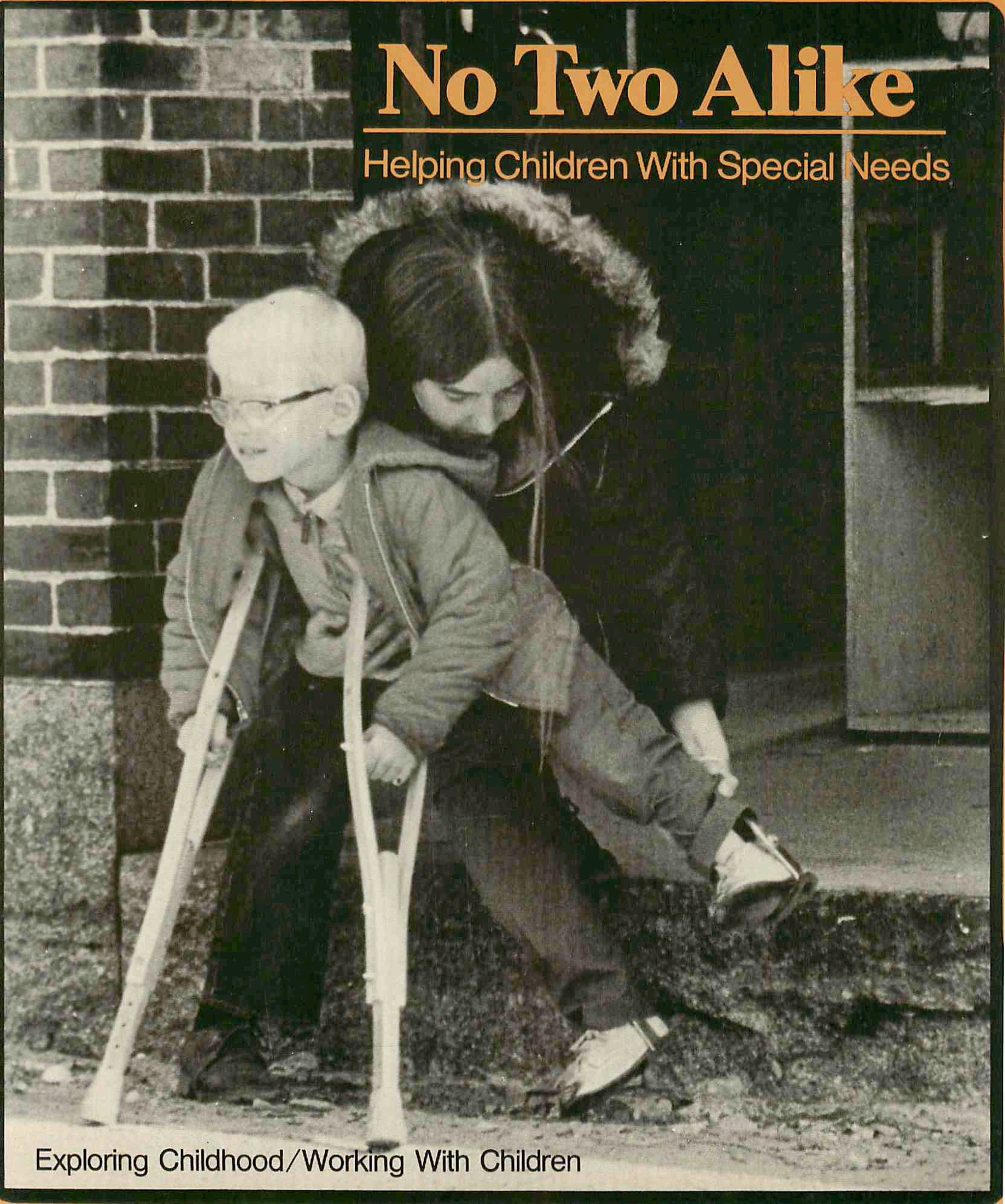
No Two Alike

Helping Children With Special Needs



Exploring Childhood/Working With Children

No Two Alike

Helping Children With Special Needs

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Henry Felt

Raising Some of the Issues

What Do We Mean by "Special Needs"?

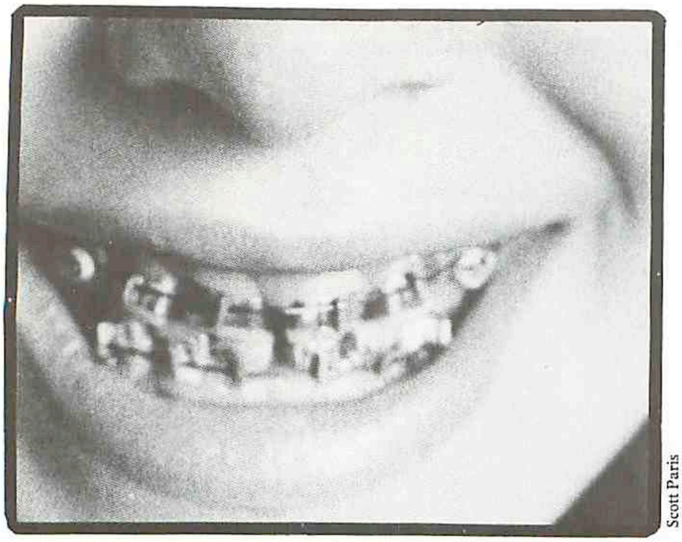
Children with special needs are those who are often called "handicapped." Some of these children have poor vision or hearing. Others have crippling conditions and must wear leg braces in order to walk. Still others require special attention in learning to speak, read, or play with other children. To call these children handicapped implies that they cannot do certain things, and that their growth must ultimately be limited. In describing a child as handicapped, the emphasis is not on his or her *potential* for growth, but on his or her disability.

What does the term "handicapped" suggest to you? To find out, try the exercises below with other members of your class.

Word Association

Write the word "handicapped" at the top of a sheet of paper. Give yourself five minutes to put down all the words (pictures and ideas) that come to mind in connection with the word. Then compare notes with your classmates. What words or ideas come up most frequently?

Can you recall the first time you heard a person described as "handicapped"? Who was that person? What was your impression of him or her? Do you think it was a fair one?


Scott Paris

When might this person be labelled "handicapped":

- by the braces themselves?
- by his or her feelings about wearing braces?
- by other people's feelings about them?

Would *not* wearing braces be more or less of a handicap for this person? Explain.

Do the braces answer this person's special needs? Do they *create* any special needs?

Is a person who wears glasses "handicapped"?

Can you think of other examples of situations in which people might be called "handicapped":

- by an actual disability?
- by his or her own or others' attitudes?
- by temporary circumstances?
- by the limitations of the physical environment?
- by social prejudices?

To Think About:

What is the difference between having a *special need* and being handicapped?

The Hazards of Labeling

For many of us, the term "handicapped" calls to mind images of unhappiness and embarrassment. It suggests to us a person who feels sorry for him- or herself, and who expects others to pity him or her.

Teachers and therapists who work with young children know that if special needs are provided for properly, the child who is born blind, deaf, or crippled can still grow up with confidence in his or her own abilities and talents. If a special need is not met adequately, however, the child's frustration and unhappiness may indeed handicap him or her. For most young children, however, the idea of being "handicapped" need not exist, unless other people's attitudes make a child feel that he or she doesn't measure up. That is why many teachers and doctors choose to identify children's specific needs without pinning the labels "handicapped" or "defective" on the whole child.

Have you ever been stuck with a label or reputation you felt you didn't deserve?

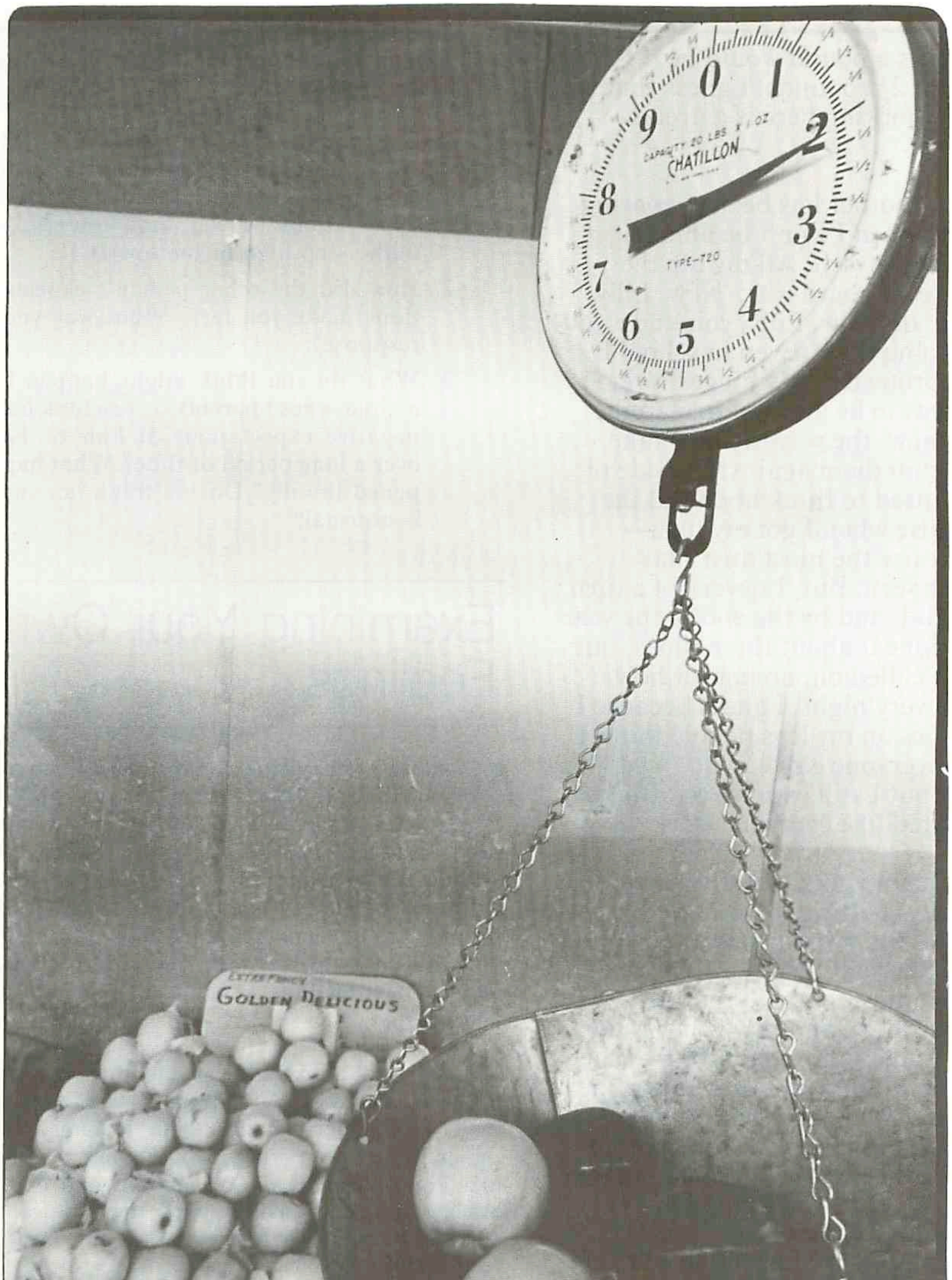
How did it affect your view of yourself? your behavior?

In the following story, a girl who is *not* handicapped by her special needs hopes that other people will not view her as helpless. Her greatest wish is to be treated just like everyone else.

Lilly

In a busy corner produce market, Lilly, a tall, willowy 15-year-old with multiple sclerosis, stacks ripe tomatoes in beautiful pyramids of red.

"I can't tell you how much this job means to me. It's funny, but all my life I've wanted to work in a store like this . . . you know, wear one of those starched white aprons and be able to figure out in a second how much



Rogier Gregoire

apples at 43 cents a pound would be if someone bought 2¼ pounds. I guess that's silly, but to me working here is a dream come true.

"All my life my mother has been preparing me for the time when I won't be able to get around so well by myself. All my life the only thing I've ever heard was, 'Now, Lilly, you be careful,' or 'Now, Lilly, you know you shouldn't be doing that.' Even in school I was always so protected. My biggest dream in first grade was to be allowed to clap the erasers. You know, the way the kids take them out and clap them against the side of the building. I used to think about all the dust I would raise when I got my turn—I was going to raise the most dust that school had ever seen. But, I never got a turn. Everyone else did, and by the end of the year everyone had done it about three times, but I just never got called on, no matter how hard I prayed every night. I guess because I have these braces on my legs people think I can't do what everyone else can do. And maybe I can't, but I still want to try. I just want to be treated like everyone else.

"That's why I feel so good about this job. I feel good that I'm getting to do something I've dreamed of. My mother was against my working here. She said I wouldn't be able to get around the crates to weigh the stuff. When I told her that Sam, the owner, said that he would make more room for me, she said that people would feel funny about me being in braces and walking with a wobble. She said that they might even stop coming to Sam's market if they always saw someone they felt sorry for. But, you know something? All anyone seems to care about is whether I can figure out how much 2¼ pounds of apples cost at 43 cents a pound."

Some Questions to Consider

Lilly's story is an example of how other people's attitudes may either limit or expand your opportunities to do what you know you can do.

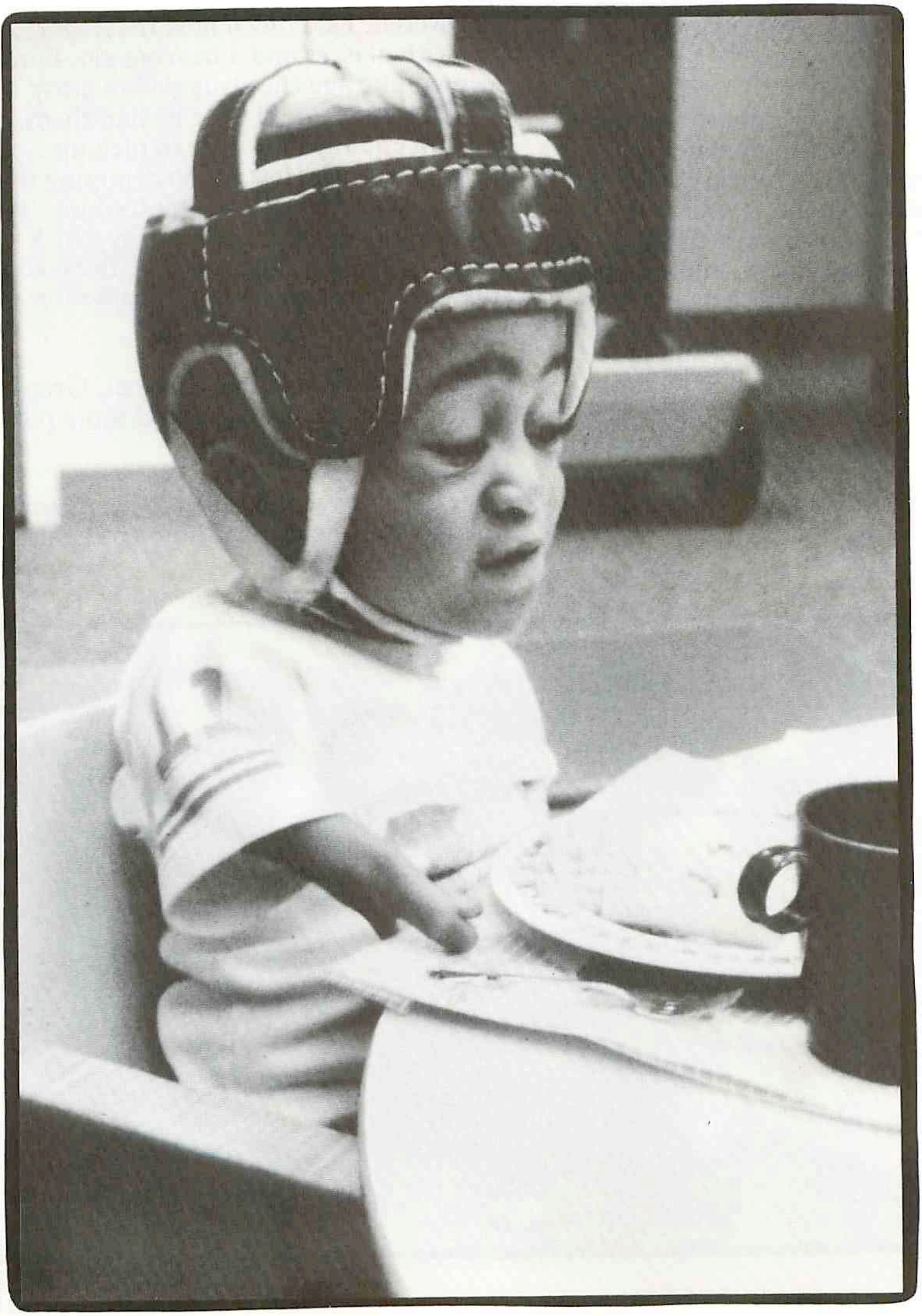
1. Can you recall a situation in which you were or were not allowed to do something because another person's expectations of you were unrealistic (either too high or too low)?
2. How did the other person's expectations make you feel? What was your response?
3. What do you think might happen to a child whose parents or teachers had negative expectations of him or her over a long period of time? What happened to Lilly? Do you think her case is unusual?

Examining Your Own Feelings

Most of us have little contact with people who have special physical or emotional problems. When students first meet children with special needs at their fieldsites, they may find that some of their reactions are surprisingly strong and difficult to cope with. Everyone has feelings about people with special problems, including the people who have them. Sometimes the best way to handle these feelings is to confront them honestly and openly.

You will probably find that the more contact you have with the special children at your fieldsite the easier it will be to handle your feelings. During the course of your work, you will come to recognize and anticipate these reactions and how they affect your relationships with the children. Instead of being overwhelmed by the power of your feelings, then, you can learn to accept them and to make more realistic demands on yourself as a classroom worker.

In the next story, Glenda is unprepared for the feelings of embarrassment and awkwardness that disrupt her first morning's work at the fieldsite.



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In the beginning, your own feelings sometimes make it hard to help the child with special needs.

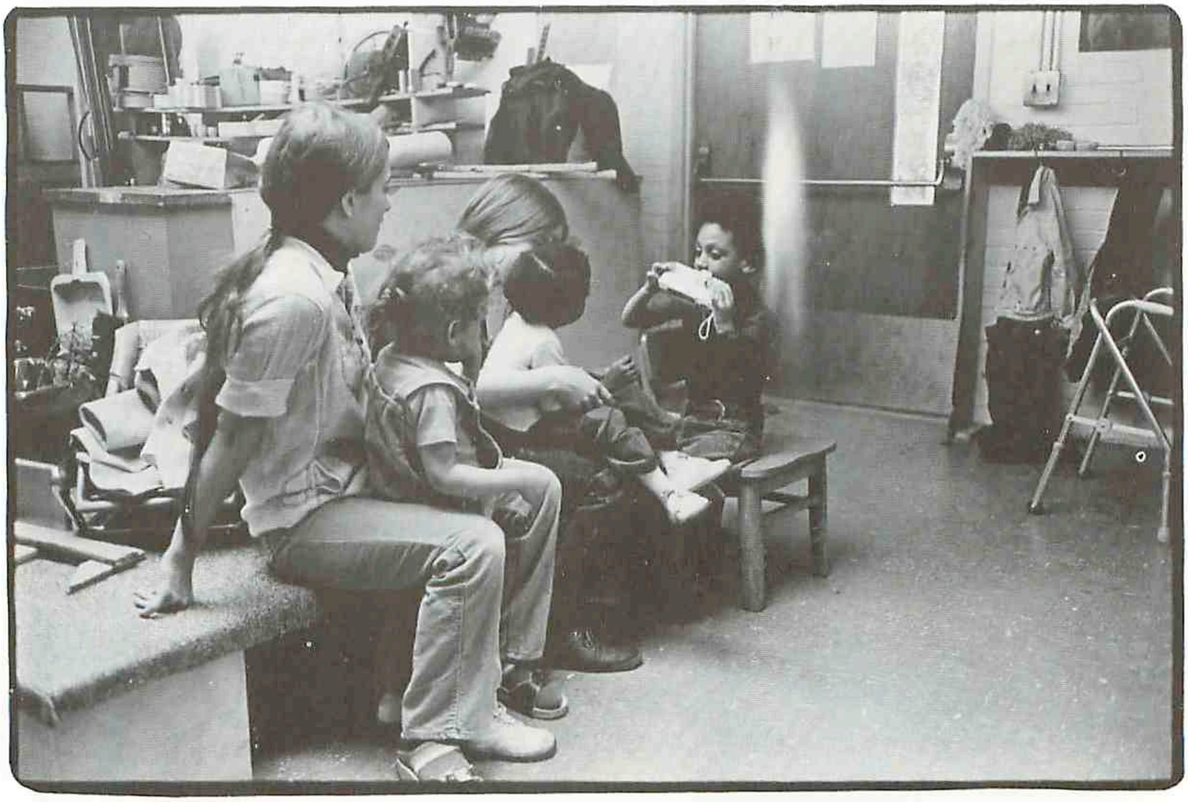
Glenda and Gregory

"I wish I could do it all over again. It makes me feel embarrassed just to remember what happened yesterday at the nursery school. I wandered around looking for ways to be helpful. Some of the kids looked so fragile I was afraid to get close to them, and others had a lot of trouble speaking clearly, and I had trouble understanding them. I was very relieved when I finally found a group of children who were sitting at a table busily cutting and pasting. Here was something that looked familiar to me and it was definitely something I knew I could help them with.

"But it wasn't as easy as it looked, I soon discovered. I sat down next to Gregory, a boy with glasses and a hearing aid. For what seemed like ages he struggled to grasp a pair of scissors, and once he had them, he took an equally long time to pick up a piece of paper to cut. He kept on dropping the paper, so I offered to hold it for him. 'Hold paper,' he said in a sort of foggy, thick voice. I held the paper until he finished cutting out the rough outline of some sort of foamy, bubbly pie.

" 'This looks good enough to eat, Gregory,' I said. 'Let's see if we can find more pictures of things to eat.'

"But Gregory wanted to glue his picture first. That is, he wanted me to put glue on



"Some of the kids looked so fragile I was afraid to get close to them..."

Rogier Gregoire

the paper for him. After I put the glue on the paper, Gregory pressed the picture down and lifted it and pressed and lifted and pressed and lifted. I had no idea whether to encourage him to 'keep at it,' or to suggest something new because he was having such a hard time. At last he decided on his own to try the scissors again. Even the decision to change from one thing to another seemed to take a lot of energy and effort; I could practically hear the gears grinding in his head.

"This time, Gregory ran out of energy and concentration. He couldn't get his fingers properly hooked into the scissors. I began to feel very bad for him.

" 'It's very hard for you, isn't it, Gregory?' I pointed out, swiftly putting my foot in my mouth.

"Gregory agreed that it was and put down the scissors. I felt like such a fool that I had to leave the table. He was trying so hard and I made him feel so much worse by saying that. Why had I ever imagined that I could be helpful to Gregory? Obviously, he needed my help like a hole in the head."

Questions for Discussion

1. What kinds of preparation might have made the first day at the nursery easier for Glenda?
2. How did Glenda's feelings about Gregory's abilities get in the way of her helping him?
3. Do you think Glenda tried to do too much for Gregory?
4. What would you have done, if you had noticed that Gregory was having a great deal of trouble with the scissors?
5. Can you think of some other way Glenda could have conveyed her sympathy to Gregory, other than saying, "It's hard for you, isn't it?"

Observing at the Fieldsite

It is often difficult to determine whether or not a child has special needs. Since there can be many explanations for a given behavior, it takes a trained specialist to determine why a child acts in a particular way. It is important not to make your own diagnosis. No one likes to be labeled. Try to treat each child the same.

The stories about Lilly and Glenda remind us that sometimes we jump to conclusions about the capabilities or inner feelings of people who are different from us in some way. We may fall into the trap of prejudging them, or of assuming that because they are different in one way, they must be different in every way.

One way to avoid this kind of prejudging at the fieldsite is to spend the first week simply observing the children there. Take time to "react" to the children and to become aware of your feelings about them. Try also to see how the children feel about themselves, and to realize what they can do for themselves. Don't be in a rush to help.

Below is a description of what happened to Isabel, a child whose special needs were not observed or responded to until it was nearly too late.

Isabel

Isabel was always silent in her first grade class. The teacher, Mrs. Grenville, assumed that Isabel was probably a slow learner, perhaps even retarded. Mrs. Grenville wished that she had more time to work with Isabel, but with 20 other children in the class it was hard for her to make time for one child. Isabel almost never spoke, and by October Mrs. Grenville and most of the other children had forgotten that she even existed. Mrs. Grenville had even stopped giving her school work to do. She assumed

"Isabel was always silent. . . "

Ira Kirschenbaum/Stock, Boston

that Isabel was too "disturbed" to do it, anyway.

In January, a student teacher joined the class. When Mrs. Grenville described the children to the student she said that Isabel seemed to be either emotionally disturbed or "retarded," and that she was very unresponsive to anything.

One day, while flipping through some picture cards, the student teacher came across a card of an apple tree in full bloom. She handed the card to Isabel and said, "tree."

Isabel just looked in her face.

"Tree," the student said, forming her mouth very carefully. "Do you know what kind of tree this is, Isabel?"

Isabel just looked in her face.

"I know a song about trees," continued the student.

She began to sing, "*L'arbre* is what I wait under for my love. *Los arboles* in my garden grow. . . ."

But before she could finish, Isabel grabbed her hand and started saying, "*Arboles, los arboles. Me gusto los arboles*," and a rush of other Spanish words. It was soon apparent to everyone that Isabel spoke almost no English. She spoke Spanish.

Questions to Consider

1. What might have happened to Isabel if she had been stuck with the label "disturbed" or "retarded" for the entire year?
2. Do you think it is safe to pay no special attention to a child who is exceptionally "good" and quiet? When might this behavior be a signal that something is wrong?
3. Can you remember any situation in which another person jumped to a conclusion about you? How did that make you feel?

   Have you ever done the same thing to someone you didn't know very well? What was the result?

Training to Observe

As you have seen, the importance of getting to know a child and his or her specific capabilities cannot be overestimated. Preschool teachers often collect essential information about children by interviewing them and their parents, and by having families fill out records containing information about the child's development. When the child enters school, the teacher already has some notion of the sort of "equipment" the child will bring with him or her.

You may not have access to records or parent interviews as a teacher's assistant at the fieldsite. Your most useful source of information about the children will be your own eyes and ears. Therefore, you must learn to be a skilled observer.

In the Exploring Childhood booklet called *Getting Involved*, there is a discussion of observing and how it can help a student to provide for a child's classroom needs. It is reprinted here for your convenience.

Observing

Observing is a process of watching closely and writing down what you see. It is an organized way of paying special attention to something that you want to learn about. It helps in figuring out what to do with or for a certain child or children because you see what is really going on, where the problem probably lies, and you have information you can go back over later.

In the example shown, the student "stood back" from being involved in mobile-making and in a sense also stood back from his emotional reactions—being angry at Hannah's disruptiveness. While standing back, he noticed that Hannah sat down, began to cut, then jumped up and ran off; he wondered if Hannah didn't like to cut. At the next opportunity the student watched again and saw she was clumsy with scissors. This led him to act in a new way—sitting down and trying to teach Hannah—which in turn led him into another observing cycle. "Hannah is left-handed, I wonder if that's the problem." Getting left-handed scissors helped Hannah in at least a small way by giving her a better tool to use.

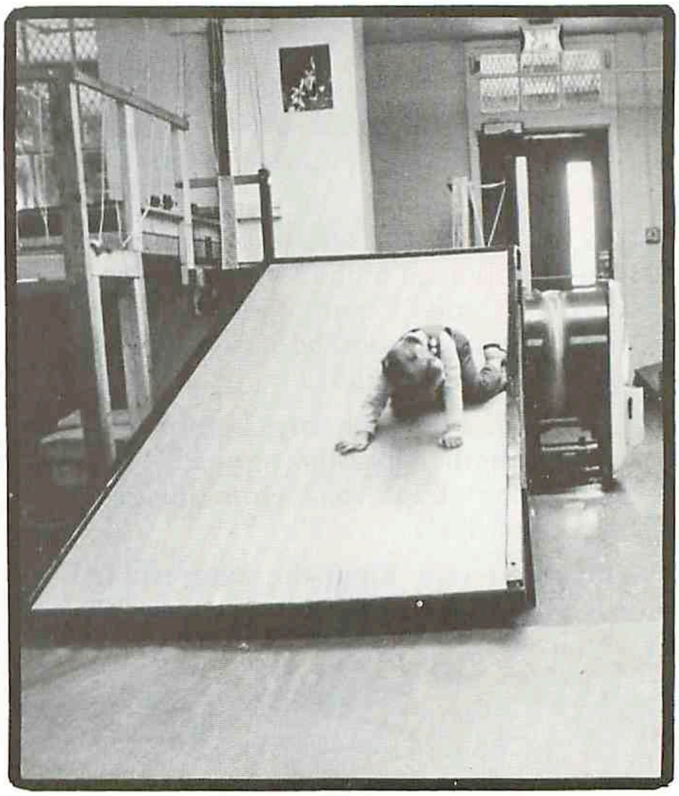
To help insure that your own observing will get at what's really going on the way this student's did, here are a few techniques which can be used.

Standing Back

Literally stand back out of the mainstream of ongoing activities where you won't be distracted by children's requests and questions or tempted to join in the fun. (It's a good idea to mention what you intend to do to your fieldsite teacher ahead of time so your assistance will not be counted on during the time you are observing.)

Getting a Question

Sometimes the things you notice and wonder about will be very broad questions or problems like "why are things always so noisy?" Since observing thirty children all morning would be impossible, it is necessary to break such a large question down into smaller questions, each of



which can serve as a focus for a series of related observations. Focusing questions in this case might be "Which activities are the noisiest?" (Do a five-minute listening observation in the middle of each new activity and rate them for noise level.) "Which children seem to be the noisiest?" (Step back and observe during a particularly noisy time.) From this kind of observation you could move to observing particular children in particular activities or situations. You might see what stimulates them to make noise, and then form some ideas about approaching the noisy activity differently to keep the noise down, if that is what you think needs to be done.

Collecting Good Information

Try to keep notes factual, and be specific about what is actually happening. Develop and practice your own shorthand. For example, if you are watching Ted, a noisy child, to see why he's so noisy, you might find yourself making notes like these: "B. drawing house. Looked for red crayon. Didn't have one. Took T.'s red. T. yelled 'give me back my crayon.'" This kind of specific note would give you more valuable and useful information than, "T. got mad at B. and started yelling."

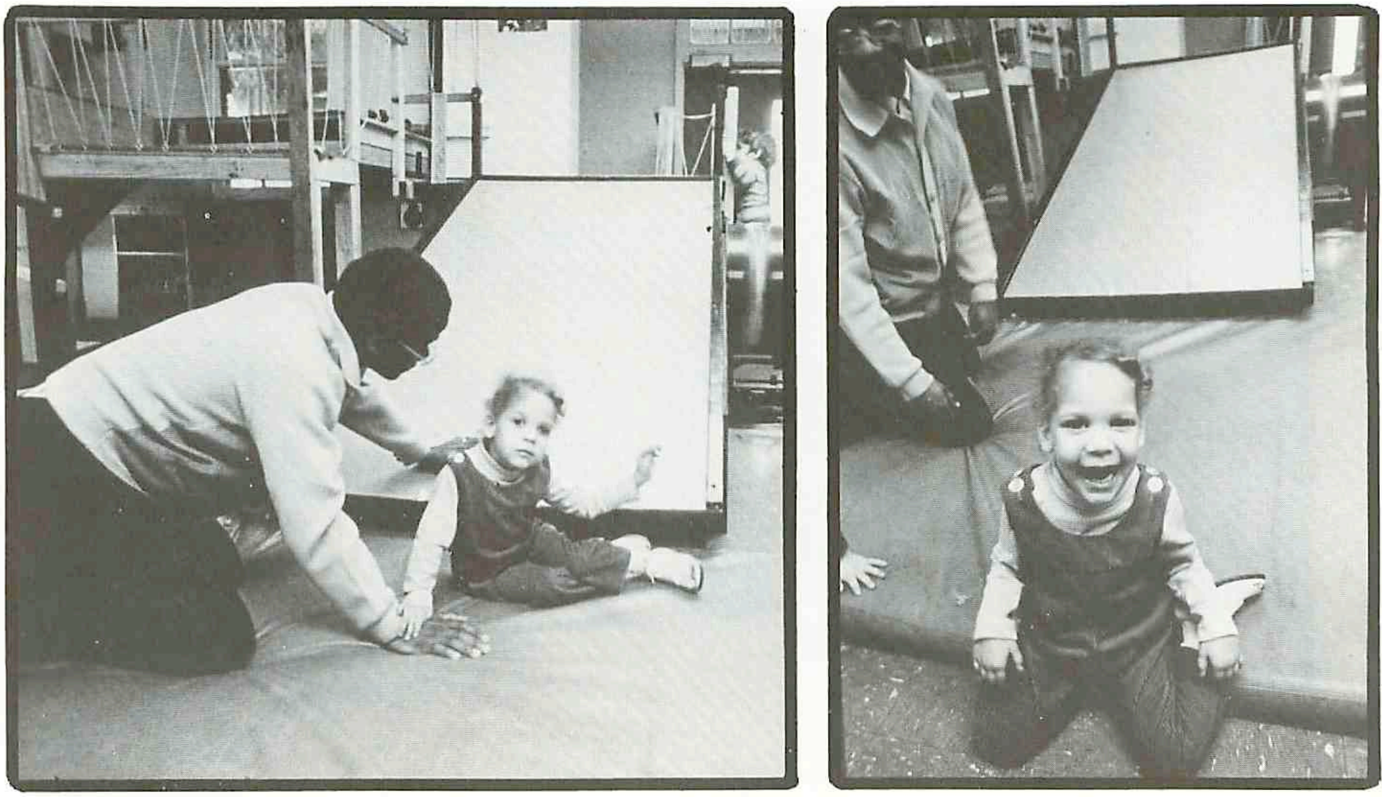
Doing an Observation

To become more skilled at using these techniques before entering the buzzing world of the fieldsite, try planning and doing an observation at your school, perhaps in the cafeteria, front office, or a hallway. If two or more people do the same observation, compare notes, problems, ideas that work, to help each other refine observing skills.

Ideas for Observations

Use observing to help deal with issues in your field work. Here are some samples of possible questions for which you could do an observation:

- What kinds of outdoor games do children enjoy?
- Darryl's mother is afraid he may be a slow learner. Can I help?
- I have to set up the dramatic play corner. Where's the best place?
- Why is the art room always so messy?



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- How long should I plan an activity to be?
- Why don't the other children play with Trudy?
- Why is there so much running in this room?
- Do children use the quiet area?

Brainstorm how you might do observations to answer these questions.

You can begin answering questions you may have about children by observing children you see outside the fieldsite. For example:

- What might be good for a three-year-old but dangerous for a two-year-old on a playground?
- How do small children act in toy stores? in supermarkets?
- Are children more aggressive when they are playing outside than when they are playing inside?
- How long can a five-year-old stick with a project?

After you have read the section on observing, you might try to "brainstorm" a list of observation questions and ideas for the children at your fieldsite. Do you think that the observation questions for children with special needs would necessarily be different from those suggested in *Getting Involved*?

Some possible differences might be:

- more attention to what kinds of help the child needs with self-care skills;
- more attention to what kinds of things might prove either frustrating or dangerous for a child;
- more attention to things or situations that might frighten a child;
- more attention to times when a child might need adult help;
- more attention to individuals, rather than to groups of children.

Can you think of other differences?

You may want to do your observations in pairs, and then compare notes. This is a good way to check the accuracy of your observations.

Rogier Gregoire

Making Room for the Child with Special Needs

Making Room in the Fieldsite

Every child needs special consideration in preschool or kindergarten at one time or another. The child just recovering from a long illness, the child who has had to cope with the appearance of a new baby at home, the child who is frightened of thunderstorms—each may be unable to work within the usual structure and routines of his or her classroom on a given day, or for a certain period of time.

Take Benjamin, for example. Benjamin is allergic to chocolate. Last week his class made brownies. Jessica, the student in charge of the activity, had forgotten about Benjamin's allergy and had not thought ahead about whether or not to include him in the project. She hoped that perhaps he might get absorbed in painting or block building, but when she set up the table for cooking, there was Benjamin, ready and waiting.

What was Jessica to do?

What would you have done?

The Proper Ratio

Making room for a child may call for relatively minor adjustments in schedule, staffing, or environment. It may also call for a highly individualized program, with the staff working on a one-to-one basis with the children.

Some teachers favor mixing children with special needs with "normal" children in equal numbers in a preschool program. In this way, they reason, no child will be in the minority. Others believe that this 50-50 ratio only guarantees separation of the two groups, and that they might as well be in separate classes altogether. Still another opinion is that it doesn't matter how many special children are enrolled in a class, so long as they are taken out of the classroom for some part of the day to receive tutoring or some form of therapy. Whatever the ratio, adjustments will almost certainly have to be made to make room for children with special needs.

What is the ratio of children with special needs to "normal" children at your fieldsite?

Do you know why the program has been set up this way?

Why might parents prefer an integrated class for their children?

Ms. Albright, a teacher at the Parkman School for blind children, tells the story of Jim. Jim came to Parkman when he was six. At Parkman, Jim was a star athlete and the captain of the soccer team. When he reached eleventh grade, Jim transferred to the Waterville Regional High School, a public school. He had to give up participation in soccer and other team sports, because there was no room for a blind boy on a team of sighted soccer players. Ms. Albright thinks it was probably a mistake for Jim to leave Parkman when he did.

What do you think?

The successful integration of a child with special needs into a preschool class obviously depends on a number of factors: the child's own strengths and abilities, the number of staff members assigned to the class, the physical facilities, and the acceptance of the child by his or her classmates. In some cases, "making room" for the child proves impossible because his or her needs have not been anticipated and provided for. But many changes and adjustments can be made along the way.

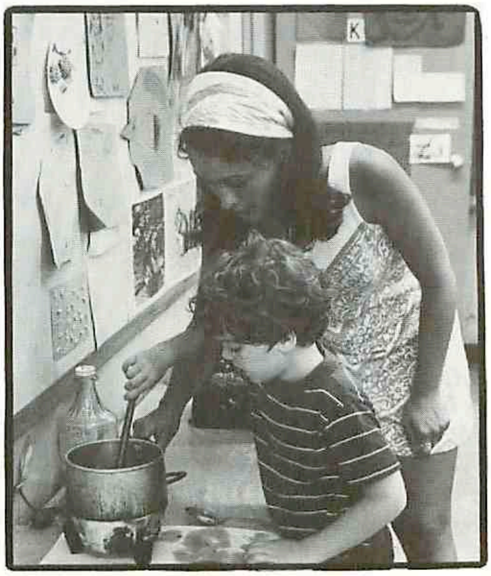
Imaginary Companions

Imagine that a child with special needs is going to spend a typical morning at your fieldsite. What preparations will need to be made, if any? The following exercise is designed to help you think about such a situation.

Divide into small groups (four to six students) according to fieldsite placement. (If there are only one or two fieldsite placements, you may want to subdivide into smaller working groups.)

As a group, write out a description of a particular "special need" on a slip of paper. (You might refer to the Glossary of Medical Terms, page 86, for an alphabetical listing of "special" conditions and their definitions.) After pooling the descriptions, one student from each group should draw from the pile.

In your group, work out a "portrait" of the child with special needs you have chosen. Next, make a careful outline of a typical day's routines at your fieldsite. Where do the children go, what do they do, and with whom? Now try to imagine your "special child" participating in all



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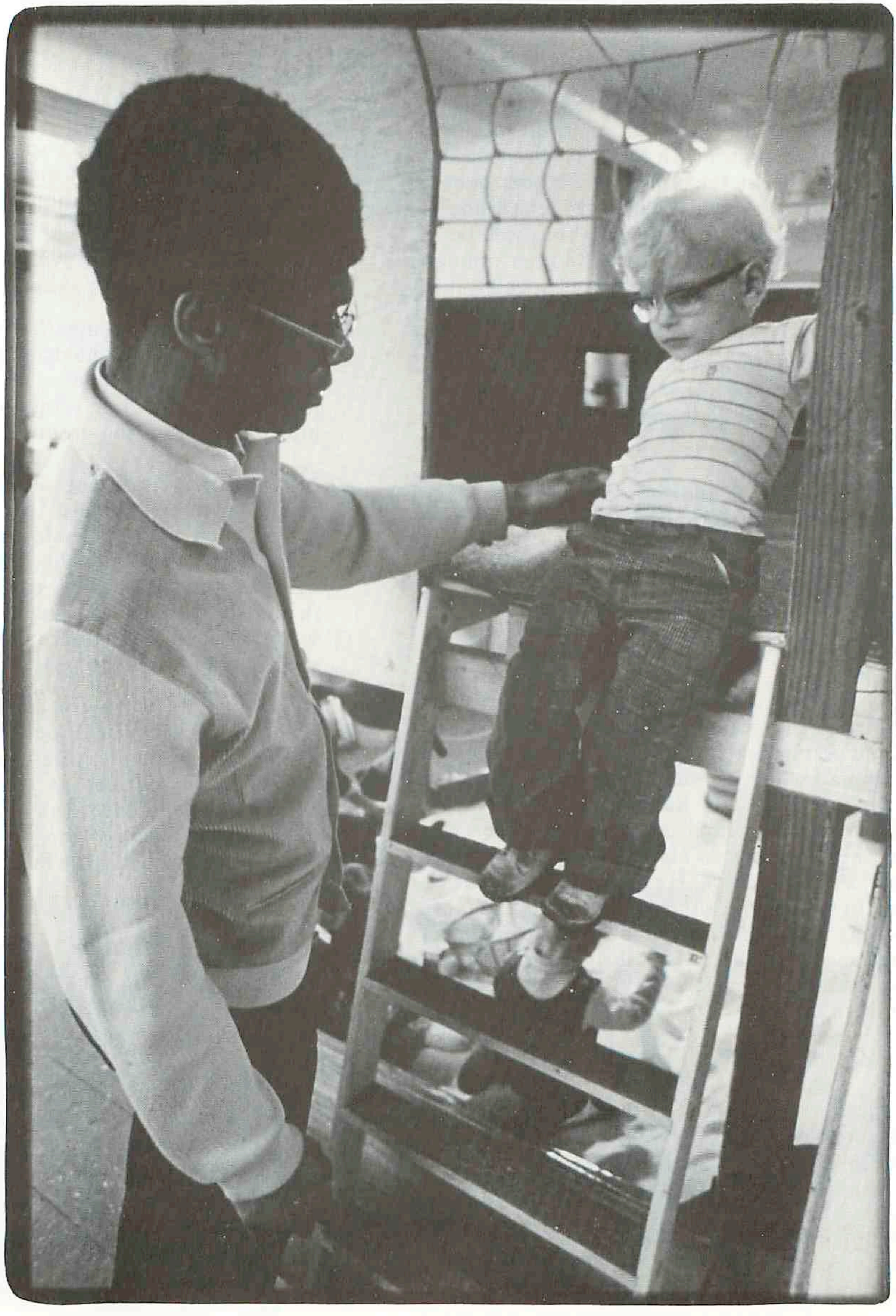

A ladder can be tricky when you wear leg braces.

Rogier Gregoire

of these routines, without your intervention or help.

- What things are the other children expected to do for themselves that he or she cannot do alone?
- What places/things in the classroom might be unsafe or unmanageable?
- What activities might he or she find overwhelming or scary at first?
- What activities/places/routines might be the most fun for the child?
- In what kinds of activities will the child be able to participate easily as a member of the group? When will he or she feel most comfortable with other children? When will alternative activities be advisable?
- Do you predict that this child will begin by spending most of his/her time alone? in the company of a teacher? with one other child? with a group? On what do you base your prediction?

Finally, consider how staffing, equipment, activities, and routines might need to be modified to provide for the needs of your child.

Reactions of Classmates

As you can see, it takes careful planning on the part of staff members to make room for the child with special needs. But there is another factor involved in the child's integration that cannot always be calculated ahead of time. That factor is the response of the child's classmates to his or her enrollment in the class.

How do children accept the presence of classmates with special needs? Can their reactions be anticipated? How should negative reactions be dealt with by the staff? These and other difficult questions will have to be thought out ahead of time.

In anticipating how a four-year-old will react to a child who is clearly different from him- or herself in some way, it helps to keep in mind that four-year-olds do not think the same way grownups do: four-year-olds see other people in terms of what they know and feel about *themselves.* You might reread pages 11 to 27 in *Child's Eye View,* to review the ways in which the child's perceptions differ from the adult's.

Keeping in mind the child's "eye view," try the following exercise.

Predicting Reactions

Imagine that a boy with only one arm has entered a class along with 14 other children. Would you expect the others to:

a) avoid the child, and exclude him from their group?
b) ask candid questions about the child's disability?
c) make fun of or ridicule the child because of his disability?
d) be afraid of the child?
e) try to do everything for the child because of his disability?
f) pretend not to notice the child's disability and accept him like any other child in the group?

On what do you base your prediction? How would you handle each of the above situations, if it were to occur?

Making Room in the Family

View the film, "Sara Has Down's Syndrome," then discuss the following questions.

Questions for Discussion

1. How have the Sibleys "made room" in their family for Sara?
2. Have some family members had to

Sara Sibley and her mother, at home.

Bill Burke

make greater adjustments than others? Explain.

3. Does there seem to be any disagreement among family members as to how much they should have to accommodate Sara? If so, with whom do you agree?
4. How would you feel about having a sister like Sara in your own family? What things might have to change?

Family Comments

Sara's mother says that theirs has always been a "child-oriented" family, and that Sara's presence doesn't really change things. "We've always let the children set the pace for vacations and other family activities," she notes. "With Sara, we have to be careful when we go visiting—she gets into everything, you know—but that doesn't matter. ...And we had to put locks on Sara's door and on some of the outside doors, because she was running away or waking up at 4 A.M. and wandering around the house with her diapers off. But those are little things. You just do what you need to do for your children."

Following is a sampling of comments from other parents about the change (or lack of change) in family life style brought about by the birth of a child with special needs.

Ned is a child with a learning disability and impaired physical coordination due to brain damage. Ned's mother says, "We have never thought of Ned as an oddity in our family. He fits in easily, because he shares the rest of the family's strengths and interests. He is good with words, like the rest of us, and not so good with a baseball. I suppose that if he'd had a father who wanted him to be a Little League champion, or a mother who cared about keeping the house superneat, he would have had a hard time. But as it is, we find that we are all very compatible. Sure, he was angry when his younger brother learned to ride a two-wheeler and he was unable to, but Matthew is very understanding and didn't carry on about it the way some boys might have done."

Jeffy is a hyperactive child. Jeffy's mother comments, "I know that when Jeffy is feeling his oats and speeding around here, no one has any peace. ...Sometimes he has so much energy that some of it just seems to have to turn destructive. He used to make us feel scared and embarrassed, until we discovered that other parents had children like Jeffy, too."

Alan is an autistic child. Alan's father expresses some regrets. "It's too late, now, I guess, but if we had it to do over again, I think we would enroll Alan in a residential school. We have given so much to him, and he gives so little in return. It has taken its toll on our marriage, and on Alan's older brother, Curt. The strain has numbed us all."

Nigel is a Down's Syndrome child. "Nigel has brought us untold joy," his father says. "He has been loving, considerate, generous, and immensely rewarding. In many ways we have far fewer problems than do most parents of modern teenagers. In many ways he is far more capable of looking after himself. And he has started his first book at the age of 17."*

Lisa is the youngest of five blind children in her family. Her mother relates, "By the time Lisa came along, the others just helped her to follow in their footsteps. They know better than her father and I how to teach Lisa to get along in the world."

Questions for Discussion

1. What is your reaction to these parents' comments?
2. What clues do they give as to the kinds of factors involved in making room at home for a child with special needs? List as many of these factors as you can.
3. Do you think it might ever be impossible to keep a child with special needs at home? Under what circumstances?

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*From Nigel Hunt, *The World of Nigel Hunt: The Diary of a Mongoloid Youth*. New York: Garrett Publishers, 1967.

Making Room in the Culture

Some communities and societies pay special attention to the integration of groups of people who might otherwise find it difficult to lead useful, meaningful lives. People do not always agree how best to care for the retarded, elderly, or disabled citizens in their communities. One community's solution does not necessarily meet the needs of another. Still, most people would agree that it is important to give every citizen the opportunity to lead the fullest possible life, without regard to age or physical or mental capacities. The following articles describe two communities where such a goal has been admirably fulfilled.

Model Communities

Sheltered Workshops*

The first article reports on sheltered workshops where retarded citizens may live and work as members of the community.

> *. . . In the group homes, the prime consideration must be given to community adjustment, training in money management, transportation, telephone usage, shopping, banking, traveling and personal hygiene. The following community resources should be made available on a part-time basis: the services of a physician, psychologist, social worker, recreational worker, and a vocational counselor. Leisure time activities should include social gatherings, religious services, music, story reading, choir singing, film showing, folk dancing, trips, outings and picnics. . . .*
>
> *The first of the Circle of Homes in Cleveland Heights, Ohio opened May 5, 1971, offering family-like residence to eight retarded youths who worked in the community or in sheltered workshops. It is funded by the Parents Volunteer Association, a private, non-sectarian, non-profit organization. The spacious house is advantageously located near transportation and community activities. The staff, consisting of administrator, house parents, relief parents and aide are family surrogates.*
>
> *The home-like milieu provides for semi-independence with supervisory control, good peer interrelationships, stimulating social development and maximum community participation. The youths are involved in the recreational activities at the Jewish Community Center and in parties and canteens at Forest Hill Church. The program included swimming, bowling, hiking, football and baseball. Adult volunteers and college students are group leaders.*
>
> *Trips are made to outstanding points of interest. During the summer, weekly picnics include non-resident retardates and their families. Thus people in the community become involved and acquainted with the Home and the residents; peer groups are invited to the Home. Should a retardate lose his family, entering a home in which he has spent pleasant hours is a natural step.*
>
> *The Home can provide permanent residence or short-term residency for the amelioration of crisis situations. Where would Jim, a retarded youth, stay while his mother was in the hospital? During the emergency, he lived at the Home and was so happy that even after his mother returned, he continued to spend weekends there.*
>
> *College students, the staff and the residents are involved in current training programs. There is counseling on a group or one-to-one supportive basis concerning banking and money management, behavior problems, personal care, work problems, and peer and community interrelationships.*
>
> *The family-like home is an innovation in services for the working retarded youth who has lost his family. It is a focal point for recrea-*

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*From "Circle of Homes: Group Homes for the Retarded in Cuyahoga County," *Mental Retardation*, Vol. II, #3.

tional activities, not only for the residents, but for the peer groups in the community. It is a training center for college students to explore the possibilities of a career in the field of mental retardation. For retarded youths who need a supervised family-like residence, the Circle of Homes provides an excellent solution to living, working and belonging in the community.

The Oldest People*

This article describes a mountain community in a remote part of the U.S.S.R., where people commonly live to ripe old age and no one has ever heard of "retirement" from work.

> *A striking feature* [*of this culture*] *is the high social status of the aged. Each of the very elderly persons I saw lived with family and close relatives—often an extensive household—and occupied a central and privileged position within this group. The sense of family continuity is strong.*
>
> *There is also a sense of usefulness. Even those well over 100 for the most part continue to perform essential duties and contribute to the economy of the community. These duties included weeding in the fields, feeding the poultry, tending flocks, picking tea, washing*

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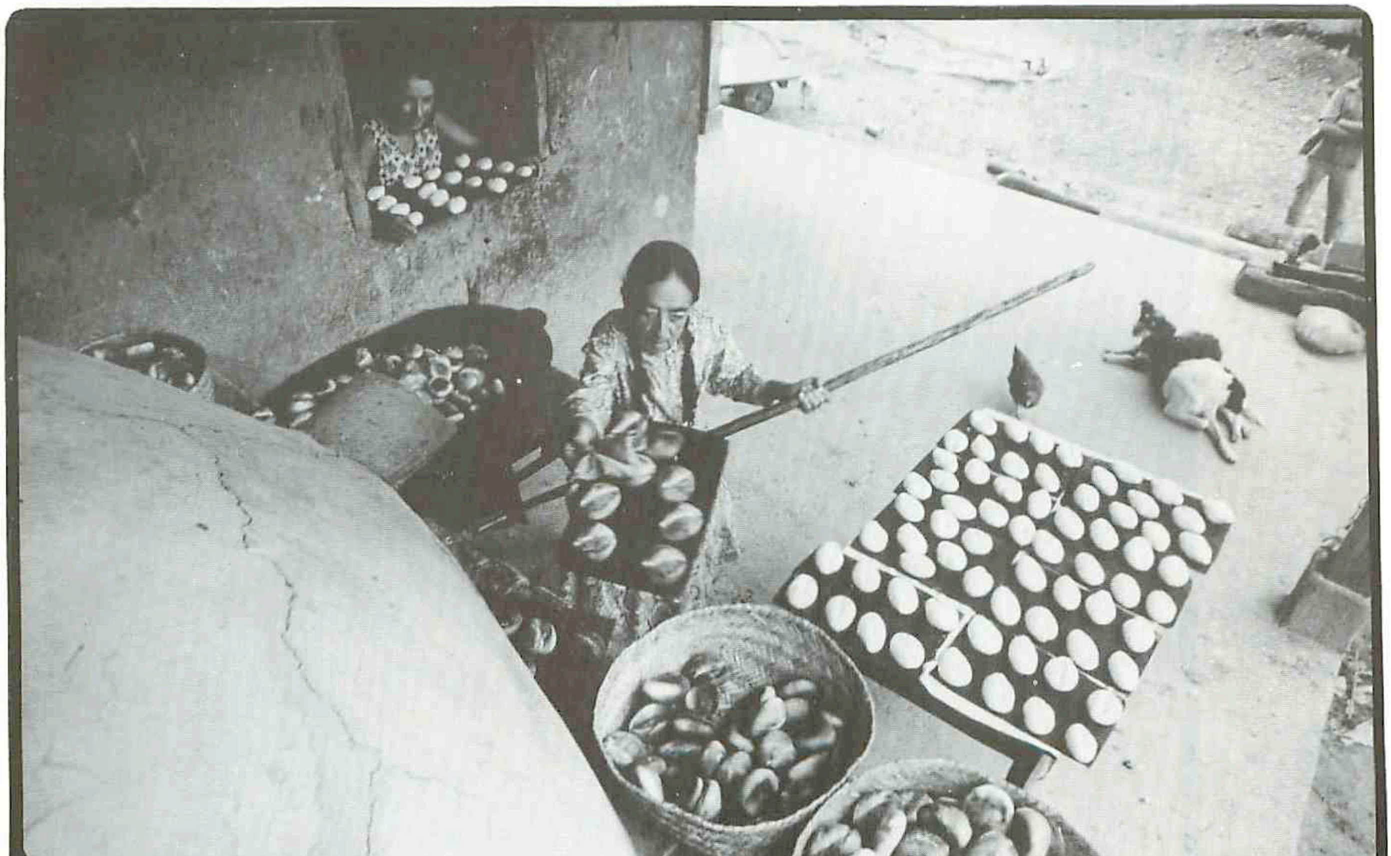
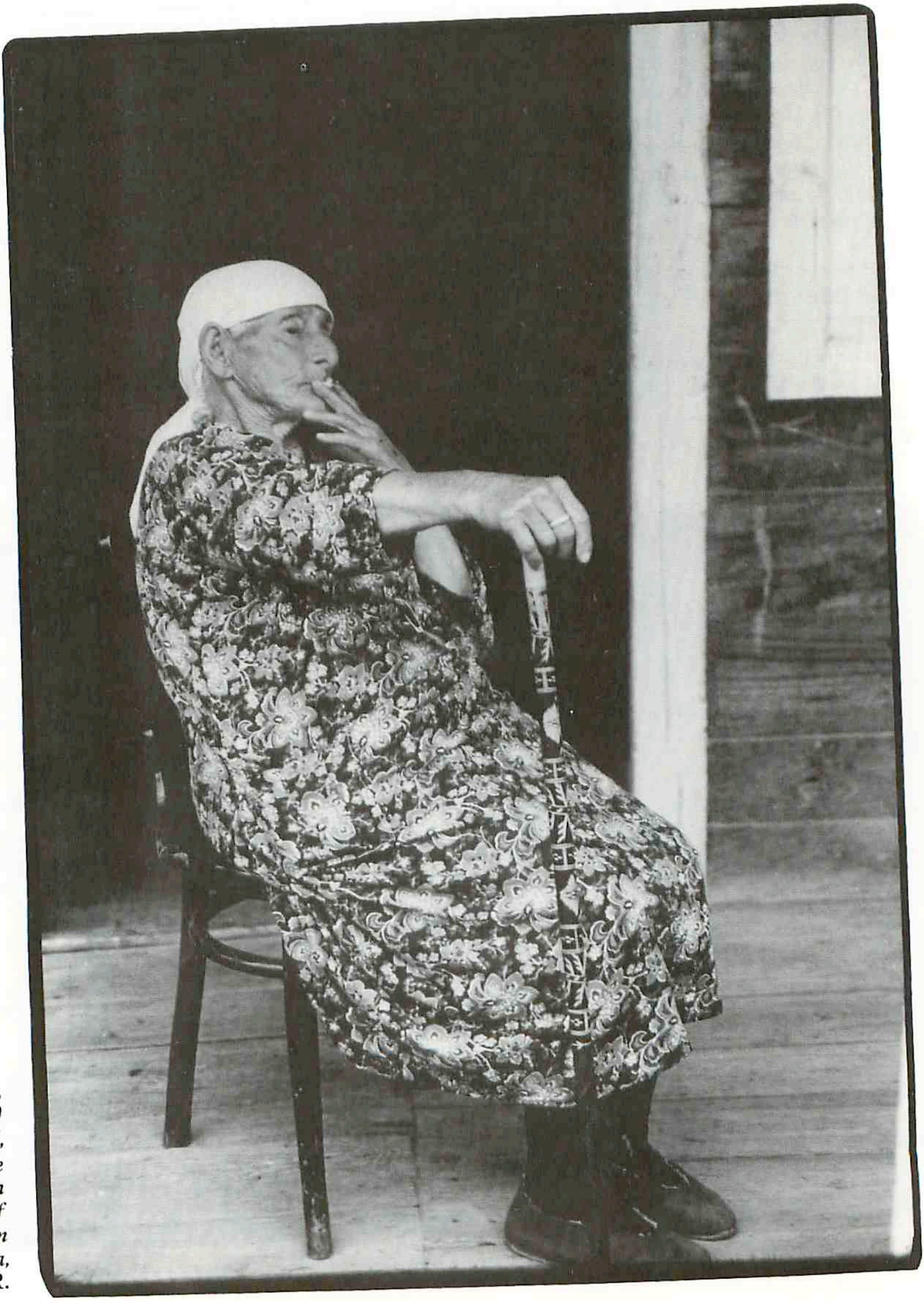
*From "Search for the Oldest People," *National Geographic*. January 1973.



John Launois/Black Star

Mrs. Hermelinda Leon, age 95, helping out at the local bakery.



Khfaf Lasuria, more than 130 years old, watches the world from the porch of her home in Abkhazia, USSR.

John Launois/Black Star

the laundry, cleaning house, or caring for grandchildren, all on a regular daily basis.

In addition, the ages are esteemed for the wisdom that is thought to derive from long experience, and their word in the family group is generally law.

In Hunza this last point was evident even in the way the state is governed. The mir [head of government] holds court daily at 10 A.M. with a council of elders. The council is comprised of some twenty wise old men of the state. They sit in a circle on carpets spread at the foot of the mir's wooden throne and listen to disputes among citizens and to other domestic problems. After a lively discussion (often marked by three or four elders talking simultaneously) with the mir presiding, a consensus is reached, and the mir announces his government's decision.

In none of the three communities is there any forced retirement age, and the elderly are not shelved, as occurs in most of our industrialized societies. Khfaf Lasuria, the former tea picker, had retired only two years before I met her. When I asked Seliac Butba, age 121, if he was helping in the construction of a new house springing up next to his own, he responded, "Of course, they can't do without me."

Temur Tarba, a vigorous horse-riding member of the collective farm at Duripshi, had celebrated his hundredth birthday just three weeks before my visit. He showed from his bearing and happy manner that he felt he had "arrived." A few years earlier he had been designated a "Hero of Labor"; he was awarded this high Soviet honor for his cultivation of corn.

He smoked a good deal while I talked to him, but he did not inhale. He devotes the mornings to picking tea and cultivating his garden. "It is best to be a youth," Temur states, "but I have good health, feel well, have wonderful children, and I enjoy myself greatly now." He paused a moment in thought, and then added, "Every day is a gift when you are over a hundred."

Tracking Down Community Resources

Do you know what kinds of resources are available in your own community for people with special needs? You might want to track down some of the schools, agencies, tutoring programs, residences, etc. serving your community. With enough time, you might even put together a "Yellow Pages" directory for residents with special needs and distribute it in your community. Your teacher may wish to tie in this project with suggested *Inquirer* activities later in the year.

Another way to tell how a community or society feels about and provides for the needs of its "special" citizens is to scan newspapers and magazines for articles on the subject of groups with special needs (the Sunday papers often have feature articles on this sort of subject). If you do this with the other members of your class over the course of a month, you will probably collect numerous documents, representing a wide variety of opinions. These might be put into a reference scrapbook for the class, to be used for projects, discussions, and inquiries.

Beginning on page 23 is a sampling of articles included in one class's "reference scrapbook." They were compiled by three students in four weeks!

Can you think of some interesting ways to follow up the "leads" suggested by these articles? How would you go about obtaining more information on these issues? Is one of them of particular interest to the members of your own community? the parents of children at your fieldsite? members of your class? If so, you might choose to explore that one issue in depth by collecting additional readings, finding films on the subject, interviewing medical and legal people connected with the decision process, or arranging a panel discussion with parents and others concerned with the subject.

REFERENCE SCRAPBOOK

Newsweek Magazine:
February 11, 1974

Arguments for and against the public school integration of children with special needs -
legal considerations
personal considerations

What Bart Really Wanted

Bart Bradish, 9, has cerebral palsy and until early this year attended a special institution for handicapped children. But his parents feared that he was too sheltered from the realities of the normal world and transferred him to an ordinary elementary school near Los Angeles. When he first came to class, precariously supported by leg braces and two canes, Bart's new classmates nicknamed him "Old Man," and refused to let him play handball with them. Bart's father took care of the nickname problem: he persuaded his son that as nicknames go, Old Man wasn't really that bad. Next, Bart's teacher intervened and persuaded the other youngsters to let Bart in on their handball games. Recently—and on their own—his classmates modified their rules for kickball so that Bart could play, swinging both legs by bracing himself with his canes. "That's all Bart really wanted," his pleased father reports—"to be included."

Bart is one of the 6 million American children of school age who suffer from handicaps—physical, intellectual and emotional—that seriously hamper their performance in school. Their afflictions range in severity from mild learning disabilities to the most debilitating kinds of brain damage. Until recently, many educators felt that the needs of most handicapped children were best served by schooling in isolated institutions, protected from the inevitable taunts and cruelties of their peers and bolstered by teachers trained to deal just with them.

But nowadays the experts are increasingly persuaded that handicapped children who can handle it should remain in the mainstream of education. Children like Bart, they say, profit inestimably from early immersion in the world they will face as adults. And their classmates, too, learn valuable lessons from mixing with people who are different. In the past five years, more than a dozen states have enacted legislation or responded to court orders to integrate handicapped children into the public schools wherever possible; and in corollary decisions, these states have also directed the school districts to provide the supportive personnel and programs necessary to meet the children's special needs.

Laws: But courts and legislatures do not solve all the problems. The Council for Exceptional Children in Virginia reports that even with all this governmental intervention, some 60 per cent of the nation's handicapped children still receive inappropriate education—or no education at all. In New York City, for example, where laws have long been in effect requiring schools to provide for special children, an estimated 24,000 handicapped children do not receive the kind of schooling they need. One major reason is financial. The cost of educating handicapped children properly is fully three times as high as providing schooling for normal students.

Much of the extra money, of course, goes to pay for qualified personnel to direct the supportive programs special children require. When appropriate teachers are lacking, the results can be tragic. In Chicago, 14-year-old Steven Guy entered the eighth grade last year with a long record of class disruption. Teachers had twice referred him for psychological testing because he seemed to be in the grip of severe emotional disturbances. But none of his teachers had the qualifications to give him special help. Finally, his principal decided to send Steven to a "social adjustment center" and suspended him from school. Three weeks ago, enraged by the decision, Steven showed up at the school with a .38-caliber snub-nosed revolver and a .45 automatic. He shot the principal dead, and wounded the assistant principal, a teacher and a school guard. Steven is now in protective custody.

Cope: Steven's case is extreme, but lesser instances can be found in most school districts. Teachers who are not trained to cope with special problems often get rid of them simply by dismissing the troublesome students. Sometimes, they simply don't recognize children's problems for what they are. Another student, Mark Sidney, spent six years in a class for retarded children because the teachers didn't know he had a correctable learning disability called "mirror vision" and otherwise had normal intelligence. "The difficult fight is to get the general educators to see these kids as their kids," says Fred Weintraub, assistant director of the Council for Exceptional Children. "They've got to see that education of the handicapped is more than reading, writing and arithmetic—it might involve toilet training. But they think if it's not in the primer, it's not their responsibility."

This year, Massachusetts will implement legislation that may finally make it possible for handicapped youngsters to get a mainstream education. By September, Massachusetts school districts must individually evaluate all children with special educational needs, decide on the best plan for each one, and then implement it. In a 108-page set of guidelines, the state requires that those children considered capable of full-time instruction in a regular classroom must receive it, and that consulting specialists must be available at all times. A child who can spend only 75 per cent of his time with his normal peers will do so, and devote the rest of the day to special therapy. A child whose individual testing shows he would be better off with special training alone receives no regular classroom instruction at all.

Already, several Massachusetts school districts are building ramps for wheelchairs onto their regular school buses. And despite complaints about the rises in local property taxes needed to support the project, state education officials are confident that their plan will work. "What this means," says state education commissioner Gregory R. Anrig, "is that we are arriving at and filling an individual educational prescription for each kid—and that, after all, is what education should be for every child."

Newsweek
(letters to the editors)
February 18, 1974

Handicapped Children

Hurray for NEWSWEEK's article about placing handicapped children in regular classes (EDUCATION, Feb. 11). Our hearing-impaired daughter sat for three years in special classes; now, she receives special assistance from a tutor who is trained to help her each day. She is doing very well academically, and a whole new world has opened up for her socially—now she is accepted by her peers and is invited to parties for the first time.

MRS. THOMAS KEARNS
Braintree, Mass.

■ I can't help wondering if some of the lawmakers who are enthusiastically legislating special children into the regular classroom have ever come to grips with the problem of diapering a teen-age child. Research suggests that specially trained teachers are more accepting of deviant children than are regular teachers. Is it really the welfare of the children which is at stake, or the welfare of the budget?

GERALDINE ARUNDEL
Long Beach, Calif.

Special education law could cost $100m

Unfunded Chap. 766: Who, finally, will foot the bill?

By Mary Thornton
Globe Staff

Beginning Sept. 1, a controversial state law for special education, at a cost estimated as high as $100,000,000, will go into effect, requiring every community to provide an equal education within the public schools for all physically or mentally handicapped children.

First year costs for the new program are expected to add at least several dollars to the tax rate in each of the 351 cities and towns in Massachusetts.

The communities are guaranteed by the law that part of the expenses will be reimbursed by the state after the first year, but though the state legislature cheerfully approved the new law, it has not bothered to appropriate the funds to pay for it.

In order to comply with the new law, school committees across the state are required to appropriate what they think the program may cost, relying on a 108-page set of often-confusing state guidelines, and once the school committee sets its figure, neither the mayor nor a town meeting has the power to overrule the school committee.

"Coming up with this kind of a program without financial backing is a fraud," says state Secretary of Administration and Finance William Cowin. "But maybe it will be a dramatic enough lesson to teach us that we have to stop passing laws without coming up with the money to pay for them."

And Malden Mayor Walter J. Kelliher called Chapter 766 "the most ill-conceived piece of legislation I ever saw. It shows a total lack of fiscal responsibility at the governor's level and at the legislative level."

"Actually no one has the foggiest notion what this thing is going to cost, but unless the law is changed or unless there's massive violation of the law, the lion's share of the cost will fall on the municipal property tax," Cowin said.

Cowin said that even if Bartley or Daly could get approval from the Legislature for extra money, it would not be enough and "both the governor and the Legislature say they are committed not to raise taxes."

CH. 766 PROVISIONS

The law, which takes effect in September, calls for:

- Public schools for everyone with special needs (up to age 21 for those who have not obtained a high school diploma or its equivalent).
- Special needs are classified as temporary or permanent adjustment difficulties with vision, hearing, speech, cerebral or perceptual functions, physical handicaps, behavior, mental development or maturation.
- Children with these disabilities can no longer be labeled as retarded, blind, deaf, etc. All will be classified together as children with special needs.
- Full core evaluations must be made of any child when requested by a parent, teacher or other person within 30 days of the request.
- An evaluation team includes a registered nurse, a doctor, a psychologist, teachers and, in most cases, a parent.
- Integration of special needs children into a normal classroom setting as much as possible. The program options range from regular classroom placement to hospital or residential school placement and combinations of training and tutoring services.
- Cities and towns will be required to pay tuition for special needs students who are unable to go to a public school classroom and must remain in state or private institutions. Up to now this has been paid by the state or by the parents.

"It shows a total lack of fiscal responsibility at the governor's level and at the legislative level."

WALTER J. KELLIHER,
Malden mayor

"Coming up with this kind of a program without financial backing is a fraud."

WILLIAM COWIN,
secretary of administration
and finance

Mayor Kelleher of Malden believes: "The net result of the whole thing is that cities and towns are going to pay 100 percent of the costs. Nobody quarrels with the purpose of the legislation. But it doesn't go far enough."

Kelleher said Malden has added an extra $728,000 to its budget for 766, which is equal to $4 on the tax rate. And he added that he's filed a bill in the Legislature "to suspend the effective date indefinitely until such time as the Legislature comes up with the dough."

Robert Hatheway of the Massachusetts League of Cities and Towns says that 766 is going to present a major problem to most communities in the Commonwealth.

"They say there is $9 million in front money, but it really is only $3 million. At least $6 million is just paper money because that's what it's going to cost the cities and towns to reimburse the state for those handicapped children who have to remain in state institutions," Hathaway said.

Many cities and towns are finding it confusing to come up with a budget estimate.

Hatheway says that though Springfield and Worcester are cities of comparable size, "Worcester budgeted only about $300,000 for 766 while Springfield was asking for $5.7 million. Obviously, something's wrong."

James Kane of the Springfield School system says the figure for Springfield may be cut in half, but even that is far out of line with Worcester, and he adds that he is dubious about the likelihood of state reimbursement. "There's very little front money and I expect there will be very little caboose money."

Alice Casey, associate superintendent for special education in Boston, thinks that the hardest problem so far is getting enough money to start a program. To comply with the program fully, she said Boston would need $25 million for the first year.

"But there was no way of getting that kind of money," she said. "You just can't ask for something that's beyond belief, so we're going to cover only the most critical aspects of the law and we'll expand over a five-year program."

"Our big problem is the up-front funding," Dr. Casey said. "We have about 10 percent of the state's students, but even if they give us 10 percent of that $9 million, it wouldn't begin to cover our start-up expenses. And if we don't get more money than that, we're just going to have to reduce our program even further."

<u>Boston Globe</u>:
February 24, 1974

Who is responsible for paying for the public education of children with special needs?

Boston Globe:
March 17, 1974

Parents have different opinions about public education for children with special needs -

Pro:

Chapter 766 — new hopes and new fears

By Mary Thornton
Globe Staff

Jamie Yos is 10 years old. He'll probably never be able to read or write and he'll never be independent or self-sufficient. He is a victim of congenital brain damage and has been mentally retarded since birth.

But under the state's new special education program, Chapter 766, which goes into effect in September, Jamie's parents are hoping that he will be given the chance for an education and a useful life.

Mrs. Ann Yos of Lincoln, Jamie's mother, has tried since he was about three years old to obtain education and training for her child. She is education chairman of the Minuteman Association for Retarded Citizens.

"I doubt if he'll ever learn to read or write," she said, "but Jamie just needs the basic living skills like how to dress and take care of himself or even how to go into a store and buy something—things that everyone else takes for granted."

In the past two years, 11 towns in the Concord area have banded together to provide special education programs for retarded and emotionally disturbed children in the area. In many ways, this 11-town group has already complied with a number of the requirements of 766.

"And it's been like night and day," Mrs. Yos said. "Jamie has blossomed."

This has been the first time in Jamie's school career that a program has really worked. "Jamie is a special case. He just doesn't fit under any of the usual labels — he's still learning to speak and to dress himself.

"I used to accept it when they told me there wasn't any place for Jamie, but I've been paying taxes for years, just like everyone else, and I'm tired of being shuffled from place to place and hearing that Jamie isn't entitled to an education like other children," she said. "It was impossible to find out even what programs were available.

"Just because he has some limitations doesn't make him any less a person. Jamie has interests just like other children his age. Basically he lives a very simple life. He likes to watch clouds and he loves nature — trees, the water and fish. He loves to look at books."

Yet, even under the progressive program which is going on in the Concord area, mentally retarded children don't have all the opportunities of so-called normal children.

"He only gets to be in school for four hours per day, and that is hard on him — he doesn't get to go on the bus with his brothers and he wonders why he's different.

"And there are no recreational programs for him, no art, music or gym classes. He ends up coming home and riding his bike or climbing trees by himself. He leads a very isolated existence."

Under the provisions of 766, communities are expected to set up core evaluation teams, made up of a registered nurse, doctor, psychologist, teacher and in some cases a parent, to evaluate children and determine what special programs they need, and as much as possible integrate the children into a regular classroom.

If a child needs special classes, tutoring, or a special sort of therapy, the community is required to provide it for him.

The law covers children with all sorts of handicaps —behavior problems, slow learners, children with difficulties in speech, hearing or sight, and the emotionally ill and mentally retarded. When fully implemented, it is expected to involve nearly 200,000 children aged three to 21.

Education for the handicapped — long considered a state responsibility though almost nonexistant in many areas — under 766 would be the responsibility of the cities and towns which are now responsible for educating other children.

"We would just like them to make as much effort to educate the handicapped child, as they do for regular children," Mrs. Yos said, "and maybe by making this much of an investment now, they won't have these children grow up to collect welfare for the rest of their lives."

Mrs. Paul Butler of Walpole has a different opinion of 766. Her 3-year-old, mentally retarded daughter Angela is in a program at the Kennedy Center for Handicapped Children in Foxboro.

The school has been dependent on a research grant which is about to run out, and she is hopeful that with the help of 766 the school can continue to operate.

"Most handicapped children have been discriminated against. They tell you things like take the child home and give it love — all those platitudes, but they don't do anything for you," Mrs. Butler said. "But under 766 I'm hoping she will have some of the opportunities that parents expect for normal children.

"My husband works hard and we pay taxes, but there's no way we could afford a private school and I wouldn't send her to a state nursery — that's nothing more than day care," Mrs. Butler said.

Mrs. Yos, faced with the same prospects about seven years ago, organized her own nursery school for retarded children which she operated until Jamie was about five years old.

Mrs. Butler says that **"766 will be our livelihood.** Up to now Angela's tuition has been paid by the research grant. The state is paying $155 per week for the welfare children who attend the school and there's no way we could afford that."

One of the most common fears among parents is that the local school systems may try to throw their handicapped children into a regular classroom without any preparation, but most teachers discount the likelihood of this.

"There's no way they could do it," said Nancy Snow, a teacher at the Kennedy school. "Some of these kids can't even sit up. The law is going to have to take into consideration that there are many children with special needs who will never even see a regular classroom.

"If they tried to integrate everyone, it would be like going back 100 years, back to the days when handicapped children were just stuffed i the corner of a classroom.

And the parents of som severely or multiple handicapped children fea that higher priority ma be given to children wit fewer problems and thos who have in some way a ready been integrated in the school systems.

"The idea of the law wonderful," Snow co cluded, "But we're goi to have to be very caref law is certainly intend to be for the good of handicapped children the state, but we have make sure that the chi doesn't get lost in t shuffle."

and Con:

Most parents of handicapped children seem to be hopeful that after years of inequality in education their children may finally have a chance. But others are afraid that to save money communities may not do what is best for their children.

Many are afraid their children will be taken from public-funded private programs or various state programs and placed in the local school system to save money — since the cities and towns are now responsible for programs that were once supported by the state.

Edward Collins of Burlington, president of the New England Assn. of Parents of Visually Handicapped Children, is also willing to go to court to keep his 15-year-old blind son from being moved from the Perkins School for the Blind in Watertown.

"We went through all sorts of programs, integrated classrooms and everything — this is the first thing that's ever worked," Collins said.

Under the law, Collins said he doesn't think the local community has the power to move his child against his wishes, "but I don't think they understand that part of the law.

"They've already asked Perkins for my son's records, and I'm ordering that they not be released. There are some pretty confidential things on school records and I just don't want them kicking around.

"I know at least 70 other parents who are having similar problems, and we're all prepared to go to court to keep our children in the programs they're in," Collins said.

"I'm prepared to go to court to make sure my child is kept in his current program.' said Arthur G. MacDonald of Burlington, father of a deaf, 7-year-old boy who attends the Beverly School for the Deaf.

"I spent thousands of dollars having my child evaluated by professionals in the field of deafness, and now they think they're going to tell me where he should be.

"You know, I think the law is typical of the Massachusetts approach of doing everything in one splash — and then spending years picking up the pieces.

"The schools are just not prepared for this sort of thing," he said. "They don't have the teachers for handicapped kids.

"They don't even have the physical safety features that are necessary for handicapped children — how many regular schools do you know of with ramps for wheelchairs and elevators; how many have the flashing light systems which are used for fire alarms for deaf children?

"I'm prepared to fight any system that's going to move my child to an unsafe place," he concluded.

Boston Globe: March 3, 1974 - Residential vs. institutional care for mentally retarded - who is qualified to care for these people?

Weymouth tells couple: 8 retarded boarders must leave

By Tony Chamberlain
Special to The Globe

An East Weymouth couple, whose home for four-and-a-half years has served as an alternative to hospitalization for eight mentally retarded adults, say their "family" is being broken up this weekend by an order from Weymouth officials.

Raymond and Mary Glover say they have cared for the former state Department of Mental Health patients with room and board assistance from welfare amounting to $5.27 per person a day. Along with their three children, the home was "one big happy family," Mrs. Glover said, until selectmen served a notice to "cease immediately" after inspecting the house last month.

Mrs. Glover said officials from the Medfield State Hospital had inspected her home and made recommendations for improvements. Before the Glovers could begin repairs to the Middle street home, however, Police Chief Joseph B. O'Kane, acting on selectmen's orders, told Mrs. Glover the boarders would have to be out this weekend.

William J. Gunville, chairman of the Board of Selectmen, said the board issued the order because the Glovers are violating town zoning bylaws, and the couple failed to get a boarding house license from the town.

Gunville said the situation was called to the town's attention by a neighbor who told police people were being kept "illegally" in the Glover home.

"These people, to the best of our knowledge, were being kept inside the house and never allowed to go outside," Gunville said. "They were never seen around the neighborhood."

Mrs. Glover maintains her boarders go on regular shopping and exercise trips. She said she did not know where Gunville got his information.

Meanwhile, the Glovers were looking for a place to move rather than "break up the family." They thought they had secured a boarding house in Plymouth which they could rent with an option to buy. But the owners of the house last Thursday withdrew that offer to rent, Mrs. Glover said, leaving the eight boarders with "no place to go but back to a hospital."

"They know what's going on and they're afraid to go back," said Raymond Glover, a wallpaper hanger. "I'm afraid all the progress we've made with them will be lost," he said.

The Glovers are not professional therapists, but feel that their patience and understanding have given comfort to people who "are not sick, do not belong in a hospital, but who cannot take care of themselves."

Five of the former patients spend days at workshops in the New England Villages in Pembroke.

After a battle with Weymouth selectmen Mrs. Mary Glover begins search for a new home for her "family," which includes former mental patients. (Stanley Bauman Photo)

"Homes like this allow people to grow into a community," said Charles Carley, a friend of the Glovers, who works in a home for emotionally disturbed children. "And they do need homes, not hospitals."

Mrs. Glover acknowledges that her Weymouth home did not qualify as a boarding house, but said she and her husband were willing to install two more toilets and improve the kitchen, inadequacies cited by town inspectors. But, she said, Social Security assistance is already behind by $2700 and the family needed time. "I had hoped the community would cooperate with us."

The Glovers say they hoped to sell the Weymouth house and put the money into the $48,000 purchase price of the Plymouth home.

Mrs. Glover said she could not imagine why Weymouth officials suddenly decided to inspect the house, but that she had heard of rumors that she and her husband were "making a bundle from the state" by caring for the retarded perons ages 21 to 60.

Many provisions, including furniture and some bedding, Mrs. Glover said, "have come out of our own pocket."

"It's hard to put into words just why we do this," Ray Glover said. "But to see these people in hospitals is a sad, sad sight. It's a sin. Even their their own families desert them.'

Boston Globe: March 24, 1974

Chapter 766 offers hope at Fernald

Mary Thornton
obe Staff

Susie is about 18 years d, but looks only six or ven. She can't walk, talk feed or dress herself. e lives in a crib which e hasn't left for 15 ars.

Her drab room is silent cept for an occasional y or movement from one the many other metal ibs nearby. Each of these s on old, faded stuffed imal tied to one end — t of reach of the occu- nt.

Susie's hands are tied in sort of straitjacket be- use she is self-destruc- ve, but she still manages kick herself occasion- ly. She is also blind and entally retarded. Her me is a ward at the Fer- ld State School in Wal- am.

It's probably too late to much for Susie because her age, but hundreds younger children at the hool may have a chance w under the state's new ecial education program.

Under the new Chapter 66, cities and towns are take responsibility from e state for educating entally retarded chil- en, slow learners, and ose with hearing, sight or speech problems, emotional disturbances or behavioral problems.

As of Sept. 1, communities are required ot set up core evaluation teams to assess all children with difficulties provide the types of therapy and services they need and, as much as possible, assimilate them into the local school systems.

The law applies to all children aged three to 21, and 400 of the 1770 at the Fernald School are in this group.

By even the most optimistic estimates, no more than 50 percent of the children at Fernald are ever likely to be assimilated into a special program in a public school. Nevertheless, Fernald superintendent Hugo Mosher is hopeful that 766 will have a profound effect on the institution's children and adults.

In the past year, the school has begun to phase in some aspects of 766. Daily, 45 to 50 children are transported to special programs at nearby schools others are ready to go into these special classes, but they come from areas too far from Waltham. Their home communities have not been willing to set up programs with school systems closer to Fernald.

"We're hoping that when 766 goes into effect, they can be forced to do this sort of thing," said James McCormack, state coordinator for Chapter 766 and a former teacher at the Fernald school.

Fernald staff members are hoping that since the cities and towns won't have to provide services on the local level for children who cannot leave the institution, they may be willing to send teachers or staff members to Fernald to help with the severe staff shortage.

"For the first time, we're hoping to have enough teachers freed up to work with the profoundly retarded, rather than just with mildly retarded as they used to," McCormack said.

When attention is given to children classified as severly and profoundly retarded (those with a measured IQ of less than 15), McCormack said the results are sometimes amazing.

While he was teaching at Fernald, he was able to set up a program for a group of 15 children who had been classified profoundly retarded, and who were considered unteachable. Now, only a year later, they are toilet trained, able to dress themselves, and a number may be able to go into the public school program.

"The problem is that many children have received faulty testing. They fail to respond to a certain test, so instead of questioning the test, the tester assumes that the child is retarded," McCormack said.

"In the past, people have assumed that you can't do anything with this sort of child. But we're finding out that you just can't tell. It may take patience and a lot of time, but we're finding that many of these children can do a lot more than people thought they could."

Until now, Fernald personnel have concentrated on teaching the mildly retarded, and with the staff shortage this was all they could do, McCormack said. "The severely retarded received basically custodial care, and that was it.

"This has been changing, and should change even more dramatically when 766 takes effect."

The stated purpose the law is to provide cialists to children need them, and the nald staff is hoping this may actually happ

"On the entire grou we have only one sp therapist, and in Green Blind Unit, more than 200 child many crippled, there only a half-time phy therapist," McCorn said.

There is a despe need for these service a school like Fern Children who have s years tied in cribs ar weak that it takes spec ists to even know how move them.

Some basic char have been made in the stitutions in anticipatio improvements.

According to Dr. Mo er, the school is conc trating on short ran programs, especially children, rather than term admissions.

In the past, he said, ple were often put into school for the wrong sons. "We have 200 to older patients here should never have put in Fernald, but it's late for them to lea

State institution staff sees public education for some of its children as a means of freeing specially trained therapists to work with those wh need greatest attention and who will remain institutionalized

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Parents ask halt to state plan for retarded

By Jean Dietz
Globe Staff

Charging that statewide abuses will lead the retarded "right back to the attic," parents of residents of the Fernald State School in Waltham have called for an immediate halt to the state's community residence program.

Boston Globe: March 3, 1974

A group of parents fights to retain institutional care for retarded children

An agonizing choice for parents, doctors

Defective newborns: Life or death issue

By Richard A. Knox
Globe Staff

In the next month at least a half-dozen young couples throughout New England will face the most agonizing decision in their lives.

Fate will decree, often without warning, that their babies will be born defective in some way — severely premature, physically deformed, mentally deficient, metabolically imbalanced or with various combinations of the above.

Until very recently, nearly all these severely defective babies would have died regardless of medicine's best efforts. But, as Dr. I. David Todres of the Massachusetts General Hospital points out, since 1971 there has been a complete turnaround in the prognosis for very low birthweight babies.

Meanwhile, over the past decade there has been correspondingly dramatic progress in pediatric surgery, rendering doctors capable of mending tiny hearts and digestive tracts once considered beyond repair.

Life-death choice

Armed with such awesome new technologies and techniques, doctors can now offer parents of defective newborns a perplexing, double-edged choice. We may be able to save your baby, the doctors will say, but we cannot guarantee he will be whole and normal. He may be a lifelong physical and mental cripple.

Or there is the other option, sometimes spoken, sometimes only hinted at: We can withold our most aggressive therapies and let nature take its course. In some cases doctors are going further and saying we can turn off the respirator or discontinue intravenous feeding.

Faced with such a no-win choice, more parents and doctors are opting for merciful death rather than what they view as a hopeless death-in-life for the mute and helpless infant.

Doctor vs. parents

The dilemma is generating a debate of profound significance in the medical profession. Moreover, the highly-charged issue is beginning to be discussed openly as both the professionals and the public become aware that such decisions are being made on a daily basis in the special-care nurseries of the largest hospitals, where more and more severely ill newborns are being referred.

The debate is further spurred by such cases as the widely publicized dispute three weeks ago over a severely deformed baby born to a Portland, Me., couple.

In that case the parents, worried over the long-term burden of supporting a severely handicapped child, asked the Maine Medical Center to halt life-sustaining measures and forego corrective surgery. But the attending physician, Dr. Martin A. Barron Jr., argued that the deformities might well be correctable and persuaded the hospital to seek an injunction against the parents.

A superior court judge granted the injuction, saying in effect that the parents had no right to withhold permission to perform lifesaving surgery. But the child's condition worsened before doctors could act, and he subsequently died.

"I just wanted to buy some time," Dr. Barron explained the other day in a Boston interview, adding that he would do the same thing again. Earlier he had told a symposium on the issue at the Massachusetts General Hospital: "I was in a quandary. I felt I had a pretty good baby with cosmetic defects."

OPPOSING VIEWS:

"Equality of life" position—Every infant is implicity entiled to equal medical attention. Life is so precious . . . we should keep alive our desire to be zealous in protecting it.

"Quality of life" position—Many factors should be considered in making a decision. "Twilight existence" of a severely handicapped infant and psychological health of the family are important considerations.

The frequency with which such hard decisions are being made was first revealed publicly by two Yale pediatricians, Dr. Raymond S. Duff and Dr. A. G. M. Campbell, in a report last October in the New England Journal of Medicine that is still generating strong comment in the Journal's letters section.

Equality vs. quality

Duff and Campbell reported that 43 severely defective infants were allowed to die during a 2½-year period at their hospital—that is, so-called "heroic" measures were withheld—because both doctors and parents felt their children's lives would have been devoid of "meaningful human good."

Discussing these decisions at the recent MGH symposium, Dr. Duff told his colleagues: "Infant A would survive and infant B, with exactly the same condition, would not. I can't tell you if that is right. I can

<u>Boston Globe</u>: March 10, 1974 The "Right to life" -
Who decides, and on what grounds?

tell you that the decisions were made by the parents, and that a good deal of sorrow accompanied every decision, whether for life or for death."

As two Yale colleagues of Dr. Duff's wrote in the Feb. 28 New England Journal of Medicine, "It is troubling to us to hear young pediatric interns ask first, 'should we treat' rather than 'how do we treat'; we are fearful that this feeling of nihilism may not remain restricted to the newborn special care unit."

In much the same vein, Prof. Arthur Dyck of the Harvard School of Public Health and the Harvard Divinity School argued fervently at the MGH symposium for what he calls the "equality of life" position, as opposed to the "quality of life" stand.

Which side to pick?

In Prof. Dyck's lexicon, the "equality of life" position holds that every infant is implicitly entitled to equal medical attention, while the "quality of life" proponents favor weighing the likely meaningfulness of an infant's life in making a treatment decision.

"The question," he said, "is on what side do you want to err? The quality of life view favors a merit system of deciding life, and that tends to erode attitudes toward life. The equality of life view can err on the side of suffering. But to me life is so precious that I would rather live with that. The equality of life view will keep alive our desire to be zealous in protecting life."

Some doctors and nurses feel strongly that Dr. Duff and those who agree with his relativistic philosophy have no right to decide whether a given infant's life would be "meaningful" or not.

A medical prognosis, some argue, is often merely an educated guess. And when it comes to assessing mental capacities, a definitive prognosis is often impossible in the first weeks of life in all but the most clear-cut cases.

But on a deeper philosophical level, the issue is challenging what many doctors view as their sacred duty to do everything in their power to sustain life in all cases.

The story of 2 babies –A and B

Baby A lived after extremes –Baby B died

BABY A

Baby A was born three months early, an infant so tiny that he was barely recognizable as human, with wrists the size of lead pencils and a neck as big around as a man's thumb.

The odds were stacked against him from the start. Just a few years ago--as recently as, say, 1970--he wouldn't have survived the first few treacherous days of life.

Baby B was also born prematurely and weighed about the same --barely two pounds. In addition he had Pierre Robin Syndrome, a set of facial deformities that included a deformed ear, cleft palate and a tongue placed too far back in his mouth. But doctors were convinced that surgery could correct these defects.

Soon after birth both infants began to have severe breathing difficulties, as many severely premature babies do.

At the age of 20 days, Baby A was transferred from a community hospital to the Massachusetts General Hospital, which admits about one such severely ill newborn a day to its pediatric intensive care unit, one of a handful in the state.

At that point his tenuous grip on life was failing. He had actually lost weight since birth. Fluid began to collect in his lungs, and he had spells every 20 minutes when he stopped breathing and had to be resuscitated.

The MGH doctors put him on a respirator, but the pneumonia worsened. He became anemic. At one point his heart went into a wildly irregular beat pattern that had to be tamed with drugs.

After more than two weeks of nip-and-tuck the MGH staff began to wonder if they should continue pouring the hospital's resources into the care of this particular baby, at a rate of several hundred dollars a day. But the parents, a young Attleboro couple who had lost three previous babies, were insistent.

"This mother essentially had been pregnant for four years and this was her only living child," explained Anthony DiMarco, one of the doctors in the case. "This added to our desire and our hopes--and also to our fatigue."

After 69 days Baby A was thought to be well enough to go home, though still frail and difficult to feed. Five days later he returned for surgery to repair hernias, and after the operation stopped breathing twice. But the staff pulled him through and sent him home again.

He was back at the MGH three weeks later, on the brink of heart and lung failure. By this time he was also having seizures, his neck control was poor, and his brain waves were abnormal--all ominous portents of possible brain damage. After a week on the respirator an attempt was made to see if he could breathe without support, but portions of both lungs collapsed, he turned an alarming blue color and his heart rate slowed dangerously.

At this point many doctors and nurses at the MGH unit thought the fight for this baby's life should be discontinued. "By this time," said the chief nurse on the unit, Paula Moynihan, "almost no one wanted to take care of this baby. One girl, who was new, could feel the negative pull on the part of the others, who urged her to 'take care of the others first.''

The parents, informed of the worsening prognosis, were so disheartened that they stopped keeping a diary of their baby's condition.

But fortunately for Baby A, by the time of his third admission, it was past July 1. That's the date when a new crop of doctors-in-training join the unit, and there were a few new nurses as well. As Ms. Moynihan put it, "After July 1, things are more gung ho." This mixing of options, those few positive votes, were part of what kept things going for this baby.

As a result, Baby A was pulled through--the smallest preemie saved by the MGH crew up to that time. Today he's 22 months old, appears to be catching up in growth and development, and seems to react normally.

BABY B

What about Baby B? Within 48 hours of birth, on top of his respiratory distress, he began vomiting and his belly swelled. X-rays revealed a congenital intestinal obstruction.

The parents, who had been hopeful initially, were told that while the individual defects were all correctible, the combination of everything made survival very doubtful.

They acquiesced, and the decision was made not to keep the baby on the respirator or to perform corrective surgery. Within 18 hours of the decision, he was dead.--R.A.K.

LETTERS TO THE EDITOR

High-level birth defect conference excluded concerned parents

Your article, "Defective Newborns: Life or Death Issue" (March 10, Globe) left out more important points than it raised. As a member of a group including more than 100 Massachusetts families of children and adults born with a serious birth defect, I am acquainted with many people who have been faced with the difficult situation described in the article. Although it is impossible to characterize a general view held by all of us parents of birth defect children, there is one point where we generally do agree: we are seldom asked for our point of view.

The conference at MGH described in your article explored situations where some parents of newborn infants currently are being asked to make life or death decisions about their own child. Other parents have the decision made for them by the attending physician. It is typical that the MGH conference apparently included no parents or disabled adults...

Let me raise a few points which almost certainly would have been covered had parent or disabled adult been consulted... There was no mention of the rights of the newborn infant, as opposed to those of the parent, the physician, or what these people interpret as the rights of "society". Most of our adult friends born with serious birth defects question whether their doctor or even their parents ever really were entitled to decide whether they had a right to life. If such decisions are to be made, who represents the infant's point of view, without injecting his own vested interest? Surely not the physician or the parent who has already decided that the burden imposed by the child would be too great for him.

What about adoption? We know of many families who have happily adopted children whose parents were unable or unwilling to care for them. Is it necessary to impose the death penalty to relieve parents of an unwanted burden? What of the many, many children who have "heroic" medical measures withheld, but manage to survive anyway, only now they are significantly more severely handicapped, more of a "burden" on society?

Finally, there is the point of view attributed to Ms. Margaret Adams, that the "psychological health of the family may be more important than the survival of one defective infant." I know of many families which are clearly more psychologically healthy (even robust) because there is a handicapped child in the family. All of these families were shocked and confused when their defective infants were born; I defy Ms. Adams to have predicted then the way they have adjusted now. Obviously there is not always a happy ending to these stories, but there is a peculiar tendency among professionals to focus on the most disastrous possible outcome and seize upon it as the norm, then to base all arguments on that false norm.

Professionals as a group seem unlikely to listen to parents; it is in most cases contrary to their makeup. I do hope that the Globe can mend its ways in this regard, however.

Boston Globe: March 1974 -
Parents complain that
doctors do not listen to their
opinions about birth defects and
the right to life.

Psychology Today:
March 1974

A growing number of doctors and social scientists—but still clearly a minority—criticize the prevalent conception of mental retardation. They emphasize instead the societal standards and social pressures that lead to the term's use as a diagnostic label. Some maintain that these social factors *produce* the intellectual deficit; others stress the motivational and emotional differences between normals and retardates; still others (including ourselves) reject altogether the notion of differences as well as the concept of mental retardation.

Resourceful Retardates. We have evidence for our point of view from studies we conducted at two large state institutions and one small private facility for the retarded. As in our prior work, we embarked upon a systematic program of research that would pit our observations against the dominant conceptions of mental retardation. We found that many "retardates" are adept, rational, resourceful and intelligent human beings capable of protecting their own interests by using complex, subtle interpersonal tactics. Within the confines of the large training schools, these youngsters controlled, to a great degree, a somewhat hostile environment in order to live in a manner they personally desired.

Psychology Today:
March 1974
Interview with
Mike Tinbergen - A
unique explanation for
the causes of autism - can
it be proven?
What are opposing
views?

Tinbergen: In stress diseases, in increased admissions to mental hospitals. To mention one example about which my wife and I know something, stress appears to have led to a sharp increase of autism in industrialized societies. When Leo Kanner first described autism in 1943, he had great difficulty finding autistic children. Many pediatricians said they didn't know what he was talking about; now there is no pediatrician who hasn't seen such a child. Today there are societies for autistic children in America, Britain, Germany and Japan. It is no accident that those are all industrialized, pressurized societies.

Tinbergen: Many people, without any evidence, have concluded that Kanner's syndrome is a purely genetic deviation. We don't think so. Abnormal brain patterns can be a consequence as well as a cause. But some people jump from a correlation to a cause-effect relationship. No autopsies have ever found brain damage in these children. And if you find that identical twins are both autistic, that says nothing on either side of the question. But if you have identical twins who grew up in the same family and only one becomes autistic, it *must* be due to environmental differences. And two such cases are known. We don't deny genetic components, of course. Some children will be genetically more predisposed to autism than others. But a lot of the causation is external. People think too little about the possible kinds of environmental damage. For example, there is a higher incidence of autism among children of mothers who had rubella [German measles] during their pregnancies. And the importance of early interaction between mother and child is overlooked. Twenty years ago, Helen Blauvelt studied early interaction in goats and sheep and discovered that the first few moments after birth were incredibly important for the mutual bonding from which all later socialization radiates. Now this may also be true in man. Consider all the mothers who have an anesthetic during birth. We don't know what that does to the bonding process. My wife can speak from experience here.

Tinbergen: Fortunately, it's now becoming the custom in Britain to have th mother fully conscious, if at all possible and to give her the baby even before it i washed. In the past it was believed that th only reinforcer was food, and because th mother had no milk yet, there was n point in putting the child to the breast Now it becomes clear that suckling immediately after birth greatly helps to start th bonding. The newborn child is alert an expects contact with his mother; he i programed for certain things that mus come from her. So an unconsciou mother and an infant whisked off to a nursery may set a vicious circle in motion.

Hall: But you remain convinced tha many cases of autism come out of the family situation?

Tinbergen: A number of these children *are* damaged by their parents, even though the parents may have acted with the best of intentions. But they shouldn' feel guilty about it. Many psychiatrist have said that the parents of autistic children are odd in some way—either straine or apprehensive or overserious. We hav gradually come to the conclusion that very important part of life is lighthearted childish fun. When we lived with the Eskimo, they showed the silly jokes an healthy fun that is characteristic of primitive peoples. Some of the early film record their beautiful, happy, musica laughter. When that carefree spirit i gone, people are in trouble.

When are people
wrongly labelled as
"retarded," and why?

Formalizing "Defectiveness." By now it should be clear that any child of the surplus poor is a potential retardate lacking only the formal recognition of his "defectiveness." Recognition occurs as soon as he is separated from his family, ejected by them or extracted from them by social agents. Few refuges exist for such a child

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Psychologists, educators, social workers and other "helping" professionals all play a vital role in the metamorphosis of the child. Just as they unwittingly transform surplus adults into emotional defectives (e.g. schizophrenics), they transform discarded children into intellectual defectives (e.g. cultural-familial retardates). Mental retardation, like mental illness, is not a psychological concept but rather a sociopolitical one. It is another of the many myths perpetrated by a society that refuses to recognize its needed social reforms. The camouflage of the politics of diagnosis and incarceration have led to an enormous expenditure of time, effort and money in a useless search for psychological and biological factors when the real problems exist in society.

We need to move away from the traditional realm of psychology and psychiatry to an objective analysis of the politics of deviancy. This would lead not only to creative new theories and research, but would provide new forms of management and treatment for deviants—forms that would no longer dehumanize and degrade the recipients of our professional help and would free professionals from having to justify their roles by defending a delusion.

Two Mothers

There is no doubt that cultural attitudes can greatly influence the kinds of provisions we are able to make for a person with special needs. They may even influence whether or not we see that person as having special needs in the first place. In the Russian village described earlier, a man of 120 is not perceived as handicapped. In our own country, he would have a very hard time finding employment.

Here are the stories of two mothers. Both have Down's Syndrome children, but their experiences as parents have been very different. In what ways were their communities responsible for this difference?

Donna

"I felt so alone as the door closed behind my husband, Charles. I could see him walking down the hospital corridor getting smaller and smaller. Sobs shook my body, and I imagine they shook his body as he got into the cold car.

"I knew that he had difficult things to do. How do you phone the message he was carrying? Only this morning, he had phoned our parents and our sisters with the joyous news that our baby had been born—our first child, their first grandson. And now the words so hard to speak, to believe, to understand: 'but he is a mongoloid child.'

"In 1956 there were no other descriptive phrases to use; just the word 'Mongoloid' was used, and that described the superficial features of eyes slightly slanted upward. It wasn't until 1959, when three French doctors isolated the chromosomal reasons for these defects, that the term 'Down Syndrome' came into use. Whatever the terminology, our child would be 'profoundly retarded.'

"I felt so alone. Even my silent but very present companion of the last nine months was no longer within me. He lay somewhere down the hall in a small crib in a large room —also by himself. The nurses had explained that they don't keep "such" babies in the nursery. They felt it might disturb the other parents to see an abnormal child there.

"And so the three of us who had seemed so close during these past months were now apart, and alone.

"My husband's parents had planned to be with us a day or two after the baby was born to 'help out,' a role they had played at the birth of their other grandchildren. I was glad they were coming because it meant my husband would have some company. The next day I asked him when they would be arriving. He answered, 'They won't be coming, now.'

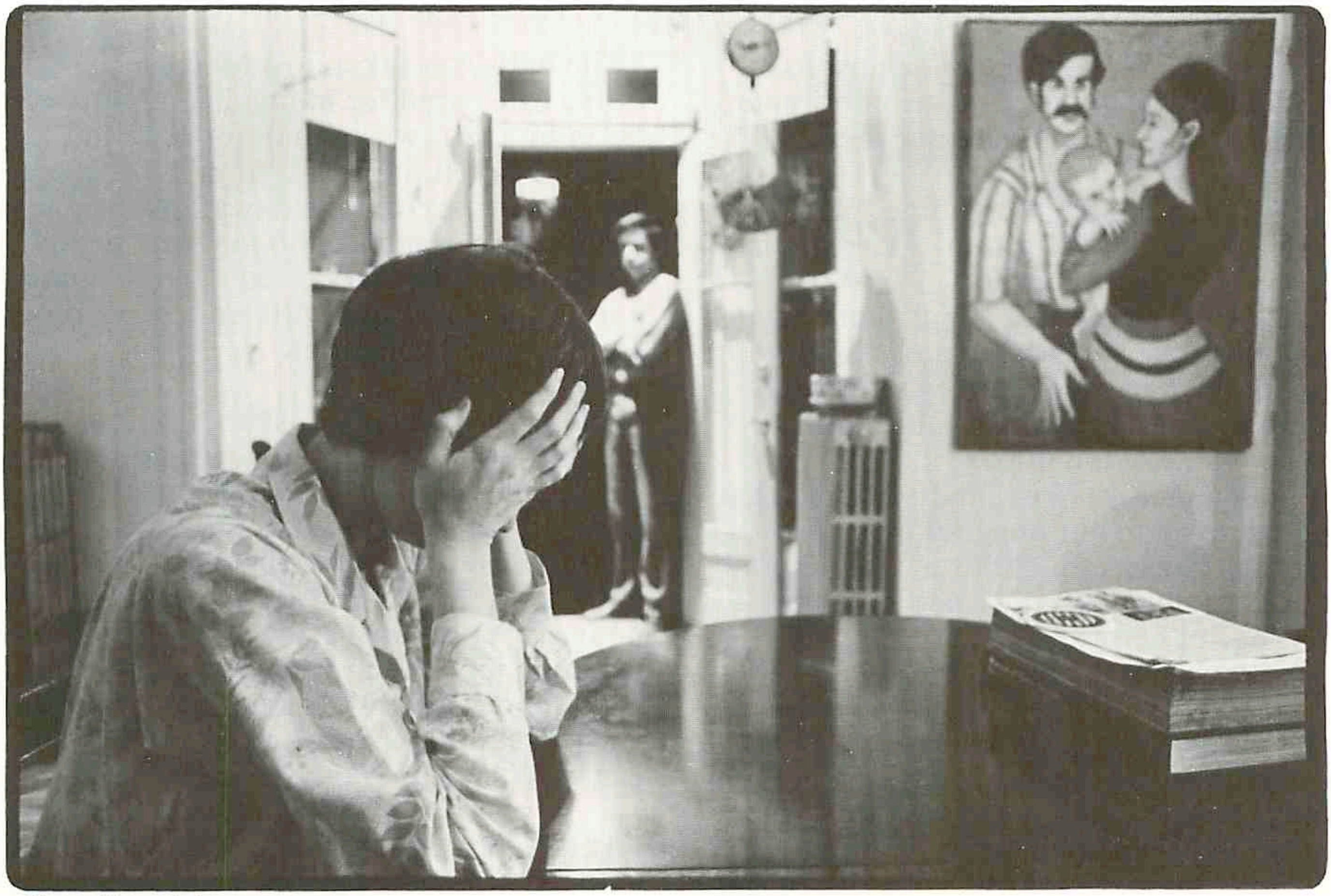
" 'What do you mean?' I asked.

" 'Mother said, "Well, darling, this is a door that you must close behind you, and never open again. You must do what you must do, and never look back. You must go on to new things." '

" 'But what does she mean?' I was incredulous. 'He exists. He is. How do you put that behind you?'

"Charles said nothing. He just looked confused and alone. I lapsed into silent tears.

" 'What should we talk about first?' I wondered, as item after item crowded for a place on the agenda in my head. The pediatrician had painted a chilling picture for us the day before.



Rogier Gregoire

Our attempts to talk always ended in tears.

"'You won't be able to find baby sitters,' he said. 'These children have feeding problems. When you have other children they will be teased and questioned by their friends. They will be embarrassed. Other young mothers will find it difficult to be with you.'

"He ended the description with the statement, 'Well, you, Charles, are here in graduate school, and you, Donna, are a teacher. Let's see if you are capable of making a rational decision, and not one based purely on emotions, a large part of which is guilt. Have this child cared for. Go on with your lives.'

"Should we talk about what he had said? Or should we talk about our rapidly dwindling resources: the private room for the baby, a consulting pediatrician for another opinion, the special nurse automatically put on for the difficult feeding? What did my mother say? What did your sister say?

"I wanted to ask all these things at once, and didn't know where to begin. My husband was locked in sorrow. How I wanted to comfort him, to comfort myself!

"A couple of nurses stopped in to say, 'Be glad you have a doctor who told you. It might seem hard now, but lots of them don't tell the parents—they let them find out by themselves, little by little.'

"Otherwise, no one came. The hospital allowed only husbands and grandparents, and the grandparents were not there.

"Should we take Stephen home? Should we find a private home for him? How much do they cost? How do you find out? Where would we get the money? Was there any possibility of a scholarship at the graduate school? We had saved money for my husband's tuition for two years, but that was already being eaten into by the unusual hospital expenses. We had discovered that the fine print on our hospital insurance excluded services for children with abnormalities, a phrase that we had never been conscious of before.

"I encouraged my husband to tell his department head at the university—to tell him our problem—to talk it through with someone else and to raise the scholarship question. After several days of urging, he finally did. On relating the incident to me he said that Dr. Louis had said only, 'That's rotten luck, isn't it.' And he never mentioned it again. Never. He never inquired as to our decision, he never acknowledged the scholarship request. He didn't invite us to his home for dinner, as he did with the other young couples in his department, each in turn. (Was he afraid we couldn't get a baby sitter? That we might bring the baby with us. What? What?)

"We asked the pediatrician for a list of private homes where they care for retarded children. He said he would get a list for us from the social service department at the hospital. Once when I awakened from a nap I found it at my bedside table.

"My husband drove around and looked at each place. I lay in my hospital bed with intense headaches.

"The baby was taken to a Mrs. Dana, a nurse who cared for mongoloid children in her home. She was grandmotherly and loving and called the baby, 'God's special pet.' My parents arrived the day after we took the baby to Mrs. Dana's and me back to our small apartment. We cried a lot, my parents and I; our eyes filled with tears every time we looked at each other.

"I slept a lot and my husband went off to the university—but somehow couldn't go to classes. He mostly went to the poetry room in the library and listened to recorded poetry and music. The large headphones closed out the rest of the world. My parents went home. His parents never came. I got a teaching job. When we called old friends back home they didn't mention the baby. When we did it was awkward and the subject was quickly changed.

"At the end of the school year there was a letter to Charles from Dr. Louis. It said, 'We suggest that you withdraw from the university. Your incomplete grades indicate that you are not able to handle study at the graduate level at this time.' A few other procedural forms. Nothing more.

"My husband saw the baby alone during the day while I taught. We only got a chance to see the baby together on weekends. Three years and thousands of dollars later, we put Stephen in an institution. We didn't talk much about it to each other. I tried, but Charles was silent. The attempts always ended in tears. And when I mentioned our decision to friends, the conversation would become leaden. In a sense, I guess, the early separation of each of the three of us set a pattern for the way each of us would be for the rest of our lives. Each of us, somehow, alone."

Betsy

Peter C. Reisz

Kathleen playing on back, 30 weeks.

"My husband Peter and I prepared carefully, though not elaborately, for the arrival of our first child. We knew the apartment would be too small, and decided to build a house. I was able to select cabinets, rugs, and wall colors to meet the builder's deadlines. The baby's room would be light yellow, with curtains to match. Friends sold us a white crib, we bought a clear plastic crib bumper with pink and red dots. A tiny red calico duck with yellow wings, bill, and feet sat in the crib to await the new arrival.

"Finally the big day came and I went into labor. During one of his periodic checks, the doctor suddenly said, 'The baby's heart rate has dropped to 80.' He grabbed the foot of my bed, pulled it into the hall, and pushed me to the delivery room. After a difficult delivery, the obstetrician laid the bluish baby on my flattened tummy and said, 'She has a bullish neck.'

" 'Just like her father,' Peter remarked.

"The doctor's comment was meant to alert the other doctors present to look closely at the baby. I was returned to the recovery room.

"A few minutes later, my doctor entered the room. He sat down on the foot of the bed for what we expected to be a congratulatory chat.

" 'The baby shows signs of Down's Syndrome. Do you know what that is?'

" 'No,' we replied.

" 'Mongolism.'

"A shudder swept through me. A picture from my college psychology book of a man with his tongue hanging out flashed in my head.

" 'We aren't entirely sure. The pediatrician will examine her and some tests will be done. I want to emphasize that you can have normal children.'

"We knew that he was giving us a ray of hope, but we were also sure that he was already certain of his diagnosis.

Peter C. Reisz

In bouncer, 32 weeks.

"'When you test her, what signs will you be looking for, what traits will you be checking for?' we asked anxiously.

"'A thick fold of skin at the back of the neck, short fingers, eyes that appear abnormal due to a fold of skin on the upper lid.'

Peter C. Reisz

Drinking juice, 18 months.

"'What will it mean?' we asked.

"'She'll be physically and mentally retarded for life.'

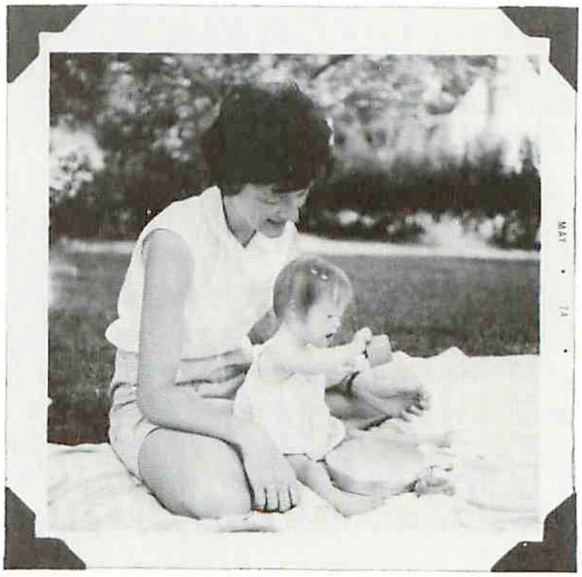
"There were no tears, then. Questions tumbled out, about the cause, the outlook, our options. We tried to grasp the reality. Peter sat beside the bed, his head in his hands.

"'I'd better start calling the families before they call the house and realize you must be in the hospital,' he said.

"After each call, Peter returned to compose himself before the next call. After responding to the disbelief, despair, and grief of grandparents, aunts, and uncles, he remarked that telling the family had been worse than finding his own father dead on the bathroom floor.

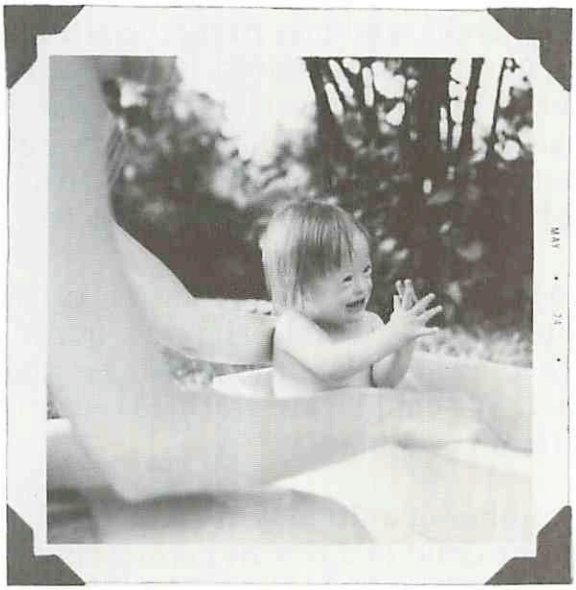
"By early afternoon I had been moved to a private room, not wanting to share a room with anyone who had given birth to a normal baby. By evening we shed the first bitter tears as wave upon wave of realization swept over us. As the days passed, Peter and I shared our feelings of rage, despair, grief, anxiety, uncertainty, and love. We read books and articles about Down's Syndrome. Letters went out to friends and professionals asking for information about institutions, and about the decisions other families had made when they had a Down's Syndrome child.

"Flowers, food, telephone calls, and letters came to the hospital and home from friends and relatives. Two colleagues had contacted a teacher of retarded children in a nearby town as well as the parent of a Down's Syndrome child. The teacher and the parents asked me to visit them as soon as I was ready and able. Another friend, a doctor, brought references from a medical library for us to read. A parent in our town, whom I had never met, came to the hospital to tell us about the decision her family had made about their Down's Syndrome child—they decided to place their child with a foster



Peter C. Reisz

Banging cup on cake pan, 18 months.



Peter C. Reisz

Pat-a-cake before bath, 18 months.

family and have the child come and live with them during the summer. She stressed how important it was to take our time and make the decision that would best fit our lifestyle. She was wonderful and very supportive, and I had never met her before that day she came to visit me in the hospital. On my last day in the hospital she sent me a bouquet of forget-me-nots, with a note asking me to come visit her when I felt up to it.

"The nurses on the ward sensed the intensity of feeling and discussion as we got deeper and deeper into the issues of institutionalization, foster care, and home care. Official visiting hours, usually so inflexible in hospitals, were relaxed. Often when my evening snack came there was an extra sandwich and beverage for Peter.

"On the day I went home I noticed that Peter had closed the door to the yellow room. We went in together, even though the bright colors didn't suit our mood. The calico duck was tilted to one side. When we walked out we left the door open.

"Since Kathleen was still in the hospital, we took turns going there to feed her. In the meantime we also gathered information about options for her care. One day Peter said, 'She's our child. It's our responsibility to give her the best care we can.'

"I answered him, 'I can't bear the thought of all the time it will take to teach her the simplest things.'

"In a discussion with our minister, an issue arose that always seemed at the heart of our deliberations: is caring for Kathleen and teaching her going to be the best use of our time, or should we use that time differently? Our minister asked what I had planned to do if I had a normal child. I quickly replied that I had intended to devote most of the first two years to caring for the child, because I knew the importance of those first few years.

Peter C. Reisz

After shampoo, pointing to toy, 18 months.

"'Is two years too much to give to this child?' he asked.

"The answer to that question was central to our decision.

"At 2:30 P.M., ten days after I had left the hospital, Kathleen's crib was rolled out of

Peter C. Reisz

Stirring spoon in imitation, 24 months.

the nursery into the hall so we could dress her for entering the outside world. At 3:15 P.M., the calico duck had a companion in the white crib.

"Often friends would come for a visit during feeding time. How good it was to talk with them about our feelings, the syndrome, and the future. How surprised I was when someone would say, 'She is very sweet.' They were seeing a child. I was seeing a retarded child. I wished that I could see through their eyes. Friends from far away sent letters of concern; some called, not just once, but weekly, monthly, to see how we were getting along. People sent stimulating toys for Kathleen.

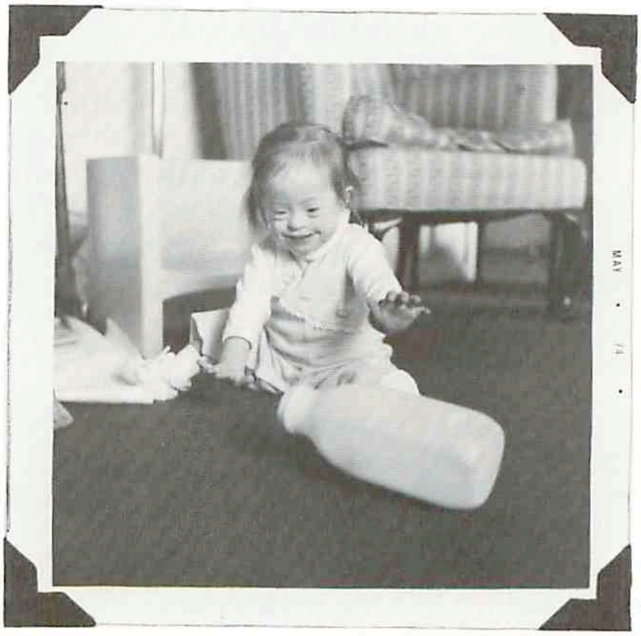
"In those early weeks, whenever a normal child came to the house or if we saw a normal child out shopping, we'd feel a combination of jealousy and wonder. The child could walk. The child could joke. The child could smile at a stranger.

"Later, we were able to understand more about the source of the feelings. In effect, we were mourning. Mourning the loss of the expected child, and mourning the affliction of the child who had arrived. Although we had not known the eye color, sex, or future occupation of the child I'd been carrying for nine months, we knew the child who had arrived was not the one we had expected.

"By the time Kathleen was four weeks old, two high school students who were not at all disturbed by her "condition" had learned to feed her. We could leave Kathleen with them for an evening.

"The mother of a three-year-old Down's Syndrome child in a nearby community invited Kathleen and me to visit with five mothers and their Down's Syndrome children. The children were 6 months, 18 months; 2, 3, and 5 years.

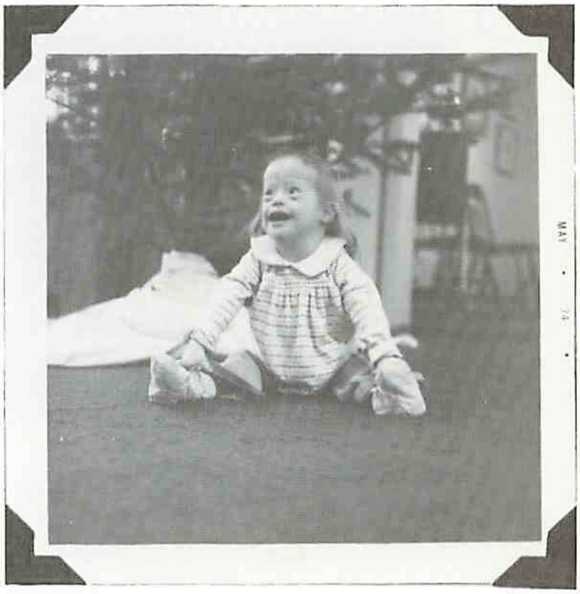
"To be sure, it was discouraging to see the six-month-old barely interested in his surroundings, but it was far from discouraging to see the 18-month-old zoom around on her crawligator, and to watch the two- and three-year-olds play with blocks and dolls,



Peter C. Reisz

Throwing plastic bottle, 23½ months.

greet the preschoolers coming and 'talking' about school. All enjoyed the juice and cake and clearly made known their desire for more. This experience was a great encouragement for me to work with Kathleen. Glimmers of progress motivated us to continue working with her, and both our investment of effort and her responses contributed to our growing acceptance of her for what she was—our child.



Peter C. Reisz

Laughing under Christmas tree, 23½ months.

"Some people have remarked that it must take all of our time to work with her. On the contrary. She demands very little attention, being very happy to play with her toys or listen to a record. The challenge is to use the time she spends with us in a purposeful manner.

"Many of the friends who stood by us at the beginning have included Kathleen in ongoing activities: an invitation to a birthday party, an egg-dyeing party at Easter, a handmade dress for her birthday, a gingerbread house for Christmas. This is the kind of acceptance parents of retarded children look forward to for their child.

"Now and then we like to talk about Kathleen, just as other parents talk about their children. If a stranger begins a conversation, either in Kathleen's presence (usually, 'How old is she?') or without Kathleen being present ('Do you have any children?'), we answer the questions directly and immediately, and give some hint that all is not completely as they might expect: 'She's small for her age because she has Down's Syndrome.' Even with their shocked or puzzled look, most people ask another question and seem to appreciate a fuller explanation.

"Peter and I understand now how very important it is for the parents of a retarded child to reach out into the community for help. And it is equally important for the community to be willing and able to help and support them. Our families and community have been very supportive of us, and that made all the difference in our ability to cope with and love Kathleen."

Questions for Discussion

1. How were community attitudes important to and responsible for the decisions that these parents made?
2. Compile a list of the resources Kathleen's parents found available to them (supportive doctors, teenagers willing to babysit, etc.). What resources were denied Stephen's parents (family support, etc.)?

Suggested Research Project

Since each child was born, what advances have been made

- in doctor and hospital attitudes?
- in community resources and attitudes?
- in care and treatment?
- in education?

The last section of this book, *Additional Help and Information* (p.83), can aid you in your research.

Rogier Gregoire

Meeting the Children:

Seven Case Histories

Sara Sibley

You have already met Sara Sibley in the film. You have seen a part of her life as it is today, in the midst of a large, loving family.

But every family has to adjust to a new baby, and the Sibleys were no exception.

Sara was born at 4 P.M. At 6 P.M. the pediatrician came into Mrs. Sibley's room and said, "The baby is healthy and strong, but she's a Mongoloid. . . ."

Mrs. Sibley did not know what "Mongolism" meant. Since she had not yet seen Sara herself, she did not know what to expect. She had not known that mothers over 35 are a bit more likely to have a child with Down's Syndrome, and was shocked by the doctor's casual reference to it. When she talks about that experience today, Mrs. Sibley says that if she had known about the possibility of having a child with Down's Syndrome, she would have had genetic counseling and testing done.

When Sara was born, the hospital staff wanted to hide her from public view. They were very surprised when Sara's mother resented it.

"I was very hurt, that they thought I should be ashamed of Sara. To me she was like any of my other children—sweet, small, and needing love. It never entered my head to be ashamed, or to want to hide Sara. I was proud that she was so healthy and strong.

"Of course," Mrs. Sibley continues, "we had to settle on a solution that would work best for Sara and for the rest of the family. We were not confronted with her 'differences' right away. The doctor had told us that it would not be until she was three or four that her retardation would be obvious. Of course, as she grew we could see the differences between Sara's rate of development and our other children's, but after a while you stop comparing Sara to other children and just look at her for herself and all the wonderful things she can do."

Mrs. Sibley and the parents and teachers in the following stories all point to the importance of allowing each child to learn and grow at his or her own speed. As you read the case histories of these children, think about the following questions:

1. What were some of the experiences parents had at the birth of these youngsters? Are there any similarities in experiences? (As you read, you might jot down the issues that seem to occur over and over in each story.)
2. What role did the hospitals and/or doctors play in supporting or not supporting parents?
3. What kinds of changes have been made in the lives of the families to accommodate these children?
4. In what ways have these children been learning and growing?
5. What is each child's self-image?
6. Are the issues any different than they would be for "normal" children?

Jeffy Conrad

Jeffy is a five-year-old boy who has been diagnosed as hyperactive, or suffering from hyperkinesis. Jeffy's hyperactivity manifests itself in his inability to keep still, and in his lack of concentration.

No one knows exactly why a child might be hyperactive. Some doctors think hyperactivity might be caused by damage to the part of the brain that controls nerve impulses. Other experts ascribe the "condition" to the fact that children everywhere are born with different temperaments, and have different ways of responding to the world. There are many possible reasons why a child might be hyperactive, but as with any problem, the cause is sometimes not as important as the treatment.

Mrs. Conrad was visited at home one evening, close to Jeffy's bedtime. When she handed Jeffy his pajamas, he grabbed them from her and raced around the room three times before she was able to quiet him down. "Bedtime is his hardest time," she said. "The fact that the day is gone seems to overwhelm him. But as soon as it sinks into his head that I really mean business, well, then he'll calm down."

His mother was right. Within 20 minutes Jeffy was in his pajamas and had listened to a story. He listened intently, but his feet and hands were constantly in motion. It was as though his brain were sending its own independent messages back and forth through his body. Eventually he settled down to sleep.

Mrs. Conrad says that "it's not that hard anymore. A year ago bedtime was impossible. Jeffy was impossible. We would start getting him ready for bed around seven o'clock and we would just be finishing up around ten or eleven—and that's no lie. Of course, we would be absolutely out of our minds.

"But now it is easier to put his problem into perspective. Before we took him to the doctor we thought that he was just a wild kid. That might sound horrible, but we couldn't understand why he was always getting into things. Ever since he could crawl, nothing in our house has been safe.

"When we finally got up enough nerve to tell our pediatrician some of the things Jeffy did, and the way he behaved, we were shocked that the doctor was familiar with our problem. I guess that is why it's important that parents don't hide their worries from people outside the family. The truth is, we were ashamed that Jeffy was so disobedient and jumpy.

"When I talked with our doctor, I found there were a lot of parents out there coping with the same problem. We were very relieved when the doctor told us that many male children suffer from hyperkinesis. You know, when your kid doesn't seem quite right, you tend to blame yourself and sometimes your husband blames you or you blame him and it can get you upset. Sometimes people outside of the family aren't very helpful either. I've been asked to leave many stores because of Jeffy, and I haven't always been asked politely. It's just that some people don't understand what hyperactivity is about and they wrongly blame the kid. They call him naughty, ornery, and that just isn't the reason why someone is hyperactive.

"The doctor gave us some medication for Jeffy when he started nursery school. The teacher there recommended that we get some. Actually, she said that if we didn't get something for Jeffy, she wasn't going to accept him. Teachers seem to feel that one hyperactive child can upset a class. I guess I can understand their point of view, because I know that when Jeffy is feeling his oats and speeding around here, no one has any peace.

"When he's like that it's also really hard on the other kids. Sometimes he has so much energy that some of it just seems to have to turn destructive. I would say that basically he isn't a destructive child. Actually, he's pretty considerate and sweet. But try telling that to a child after Jeffy has just destroyed his sand castle. Poor Jeffy. He wants so much to have friends, but other children just seem to be turned off to hyperactive kids. All of Jeffy's intentions are noble, in a way; it's just that his bouncing overwhelms the others. He sort of reminds me of that character in the Pooh book, Tigger, the stuffed tiger. Remember, he had to get unbounced—he was scaring all the other animals with his bouncing. I see Jeffy as that kind of hero. He wants to sway people with his particular rhythm, but he's just too much for most folks.

"The thing that I'm most concerned about is what will happen to Jeffy as he progresses in school. Schools tend to pretend that all children are alike. If they determine a kid's needs on that assumption, they're apt to make mistakes. Luckily, he now has a teacher who is very sensitive to his needs. She has made a special effort to make sure that he has things to do that are stimulating for him. I just hope all of his teachers are able to cope with his restlessness and constant movement. His concentration is very low, but he will follow along at an amazing speed if the work is stimulating and fast. He can already add quite easily and correctly because the faster you are the better you can be. This particular teacher has made Jeffy feel just wonderful about his skill. Now when we go to the market Jeffy tries to add some of the purchases together. This is a great example of how 'problem behavior'

Daniel S. Brody/Stock, Boston

". . . when Jeffy is feeling his oats and speeding around here, no one has any peace."

can be channeled into something constructive that the child can be proud of.

"Hyperactivity can sometimes cause severe learning problems for youngsters because of their low concentration abilities. But if Jeffy has new things to do, he's okay. Heaven help a teacher who doesn't understand his hyperactivity, though, because he'll put her through a trip that she's never been on before. If Jeffy's energy isn't channelled, well, someone pays.

"At his present school they know his problem, so it's been arranged for him to have a playtime when he arrives in the morning. After 20 minutes on the playground he comes to class very mild-mannered and gentle. I think this is a great idea. It might even be good for kids who, while not necessarily diagnosed as hyperactive, need time to use up their morning energy.

"When I was in college I noticed that my roommate took her time getting up in the morning, while I just jumped out of bed and immediately began my day. In my sophomore year I was voted the girl who attended breakfast most often. I've been remembering things like that from when I was younger. Maybe Jeffy is more like me than I know."

The Problem of Blaming

Jeffy's mother talks about the need for parents to express their feelings of confusion and guilt. She hints at the feelings of resentment and guilt that people who come into contact with a misbehaving hyperactive child may have. The tally of responses mentioned looks something like this:

- parents blame each other
- parents blame the child
- strangers blame the parents
- teachers blame the parents
- teachers blame the child
- other children blame the child
- and ultimately, perhaps, the child blames him- or herself.

Questions for Discussion

When you have been upset, annoyed, or hurt, you naturally feel that someone is to blame and should be called to account. Even if you understand that a nebulous demon called "hyperkinesis" is the culprit, it is still difficult to get away from natural feelings of resentment over having been ill used.

1. What do you do about those blaming feelings?
2. How can you, as a student, help other children in the class deal with feelings of resentment without blaming or casting out the hyperactive child?
3. How can you help the hyperactive child avoid blaming him- or herself, and thinking of him- or herself as a "bad kid"?
4. Should a misbehaving hyperactive child be called to account for misbehavior? How and to what extent?

Planning Activities

Try your hand at devising some activities for a hyperactive child. What activities can be used in the home? in school? in an outdoor play area? Keep in mind the child's low level of concentration, the child's need to move around a lot, and the importance of "work that is stimulating and fast."

Diana Feinstein

Frequently, children who are born prematurely have a series of connected disabilities. In Diana's case, visual impairment was complicated by a mild form of cerebral palsy. This double problem made learning a special chore for Diana.

Diana came to live at the Parkman School last September. Her parents thought that being in a residential school with other blind and visually impaired children would give her a much needed "lift." She was accustomed to being the center of attention at home, and at Parkman she would have the chance to be with other children whose needs were just as great as her own. In addition, she would be receiving daily physical therapy for weakened muscles, which were a result of cerebral palsy.

"It's so easy," her mother says, "to get into the habit of carrying Diana upstairs, or putting a diaper on her instead of taking her to the bathroom. Before you know it, you've got a spoiled child on your hands, and you didn't really mean to do it that way. Maybe what Diana needs is a fresh start."

In the Parkman School kindergarten, Diana had ample opportunity to make a fresh start. The entire program is specially designed to help children navigate the world on their own. The classroom itself is very well lighted, to enable partially sighted children to use every bit of their seeing power. Tables and chairs are arranged in fixed positions, so that children can learn their way around. In addition, every chair has a special textured tag attached to the back, so that children can identify their own places.

The shelves are stacked with games and puzzles that make maximum use of the children's senses of touch and hearing. Self-help skills are high on the list of learning priorities in the classroom, and the toys and games reflect this practical emphasis. There are shoes for tying; door knobs, light switches, and chain locks to manipulate; and lotto games to help children perceive and identify colors. Each of these objects has a special place on the shelves, and the children learn to return them to the same spot every time.

Diana had trouble, though. When it was time to put things away, or to pick up something that had dropped to the floor, Diana seemed unable to cooperate. At first Miss Politzer, the class teacher, assumed that Diana just wanted to be waited on, as she had been at home. After two days of careful observation, however, Miss Politzer began to notice that there might be another reason for Diana's apparent lack of cooperation. She simply had no sense of direction—what is called "spatial awareness." The combination of visual impairment and cerebral palsy made it particularly difficult for her to understand and act on such directional terms as the words "next to," "in front of," and "behind."

Rogier Gregoire

Dolls were an important teaching tool for Diana.

Miss Politzer decided to try a set of therapeutic exercises designed to improve Diana's sense of direction. She knew that the two things Diana enjoyed most in school

Diana had difficulty finding activities that she really enjoyed.

Rogier Gregoire

were doll play and music, so she used dolls and songs as her main teaching "tools." Diana learned to pick up a doll placed next to, in front of, or behind her. Gradually, she grew familiar enough with the location of things in the doll corner so that she could feed a doll and put it to bed all by herself. After two weeks, she was so pleased with her mastery of the doll corner area that she was ready to tackle another part of the classroom. Her familiarity with the room, which had started in one small space on the floor of the doll corner, extended in slowly widening circles.

Music also encouraged Diana to be aware of her body and its coordination. When the words of a song told her to put her hands on her knees, or to walk to the left, the directions seemed easier because they were given musically. And when she sensed the other children's bodies moving along with hers, it pleased her to be part of the group. She listened very carefully to the sound of other children's footsteps when she danced, as if she were trying to "see" the children through their sounds. She knew, for instance, that Lisa's shoes made a light clicking noise when she danced, while Andy's rubber soles went thumpeta-thump, and Gerald's sneakers made hardly any sound at all.

Diana wanted to dance next to the shoes with the clicking sound. By listening closely, she was able to find Lisa when it came time to choose partners for "Skip to My Lou." She liked the feel of Lisa's small hand clasped in her larger, stronger one. She decided that Lisa would be her dancing partner every day from now on, and that she was going to ask her mother for a pair of clicking shoes for her sixth birthday.

Issues to Consider

1. Diana's parents hoped that she would get a fresh start away from home. Do you think they were asking too much of her school? Were their expectations realistic?
2. Were they correct in saying that they had spoiled her at home? What kinds of things do you think of when you hear a child described as being "spoiled"?
3. How do you feel about a classroom like Diana's, in which the children are assigned learning tasks and the morning is never devoted to "free play"?

Cary S. Wolinsky/Stock, Boston

Roberto Martinez

Roberto is a four-and-a-half year old deaf child who attends a special nursery school for deaf children. There are children in his class who have total hearing, but most of the children are either moderately deaf or profoundly deaf.*

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*"Profoundly deaf" means almost total loss of hearing.

The nursery school looks like any other preschool—except for the fact that most of the children wear hearing aids. . .

Rogier Gregoire

Roberto's nursery school looks like any other preschool—with its blocks and toys, and shouting, playing children—except for the fact that most of the children wear hearing aids and the teachers speak very clearly and loudly, their words well pronounced and distinct.

During the morning hours at school, a therapist takes each deaf child out of the room for a lesson, one at a time. The lessons vary according to the needs and skills of the particular child. One four-year-old is already working on reading words, and is doing very well. Roberto's favorite lesson with the therapist is doing puzzles in which objects are matched to words. The therapist uses a puzzle board that has pictures of different things on it; part of the picture is missing, and the child must find the right part. For example, one picture shows a snowman, but without a snowman face with charcoal eyes and carrot nose. The therapist might say, "Who is this, Roberto? What is missing?" Not only is this a fun game, but the children are encouraged to talk and mimic the therapist, who speaks very clearly. Since deaf children cannot hear themselves speaking, it is important that they learn the way different letters sound. Through these games, Roberto is learning to associate words with pictures, and pictures and written words with sound. His speech has improved a great deal since he entered the school.

Roberto's parents are very happy with his progress. His mother, who attends the parent group at the nursery school, says she feels very supported by the program. She and her husband now have a sense of hope and accomplishment.

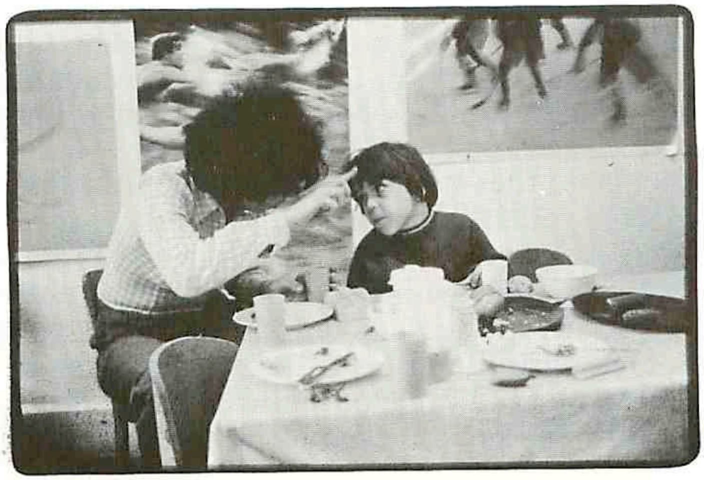
"We first suspected something was wrong with Roberto when he was about six months old," Mrs. Martinez says. "Things would be dropping and he wouldn't even respond. But when my husband and I took him to the doctor, he just said that we were nervous, new parents and that we should go home and relax. Every time I remember how he just dismissed all of our worries so easily, I see red. I guess it's not his fault, but doctors and probably the public in general should have more information on common handicaps.

"By the time Roberto was a year and a half old, we knew there was definitely something wrong. If his back was turned toward us, he didn't respond when we talked to him. He also did not speak. He didn't say a word. We took him back to our pediatrician, who said that if Roberto didn't listen when we talked to him, we should just 'swat' him. I couldn't believe my ears, but that's exactly what he said. Then we took him to hospitals and other doctors, but they all said that he was too young to test. I was furious, because I knew that babies could be tested for deafness and Roberto was almost two years old.

"It wasn't until a few months later that we finally got someone to look at him—a whole year after I first detected that something was wrong. When I think of all the things I could have been doing for him during that wasted time, I get very angry. But now when I talk to the other mothers here at the nursery, I realize that almost all of us had the same experience.

"When we finally had Roberto diagnosed, we learned that he was profoundly deaf, but that a hearing aid would allow him to pick up loud voices and that he would probably even learn to talk clearly. Which he has. Roberto's baby sister Maria was tested along with him, and we were told that she was also deaf, though only moderately. The kind of deafness our children have is hereditary. That's why it's so important to get genetic counselling. There are certain genes that are passed through families, and if a 'bad' gene is detected early enough, trouble sometimes can be avoided. I learned so much from being at the nursery. The teachers and therapist are very supportive of the parents and children. The special therapy given here is geared toward picking up on a child's good points. I think that too often a child is made to feel that he really is handicapped, when he has a lot of other things going for him. Here, they emphasize the good things.

"When you have a child with a special problem you tend to think that everything he does is abnormal or different from other children. But when you see your child interact with a child who has his hearing, you realize that kids are really kids. That may sound very simplistic, but really, it's simply true."



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The child is encouraged to talk and mimic the therapist, who speaks very clearly.

Issues to Consider

1. How do you feel about the responses the Martinezes got from the doctors and hospitals they visited?
2. Can you think of any good reasons why the doctors may have responded in this way?
3. Can you think of any reasons why parents may not challenge responses like these sooner or more strongly?
4. There is an apparent paradox in Mrs. Martinez's statement that "kids are really kids" regardless of special needs. Roberto attends a school for children with special needs. Surrounded by peers with the same problem as his, hearing impairment, do you feel that Roberto can avoid developing a "special" self-identity? How can we deal with a child with special needs without emphasizing his or her disability?

Ned Becker

Ned's main learning disability is a special form of dyslexia called "dysgraphia." This means that while he *sees* words accurately, he cannot write them as he sees them. In many dyslexic children, the problem involves both reading and writing.

Ned's mother remembers that she first suspected something wasn't quite right with Ned even before he was one year old. Other babies were learning to hold their bottles by themselves, but Ned couldn't quite get the knack of tipping the bottle to drink from it. He just let it dangle pathetically from his mouth and got angry at it for not feeding him.

There were other clues during the next two years. Ned was very slow to begin crawling, and he didn't walk until he was nearly two. Mrs. Becker would have been really worried at this point, but her pediatrician assured her that premature babies (Ned had weighed only three pounds at birth) reach these developmental "landmarks" later than other children. Besides, Ned was astonishingly talkative for a two-year-old, and Mrs. Becker had to admit he seemed like a bright, lively child in most ways.

Ned's nursery school teacher first sounded the alarm when Ned was four and still unable to ride a tricycle. He told Ned's mother that Ned spent a great deal of time playing by himself and spinning stories. The other children had begun to notice that Ned "talked to himself" a lot, and that he refused to join the group for games and stories.

The Beckers decided that it was time to look into the situation more carefully. They took Ned to a large hospital clinic, where a group of doctors asked Mrs. Becker many questions about herself and Ned. After several tests and interviews, the doctors reached a couple of conclusions. Ned might be retarded. Or perhaps his mother wasn't "helping him to grow"; maybe she was still treating him like a baby and doing too much for him. They admitted that they weren't too sure what the problem was.

The Beckers next took Ned to one of the best children's medical clinics in the country. The second verdict offered more hope than the first, but it wasn't much clearer. Ned apparently had suffered a small amount of brain damage at birth, possibly because of an inadequate supply of oxygen to his brain. The result, a very small lesion or scar in one part of the brain, meant that messages from Ned's brain to certain muscles were either "scrambled" or not powerful enough. He had special difficulty picking up visual messages and translating them into action.

Ruth Silverman/Stock, Boston

"When I am a famous writer," Ned says, "I will have the most expensive type-writer in the whole world. . ."

"It was a relief to be told that Ned's difficulty wasn't our fault," his mother says, "but we still didn't know how to help him. Ten years ago no one had heard of dyslexia, disabilities that make it hard for a child to learn to read or write. We really didn't know what was in store for Ned, or for us. Instead, we just played it by ear.

"We discovered, for instance, that Ned would show us how he learned best if we watched him carefully. He always explored things by touching them—as if looking wasn't good enough. So we began to teach him self-care skills at home by the "touch and feel" method. If I wanted to show Ned how to button his shirt or tie his shoes, I had to 'feel through' the process with him step by step, instead of demonstrating it for him. Demonstrations never worked.

"When Ned entered first grade, he had a stroke of good luck. His teacher was a very flexible, sympathetic person who gave him a lot of room to learn as he needed to. One thing about dyslexic children is that they are often hyperactive as well—they have a hard time sitting still in a classroom. Ned's teacher didn't make him sit still. She let him hang by his heels from his chair if he seemed to be able to concentrate that way. She also introduced him to reading by drawing on his gift of speech, rather than making him look at words. During that first-grade year, he dictated a whole book of stories to her. She wrote them down, and the other children in the class made pictures for them. Ned himself was still unable to draw recognizable shapes at the time. Making a pencil work properly was still a mystery to him.

"In the second grade, Ned's luck turned. We moved to another community, and when his new school received his records, they decided he was a slow learner. On top of that, his teacher, Mrs. Ross, didn't like him very much and easily grew impatient with him. Ned managed to preserve his faith in himself with our help and that of a special language-skills tutor who worked with him three hours a week. Ned began to write that year, but letters often cropped up backwards or in the wrong place in words. Often he wrote the last letter in his name as a 'b,' which earned him the nickname 'Nebbish' at home. Ned told me, 'I know Mrs. Ross thinks I'm dumb, but I know I'm not.' "

Looking back at Ned's primary school years, his mother thinks that he was probably helped most by his family and by his special tutors. The school was always asking Ned to learn in ways that were hard for him. He couldn't manage a pencil well, but if he had been allowed to use an electric typewriter from first grade on, his writing difficulties might not have been an obstacle to getting good grades. He had trouble keeping numbers in the proper columns when doing arithmetic, but he was not permitted to use special graph paper to "organize" his addition for him. And no one would allow him to take tests orally, instead of on paper. The school didn't want to make a "special case" out of Ned.

Ned refused to be discouraged by the demands of school and the "real world," however. He always found a better way for himself. Riding a bicycle and playing ball proved too much for him, but he did learn to swim and, later, to ski. He couldn't fight with his fists, but his quick wit cut opponents down to size and proved a very effective weapon in battle. His fondness for playing by himself and making up wonderful fantasies has now grown into a desire to be a writer.

"When I am a famous writer," he tells his parents, "I will have the most expensive typewriter in the whole world and no one else will be allowed to touch it. And I will send Mrs. Ross (his second-grade teacher) a copy of my first book with a letter that says, 'I guess you were wrong about me, weren't you?' "

Issues to Consider

1. Sometimes a child spends a lot of time by him- or herself in a nursery school class. In Ned's case, this was an alarm signal, indicating that something was not right. Can you think of other reasons why a child might play alone all the time in school? What do you need to know before stepping in and doing something about the child's isolation from the class?
2. In what ways was Ned lucky? Unlucky? Do you think that good or bad luck can make a big difference in a child's school experience? Has it made a difference in your own school experience?
3. What kind of experiences helped Ned to keep his "fighting spirit"?

Optional Exercise

Ned's mother couldn't rely on the usual methods for teaching her child self-care skills, so she devised a "touch" method. You might try the touch method in class to see for yourselves how easy or difficult it is to teach or learn something in this manner. A day of advance planning will be necessary.

First, poll the members of your class to see who has a unique skill: e.g., wrapping a sari, eating with chopsticks, playing the French horn. The "skilled" people should then each choose a partner as a "student." *Without using words,* they will teach their partners how to perform their particular skill. If there are not enough skilled people to go around, the *newly* skilled people could try teaching any extra students.

Charlie O'Neill

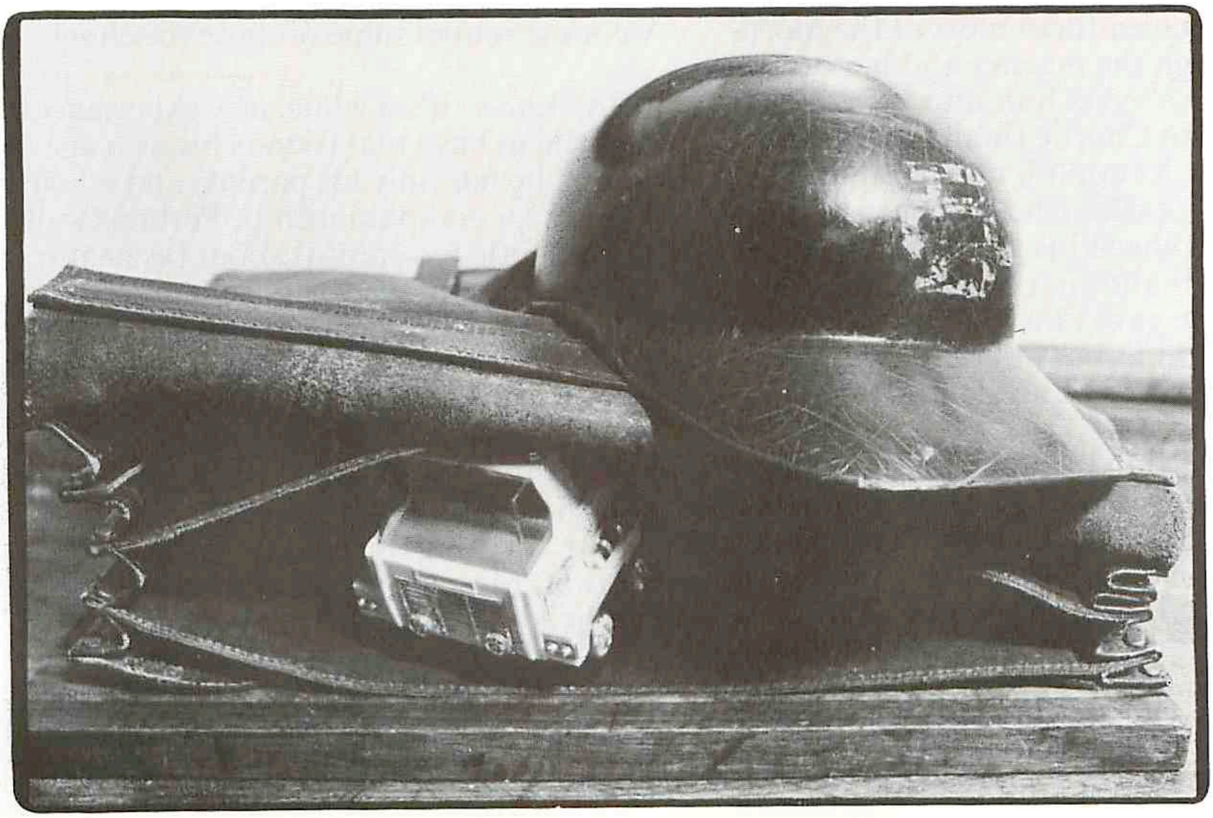
Charlie's difficulty in adjusting to school required special attention. Most children get over their separation from home and parents during the first few weeks. Charlie's increasing withdrawal, at a time when other children were beginning to feel safe and comfortable, was a distress signal to parents and teachers.

Charlie looked like a small, undernourished grownup. He always came to school wearing a neatly pressed white shirt and sport jacket, his horn-rimmed glasses sliding down his nose. He carried a small satchel of toys with him at all times, holding on to it as if it were a briefcase full of secret documents.

Charlie was in fact the youngest and smallest child in his nursery school class. As an infant he had had delicate open-heart surgery to repair a birth defect, and his whole first year had been rather precarious. Now he was in good health, but his mother's attempts to build him up with vitamins and good food seemed to have had little effect. Charlie was taking his time about growing.

Charlie's biggest asset in school was his imagination. Sometimes he told the other children fanciful stories about himself, in which he was a combination of Robin Hood and Superman—very daring and strong. He would take small objects out of his satchel and weave them into his stories.

When it came to following another child's lead, or sitting down to an activity with the others, Charlie wasn't so full of courage and confidence, however. Mrs. Randolph noticed that Charlie frequently shied away from trying new things, especially when they involved physical daring.



Rogier Gregoire

Charlie carried a small satchel of toys with him at all times.

After the children had been in school for a few weeks, one of the girls in the class came to Mrs. Randolph, the teacher, to tell her that she couldn't find a small toy mouse that she had brought to school with her. Mrs. Randolph organized a hunt for the mouse, but it didn't turn up. A few days later, another child's toy, an airplane, was missing. The list of lost objects grew, until it became clear that someone was taking things from the classroom.

Charlie seemed especially excited and agitated whenever a toy was reported missing, but he never volunteered any information about the missing objects. Mrs. Randolph noticed that Charlie was spending more and more time alone. If he played with others at all, he usually chose the company of girls. And he never let his satchel out of sight.

One day Charlie seemed particularly solitary. He found a place away from the other children and stayed there most of the morning, even though the teacher and her assistant both tried to coax him into various activities. When Charlie finally rose from his chair, Mrs. Randolph noticed that there was a damp spot where he had been sitting. She decided to check his pants for a possible accident, and found that he had indeed wet his clothes. She gave him a set of dry clothes and reminded him that he could use the bathroom whenever he needed to.

Three more wetting incidents followed the first one. At this point, Mrs. Randolph decided that perhaps she had better schedule a home visit. Usually she waited until October before scheduling parent conferences, but in Charlie's case it seemed advisable to meet with the parents sooner. Mrs. O'Neill seemed relieved when Mrs. Randolph asked if she would be able to come in for a chat, and they made an appointment for Friday afternoon. In the meantime, Mrs. Randolph and her assistant stayed close to Charlie, and made sure to take him to the bathroom at regularly scheduled intervals.

Mrs. O'Neill arrived for the conference a bit late, without her husband. "I'm terribly sorry," she explained, "but my husband called from work to say that he was tied up and wouldn't be able to come, after all."

Mrs. Randolph explained why she had arranged the conference so hastily. She described Charlie's withdrawal in school, and his wetting problem. Mrs. O'Neill was surprised to learn that Charlie was having trouble staying dry, since that had never been a problem for him at home. And she seemed puzzled by the description of his seclusion.

"That's funny," she commented. "Charlie often comes home and talks about the nice times he has had with the other children. Lately he's been bringing home toys that his friends let him borrow. That reminds me, we must return some of those to school.

"You know, it's a whole new experience for Charlie to have real friends his own age. At home, he has only his parents and a housekeeper for companionship. Perhaps we've been a little too careful about his health, keeping him in the house so much and making sure that he wasn't exposed to colds or flu. But he was such a delicate child, you know."

Mrs. Randolph asked Mrs. O'Neill whether Charlie might have been especially worried about anything during the past two weeks. At first, Mrs. O'Neill hesitated and shook her head. But finally she spoke.

"Raising Charlie has been so much fun for us. He's so neat and quiet, just like a little man. We wanted badly to have another child, to give Charlie a little brother or sister. When I got pregnant we were delighted. We told Charlie that I was pregnant and he was very excited, too, and would even put his hand on my stomach to feel the baby moving. Then about three weeks ago I had a miscarriage. We tried very hard not to let Charlie see how upset we were, but I guess children have a way of finding out, anyway, don't they?"

Issues to Consider

1. How do you think Mrs. Randolph explained the case of the missing toys to Charlie's mother? Do you think it would be necessary to explain that the toys were stolen, and not borrowed? Why might a preschooler be compelled to steal things from others? What about the child who takes only sweets, or classroom equipment? Are that child's needs necessarily the same as Charlie's?
2. Do you think the recent upset in Charlie's family entirely explains his school problems? Might another child have reacted differently? How could Mrs. Randolph offer help and support to Charlie's parents? How much involvement with the family might be appropriate in this case?
3. Now that Mrs. Randolph has a better understanding of Charlie's home life and the recent family upset, how can she help him in school?
4. Have you ever known a child who suddenly began to behave at a much earlier level of development (baby talk, fear of the dark, clinging to mother) after appearing to function at a more grown-up level for some time? What were the reasons for going backward (regression) in development?
5. Compare Charlie's self-isolation to Ned's (p. 53). What similarities and differences can you find? How would the solutions be similar? Different?

Elise Brown

Elise works at a fieldsite where there are children with special needs. She brings a special perspective because she was born with hemiplegic cerebral palsy, a form of cerebral palsy affecting the muscles of only one side of the body. Here is what Elise has to say about what it was like for her to grow up with cerebral palsy.

"The whole time I was growing up I had friends who were older than I, because kids my own age just never accepted me. I had braces on my legs until I was in the fourth grade. The kids were always making fun of me and being cruel. They would never let me join in games with them. I guess older kids tolerated me because they saw me as just a young kid hanging around with them. I was fat when I was younger, and because my cerebral palsy made it hard for me to go to the bathroom, I was always wetting my pants. That made things worse, because not only did I look terrible, I also smelled terrible.

"My mother would get very upset when I wet my pants. She thought I did it because I was too lazy to go to the bathroom. It would get to the point where I was wetting my pants every day, and my mother would let it go for about a week and then she would explode. She was very hurt and angered by my problem, and she also was ashamed that I couldn't control myself better.

"I had the same problem in school. My first grade teacher, Miss Dudy, wouldn't let me use the bathroom by myself. She used to claim that I couldn't walk down the stairs alone, which was completely untrue. This meant I didn't get a chance to use the bathroom all day, and by the time I got home I had already wet my pants.

"When I was in school, I would start crying

"At the age of 7 (when this photo was taken) I thought of myself as a fat, crippled little girl.

if any of the other children started talking about my braces or the way I walked. I spent most of my elementary school years in the back of the classroom crying. The kids didn't even have to say anything malicious; they only needed to mention that I was different to start me crying. I just couldn't cope with hearing about how different I was.

"In the seventh grade, when I was 11, I had an operation on my bladder. I finally had some control over myself and stopped wetting my pants. That improved my self-image a lot. I also started going to a new school—it was like I was making a new start in life. I took theatre and music lessons, and learned how to handle a camera.

"Theatre was the best thing that happened at that time. For the first time in my life, I started seeing myself as a person and not just a fat, crippled girl. When you are involved in theatre you have to be very honest with yourself. I had to start coping with and accepting the fact that I was different. Once I could admit this, I was on my way to becoming able to deal with other people's reactions to me.

"I know that I will never be able to do things that take a lot of physical strength or endurance. I've tried dance, skiing, roller skating, baseball, football—almost everything you could think of. I can't do any of these things well, but it's very important to me that I've been willing to try them.

I'll always have my funny gait. It's really very slight and other people don't always notice it, but I do. And sometimes when I go to buy a dress, the hem will hang more on one side than the other because my body is slightly lopsided. I can start feeling very sorry for myself at times, but when I think how very far I've come since all that crying I used to do in the back of the room, I really feel very lucky."

Issues to Consider

1. Elise seems to have outgrown her poor self-image, for the most part. Do you think that her self-image would have been different if there had been other children with special needs in school with her as she grew up? Would her "normal" classmates then have felt differently about Elise?
2. It bothers Elise that she can't do some kinds of physical activities well, but everyone has some personal limitations. Can you think of anything you really wish you could do, but can't? Have you developed any other skills or talents to compensate for your limitations?

Summing Up

1. You have read the stories of seven children who have very different sorts of special needs. Looking back on them (using any notes you may have taken), do you think that you could make statements concerning
   a) parents' attitudes and feelings
   b) therapeutic school experiences
   c) the child's self-awareness

   that would be *equally true* of all the children? Why or why not?
2. In what ways were the children's experiences, both at home and at school, different from one another? What kinds of learning experiences seemed especially beneficial? Who was responsible for these experiences?
3. Would you say that development in children with special needs is more or less similar than development in any randomly selected group of preschoolers? Give reasons for your opinion, based on what you have read and on observations in your fieldsite.

Rogier Gregoire

Building a Relationship: The One-to-One Model

If you have an interest in children with special needs, or an interest in a particular "special need," you may want to use the One-to-One Model. Working one-to-one, you will develop an ongoing relationship with a particular child for the duration of your involvement at the fieldsite. For example, Elise is a seventeen-year-old high school senior who was particularly interested in finding out about infantile autism, a disorder characterized by acting out and withdrawal (see the glossary, p. 86, for more complete definition). She arranged to work with Timmy, a five-year-old autistic child. For four months, Elise maintained a one-to-one relationship with Timmy. Here are her comments about the experience:

"At first, I was just very, very scared. I was thinking in terms of how he would think of me. I thought that love conquered all, which isn't true. Even though I didn't have much professional background at all, I thought that maybe with love and sensitivity I could kind of break through. I found out this wasn't really the case. But a teacher of mine told me that I couldn't do any more damage than was already done, and all I could do was help the situation. I was still afraid, though, that I wouldn't know what to do when I got really involved. So there were two feelings conflicting for a long time.

"I was only there about twice or three times a week, and there were times when there had to be someone else there with Timmy because he needed special attention.

"The head teacher, Ms. Wright, and assistant teacher, Ruth, were both working with him, but on a different basis—the two of them together. It depended on who was there at the time and who was doing what, although he responded well to both of them. Sometimes I thought their expectations of Timmy were a little high, although high expectations are very necessary when working with an emotionally disturbed child. In Timmy's case, part of the problem was that his mother had no expectations of him at all. In order for a child to develop and grow, he has to have some kind of challenge.

"There were many things I really got very upset with Ms. Wright about, too. She would make Timmy do things like put the brush back in the same color when he was painting. That kind of distinction seemed premature to me. That would come with time. He didn't even know what a brush was, and he thought paint was water, and he wanted to slop on the floor. I mean, *that* was the problem that should have been dealt with, and not *all* the problems at one time. So there were times when we disagreed. But still, if I had any questions, I would either ask them right away, or I'd be sure to ask them about it right after the school session was over, so that I could know how to deal with it the next time.

"Every day when I got home I would write in my journal about different incidents that had happened, and different feelings I was having. It was really good, because it kind of got everything out. There were times when I'd get home and be very, very frustrated and very exhausted. There were days when he would have such tantrums, and I'd be restraining him for so long that I'd be, like, in a shaking sweat. And I'd just feel really frustrated. I really had high expectations of him because I knew he was very intelligent, and I felt that he really had a chance. Timmy has a chance."

Your Own Expectations

With the One-to-One Model, you will be working almost exclusively with one child. That means you will be learning about children in general from a relatively intense involvement with one child. Choosing this particular model, you might miss certain experiences and learning that you might get working with a whole group of children. But you will gain experiences and insights that you could not get without working closely with one child.

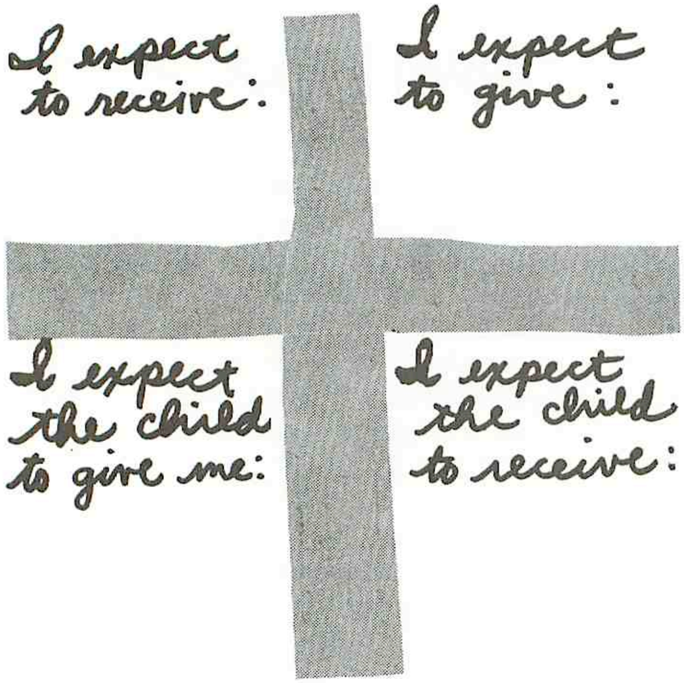
As you have read, Elise wanted to work miracles with love and understanding. In working with any child—and especially with a child with special needs—it is very easy to get so involved, and to want so badly to help, that you find yourself

Henry Felt

You may feel angry and frustrated when a child doesn't respond to your attempts to help.

having unrealistic expectations of yourself and/or the child. Some degree of frustration and disappointment is to be expected in any difficult task that you really care about. Taking a good, hard look ahead of time at your expectations may help you to avoid making unfair demands on yourself and the child.

It may be helpful to put down on paper all of the expectations you have about the relationship. Since any relationship is a matter of both giving and receiving, try dividing up a page of your journal into these four quadrants.



In each space list *all* of your expectations. Don't censor yourself—be honest. Try to pin down any fantasies about this experience that might be rattling around the back of your head. Expectations include hopes and wishes, as well as fears.

When you have completed your lists, analyze what you have written down. Note where your expectations are contradictory, and decide which expectations are most realistic. Looking over your list, it may strike you that the child may not be able to give some of the things you expect from him or her (attention, for example). On the other hand, some of the things you may ardently want to give (affection, for instance), the child may not be able to accept right away.

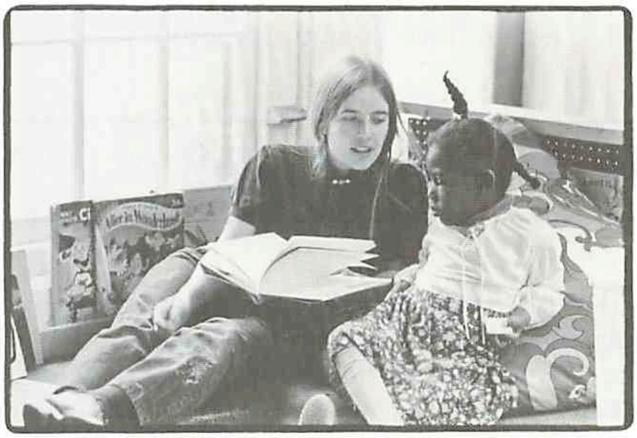
Making Contact

Elise described her first meeting with Timmy in her journal.

"He just seemed really lovely, and I fell in love with him. He has this big grin: he's really beautiful. The first day he ran in—just ran in—and he was kind of babbling to himself into the pillow (there was one special big pillow that he loved), and he just kind of sat there. I guess he sat there for half an hour, he'd just sit. Then, if he was doing something, like if he was picking something up and tipping it over, he would just go into these tantrums. He went through about four or five the first day. Ms. Wright would scream at him and take him out of the room, and I'd hear this screaming and crying, you know. And I sat there and just didn't know how to react—because I'd already gotten attached—but I didn't want to intrude at all. I did play with him a little that day, but he would be very dispersed; his energies are, even today, always very dispersed. He'd go from one thing to another, and keeping up with him was a problem. There were some things that he'd get very involved with, and he wouldn't really realize you were there, it seemed. He loved water. The first day, he was playing with water, and moving it back and forth. This is also an autistic symptom.

"He struck me as being very, very intelligent. That first day, he used my hand as a tool, which is also an autistic symptom—to use other people as a kind of mediator or go-between with something you're trying to do. For instance, instead of turning off the light, an autistic kid will take someone's hand and reach over to the light. Timmy took my hand and made my hand into a shovel, and I thought that was really ingenious. It's actually a smart thing for *any* kid to do, whether he's autistic or not. Timmy was playing by himself and then with my hand, and then by himself again."

It's only natural to feel both excited and nervous about meeting the child you will be working with for the first time. You're anxious to get off to a good start. You want the child to like you. Possibly you're feeling unsure about just how you will begin to build this new relationship.


Rogier Gregoire

You're feeling unsure about how to begin. . .

Possible Beginnings

When you enter the classroom, the child you have chosen to work with may be playing with a small group of children. You may be able to join their group play. It might then be very natural for you to follow the child's lead, accompanying him or her from activity to activity.

Or you could spend the first day just observing the child, becoming familiar with his or her pattern of behavior, noting what the child likes to do and how he/she relates to others (see the section and exercise on observing, p. 10).

Elise talks about how she "made contact" with Timmy.

"In the beginning, I was just following what he did. If he got to a table with blocks or something, I would try to verbalize with him, and just try to be there to introduce new things, to follow through with new things.

"For me, the beginning was actually when he started showing affection, because it's very important that Timmy have affection, and I would cuddle him. When he finally would reach back, once in awhile, I thought that in itself was good. It was very difficult because he is not focused, so that even when I left (I was working for about two months), we very rarely had eye contact.

"So it was very hard for me to feel attached at all, although there were times when he'd come and take my hand, and he loved running up and down the hall with me. He would do that with me for 45 minutes at a stretch. He'd take me by the hand, and we'd sit, then he'd look at the other end of the room, grab me by the hand, and run over. Or he'd close the door on me, and know enough to open the door and see that I was still there. That kind of thing came gradually, too, but knowing that he wanted to take me on some kind of journey with him was a breakthrough in itself, I think.

"He did develop an attachment for me, but, you know, love and hate are extremes of the same emotion. He would show a lot of affection for me, and also strike out at me. This was very hard for me to take, at first, because if he was feeling aggressive, he'd just come over and take it out on me. I had to decide that I wouldn't take this from him. It was very hard, too, because I didn't want to be too strict. But I did want to be consistent. It was really very difficult for me at the beginning."

Reaching Out

Some children are easy to get close to. Other children are reluctant to accept a new person. Still others are unable to "make contact" with other people (or even with their physical environment), because of barriers caused by their special needs.

You may want to try this exercise with your fellow students. It involves reaching out and trying to make contact with someone who is unable or unwilling to reach out. The purpose is *not* to role play an autistic or withdrawn child and his or her teacher, but to be yourself in active and passive roles.

First, divide the group up into pairs. One partner in each pair will attempt to withdraw physically and mentally into him- or herself. (It is helpful to fantasize that you are somewhere else, or to blank your mind completely.)

The task of the other partner is to interact in some way with the withdrawn partner. The active partner may want to relate to the passive partner physically (touching, tickling, pushing, etc.) or verbally (talking or singing). The active partner may want to try to make the passive partner respond in some way (of course, no dangerous force may be used). It is up to the passive partner to react in whatever way feels most natural to him/her.

After a certain amount of time, your teacher will ask you to switch roles. When everyone has had a turn at being active and passive, discuss as a group how you felt during the exercise.

As the active partner:

- What did you try to do?
- How did your partner react?
- How did you feel when you were reaching out to your withdrawn partner?
- Did you feel that you were taking a risk? What were you risking?
- How did you feel toward your partner? How do you think he/she felt?

As the passive partner:

- How withdrawn were you?
- How did your partner reach out to you?
- How did you feel about his/her advances?
- How did you feel about yourself? about your partner?
- What would you have liked your partner to have done differently?

Bad Beginnings?

Although "beginnings" at the fieldsite are important, they aren't necessarily critical. A bad day like Glenda's first day with Gregory (see p. 7) doesn't necessarily mean the relationship will be permanently damaged. Far from it, if you are able to learn from your mistakes. Glenda had a more positive experience with Gregory several days after her "blunder."

"Today Greg and I did puzzles. I was surprised he even let me near him after Monday. He was looking at a table covered with kids' war puzzles, and he grabbed my hand and dragged me over to the cupboard to get him one.

"The big wooden puzzle that the other kids do so easily was a real challenge to Greg. His cerebral palsy makes his hands unsteady, and even when he knows where the pieces go, he has trouble putting them in.

"I sat and watched and talked to him while he worked. Instead of trying to help put the pieces in, I said, 'Yes, that looks like it goes there—it's the right color, isn't it, Greg?' And he said, 'Red.' Then he said, 'Apple!' with a big grin and the piece fell in. 'Good Greg!' I yelped, and we both laughed like it was the biggest joke in the world!"

Rogier Gregoire

"The big wooden puzzle that the other kids do so easily was a real challenge to Greg."

Getting Involved in Teaching

All young children are involved in learning skills, gaining knowledge, learning how to relate to people, and developing a healthy self-image. For special children, sometimes the *means* of accomplishing these goals must be special. You may find yourself helping a child to compensate for things that his or her special need makes him/her unable to do. (What could Jessica and Benjamin do about the chocolate brownies?) For a child like Sara, you may simply have to repeat something over and over until she "gets it." With a hyperactive child, you may need to explain and enforce limits in a much more specific and persistent way, in order for him or her to learn how to control his/her impulses.

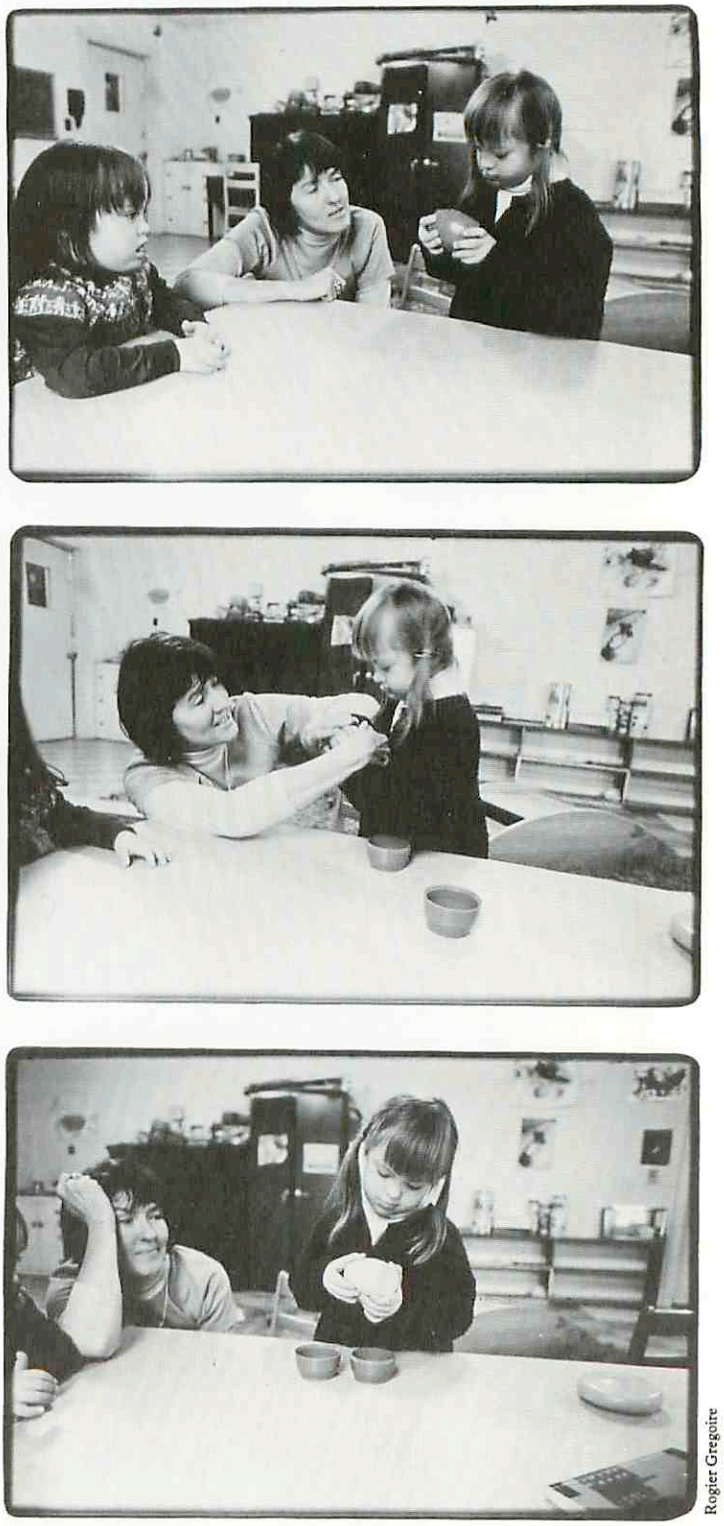
With any child, it is very important to start at the child's present level of functioning. In order to know how to help a child with special needs, you should pay attention to *what* the child knows and *how* he or she goes about learning and doing things.

Observing a Specific Task

You can discover what a child knows and how a child goes about learning and doing things by observing him or her at a specific task. You can either present the child with a task or activity, or sit with the child when he or she is already involved in something.

Try to answer the following questions as you observe:

1. How does the child respond to the activity? Is he/she initially interested in it? Is he/she reluctant to try it?
2. Does the child's special need seem to be influencing his/her ability to do the task or solve the problem? How? Be very specific.
3. Has the child developed any alternative learning modes or any compensa-



Rogier Gregoire

Sara stacks the nesting cups over and over, with her teacher's help.

tory skills or behaviors to help accomplish his/her task? Do they appear to be working?

4. How successfully does the child complete the task? How long does the child stay with it? Does he/she finish? How does the child seem to feel toward what he/she has done?

Clarifying Roles

Shortly after beginning work at the fieldsite, a serious misunderstanding arose between Elise and her fieldsite teacher. Elise explains how it happened.

"At first, I was very unsure of my situation at the school. And this became a problem within the first two weeks. I felt that I didn't really know what kinds of steps I could take. I didn't want to offend Ms. Wright. I had the feeling that she might be doing things that I shouldn't see, because Timmy would have tantrums and I thought at first that she was taking him into the hall and hitting him. It turned out not to be true, but I just got so anxious. I didn't know whether I should actually go out and watch her deal with him, because it seemed to be a very one-to-one kind of thing, and intimate in a very strange way. I sort of wanted to intrude, but I also didn't want to make anyone feel uncomfortable. It hadn't occurred to me that if Ms. Wright had anything to hide, she wouldn't have had me there to begin with.

"I had this notion—I have no idea where it came from—that intelligence came from books. Well, that's not really true, I realize now. But when I asked Ms. Wright for a reading list—and this is one of the first things that upset me—she didn't have anything to give me. I was shocked. I thought, 'She's working with these kids, and she doesn't know.'

"Ruth, the assistant teacher, was getting a doctorate, so I knew that she was well-read. I had more confidence in Ruth, and found her a lot easier to talk to. About three weeks after I had started there, I finally talked to Ruth about it. I told her I just felt lousy, because I hadn't talked at all about what I was feeling. I explained to her that I wanted to work with Timmy, and that I had certain expectations. I told her what I wanted to accomplish, the kinds of books I was reading, and how I wanted to apply them. After that, we became very close, and I later became very close to Ms. Wright, too.

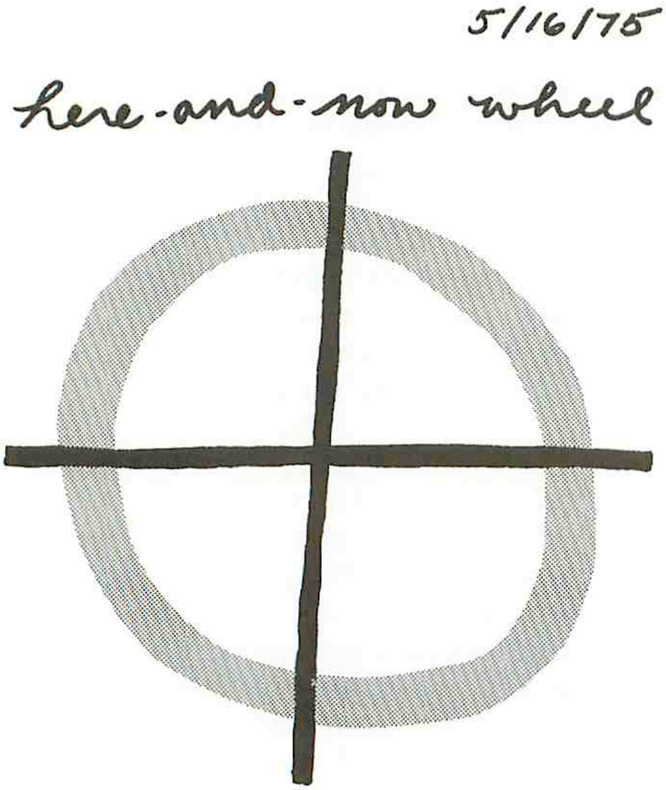
"I think it's very hard to figure out your role when you don't really know someone. You're dealing with human emotions. I was just turned off by Ms. Wright at the beginning because she seemed kind of removed from me and not that interested in what I was doing. I didn't want to get her jealous of me or make her feel uncomfortable. I was afraid she would think I was nosy. I realize now that she understood that I was just trying to learn something. In a way, it was all my misunderstanding. So it worked out really well."

Elise's misinterpretation of Ms. Wright's behavior might have been cleared up sooner if she had been able to voice her feelings to Ms. Wright. Part of her problem was that her feelings were very confused, and she was unsure of her role. It is helpful for any person entering a new situation to clarify his or her role and the roles of others. The Here-and-Now Wheel, described below, is a device by which a person can sort out confusing feelings.

For the first week or so at your fieldsite, it might be very helpful to do this simple here-and-now exercise daily, to help you think about feelings you might otherwise ignore or repress.

The Here-and-Now Wheel

After you have finished at your fieldsite for the day, take a moment to relax and clear your head. On a fresh page in your journal, draw a circle with four "spokes," like this:



Think about how you feel physically and emotionally "right now and right here," and write one word or a very short phrase above each spoke of the wheel, describing each separate feeling that you are experiencing. Reflect a moment on the feelings you've named, then pick one feeling that seems uppermost or most significant to you, and write a sentence or two about it.

After doing a here-and-now wheel you may have a better idea of what needs to be talked over. The clearer your feelings are to you, the easier it will be to discuss them before they become a barrier to your work and to your working relationships. After the first week, you may only want to do here-and-now wheels at the end of the week or when you feel the need to get in touch with yourself.

Parents and You

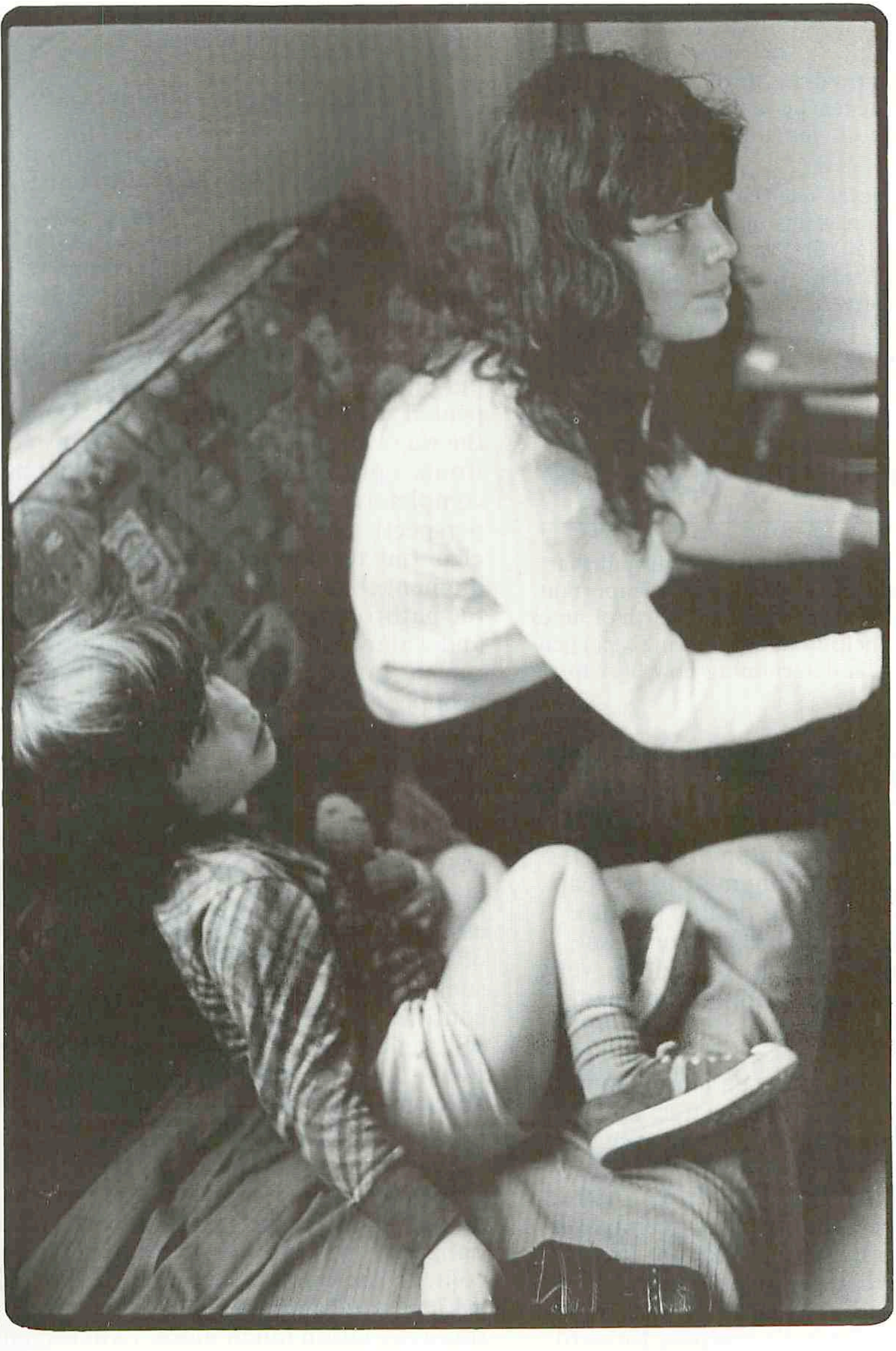
Some preschools require that parents be actively involved in their programs. They might ask parents to attend staff or special meetings to discuss their child's progress, or request parent volunteers to help out in the classroom now and then. You should be able to meet parents at such times, which is helpful in gaining another perspective on your special child. If no such occasion arises, however, you might want to take the initiative and set up a meeting with your child's parents. Your fieldsite teacher can help you arrange a visit at the preschool, or at the parents' home.

Elise was very encouraged by her meeting with Timmy's mother.

"Eventually Ms. Wright and Ruth pushed me into contacting Timmy's mother. That was a very, very difficult thing for me to do, because I didn't want to offend her. I didn't want to make her feel like I thought I was Miss God coming in to fix her child, because I didn't really have that kind of experience. I was trying to *learn* from Timmy as well as give to him.

"I finally realized that I should talk with her to make her feel that she was my resource, which she was. I was trying to learn from her about Timmy, and wanted to let her know just how very attached I was to Timmy. I would have done anything for him.

"After letting her know that I had that kind of interest and that I was sincere and wanted to help in any way I could, she was very open with me. She was *thrilled*, in fact, because no one had ever taken an interest in Timmy before. It was really great to have someone be that open with me. It was really great."



Rogier Gregoire

Timmy's mother was glad to have Elise take such an active interest in her son.

Issues to Consider

1. Elise was afraid to "intrude," on both her fieldsite teacher and Timmy's parents. Why do you think she felt this way?
2. Have you ever felt that you might be "stepping on someone's toes"? Have you ever felt that someone else was trying to "take over" responsibilities or prerogatives that you considered your own? How did you resolve such situations?

Working Out Problems

Using the one-to-one model, you will find that keeping a journal is particularly important. Re-reading several days' or weeks' worth of notes can be extremely helpful in pinpointing a particular problem, and in determining how best to respond to it.

This excerpt from Elise's journal describes working with Timmy on a specific problem, water play, and determining how to check his tantrums.

"Timmy spent the beginning of the morning playing with a molding mixture of soap flakes and water. It was a pliable mixture and he enjoyed scooping it from one container to another and back, a sequence very similar to his earlier procedures with water and cornmeal.

"Then a new problem arose. Timmy moved from the soapy dough to the water, and started spreading soapy water everywhere. I found that I had to restrain him from moving water over such a large distance. As I did so, Timmy's response to me seemed very different from other situations that I had encountered earlier—his eyes seemed more focused. (Maybe I'm getting through to him?) But I found myself jumping forward with a negative and almost violently defensive reaction, which scared me.

"It was a bad morning. Timmy was enthralled with the children in the preschool next door, and four times during the morning he ran out into the hall and went around touching all the children. The teachers seemed threatened by Timmy, though the kids didn't seem to mind him. I had to pull Timmy away and explain to him that this was not his classroom. He then ran out to the front door and opened it. 'Timmy must put on coat,' I said. 'Coat and boots,' I repeated. But I didn't quite follow through the way I should have. When Timmy confronts a problem, he sometimes must be completely removed in order to gain any perspective or understanding. We 'struggled' (my term for confrontations during a moment that is uncontrolled). He ran into the bathroom and began playing with soap and water. That was all right, but then he ran out into the hall with the soap and dropped it all over the floor. I had to explain that the soap was 'to stay' in the bathroom, because the other kids needed to use it.

"I have realized through my contact with Timmy the importance of 1) my consistency, 2) my immediacy, 3) my use of short, *simple* associating phrases, 4) my clear definition of what is acceptable, 5) my supply of reasons and alternatives, and most of all, 6) my confidence and special preparation of myself so that these goals will be accomplished. I have based my definition of what is acceptable on the simple "rights" of the people having contact with Timmy.

"During snack, Timmy had to ask for juice and cracker. He didn't get any until he verbalized. It was more difficult, but I have come to realize that Timmy is capable of asking, and I have decided to encourage this association much more. I am becoming aware of Timmy's 'testing' of me and also of his different types of crys. Whenever we struggle, his reactions follow a certain pattern. There is sudden grabbing and screaming, hair pulling, speech, and biting. This intensifies to a peak and then descends. At this point Timmy will try to run away. If I let him go, he will run and tip something over; or if he is past that stage he will murmur, cry softly, and go back to normal. Many times if I do follow through he will completely break down in tears, whine, murmur, isolate himself, and then return to normal."


Rogier Gregoire

After gathering specific information on your special child, it is much simpler to seek help. Once she had recognized Timmy's problems, Elise sought help and support in the following ways.

"I started with *The Magic Years*, which is really about healthy children. It describes the different problems that they go through —even if their parents follow the book word for word. Then I began to read Bettelheim (a psychiatrist who works with children) and different autobiographical writing by people with autistic children. Then I found magazine articles and read about behavior modification.

"I looked at the records, and had conferences with Ms. Wright. There were times when we'd talk on the phone about Timmy and the kids for about two hours, just talking about different incidents that happened. Or we'd talk about things that had been written about a certain type of child or about a specific case study.

"I only met with my project advisor for an hour and a half. We sat and had coffee. There were many times when I was very upset about things, and he would sit down and give me a punch one way or another, which was really good, because I needed it from someone. He also helped me with my reading list, and read my journal and commented on it."

Forming a Support Group

You can relate to your fellow students and course teacher in much the same way that Elise related to Ms. Wright and to her advisor. You may want to form a smaller "support group" of students who are all working one-to-one with a child with special needs. Together you can share problems and frustrations, and get feedback. You can brainstorm solutions for specific problems, or share solutions that have worked for you. The support group could also keep a bibliography of helpful books and articles as students come across them.

Using Your Journal

Your journal is a most important tool for keeping track of your progress and the child's. In it you should attempt to note:

1. The child's progress:
    - what methods worked for him/her;
    - what methods didn't work;
    - how his/her abilities, behavior, and/or self-image have changed.
2. Your own progress:
    - what you've learned about children;
    - what you've learned about your special child and about special needs in general;
    - what you've learned about yourself;

- how you feel about the experience;
- how you've changed.

Periodically making a list of things you have learned or need to learn might be an even more specific way to help keep track of progress. Regularly, perhaps once a week, you might make a list in your journal similar to the one shown here.

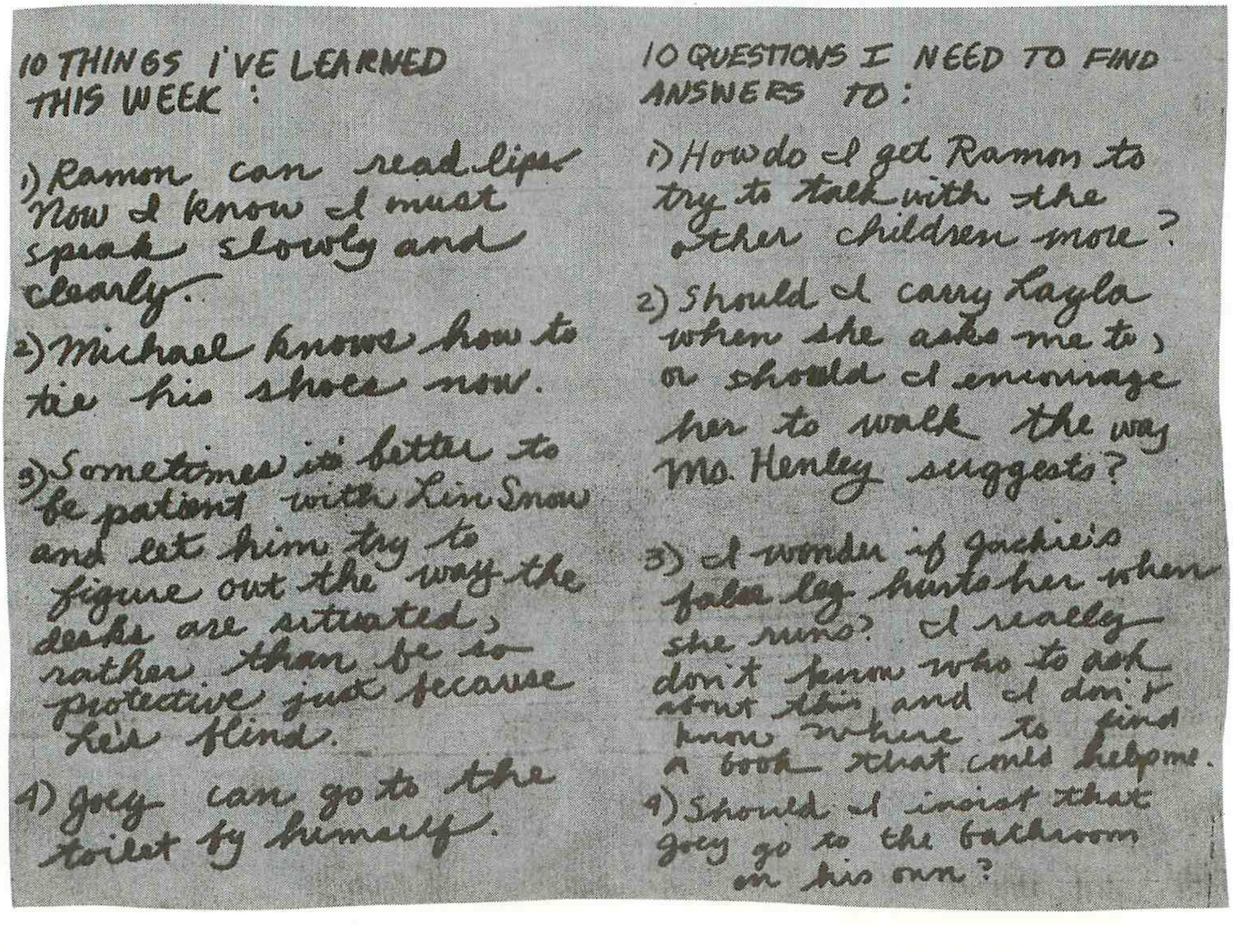
Try to make yourself list ten things in each list. Something that seems unimportant now may later prove to be the key to a basic problem. You should find your lists getting more specific and more useful as time goes on.

Some items will appear week after week: you may find that you are relearning the same things. Listing them again can help you to become conscious of what you are doing. Tough questions that remain unanswered for weeks may point to a need to seek help from the library, from the child's parents, or perhaps from a professional.

Elise wrote the following journal entry to evaluate Timmy's progress and her own.

"I didn't accomplish nearly what I thought I would accomplish with Timmy. My expectations of him are now very, very different than they were. But he has really accomplished a lot.

"At the beginning I spent time with all the kids. And then there was a time when I was strictly with Timmy. And then as Timmy



10 THINGS I'VE LEARNED THIS WEEK:

1) Ramon can read lips. Now I know I must speak slowly and clearly.

2) Michael knows how to tie his shoes now.

3) Sometimes it's better to be patient with Lin Snow and let him try to figure out the way the desks are situated, rather than be so protective just because he's blind.

4) Joey can go to the toilet by himself.

10 QUESTIONS I NEED TO FIND ANSWERS TO:

1) How do I get Ramon to try to talk with the other children more?

2) Should I carry Layla when she asks me to, or should I encourage her to walk the way Ms. Henley suggests?

3) I wonder if Jackie's false leg hurts her when she runs? I really don't know who to ask about this and I don't know where to find a book that could help me.

4) Should I insist that Joey go to the bathroom on his own?

became more and more involved with the kids, which is what we were trying to get him to do, there was less need for me to be actually 'on him' all the time. He'd get annoyed, finally, when I was on him all the time, because he didn't want me to follow him—he didn't want to be different. It got to the point where I'd be playing with the other kids, too, and if he got into a problem of some kind, I would be there to help him cope with it. I could play with him and play with all the kids, but it wouldn't be on such a one-to-one basis. I don't know, it really depends on what you want to learn, and on the whole school set-up. It worked out very well for me the way it was.

"Timmy now enjoys relating to the kids, and he really does get annoyed at me for singling him out. I knew that pulling him away really bothered him, so when he wasn't dealing properly with the kids, I'd just take him away to a room by himself. I'd say, 'Timmy play nicely, have to play nicely,' and he'd understand that in order to be let out he would have to behave. If he misbehaved again he'd just go right back into the room. In a way this was dangerous, because I didn't want him to start withdrawing again. But I really didn't have to do it very often, and it was very, very, very effective.

"In the beginning, if he wanted to do something or if something didn't go his way, Timmy would scream and pull things down, scratch, bite, pull hair. . . . There were times when he'd get so hysterical that I'd have to take him out of the room. He'd be screaming and ranting and raving, and I'd get welts on my body from where he was biting me—on my arms, and even on my breasts, which really scared me. The tantrums would last sometimes 15 minutes, sometimes 10, sometimes even 20 or 25. It depended. But there was a point when he would finally break down and start to cry; then you could leave him alone and after a while he'd come back and be perfectly all right. But, you know, it was a real problem.

"By the time I left the center he wasn't having tantrums like that. He was having very few, and they weren't so violent. We discovered that the tantrums didn't stem from selfishness. They seemed to happen if something wasn't working out right with someone else—if he was trying to relate to another kid who wasn't responding he'd get frustrated and go into a tantrum. We'd run over because he'd start touching and then hitting the kid, because he just wanted a response. That kind of thing was a healthy sign, because it showed his focus was changing. He was really thinking now of the other kids, which I thought was brilliant, of course, because I thought everything he did was brilliant.

"When I met Timmy I had this feeling that he was brilliant, that he was definitely going to become a very, very intelligent person. He'd come out of it, he'd be well adjusted, and he'd become a business man. I think part of it was that I never knew any autistic adolescents. That is a really hard thing to think about, and it makes me feel really sad—to think of Timmy not being small and cuddly and manageable. . . ."

Issues to Consider

Professionals who work with children with special needs often find it impossible to make a prognosis, or prediction, of how far a particular child will eventually progress. How might this uncertainty affect:

- the way you work with the child?
- how you measure the progress you make with the child?
- your feelings about ending the relationship when your fieldsite work is over?

Henry Felt

Building Skills and Self-Esteem

A Supportive Learning Environment

For any child, learning is easiest in an environment of trust and acceptance. A preschooler likes to know that the teacher is someone who understands private feelings, and who likes people for themselves. The child enjoys the reassurance of a daily greeting, a coat hook with his or her own name or photo, and a birthday cupcake.

A child's self-esteem, like yours, rests heavily on experiences of accomplishment and success. A child with special needs may come to school burdened with a backlog of discouraging or anxiety-causing experiences. Such a child may need much encouragement and support. Children who perceive themselves as having failed often in the past are likely to be reluctant to try new things, but knowing that they are valued for themselves can give them incentive to "try out their wings."

Any good preschool or kindergarten naturally provides enough flexibility and choice so that no child need think of him- or herself as a failure. For the child with special needs, you may need to adapt some learning activities to make them meaningful or effective. Your job is to *help* the child learn to use his or her resources with confidence, and to compensate for the abilities he or she may not have.

Alternative Learning Modes

> This exercise should start you thinking about alternative learning modes—ways of adapting learning activities. Suppose

your fieldsite teacher came to you and said:

1. "Tanya (a deaf child) always looks lonely and left out when the rest of the class does music. How can we include her in our music time?"
2. "What kinds of outdoor activities might be fun for Ted (a child with impaired coordination due to cerebral palsy) now that the weather is getting nicer?"
3. "Barney (a hyperactive child) has never really listened to a story with us. I would like you to work on helping Barney with books and storytime."
4. "Would you think about designing some simple art projects to do with Lavinia (a blind child)? I think she might enjoy getting her hands into some of our art materials."

Which one of the fieldsite teacher's requests appeals most to you? seems most difficult?

Choose one or two of the tasks, and describe what you would actually do with the child in class.

Adapting the Approach

In the *Doing Things* booklet is a movement and dance activity, which is reproduced below. Read through the description, keeping in mind the following questions:

- What would this activity be like with a group of children that included a child in a wheelchair? a blind child? a deaf child? a hyperactive child? a child with multiple sclerosis?
- How could you change this activity to make it more rewarding for a child with any of these special needs?

Try adapting other activities from the *Doing Things* booklet to include a child with a special need.

Just putting on a record or playing a simple rhythm on an instrument can transform rainy-day wriggles and squirms into a welcome outburst of free-form dancing. (How about a sun dance?) Be sure that you have plenty of space and won't be disturbing others by being noisy. Start simply and slowly, keeping in touch with what kind of dancing the children want to do. Let them take turns thinking up variations.

To widen the children's vocabulary of movements, and to draw them into moving freely and expressively, you might try some of the following ideas:

- Make drastic changes in the rhythm and tempo while the children dance. This will help them concentrate on listening to the sound and dancing with it.
- Start with simple warm-up exercises, like touching toes or hopping in time to the music.
- Call out different parts of the body and have the children move just that. Chin dancing is a riot!
- Add props: balloons, scarves (try big ones, or a sheet), mirrors, costumes.
- Do pantomime dancing: lumber like an elephant or weave like a snake; pretend to be a bouncing ball, a tree in the wind, someone picking up spilled pins, or someone carrying heavy packages.

If dancing ends too abruptly, the children's energy is left scattered, jagged, and raw. It's best to wind down gradually—from kangaroo steps to snail steps, from a bouncing ball to a floating feather.

Self-Care Skills

Self-care skills are particularly important to a child's sense of self-esteem. To a preschooler, being able to zip your own jacket and tie your own shoes seems concrete evidence of whether you are "still a baby" or are "really big enough to take care of yourself."

Children with special needs may need extra help and practice with mastering the skills involved in dressing (manipulating zippers, buttons, ties, snaps, etc.); washing (dealing with face cloth, soap, toothbrush, etc.); or eating (handling eating utensils, avoiding spills, even chewing and swallowing may be a problem for some children). You should deal with these problems as a matter of course, without making the child feel backward or immature.

Rogier Gregoire

Toilet-training problems can be especially sensitive matters, not only in terms of the child's self-esteem: In some cases (as in Elise's, p. 58) wetting may be caused by a physical disability completely beyond the control of the child. In other cases wetting may mark a temporary setback or regression to immature behavior caused by stress; this is not uncommon and is not necessarily serious (see Charlie's story, p. 56). Wetting can also be part of a pattern of symptoms in an emotionally disturbed child. In order to deal appropriately with toilet-training problems, it is necessary to understand the reasons in each particular case.

Rogier Gregoire

Skill-Building Strategy

Outlined here is a general approach to working with children with special needs.* Based on a "prescriptive teaching" model, this approach can be used successfully with any preschool child, especially for teaching self-care skills. It is called "prescriptive teaching" because it is very focused and individualized—"tailor-made" to the particular child's needs.

1. *Set realistic goals for the child, based on what you know about the child's present abilities.*

For instance, if a child comes to school with a vocabulary of ten or twelve words, you will first want to work toward short phrases and then toward complete sentences. This can be done by structuring situations that help the child to link together two familiar words, then longer phrases, one step at a time. When a child's speech development is slow, one meaningful word is far more effective than an incomprehensible sentence. (Think back to the simple language used to talk with Sara Sibley at lunchtime.)

2. *Reward the child's learning behavior. Never shame a child or express dissatisfaction with a child's progress.*

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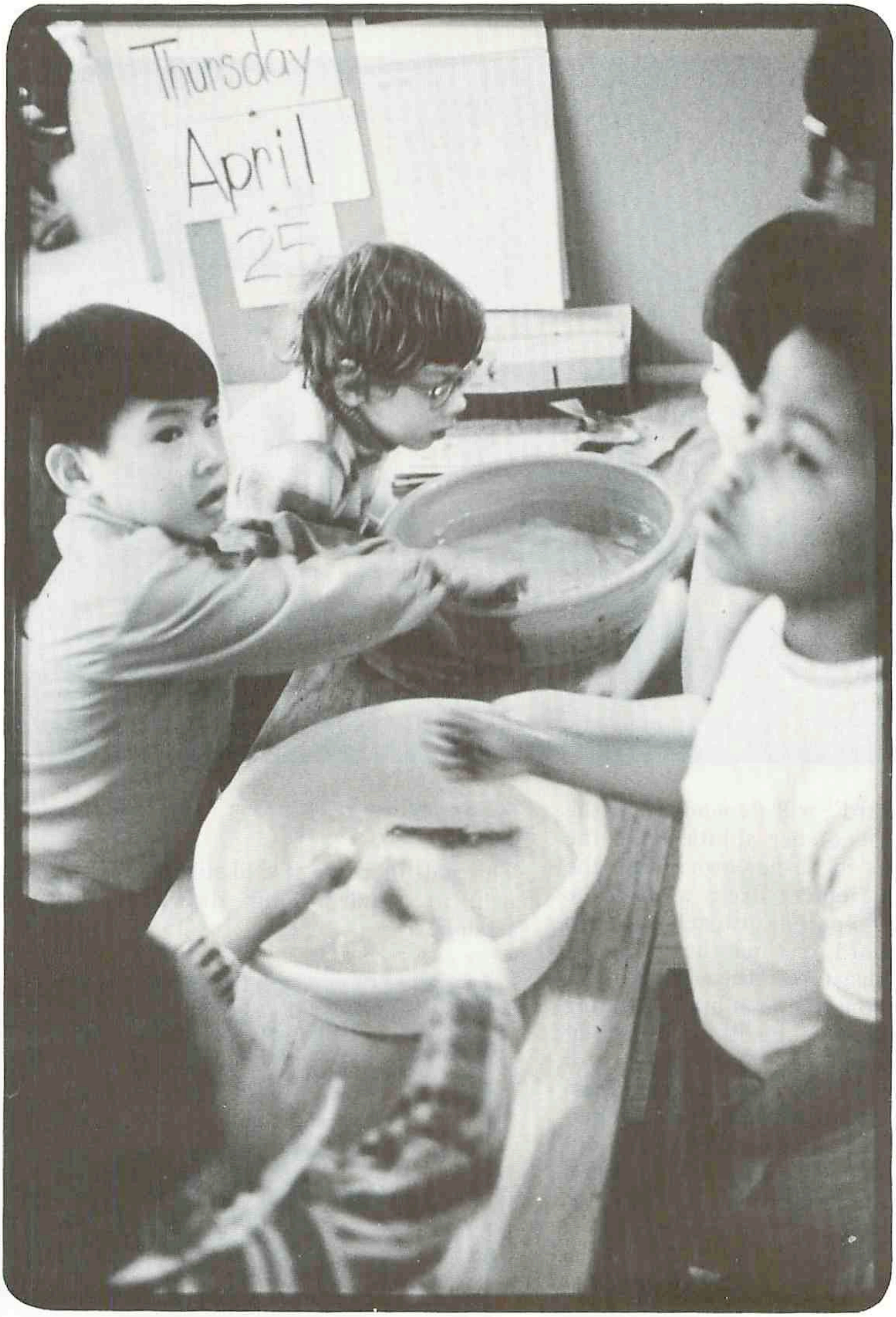
*Adapted from Lorna Wing, *Autistic Children*. New York: Brunner/Mazel, Inc. 1972.



Rogier Gregoire

Bowls of soapy water within easy reach make hand washing easier for the child with poor muscle control.

Henry Felt

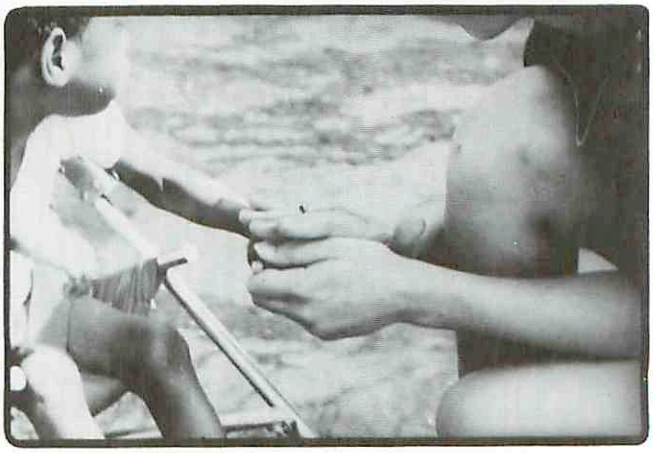
An appropriate "reward" will depend upon the individual child and his or her abilities. For the child who badly wants to tie her own shoes, the reward is in the achievement itself, and in the praise and approval of a parent or teacher. When the task is especially hard, or when the child cannot take immediate pleasure in the results of his or her work, a more concrete or morale-boosting reward may be in order—a hug, the privilege of doing something special, or a second glass of juice. A morale-boosting reward is often necessary to encourage the retarded child or the child who is very unhappy with him- or herself. In both cases, the child may at first be unable to perceive or understand the benefits of his or her achievement.

3. *Pay attention to things, situations, or activities that please the child and bolster the child's sense of self-esteem. Use these things as tools in the learning process.*

Recall examples of this approach from the case studies.

4. *Break down any new task into the smallest possible parts.*

This will increase the likelihood of success and help to avoid a long, drawn-out, frustrating session.



Henry Felt

Touching is another way of letting the child know how you feel about things.

Ned's mother found that this was the only way to teach her dyslexic son to dress himself: "I knew that when he couldn't dress himself, it was no use at all to say, 'Well, you put on a shirt this way. Do it yourself.' First I had to figure out what on earth you do when you put on a shirt, which is much more complicated than it sounds. Then I had to break down the task into small parts: (a) this is how you lay it out on the bed, (b) then you pick up this end, (c) then you put it here, and so forth. I found I had to analyze the process and go through each step on my own, before I could 'translate' it for Ned."

Henry Felt

Children with special needs may need extra practice at self-care skills.

5. *Don't wait for the child to initiate a new learning task.*

The child may need a bit of "drawing out" at first, to overcome fears or shyness, and to realize that there is something pleasurable to be gained from trying a new activity.

6. *Link new learning to old.*

Work from familiar skills to new ones through small, graded steps.

7. *Adapt your teaching approach to draw on the child's particular strengths and to work around the child's disability.*

You may find it helpful in restructuring the approach to imagine that you, too, have the disability.

Rogier Gregoire

A child may need "drawing out" at first.

Specific Training Approaches

You may find the specific training approaches suggested below helpful in meeting the particular needs of blind, deaf, and physically impaired children.

Deaf or hearing-impaired child. Communicate with the child through gestures as well as words. Puppets can make a story come to life for the child with impaired hearing.

Come close to the child when you speak to him/her; try to get on the same eye level.

Rogier Gregoire

Rogier Gregoire

Stimulate the child's awareness of everyday sounds through the vibrations they make—e.g., vacuum cleaners, telephones, radios.

Rogier Gregoire

Learn about the care and use of the child's hearing aid, if appropriate.

Rogier Gregoire

Blind or visually impaired child. Guide the child by words and touch. Let the child know how you feel about things through speech and touch, since he/she cannot see your expressions.

Give the child as many experiences with real, functioning objects as possible. Describing the way something looks has no meaning for the child who cannot see.

Select toys for their interesting textures and/or sounds. Musical toys, toys that encourage movement, and "feel books" are usually popular.

Child with motor or coordination disability. Scale down equipment for easy access. Put equipment and activities on the floor, when necessary.

Install ramps or handrails where needed.

Strapping a child's feet to a tricycle with large rubber bands can sometimes help to steady coordination.

Magic markers and large painting brushes can be substituted for smaller crayons and brushes if a child has special difficulty with fine motor skills.

Can you draw up similar lists for other kinds of special needs? For the particular special needs at your fieldsite? What do they include?

Rogier Gregoire

Hands on hands guide weakened muscles through a fingerpainting session.

F. Siteman

Additional Help and Information

It would be impossible to include in one short booklet every scrap of information concerning children with special needs. Instead, we are providing a listing of books, films, and resource agencies that covers every major category of special needs for the entire country.

You may use this list with the assistance of your course and fieldsite teachers. Others who can help you to track down useful information are your local librarian, your family doctor, and professional consultants to your fieldsite program (social worker, psychologist, pediatrician).

But don't stop with reading and film-viewing. There are many other ways to learn about resources in your community for the child with special needs. For instance, you might consider inviting a speech therapist or other specially trained person to be a guest lecturer in your class. Or you might find out whether there are any parent support groups in your area for children with special needs, and invite their members to visit your class. If there is a school for special children near you, you could try to schedule observations for the members of your class.

In addition, every community has something of its own to offer in the way of special resources and information. One town may have a special transportation service for its "handicapped" citizens, while another may support sheltered workshops, or free diagnostic clinics. In one urban area, a children's museum runs a weekly program exclusively for school children with special needs.

While your own community may not be large enough to boast its own children's museum or diagnostic clinic, it undoubtedly has at least one agency, school, or resource person worth getting to know. Make it your business to dig out these resources and use them!

Further Readings

The following is a list of especially readable and interesting books compiled by the writers of this booklet. They do not cover the whole range of special needs; in fact, many of them are quite personal and make no claim to professional knowledge or expertise. Still, reading them can deepen your understanding of what it means to live your life with special needs. Your teacher can give you a more comprehensive list of reading materials.

Personal Accounts

Brown, Christy. DOWN ALL THE DAYS. Fawcett World (PB).* A young man who grew up with cerebral palsy tells the story of his early years.

Clarke, Louise. CAN'T READ, CAN'T WRITE, CAN'T TALK TOO GOOD, EITHER. Walker & Co. The mother of a child with a serious learning disability leaves no stone unturned in her efforts to diagnose her son's problem and to find the right sort of school for him.

Craig, Eleanor. P.S., YOU'RE NOT LISTENING. New American Library (PB). A teacher assigned to a "special education" classroom finds that each of the five children in the class is a full-time responsibility.

Greenberg, Joanne. I NEVER PROMISED YOU A ROSE GARDEN. New American Library (PB). A young girl who becomes schizophrenic is helped by a therapist whom she slowly learns to trust.

Greenfeld, Josh. A CHILD CALLED NOAH. Paperback Library (PB). The father of an autistic child chronicles his family's struggle to find the proper care for their son.

Hunt, Nigel. THE WORLD OF NIGEL HUNT: THE DIARY OF A MONGOLOID YOUTH. Garrett-Helix. A seventeen-year-old boy with Down's Syndrome describes his impressions of the world in lively, charming language.

Keller, Helen. THE STORY OF MY LIFE. Airmont (PB). Deaf and blind from a childhood illness at the age of two, this famous crusader for the education of children with special needs reminisces about her life.

Killilea, Marie. KAREN. Dell (PB). A woman describes her experiences with her child, who has cerebral palsy.

Park, Clara. THE SIEGE: THE FIRST EIGHT YEARS OF AN AUTISTIC CHILD. Little, Brown (PB). This narrative describes the impact on a family when it must accommodate a seriously disturbed child.

Books by Teachers, Doctors, and Psychologists

Axline, Virginia. DIBS IN SEARCH OF SELF. Ballantine (PB). A psychologist describes how she helped a withdrawn little boy to emerge from isolation and "come back" into the world.

Bettelheim, Bruno. THE EMPTY FORTRESS: INFANTILE AUTISM AND THE BIRTH OF SELF. Free Press (PB). A doctor famous for his work with autistic children explains his own theory of autism, based on years of experience.

Bettelheim, Bruno. LOVE IS NOT ENOUGH. Free Press. A book describing the author's special school for emotionally disturbed children.

Fraiberg, Selma. THE MAGIC YEARS. Scribner (PB). Wonderful for lay people, this book explains the emotional needs of young children in non-technical language. It has become a "bible" for many parents and teachers, much like Dr. Spock's books.

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*Books marked "PB" are available in paperback editions.

Hart, Jane, and Jones, Beverly. WHERE'S HANNA? Hart. This is a handbook of resources and suggestions for working with children with learning disabilities.

Orem, R. C., ed. MONTESSORI AND THE SPECIAL CHILD. Putnam (PB). This book includes adaptations of Montessori's techniques for use with different types of special needs.

Redl, Fritz, and Wineman, David. CHILDREN WHO HATE: THE DISORGANIZATION AND BREAKDOWN OF BEHAVIOR CONTROLS. Free Press (PB). A look at children who cannot control their rage, and an explanation of the causes of such behavior.

Webb, L. CHILDREN WITH SPECIAL NEEDS IN THE INFANTS SCHOOL. Fontana (PB). The author has put together an anthology of case studies describing how the staff of one primary school was able to integrate a great variety of children into its program—by paying careful attention to each child's needs and by individualizing its program to a remarkable degree. Excellent anecdotal material.

Wing, Lorna. AUTISTIC CHILDREN. Brunner-Mazel. A British doctor describes her own view of autism and how it can be treated, with special attention to what parents and nonprofessionals can do.

Books to Read to Children

Andersen, Hans C. THE UGLY DUCKLING. Scribner (PB). This fairy tale shows how being different can handicap a person in an unfriendly environment. The parallels between special-needs issues and issues of discrimination are drawn very clearly here.

Craik, Dinah. THE LITTLE LAME PRINCE. Grosset & Dunlap. A touching, old-fashioned fairy tale about a crippled child.

Kraus, Robert. LEO THE LATE BLOOMER. E. P. Dutton Windmill Books (PB). A young tiger takes his time learning to read, much to his parents' dismay.

Lasker, Joe. HE'S MY BROTHER. Whitman, Albert. A young boy watches out for his retarded brother.

Piper, Watty. THE LITTLE ENGINE THAT COULD. Platt & Munk (PB). A plain little engine succeeds where big shiny ones have failed.

White, E. B. STUART LITTLE. Dell (PB). A child with the exact size and appearance of a mouse is born to human parents. The story of how his family accepts him and makes special provisions for his size is delightful.

Zolotow, Charlotte. WILLIAM'S DOLL. Harper & Row. William's special need is to have a doll of his own, even though his parents think it inappropriate.

Glossary of Medical Terms

The words contained in this glossary are some of the ones that may come up in any specialized reading you undertake for work with special children. A dictionary is also a good consulting source. Your science teacher can give you a more detailed description of any medical aspect that you find confusing.

A

aberration A change from the normal.

acute When referring to a disease it means one having a short course; not chronic.

allergy A sensitivity to one or more specific substances that might cause hives, rash, or cold-like symptoms. Hay fever is one example of allergic diseases.

amniocentesis A type of prenatal genetic test in which a small amount of fluid is drawn out of the placenta by inserting a needle through the mother's abdominal wall. The contents of the fluid are then analyzed for possible abnormalities.

anemia Deficiency in the oxygen-carrying material of the blood brought about by a decrease in the number or volume of red blood cells or in the hemoglobin of the blood. In mild anemia, the individual is pale and lacks energy. More severe cases cause shortness of breath on exercise, palpitation, severe headaches, loss of appetite, and dizziness.

anomaly Any change from the normal, such as in location or shape.

antihistamine A drug used in various allergic conditions, such as hay fever, serum sickness, etc.

aphasia Inability to speak due to brain damage. The voice box and other organs of speech may be uninjured.

astigmatism	Inability to focus the eye properly because of problems in one of the surfaces of the eye.
atrophy	Reduction in size; wasting.
autism	A disorder that manifests itself as early as the first few months of life, usually through the infant's failure to develop any attachment to the mother or to demonstrate awareness of human contact. Associated characteristics include preoccupation with inanimate objects; absent or delayed speech; resistance to change, in which the child responds with violent outbursts of temper; severe problems with sleeping and eating; and strange, stereotyped motor patterns.

B

behavior modification	A technique that aims toward helping to modify inappropriate behavior. It has been effectively used to help the mentally retarded, emotionally ill, and learning-disabled.
behaviorism	A theory that attempts to explain human emotional reactions. It holds that objectively observable organismic behavior constitutes the essential or exclusive scientific basis of psychological data and investigation. It stresses the importance of the environment in shaping human and animal behavior.
blindness	Partial or complete lack or loss of sight. May result from injury or from certain diseases, including cataracts and glaucoma. Can also be a birth defect. Impaired vision means that a person can distinguish shapes, but not details. The definition of blindness for legal purposes (such as driving) may vary from state to state.
blood count	The number of red cells and white cells in a standard volume of blood. Normally there are about 4.2 to 5.5 million red cells and 5 to 10 thousand white cells per cubic millimeter.

blood type	Hereditary factors in the blood, e.g., A, B, AB, or O. It is important to determine the blood types of both donor and patient before a blood transfusion, as certain combinations cause clumping of the blood cells. When blood is typed it is also tested for the Rh factor, another hereditary factor important in blood transfusion.
Braille System	Method of printing words by using raised dots which the blind can "read" by touching with the finger tips.
brain waves	Electric impulses given off by the brain. Various patterns are associated with conditions that are not normal.

C

cardiogram	The curve traced by a cardiograph, an instrument used to record the mechanical movements of the heart. Used in the diagnosis of heart defects.
catatonic	Relating to a behavior disturbance characterized by catalepsy (q.v.), and found most commonly in schizophrenia.
cerebral palsy	Not a disease, but a variety of possible disabilities resulting from damage to the brain motor tissue before or during birth. Outward manifestations include muscular incoordination and speech disturbances.
chorea	A nervous disease in which there are involuntary jerking movements of the body.
cleft palate	Congenital groove in the roof of the mouth due to failure of the palate bones to unite. Harelip is often present in persons with cleft palate.

clonus Spasm; muscles alternately tense and relax.

clubfoot Talipes; a congenitally deformed foot. The bones are twisted, causing the person to walk abnormally.

congenital Existing as such at birth but not hereditary; resulting from or developing during one's prenatal environment. A *congenital defect.*

convulsion A violent, involuntary muscular contraction (seizure), sometimes occurring with rapid onset of fever in a childhood illness; also characteristic of epilepsy and other disorders involving the brain.

D

deafness Partial or complete lack or loss of hearing. Causes include infections, especially in the head; diseases, e.g., scarlet fever, syphilis; obstructions of the auditory canal; and bone formation in the ear labyrinth capsule. Total deafness is generally very rare. Electrical aids are commonly employed for those with partial deafness (impaired hearing).

debility Weakness.

diabetes mellitus A chronic disease of the pancreas, characterized by insulin deficiency; subsequent inability to utilize carbohydrates; excess sugar in the blood and urine; excessive thirst, hunger, and urination; weakness; emaciation; imperfect combustion of fats resulting in acidosis (high acidity of the blood); and, without injection of insulin, eventual coma and death.

diabetic A person who is afflicted with the disease diabetes, which causes excessive thirst and an intense desire for sweets.

diagnose To recognize a disease.

Dilantin A proprietary medicine used to prevent epileptic seizures.

diplegia Paralysis of like parts on both sides of the body.

dominant trait The stronger of two competitive hereditary traits.

Down's Syndrome A congenital condition characterized by mental deficiency (mental age usually never exceeds eight years); and physical traits such as slanting, widely spaced eyes, flattened nose, small ears, broad hands (often with a single crease across them), and short stature. The condition is caused by an unknown "influence" on the embryo.

dysgraphia A learning disability associated with dyslexia, in which an individual's handwriting is "scrambled" with misspellings, reversed letters (b=d), etc.

dyslexia A learning disorder that shows up in almost 10% of all school children. It is seen mostly in boys of average to above-average intelligence. It is characterized by impairment of the ability to deal with letters and words as symbols, and is frequently associated with confusion of left or right handedness (mixed brain dominance), low self-esteem, and a sense of futility and hopelessness.

dystrophy, progressive muscular See muscular dystrophy.

E

echolalia A speech defect characterized by involuntary and senseless repetition by a person of a word or sentence spoken in his or her presence.

electrocardiogram	Graph of the electric current produced by the heart when contracting.
electroencephalograph	Instrument for recording brain waves.
encephalogram	X-ray of the brain.
enuresis	Inability to control urination, especially at night; bedwetting.
epilepsy	Nervous disease in which there are convulsive seizures. It can be kept under control with medication (usually Dilantin).

F

farsightedness	Hyperopia; an inability to see things close to the eyes, so that vision is better for distant than near objects.

G

genetic counseling	A type of family-planning counseling in which prospective parents receive advice related to the possibility or probability of birth defects in their children because of poor genetic combinations.
grand mal	An epileptic attack in which the patient loses consciousness.

H

harelip	A cleft in the upper lip due to a failure of the bones to unite.
hearing aid	An instrument to amplify sounds for the hard of hearing.
hemiplegia	Paralysis of one side of the body.
hemophilia	A hereditary condition in which the blood cannot coagulate, resulting in severe bleeding from any wound. The condition affects only males, but is passed from mother to son.
hereditary	Inherited; passed from parents to offspring.
heredity	The characteristics transmitted from parent to offspring and determined by the genes and chromosomes of the cells.
hives	Urticaria; itchy swellings that suddenly appear on the skin. They usually are not accompanied by any other symptoms, and disappear in a day or two. They are caused by an allergic reaction.
hydrocephaly	A usually congenital condition in which the head and forehead are enlarged because of an abnormal increase in the fluids in the brain.
hydrotherapy	Treatment of disease with water by means of wet packs or baths.
hyperkinesis	Characterized by hyperactivity, aggressiveness, poor performance in school and defined by the complaints of the parent or teacher, not the child. It can be seen alone or as part of a related disorder such as dyslexia, and is more common in boys than in girls.

I

idiopathic	Of unknown origin.
impairment	Diminished strength, value, quantity or quality; injury or damage. A child may be visually impaired, hearing impaired, physically impaired, etc., to a minimal, moderate, or profound degree.
incipient	Just beginning.
incontinence	Inability to control urination or bowel movements.
incubator	A container in which the temperature and atmosphere are controlled; used for premature babies.
infantile paralysis	See poliomyelitis.
inoperable	Not able to be cured by operation.
insulin	Hormone produced in the pancreas and used by the tissues to get energy from blood sugar. This substance can be obtained from animals to be used in treating human diabetics.
insulin shock	Loss of consciousness caused by an overdose of insulin.

K

Kenny Method	Treatment of muscles affected by poliomyelitis. It is based on the use of hot packs to prevent muscle spasms, and exercises to "reeducate" the muscles.

L

lesion	A circumscribed pathological alteration of tissue; any wound, sore, tumor, or area of tissue breakdown.
lip reading	The technique of understanding another person's speech by watching the movements of his or her lips. The method is used by individuals with impaired hearing, in conjunction with sign language.

M

malignant	Harmful; the opposite of benign.
mental retardation	Below-average general intellectual functioning.
mongolism	See Down's Syndrome.
multiple sclerosis	A diseased condition associated with partial or complete paralysis and jerking muscle tremor.
myopia	See nearsightedness.
muscular dystrophy	A progressive disease in which skeletal muscles grow increasingly weak, resulting in disability and deformity. The disease is three times more common in boys than in girls. It is different from cerebral palsy in that no brain damage is involved, and muscles do not go into spasm.

N

nearsightedness Myopia; visual defect in which distant objects appear blurred, so that vision is better for objects that are close than those that are far away.

nervous system The entire apparatus of the body concerned with carrying impulses throughout the body.

O

occupational therapy The teaching of some useful trade or craft to sick or "handicapped" persons, to give them a useful and money-making occupation.

oculist A physician who specializes in treating eye diseases.

olfactory Pertaining to the sense of smell.

ophthalmology The branch of medicine dealing with the eye, its defects and diseases.

optician One trained to grind lenses or glasses from a prescription.

optometrist One trained in examining eyes for the purpose of prescribing glasses.

orthopedics The branch of surgery concerned with correcting deformities and treating diseases of the bones, joints, muscles, and spine.

osteoclasia	Surgical breaking of a bone to correct a deformity.
osteopathy	A system of treating disease mainly by massage and manipulation of the bones.
otorhinolaryngology	Branch of medicine dealing with the ear, nose, and throat.

P

palsy	Paralysis.
paralysis	Loss of sensation or movement in a part.
paraplegia	Paralysis of the legs and lower part of the body.
paresis	A slight paralysis.
pathological	Diseased.
pathology	1. The branch of medicine that deals with the changes in the body produced by disease. 2. Effects produced by a disease.
pediatrics	The branch of medicine that deals with the development and diseases of children.
pernicious	Tending to cause death.

personality	The characteristics and behavior that are seen in an individual.
petit mal	A mild epileptic attack.
pharmaceutical	A medicine.
phobia	Any abnormal and persistent fear.
physician	One who is licensed to practice medicine.
pituitary gland	A small, bean-shaped gland lying at the base of the brain. It has many functions, including growth and sexual development.
plastic surgery	Surgery to restore lost parts or repair defects, often by grafting tissue from another part.
play therapy	A type of psychological therapy used with emotionally or behaviorally disturbed children in which the child is allowed free play while the therapist observes and interacts verbally with the child.
poliomyelitis (polio)	An infectious viral disease occurring mainly in children. In its acute forms it attacks the central nervous system and produces paralysis, muscular atrophy, and often deformity. Also called infantile paralysis.
prematurity	Birth occurring less than 37 weeks after conception, and in which the infant weighs less than 5 lb. 8 oz. Prematurity may be caused by a number of factors, including smoking, malnutrition, or disease in the mother. The condition carries the risk of respiratory complications, blindness, and brain damage in the infant.
prescription	Written directions for preparing a medicine.

prognosis	Prediction of the probable results of a disease.
prosthetic device	An artificial substitute for a missing part, such as a hand, leg, or eye. It may be used to improve the appearance or it may be functional as well.
psychiatry	The branch of medicine that deals with mental disorders.
psychoanalysis	A technique used for treating various mental disorders.
psychology	The branch of science that deals with the mind and behavior.
psychomotor	Pertaining to voluntary movement.
psychosis	A disorder of the mind; insanity.
psychosomatic	Pertaining to both the mind and the body, such as diseases that are traced to emotional causes.

R

recessive characteristic	The weaker of two competitive hereditary traits.
reflex	Automatic reaction; action done unconsciously in response to a stimulus.
refractory	Not being cured by treatment.
regeneration	Repair of injured tissue.

regressive In psychology it refers to a return to a more childish state that had been more satisfying to the individual but is no longer in keeping with the age or social status.

rehabilitation Restoring a "handicapped" person to useful activity.

remedial Acting as a remedy.

remission A lessening of symptoms.

restraint Controlling the actions of mental patients by means of force.

Ritalin A stimulant drug (amphetamine) sometimes given to hyperactive children. Some experts feel that the drug has a reverse, "calming" effect in children. Its mechanism and long-range effects are not known, however, and some doctors disapprove of administering it to children.

rudimentary Undeveloped.

S

sclerosis Hardening of connective tissue, particularly the thickening of the walls of blood vessels.

sedation Act of calming the nerves by use of a drug.

seizure A sudden spasm or fit; convulsion.

sensitized	Made more sensitive or susceptible to a particular substance; allergic.
sickle cell disease	A type of anemia involving hemoglobin production, occurring almost exclusively in black children. The disease causes painful crises involving swelling, convulsions, and sometimes even coma. Children suffering from sickle cell disease may need to be hospitalized periodically for blood transfusions. Three-quarters of the offspring of parents with sickle cell disease will also have this disorder.
sign language	A language made up of hand symbols, used by deaf and deaf-blind persons. (For the deaf-blind, symbols are made by placing the hand on the person's body, so that the symbols can be "felt.") In sign language, many words are represented by a single symbol, so that it is possible for a person to learn to speak very fluently using signs.
spasm	A sudden, violent, involuntary contraction, usually of muscles.
spastic	Convulsive or resembling a spasm. spastic hemiplegia. Partial paralysis of one side in which spasms are induced by movement of the affected muscles. spastic paraplegia. Paralysis of the lower legs with muscle spasms when the affected parts are moved.
stereotypic movements	Repeated rocking, swaying, tapping, or stroking movements that can be observed in autistic children, and occasionally in retarded or brain-damaged children as well. It is thought by some that these movements are deliberately "used" to "block out" the external world, and to provide an internal supply of sensory stimulation.
stimulus	Anything that arouses action in a body organ, such as muscle contraction, gland secretion, or nerve impulse.
symptom	Any change from the normal that indicates disease.

syndrome	A group of symptoms that occur together and seem to have the same cause.
systemic	Affecting the entire body.

T

tensor	A muscle that makes a part firm or tense.
Thalidomide	A tranquilizer commonly prescribed in the 1950s and 1960s, which resulted in birth deformities in children of mothers who took the drug during pregnancy.
therapy	The treatment of illness or disability.
tone	Normal strength and tension of the body or of muscles.
tonic	A medicine that helps restore normal tone.
topical	Local; in a definite area.
torpor	Numbness; apathy.
trauma	In pathology, a wound, especially one produced by sudden physical injury. In psychiatry, an emotional shock that creates substantial and lasting damage to the psychological development of the individual, sometimes leading to neurosis.
tremor	An involuntary quiver.

U

ulcer An open sore other than a wound that can also be internal.

urology The branch of medicine dealing with the diseases of the male urogenital system and the female urinary system.

John Running

Community Resources

This list includes some of the many resources day care programs have discovered in their communities. Valuable resources often go unused simply because people don't think of calling on them. Find out who's doing what in your community and establish working contacts wherever possible. You'll benefit all the children in your program, not just the ones with special needs.

Special Clinics and Clinicians

Pediatric Clinics, Public Health Clinics, Maternal and Child Health Clinics, Child Development Clinics, Well-Baby Clinics, Neighborhood Health Clinics, Pediatricians, Physicians, Public Health Nurses Can:

- *identify, evaluate, and diagnose general health conditions of children—physical, muscular, heart-related, neurologically-related, etc.*
- *identify emotional and learning problems in children*
- *refer a child with a special problem to a specialist in that area*
- *provide instruction and counseling for parents*
- *consult with your staff on health problems of particular children or*

activities to promote general health of all children
- *serve as a referral source to your program*

Mental Health Centers, Child Guidance Clinics Can:

- *identify, evaluate and diagnose emotional problems in children*
- *identify, evaluate and diagnose learning problems in children*
- *offer therapy and medication, if necessary*

Community Action Agencies, Social Service Agencies, Community Welfare Councils, Welfare Offices, Neighborhood Centers Can:

- *identify and evaluate children with special problems or refer them to diagnostic clinics*
- *refer children and families to proper specialists*
- *offer financial assistance to families or refer them to other sources of financial assistance*
- *provide funds for day care programs*
- *offer family counseling services*
- *offer recreational programs for children*
- *serve as a referral source for your program*

Rehabilitation Centers Can:

- *identify, evaluate and diagnose physical and motor problems in children*
- *provide physical therapy—exercises and activities to restore gross motor functions and develop necessary muscles for sitting, creeping, walking, etc.*
- *provide occupational therapy—exercises to develop fine-motor coordination and muscular development for activities such as feeding, dressing, writing, cutting, pasting, etc.*
- *help fit children for braces, prosthetic devices, crutches, wheelchairs*
- *provide instruction and counseling for parents*
- *consult with your staff on problems of particular children or activities to exercise physical and motor development of all children*
- *refer children from the clinic to your program, if appropriate*

Speech and Hearing Clinics Can:

- *assess a child's hearing*
- *prescribe hearing aids, if necessary*
- *identify, evaluate and diagnose speech problems*
- *offer speech therapy and speech correction*
- *offer language evaluation and diagnose problems*
- *provide instruction and counseling for parents*
- *consult with your staff on problems of particular children or activities to exercise speech and hearing development for all children*
- *refer children from the clinic to your day care program, if appropriate*

Vision Clinics, Offices of Optometrists and Ophthalmologists Can:

- *assess a child's vision*
- *diagnose visual learning problems*
- *prescribe eyeglasses or corrective devices, if necessary*
- *provide instruction and counseling for parents*
- *consult with your staff on vision problems of particular children or activities to exercise the visual development of all children*
- *serve as a referral source to your program*

4-C Councils

The 4-C (Community Coordinated Child Care) Councils encourage communities to take a comprehensive, coordinated approach to day care and preschool services. These councils, composed of interested day care and preschool operations, gather information about the community's child care needs and the resources and funds available. Administered by the Office of Child Development, 4-C is organized at the local, State, regional and Federal levels. To find out where your nearest 4-C Council is located, contact the Office of Child Development, Box 1182, Washington, D.C. 20013, or the Office of Child Development at your nearest Federal Regional Office.

Universities and Colleges

Special Education Departments Can:

- *place special education students in day care programs to practice teaching*
- *help identify and evaluate children with special problems*
- *consult with and/or train your staff to work with special children*
- *inform you about conferences and training institutes related to special children*
- *refer your staff to other programs and agencies which work with special children*

Schools of Social Work Can:

- *place social work students in day care programs for field placement—to work with families of children or coordinate community resources for special children*
- *consult with and/or train your staff in areas of family involvement, family counseling, coordination of community resources*
- *refer your staff to other programs and agencies which work with special children*

Psychology Departments Can:

- *place psychology students in day care programs for field placement—to identify, evaluate, diagnose and treat special problems, work with families*
- *consult with and/or train your staff in psychological problems of all children and of special children, ways to identify potential problems in children, how to handle the emotional problems of children and their families, the emotional needs of staff*
- *refer your staff to other programs and agencies which work with special children*

Schools of Medicine, Nursing, Public Health, Physical and Occupational Therapy Can:

- *place students for field placement in your program*
- *consult with and/or train your staff in related areas*
- *refer your staff to other programs and agencies which work with special children*
- *offer diagnostic and treatment services*

Public School Systems

Teachers of Special Classes, Itinerant and Resource Teachers for Emotionally Disturbed, Mentally Retarded or Physically Handicapped Children Can:

- *consult with and/or train your staff on the educational needs of special children*
- *share training programs and any special equipment*

- *visit and work with special children in your program who may enter their special public school classes*

Teachers of Regular Classes, School Psychologists and Social Workers Can:

- *visit your program, observe and work with special children who might enter their regular classes*

Special Schools

Special Schools Can:

- *sponsor joint activities for their children and your children on a regular or occasional basis*
- *consult with and/or train your staff on the needs of special children*
- *invite your staff to observe special school classes and activities*
- *refer their children to your program, when appropriate*

Civic Groups

Civic Groups Can:

- *volunteer for your program—either for group activities or on a one-to-one basis with a child*
- *donate or build equipment for your program*
- *contribute or raise funds for your program*
- *transport children to and from the center*
- *publicize the program in their newsletters and at their meetings*
- *lobby for legislation favorable to day care funding and programs*

State Departments

State Departments of Public Health, Mental Health, Mental Retardation, Welfare, Rehabilitation, Education and Special Education Can:

- *provide funds for day care programs, for special consultants, for staff training, or for supportive services for special children*
- *offer training and consultation for your staff*
- *refer your staff to other sources of funding, of program development*

Associations Dealing with Children and Disabilities

Contacts with associations for parents, educators, and professionals are really useful. These associations often have conferences and run training institutes which will be of interest to your staff. Their newsletter can keep you informed of new programs and services in your area, pending day care legislation, funding sources. The national offices of these associations can send you a list of their publications which will be of interest both to teachers and parents. You can get the addresses of some of the national associations for children with disabilities and for general child care from your teacher.

Credits

NO TWO ALIKE: HELPING CHILDREN WITH SPECIAL NEEDS

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Special thanks to the following consultants:
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Special thanks to the following schools:
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Manchester, Mass.

Dimock Street School
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EXPLORING CHILDHOOD has been developed by the Social Studies Program of Education Development Center under grants from The Children's Bureau, Office of Child Development; the National Institute of Mental Health; and with the support of the Office of Education.

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