approximations toward useful behaviors in areas of grooming, dressing, feeding, playing, and talking.

## **Types of Treatment Sessions**

### **Clinic**

In beginning treatment, the most successful method has been to give the mother a chance to try out suggestions while in the clinic. She and the child play together in the playroom under observation, and she practices, for example, reading to a child while he is sitting still next to her and not attending to him while he wiggles around or leaves her to go and play with something else in the room. This gives her experience in making her attention contingent on a desired behavior. As soon as she has accomplished a marked change in the child's rate of sitting and listening, she can discuss with staff the methods she used and the ways to use them at home. A following session then might be on a more marked problem behavior such as whining, tantruming when given a direction, or distracting the mother from a task at hand.

### **Home**

Concurrent with clinic sessions, the staff has conducted home treatment sessions. The therapist, having helped the family decide what problem to work on, goes to the home and observes them as they put the changes into effect. These visits are much like the early observations except that now, with definite behavioral contingencies planned, discussions will hinge on the ways in which the parents are succeeding

and on elements that deserve further consideration or possible change.

In Hawkins, Peterson, Schwend, and Bijou (1966) and Allen and Harris (in press) detailed studies, an individual set of parents was trained to work on a problem behavior at home. The program under discussion here was developed to assist a large number of parents, each dealing with a retarded child.

It is obvious that parents constitute a large portion of a child's social environment and that they have control over a variety of potent reinforcers. Behaviors which are followed either inadvertently or intentionally by one or more of these reinforcers will increase in frequency whether they are adaptive or disruptive. Teaching parents to observe carefully and to respond at times when adaptive behaviors appear in their child's repertoire will increase the child's chances of learning a significant number of skills. Only when a child has been observed interacting with his family can specific help be given. Following the isolation and treatment of one or more specific problems, the parents can begin to apply their skills in other areas of the child's behavior.

As we learn more about the repertoire of parents who have retarded children, though each case still must be treated as an individual instance, some broad patterns may appear. Systematic study of common pitfalls should aid in planning that will help parents avoid these typical problems.

BY SYLVIA SCHILD

## *Counseling with Parents of Retarded Children Living at Home*

IN THE LIGHT of the emergent philosophy and prevailing practice of encouraging home care of mentally retarded children, a re-examination of the casework counseling technique with parents is indicated. Until recent years, social workers in the field of mental retardation were primarily located in institutions and the focus of casework with families was usually geared around the problems of placement planning. With the advent of special clinics for early diagnosis and evaluation of retarded children, attention shifted to parental feelings and reactions and to ways of counseling parents more satisfactorily. The need for a sympathetic, supportive approach to the parents has been well established with the recognition that the impact of the retarded child is deeply disturbing to the ego-functioning of the parent.<sup>1</sup> The importance of having as complete a knowledge and evaluation of the child's problem as possible has been accepted as a necessary counterpart to being able to provide a meaningful explanation to the parents of the child's difficulty and to give consideration to the parental questions and emotional involvements related to having a retarded child.<sup>2</sup>

Social workers in specialized clinics and social agencies are now dealing not only with the areas of diagnosis and placement,

but with the complex task of helping the family and child live together more comfortably in the home. The purpose of providing maximum benefit to the child needs to be interlocked with minimal stress to total parental needs and family functioning. Both the child and the family are faced with making adequate adjustments to and in the community in which they live. Unless these ends are achieved, maintenance of the child in the home serves little purpose.

Professional workers, in supporting a philosophy of home care for retarded children, must be keenly aware of the responsibility to know how to help families achieve this goal with maximum ease. This paper proposes to examine some aspects of counseling with parents of retarded children living at home that are characteristic of the problem and that may lead to a better understanding of how to work with these families. These observations are drawn from experience in counseling with families receiving services in the Child Development Clinic at the Children's Hospital of Los Angeles. The clinic is a diagnostic and counseling center primarily for retarded children less than age 6. The observations thus are related to the early adjustment of the preschool child and his family, although they may

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<sup>1</sup> See Helen Beck, "Counseling Parents of Retarded Children," *Children*, Vol. 6, No. 6 (November-December 1959), pp. 225-230; and Alexander Herah, "Casework with Parents of Retarded Children," *Social Work*, Vol. 6, No. 2 (April 1961), pp. 61-66.

<sup>2</sup> A. Wheeler Mandelbaum, M.D., "The Meaning of the Defective Child to Parents," *Social Casework*, Vol. 41, No. 7 (July 1960), pp. 360-367.

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be generic to the problems of the older retardate as well.

### **AMBIVALENCE OF PARENTS' FEELINGS**

Enormous ambivalence of feeling is evoked in a parent when he learns that his child is retarded. Feelings of rejection, dejection, and disappointment collide with anxious hopefulness, doubt, anger, and self-pity. Strong emotions of guilt mix with protective parental reactions: resentment, confusion, and insecurity become pervasive. It is this ambivalence that characterizes initial work with families of retarded children. These conflicting emotions are never completely resolved, as the long-term aspect of the problem and the repeated crises that stem directly from the fact of the child's handicap stir up the ambivalence from time to time. To help the parent, it is necessary to ferret out the positive aspects of the ambivalence and help him to build on these so as to find some answers to the problem immediately at hand. Thus, ambivalence is dealt with in relation to the immediate crisis situation on a reality basis and by focusing on the areas that are conducive to meeting the needs of the family. The following case illustrates this point:

A young couple had just heard the diagnosis of retardation for the first time. In the hostile tirade the mother loosed on the social worker, she vehemently denied that this catastrophe could be true, attacked the doctors, blamed herself. Toward the end of the outburst, she cried out, "Nothing I ever do is perfect. How will I ever be able to raise this child?" In this plea for help the social worker recognized the mother's immediate fear and denial of the diagnosis as resulting from her shaken confidence in being able to successfully handle her mothering role with the defective child. The positive aspect of the ambivalence, underlying the fear of inadequacy, was her intense desire to be a good mother. This was an area that could be worked with realistically in counseling, since she was indeed performing successfully in her mothering role with her two older

children. The husband's support to his wife was encouraged. With help and attitudinal change, this mother was enabled to depend again on her own inner strengths and resources in coping with the child; this in turn paved the way toward better understanding of the child's limitations and freed her to work on other aspects of the problem.

A factor accounting for sustained ambivalence toward a retarded child is that the parents are deprived of the opportunity to project any blame for the problem onto the child himself. It is too difficult in any rational way to blame the child for his own defect. This differs from situations in which, when social pathology exists and becomes reflected in disturbed parent-child relationships (for example, in emotional disturbance and delinquency), the parent realistically is able to hold the child partially responsible for a share of the problem. This serves to alleviate some parental guilt and lowers resistance to accepting help. In the area of mental retardation the self-accusatory parent, who feels that he alone is in some way accountable for his child's limitations, is very well known.

It is an accepted fact that part of the resistance of the person seeking help stems from his feeling of responsibility for the problem. When guilt is intensified, the resistance to help will be proportionately increased. Because of this, those endeavoring to help parents of retarded children must be aware that heightened resistance is usually due to the inwardly projected guilt of the parent. In counseling, this guilt needs to be alleviated and an emphatic understanding of the problem area imparted to lower the parent's resistance, freeing him to benefit from the offered help. Most parents hope to hear an authoritative and sympathetic endorsement of themselves, of their human and parental competence, and of their right to blame themselves for what has happened.<sup>2</sup>

<sup>2</sup> L. Kanner, M.D., "Parents' Feelings about Retarded Children," *American Journal of Mental Deficiency*, Vol. 57 (1953), pp. 375-379.

One way of ameliorating the guilt of parents is to counsel them together in joint interviews. This helps to focus on the mutuality of feelings and responsibility shared by each parent and aids to shift away from individual parents the assumption of self-blame for the problem. The joint interview technique often may help to restore the marital balance around the mutual concern for the child so that the parents are better able to mobilize all their strengths to handle crisis situations.<sup>4</sup> Although mothers are generally entrusted with the major care of the child, management is a joint responsibility of both parents. Too often the father's role and share of responsibility are overlooked, especially when it is the mother who assumes the task of taking the child for his medical care and transmitting the medical information and advice to her husband. Joint interviewing frequently serves as a device to engage the father actively and to give due consideration to his concerns and attitudes, as well as to those of his wife. Counseling parents together is supportive and enables them to concentrate their energies, not as much on the fruitless searching for why this has happened to them, but more productively on how they can better perform in their parental roles in order to benefit their child.

#### CHANGES REQUIRED OF PARENTS

The hard reality that needs to be faced is that with the presence of a retarded child the family is no longer the same and; it cannot be reconstructed as it was before the arrival and impact of the defective child. Perhaps the area of greatest difficulty that needs to be resolved in the counseling process is the changes required on the part of the parents to meet the special needs of the retarded child. These often conflict with parental functioning that heretofore was considered satisfactory.

<sup>4</sup> J. Geist and N. M. Gerber. "Joint Interviewing: A Treatment Technique with Marital Partners," *Social Casework*, Vol. 61, No. 2 (February 1960), pp. 76-83.

Often the management of the retarded child is perceived by the parents as being no different from their performance with their normal offspring. Counseling needs to be directed toward helping parents to see that their attitudes and feelings relative to mental retardation per se have indeed shifted their own parental behavior.

One mother complained constantly of her child's temper tantrums. The disturbance the child was creating was upsetting to the entire household and the mother felt at her wit's end. The parents were beginning to feel that to keep the child in the home was almost impossible. The mother stated she was handling the problem behavior exactly as she had in the past coped with similar behavior in an older child.

Closer examination revealed that in reality the mother, caught up in her disappointment and her attitude that a mentally retarded child was totally worthless, considered the child not worth bothering to discipline. Also, the father was unsupportive, leaving all discipline to his wife. Hence, the mother responded to the tantrums with anger and helplessness, and was permitting herself to be manipulated by the child. The youngster, having no external controls put on his behavior, became increasingly infantile and difficult. This gave validation to the low value placed on him by his mother.

When the mother gained some insight and understanding that she was reacting differently to this child than to her normal offspring, she began to cope with the problem. Her self-esteem increased with her more effective management of the child. In addition, the father was helped to participate more meaningfully in the child's discipline, thereby giving his wife emotional support. As the child's behavior improved, the parents acquired a new appreciation of him. This in turn helped them to evaluate better the considerable potential latent in their mildly retarded son and to enjoy a more favorable relationship with him in the home situation.

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The resistance and ambivalence of the parents in counseling are amplified also by the nature of the new stresses encountered merely by virtue of being the parent of a retarded child. The problem of keeping the retarded child at home is determined by a number of factors, such as sibling relationships, social status, family attitudes, the degree of deficiency in the child, and so on. These are all potential problem areas and the ability with which problems that might arise in these areas are handled and solved vary from family to family, situation to situation.

The new stresses arising from the presence in the family of a retarded child are not pathological as such, but should be viewed as a normal complement of problems for the situation that may affect the parent-child relationship and to which adjustments need to be made. When a pathological situation (i.e., divorce) is imposed on a family and is disruptive to family functioning, the focus in counseling must be directed toward the realistic problems that occur as a result of the pathology.<sup>8</sup> It has been pointed out that the presence of a retarded child in the home is often a precipitating factor in individual or family maladjustment or breakdown.<sup>9</sup> The family that is able to adjust satisfactorily to the impact on it of a retarded child has also to deal adequately with the many normal problems that occur in relation to the situation. Their attitudes, feelings, care and management of the child, and the like must all be taken into account.

These normal problems attending the presence of a retarded child in the home must be dealt with on a reality basis to permit the best possible solutions to be effected. Some of these problems are met

often in other handicapping conditions of childhood: the increased dependence of the child on the parent, confusion and lack of finiteness in medical diagnosis, crumbling of parental aspirations for the child, rehabilitation and training problems, and the like. However, there are some conditions that occur uniquely in the case of the mentally retarded child and his parents.

One solution, which is culturally sanctioned, is often freely available to parents of the severely and moderately retarded. This is the opportunity to relinquish responsibility for care of the child to an institution if, considering the degree of his intellectual impairment, the child is eligible. Granted that placement holds the parents to a modicum of responsibility and is indeed an appropriate solution in many situations, there still is a need for recognition that this alternative presents conflict for the parents and may impair efforts to effect a successful adjustment in the home. From the time that parents are told that their child is eligible for institutionalization the ambivalence about the child and the problem increases. Again, this ambivalence needs to be handled in counseling, with the focus geared to the positive aspects inherent in the successful fulfillment of parental roles and responsibilities.

### COUNSELING SHOULD BE SPACED

One difficulty occurring in counseling with parents is that the resistance of the parent is sometimes insidiously supported by the behavior of the child himself. The parents may move well initially in shifting to more positive attitudes and methods of handling the child only to be thwarted by the slow movement of the child in responding to improved parental functioning. Although intellectually the parents can relate the slow pace to the child's mental limitations, they often become frustrated emotionally and can react by feeling that the counseling is unproductive. This can cause reversion to easier, more familiar patterns of behavior. The counselor, too, can become uneasy and impatient by the

<sup>8</sup> H. Pannor and Sylvia Schild, "Impact of Divorce on Children," *Child Welfare*, Vol. 39, No. 2 (February 1960), pp. 6-10.

<sup>9</sup> Robert M. Nadal, "A Counseling Program for Parents of Severely Retarded Preschool Children," *Social Casework*, Vol. 42, No. 2 (February 1961), pp. 78-88.

slow pace of the child's response and may fail to support the parents' efforts adequately or project blame on the parents for failure to utilize the counseling.

The most immediate help, consequently, occurs when the parents are having critical emotional distress and help can be directed toward easing their personal difficulty rather than being geared to change in the child himself. Casework for this latter goal, which is focused around the management and behavior of the child, can perhaps be best provided when spread out over proper and widely spaced intervals to give the child an opportunity to react and develop at his own speed.

A review of the reactions of forty parents to diagnosis and counseling emphasized that the parents needed time to take in the extent of their problem and solutions needed to be worked out step by step. Also, parental questions did not arise in an organized, crystallized fashion but gradually, as the child grew.<sup>1</sup> When the element of time is taken into consideration and work with the family is structured over appropriate intervals, the parents are able to bring into counseling some growth on the part of the child that might not otherwise have been apparent if counseling around the child had been sustained on an intensive basis. In other words, parents need intensive casework help at times of crisis situations but, in addition, they need a continued contact. The latter can be less intensive and made available to them over a longer period of time. Such counseling should be properly spaced and educationally focused, to help the parents with the practical problems of daily living with their retarded child. This help is often crucial in determining if the child can live in his own home and in strengthening and sustaining the mental health of the total family unit.

Counseling related to everyday living experiences with the retarded child helps to

sustain the parents' motivation to continue in a program designed to improve the child's behavior and to develop his potential. Parents need to deal with concrete situations—the success they achieve in such common daily experiences tends to ameliorate the problems of living with a retarded child. For this kind of approach the caseworker must have a keen knowledge and awareness of normal growth and development. To help the parents understand their child's behavior, it is important to assist them in relating behavior to normal functioning and expectations of children as well as to comprehend the limitations in their own child and its implications.

#### SUMMARY

In summary, this paper has discussed some aspects of helping parents who have retarded children living at home. The following points were suggested:

1. Professionals counseling parents to keep their retarded child at home assume an additional responsibility to learn how to help the parents achieve this goal comfortably. This implies not only increased understanding of the problems faced by the parents, but also better awareness and skill in involving and sustaining parents more effectively in the counseling process itself.
2. The key factor to be dealt with in the counseling process is the ever present ambivalence of the parents about their retarded child. Movement toward satisfactory solution of problems is more easily attainable when the positive aspects of the ambivalence are used constructively to meet feelings and to free parents for changes in attitudes.
3. Guilt feelings of the parents are enhanced by the fact that they cannot rationally project any responsibility of blame for the problem on the child himself. These guilt feelings heighten the resistance to meaningful participation in counseling. Involvement of both parents in joint counseling is one way of alleviating the in-

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<sup>1</sup> Charlotte H. Waskowitz, "The Parents of Retarded Children Speak for Themselves," *Pediatrics*, Vol. 64 (1959), p. 319.

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wardly directed guilt and of helping parents to focus on more rewarding functioning in their parental roles with the retarded child.

4. The presence of a retarded child changes the structure of existing family relationships. One area of great difficulty is that former parental functioning may prove to be inadequate in meeting the needs of a retarded child. Parents need help in seeing that their attitudes and feelings relevant to mental retardation per se affect their parental behavior.

5. There are many new stresses affecting families of retarded children that should be viewed as normal problems for the situation and that need to be dealt with on a reality level. Some of these, such as the easy access to shifting responsibility of the child through institutionalization and the slow reaction of the retarded child to parental teaching and management, are unique and may hamper counseling efforts.

6. Parents are best helped at times of crisis, but counseling geared to improve-

ment of the child's behavior and to daily living can be structured over spaced intervals planned to compensate for the slow movement and the maturation of the child and to offer sustained support to the parents.

The importance of more and better knowledge about how to help these families has been best expressed by a parent who has written:

The greatest single need of parents of mentally retarded children is constructive professional counseling at various stages in the child's life which will enable the parents to find the answers to their own individual problems to a reasonably satisfactory degree. . . . We need guidance from someone who can help us to see that this thing which has happened to us, even though it may be a *life-shaking* experience, does not of necessity have to be a *life-breaking* one.<sup>6</sup>

<sup>6</sup> Mrs. Max A. Murray, "Needs of Parents of Mentally Retarded Children," *American Journal of Mental Deficiency*, Vol. 63, No. 6 (May 1959), p. 1084.